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UNIVERSITY OF SOUTHAMPTON

FACULTY OF MEDICINE, HEALTH AND LIFE SCIENCES

School of Health Sciences

Family matters: An exploratory study of the influence of parental chronic renal failure on the family and the information needs of the children

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Doctorate in Clinical Practice

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ABSTRACT

FACULTY OF MEDICINE, HEALTH AND LIFE SCIENCES

SCHOOL OF HEALTH SCIENCES

Doctorate in Clinical Practice

FAMILY MATTERS: AN EXPLORATORY STUDY OF THE INFLUENCE OF PARENTAL CHRONIC RENAL FAILURE ON THE FAMILY AND THE INFORMATION NEEDS OF THE CHILDREN

by Frances Coldstream

Seven families took part in a phenomenological study to consider the effects on family life when a parent has chronic renal failure. This is a topic which has not attracted much attention, possibly because the incidence of renal failure increases with age, and as such, young families where there is parental chronic renal failure do not make a major contribution to the workload of a renal unit. Therefore their needs are not necessarily to the fore.

In looking at family life there is an acknowledgement of the fact that, for the majority of people, there is a life outside their chronic illness and hospital appointments and there is a need therefore to incorporate this other life into planning their care. It is therefore suggested that a worthwhile approach would be that of family centred care, more commonly seen within the paediatric domain, but here taken from the view of the adult at the centre, rather than the more usual centrality of the child.

From the study three central themes emerged:

- Normality in family life
- Living with uncertainty
- Protecting the family.

Overarching these themes the 'life view' of the parents was important. This is a common thread in all the themes and affects the way in which the parents approach their life. This, in turn, affects how the children from this study are involved in family discussions, about the influence of chronic renal failure on their family. This 'life view' fits well with Paterson's (2001) shifting perspectives model of chronic illness. In this study it is argued that to meet the needs of the family the information provided needs to be congruent with the 'life view' of the parent. This, combined with a family centred approach, is the best strategy to facilitate the sharing of information with the children.

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Author's declaration

I, Frances Coldstream declare that the thesis entitled

Family matters: An exploratory study of the influence of parental chronic renal failure on the family and the information needs of the children

and the work presented in the thesis are both my own, and have been generated by me as the result of my own original research. I confirm that:

- this work was done wholly or mainly while in candidature for a research degree at this University;
- where any part of this thesis has been previously submitted for a degree or any other qualification at this University or any other institution, this has been clearly stated;
- where I have consulted the published work of others, this is always clearly attributed;
- where I have quoted from the work of others, the source is always given. With the exception of such quotations, this thesis is entirely my own work;
- I have acknowledged all main sources of help;
- where the thesis is based on work done by myself jointly with others, I have made clear exactly what was done by others and what I have contributed myself;
- none of this work has been published before submission

Signature

Date

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Chapter 1

Introduction

1.1 Introduction

This chapter introduces the research project. It begins by considering chronic diseases in general and the recent policy initiatives which are driving practice in this area of care. It then moves on to look specifically at chronic renal failure (CRF),¹ and particularly at the pre-dialysis area of care where I worked as a consultant nurse. It was from following questions asked by patients, who were also parents, that the research aims were formulated. The project, using a phenomenological approach to consider the effects on family life when a parent has chronic renal failure, was therefore developed directly from clinical nursing practice. The title of the project also perhaps deserves a little explanation so that the reader is clear what to expect within these pages. The second part of the title that follows the colon is descriptive, an overall view of the study put as succinctly as possible. The part preceding the colon is a play on words – the study involves families and therefore families matter to this study, but additionally it implies to me as an adult nurse that the people we care for are part of a family and that sometimes we need to look beyond the individual in front of us to the wider context of their life. The title was also set within the contemporary political scene. As the project developed the green paper, *‘Every Child Matters’* (HM Government 2003) was published. This policy promotes a model of service delivery in which the child and family are central. ‘Family Matters’ is used conceptually to encourage those caring for adults with CRF to build services around the needs of the patient and their family. Following the identification of the research aims some of the key concepts that underpin this research are discussed. The chapter concludes by setting out the structure of the remainder of the thesis.

1.2 Chronic diseases

Within England chronic and long-term illnesses are the predominant disease patterns, rather than acute disease. This can be attributed, at least in part, to increasing life

¹ **Chronic renal failure (CRF)** – the result of a number of pathological processes causing irreversible damage to kidney tissue. Caused by slow, progressive kidney disease over a course of many years – perhaps 10 – 20 (Chalmers 2002 p 54.)

expectancy (Department of Health 2001a). However, the concept of chronic illness is relatively new and as Sidell (1997) suggests the term chronic illness is frequently not defined precisely and may mean different things to different people. A simple definition of chronic illness is given by Payne and Ellis-Hill (2001) as ‘those for which a cure is currently unavailable’ (p12). There are many potential effects of living with a chronic illness, for example physical and psychological problems as well as reduced quality of life and socio-economic difficulties (Department of Health 2001a). Importantly, the coping mechanisms employed both by the affected individual and their family are very different to those used during an acute episode of illness. There have been a number of recent policy initiatives which aim to improve the care that people with long-term conditions receive. The driving force behind many of these new documents was the NHS plan (Department of Health 2000), which set out a number of core principles. The third core principle states ‘The NHS will shape its services around the needs and preferences of individual patients, their families and their carers’ (Department of Health 2000 p 4). The subsequent expert patient programme (Department of Health 2001a) aims to encourage people to become more active in the self-management of their condition, whilst more recently a document laid out new intentions for supporting people with long-term conditions (Department of Health 2005a). This aims to provide a systematic, patient centred approach which in turn will lead to empowered and informed patients. In this latter initiative community matrons who will lead the co-ordination of care were introduced. Chronic renal failure is one of the long-term diseases covered by these initiatives, although it rarely receives a specific mention within the reports. It is to this disease and its influence on family life that we now turn, as this forms the basis of this phenomenological investigation.

1.3 Chronic renal failure

A functioning kidney is essential to life with its main purposes being to eliminate the end products of metabolism and to regulate electrolytes found in body fluids. The kidney has many roles within the body which include these excretory functions, and in addition metabolic and regulatory functions (Chalmers 2002). Initially the person with CRF suffers few problems, but symptoms such as tiredness and anorexia develop

as end-stage renal disease (ESRD)² approaches. Treatments are available for people who have CRF however, it is important to remember that these treatments will not cure the disease but are therapeutic measures to enable life to continue (Taylor 2000). The history of treatment for CRF provides an interesting backdrop to this study as medical and technical developments have meant changes in the focus of research. This historical perspective therefore forms the next part of this chapter.

1.3.1 The history of treatment for renal problems

Treatment for renal problems has a long history. Dialysis can be traced back to Roman times and the use of hot baths, but there was no understanding how the treatment worked. The understanding of the principles behind dialysis and the mechanical technology to undertake the process developed from the early 1900's (Smith and Thomas 2002). Initially, the majority of treatments focussed on those with acute renal failure, haemodialysis (HDx)³ could not be used as a regular treatment for people with ESRD until the 1960's when vascular access was improved. The design of the external arteriovenous shunt, and the internal Cimino arteriovenous fistula enabled a change in the focus of treatment to that of chronic disease management (Fleming 1999/2000). The last 40 years has seen many changes which have increased our understanding, and improved life expectancy for people with ESRD. Kidney transplantation is now, in many instances, considered the treatment of choice by both patients and healthcare professionals; it is also the most cost-effective treatment (Franklin 2002). These large, successful kidney transplant programmes have developed from very tentative beginnings in the 1950's (Smith and Thomas 2002). Dialysis technology has also changed and improved and the development of peritoneal dialysis (PD)⁴ programmes since the late 1970's have enabled more choice for patients (see for example Wild 2002 and Graham 1998). These medical and

² **End stage renal disease (ESRD)** - End stage renal disease is reached when chronic renal failure cannot be controlled by conservative management and when the patient requires either dialysis or a kidney transplant to maintain life (The Renal Association, 2002 p 156).

³ **Haemodialysis (HDx)** - A form of treatment in which the blood is purified outside the body, by passing it through a filter called a dialyser or artificial kidney. The filter is connected to a machine which pumps the blood through the filter and controls the entire process. For patients with end stage renal disease each dialysis session normally lasts from three to five hours, and sessions are usually needed three times a week (The Renal Association, 2002 p 157).

⁴ **Peritoneal dialysis (PD)** - A treatment of renal failure in which blood purification takes place, using the patient's own peritoneum as the membrane. Bags of dialysis fluid, containing glucose (sugar) and various other substances are drained in and out of the peritoneal cavity via a PD catheter (The Renal Association, 2002 p 159).

technological advances have led to increased availability of treatment for renal problems and an expansion in the numbers of people undergoing treatment. This historical perspective regarding treatment options is important for this study. Initially HDx was essentially a home based treatment and careful selection criteria were applied (Smith and Thomas 2002). An example of ideal selection criteria is given here, however it is acknowledged by the authors that such patients rarely exist:

“The ‘ideal’ patient for maintenance dialysis would be a young man or woman (aged less than 40 and more than 20) with family responsibilities and a roomy house, a stable job and marriage, a tough temperament, without systemic or coincident disease and who, although in terminal renal failure, has been well looked after and is capable of rapid rehabilitation from the many metabolic and nutritional problems of this state.”

(Cameron, Russell and Sale 1976 p 299)

These authors also consider that the first principle of regular dialysis is that ‘the patient must be independent and taught to carry out procedures for himself’ (Cameron, Russell and Sale 1976 p 106). However, what can be drawn from this is that, in the early days of HDx, the treatment usually took place in the home and the patients were generally younger than today. Home HDx then fell out of favour, but looks set for a resurgence with the National Institute for Clinical Excellence guidelines (2002) on the provision of home HDx. During the interim much HDx treatment was hospital based and now PD is also available, another homed based therapy. This historical perspective may go some way to help explain the patterns of treatment seen in the literature review reported in the next chapter, the dated nature of the articles and the prevalence of HDx.

1.3.2 Epidemiology of chronic renal failure

CRF is found across the age spectrum but is essentially seen as a disease of the elderly (Roderick and Khan, 2002). Data from the United Kingdom (UK) Renal Registry (2005), which originates from renal units and covers the year 2004, the year in which the data collection for the present study commenced, gives an indication of the activity connected with treatment for kidney problems. The estimated annual acceptance rate⁵ of adult patients starting renal replacement therapy (RRT)⁶ in the UK

⁵ **Acceptance** of newly treated patients into the RRT programmes is expressed as a rate per million of the population per annum (pmp pa). The ‘per annum’ is often implied and acceptance rate is therefore

in 2004 was 103 per million population (pmp). This equates to 6088 patients starting RRT. The median age of people starting RRT has increased from 63.3 years in 1998 to 64.7 years in 2004. These data show us that younger people who begin treatment are in a minority, and as such, it may be easy to ignore the specific needs they and their families have. When people commence therapy the majority (71%) begin on HDx, with 26.5% starting on PD and only 2.3% having a pre-emptive transplant.

1.3.3 Terminology

During the course of this study some of the terminology used within the renal speciality has changed. This is probably in an effort to make the terms more acceptable to patients, but also means that there is a consistency in terminology across the UK and North America. Chronic renal failure has become chronic kidney disease whilst end stage renal disease is now referred to as established renal failure. Chronic kidney disease has been divided into five stages based on estimated glomerular filtration rate based on an international classification developed by the United States National Kidney Federation (Department of Health 2005b), with stages 3 and 4 equating to the pre-dialysis phase. A decision was taken to complete this study using the terminology that was current at its inception. Therefore the terms chronic renal failure and end stage renal disease will be used throughout.

1.4 Current provision of renal care

The recent *National Service Frameworks (NSF) for Renal Services, part one – dialysis and transplantation* (Department of Health 2004a) and *part two – chronic kidney disease, acute renal failure and end of life care* (Department of Health 2005b) are being used to guide and improve renal care for people at all stages of their illness and aim for patients to become ‘informed partners in their care’ (Department of Health 2005b p 1). These government publications followed in part, patient and professional recommendations made in the Kidney Alliance report (2001) and the Renal Association’s (2002) Treatment of adult patients with renal failure (3rd Edition).

more usually quoted as pmp. Since pre-emptive transplantation before patients require dialysis is rare, acceptance into RRT approximates to the acceptance rate for dialysis. The two are often used synonymously (The Kidney Alliance 2001 p 20).

⁶ **Renal replacement therapy (RRT)** – used to describe treatments for end stage renal failure in which, in the absence of kidney function, the removal of waste products from the body is achieved by dialysis and other kidney functions are supplemented by drugs. The term also covers the complete replacement of all kidney functions by transplantation (The Renal Association 2002 p 150).

In this section the guidance from these documents that pertains to the pre-dialysis area will be considered. It will be linked to practice in the large, urban renal unit where I was working as a nurse consultant managing the pre-dialysis care for a group of patients with chronic renal failure. The time spent within the pre-dialysis area covers treatment prior to commencing RRT, and is essentially preparatory. This phase of care is being increasingly recognised as an important time for patients, their families and health care professionals. It has been likened to ‘a journey’ by Andrews (2001 p 72), during which the individual and their family come to accept a ‘different view of life.’ Only after this has been achieved can decisions about treatment be made. The Kidney Alliance (2001 p 41) report recommended ‘structured education and counselling of patients approaching ESRF involving the multi-disciplinary team and other patients should aim for the seamless entry onto RRT using the patient’s chosen modality.’ Whilst the Renal Association (2002 p 125) states that education and preparation for dialysis including vascular access are key elements of care in the management of those approaching ESRD. The NSF part one (Department of Health 2004a) considers that patients should spend approximately one year in the pre-dialysis phase to enable patients and carers to be adequately prepared. This latter guidance is not underpinned by research but has been suggested following professional agreement. Within the same NSF (Department of Health 2004a), the first two standards relate to access to information to enable informed decisions and appropriate clinical and psychological preparation. It also suggests that educational programmes are one means of improving information giving and encouraging an informed participation in care. It is to information giving, particularly within the context of CRF, that we now turn.

1.4.1 Information

Information giving is a well-established nursing role, classically information has been shown to reduce anxiety (Haywood 1975). The professional guidance discussed in the previous section indicates the importance of the provision of information for people with CRF. In addition, a recent Department of Health (2004b) publication, *Better information, better choices, better health. Putting information at the centre of health* gives guidance on the provision of information and expects that one of the benefits will be enabling people to manage their long-term conditions more effectively. Patients are unable to make informed decisions unless they are given enough

appropriate information (Coulter *et al.* 1999, Department of Health 2004b). For adults with a diagnosis of progressive CRF there are many things to come to terms with. There are significant psychological effects (Killingworth 1995) and diagnosis and its consequences can take time to adjust to (Coupe 1998a). The particular challenges faced by patients with ESRD are captured by the following quote:

‘Patients with ESRD are faced with complicated and demanding treatment regimens that include dietary and fluid restrictions and medication schedules. Irrespective of whether treatment is predominantly dialysis-centre based or home based, patients need to have sufficient knowledge, skill and ability to carry out their treatment regimen without direct supervision of healthcare personnel’

Klang *et al.* (1998 p 36)

Information is required by the patient to aid adaptation. Klang *et al.* (1998), in a small study of 28 patients who undertook a structured, renal education programme, found these patients showed improved functional and emotional well-being when compared with 28 patients who had not undertaken the education programme. These positive effects were apparently carried over into the first six months of dialysis. Interestingly, the positive effects seemed particularly noticeable with the younger participants. However, information needs differ for individuals as Wagner (1996) showed. By considering nurses’ and families’ perceptions of needs when a family member was being treated by haemodialysis, Wagner (1996) found that many of the family needs centred around information, whilst the nurses stressed the ability to cope in an emergency.

There appears to be a generally held belief that the earlier patients are given information about their condition the better, however with renal patients this is key. This is because the course of CRF leading to the initiation of RRT is often varied and unpredictable. As the uraemia develops, specific neurological effects including confusion, drowsiness and memory impairment (Cameron, Russell and Sale 1976) become more pronounced. Clearly this is not the best time to attempt to give someone information upon which they will base decisions about their future treatment. Early intervention is essential. This links with the recommended time to be spent in pre-dialysis care, as the information can then be given early to allow the patient and their family and carers to reflect on this, and plan for the future.

It would seem that many renal units already have the educational programmes recommended by the Department of Health (2004a). A survey conducted by the research board of the European Dialysis and Transplant Nurses Association/European Renal Care Association (EDTNA/ERCA) investigated provision of pre-ESRD information, education and counselling in renal care (Da Silva-Gane *et al.* 2002). The survey concluded that most of the participating centres (71%) had a structured pre-ESRD programme using a Multi-Disciplinary Team (MDT) approach. This type of intervention is also supported by a Canadian article - Baker and Thomas (2001), and by Klang *et al.* (1999), the latter describe how participating in an educational programme can help patients make a choice in modality of RRT. Programmes were all found to have a similar content. Topics covered include normal kidney function, medication, diet, haemodialysis, peritoneal dialysis and transplantation. Other topics sometimes considered were employment, the importance of leisure activities, holidays and Kidney Patient Associations. Educational materials used within the programmes are often produced by companies with a vested interest in RRT. Other UK literature including O'Donnell and Tucker (1999), Wilkinson (1998) and Coupe (1998b) described programmes which followed similar patterns. The education programme run in the unit where the research was undertaken offers similar sessions. The approach to education in this unit will now be discussed, as will the way in which the research question came to be formulated.

1.5 Development of the research aims

As part of my remit as the consultant nurse for pre-dialysis, I regularly reviewed adult patients and their family members. I was also responsible for the co-ordination of the monthly education sessions which were attended by patients, their families, carers and sometimes friends. In addition I undertook some of the teaching at these sessions, on a relatively formal basis, and also individual teaching sessions for families on a more informal basis, with the latter sometimes occurring in the patient's home. At all times patients were encouraged to bring their families and carers with them. As a result of these consultations, and perhaps also because I was expecting my third child at the time, patients with young children⁷ often asked what to tell their children about their illness, how to tell them, and when to tell them about treatments and the possible

⁷ **Child/Children** – for the purposes of this study, persons under the age of 18 years.

effects of these on the children's lives. Sometimes behavioural changes in the children had been noticed either by the parents, or perhaps reported to them by, for example, the child's school. As a result of these queries I delved further into this area. Brief computer searches revealed very little, conversations with the nurses in a paediatric renal unit revealed that they had information for children with CRF, and also information for the parents of the children and the response – 'surely it will be the same won't it?' I did not feel that it would be and neither did the parents with whom I discussed this lack of information in response to their initial questions. Others suggested looking within the cancer literature, as they felt that it could offer parallels. I did this, and there are some aspects which can be drawn on, but it still did not ring true – a fact to which I will return later in this thesis. Much of the cancer work at the time appeared to focus on the death of a parent, and although this may become relevant it was not the prime concern for most parents with CRF. From my initial searches there appeared to be a gap in professional knowledge concerned with CRF and its effects on the family. It seemed that I could identify what I thought it was not – to me it did not resemble having a child with CRF or having a parent with cancer, but I was no nearer identifying what it was. Reflecting on my family situation, with young children, I wondered how I would approach this situation if it were me. How and what would I tell my children? I liked to think that I would have the courage to tell them the whole truth, but would I? At a time when the parents are trying to assimilate information for themselves about how the illness may affect their future, they have to process the information and convert it into a form that their children can understand. This complex situation is obviously a challenging area of practice. Some information is available to guide practitioners concerning psychological care for families with CRF (see for example Sedgewick 1998 and Auer 2002a). However the focus, when families are discussed, is usually the spouse or the carer. Molzahn and Kikuchi (1998 p 411) note that there has been 'virtually no research' which considers the quality of life for children and adolescents when they have a parent on dialysis. More recently, Dingwall (2003 pp 51 – 57) wrote a chapter entitled 'Support for the family and carer'. Here again the focus appears to be on the spouse and carers. Children are mentioned in this chapter only once, within the context of child carers. The situation is therefore compounded because there is little research to guide the practitioner; there appears to be limited consideration of the

effects of CRF on the family where children under the age of 18 years are involved, and little material on which to base appropriate information for these children.

The material presented thus far in the thesis has indicated how CRF is essentially a disease found in older people. Therefore in considering younger patients, who potentially have young families, a sub-population has been identified for whom specific information needs are not being met. As described there is minimal information on how to deal with CRF from a family perspective. My desire was therefore to capture, in some detail, the experiences of parents and children regarding CRF, and how they consider it has influenced their family life. This will by its nature mean different things to different people and may be influenced by numerous factors such as personal experiences of family life and/or how individuals cope with their diagnosis and disease. It is a huge topic and therefore the research aims have been carefully chosen and refined to consider in depth two areas which are of particular interest to me as a person, a practitioner and a researcher. The aims are also congruent with current health care thinking and provision – for example, supporting people with long-term conditions (Department of Health 2005a) and providing information to enable people to manage their conditions more effectively (Department of Health 2004b), and firmly grounded in practice. The study has therefore taken shape as a two-part project, using a phenomenological approach, with the following aims:

Part 1

To explore the influence that a parental diagnosis of chronic renal failure has on the family and the information needs of the children within these families from the perspective of the parents.

Part 2

To explore the influence that a parental diagnosis of chronic renal failure has on the family and the information needs of the children within these families from the perspective of the children.

The aims of the research are intricately entwined and dependent on each other. Both perspectives are required to try to ensure that a full picture is obtained of the

phenomenon under consideration; how family life is affected by parental CRF. The research aims hope to develop knowledge for practice. Linking them both to the information needs of children provides an opportunity to uncover data on which changes to practice can be based. This latter aspect is particularly important within doctoral studies with an emphasis on clinical practice.

The factors, which led to the formulation of the research aims above, have been detailed. The chapter now moves on to consider key concepts that underpin the study, revisiting information provision, then moving on to the changing position of children in society and as research participants and concluding with a brief consideration of family centred care.

1.6 Information revisited

In the section above, the provision of information within renal units in general, and more specifically the unit in which I worked have been considered. What is clear is that policy makers consider information to be key, but none of the documents considered specifically address the information needs of children, unless it is the child who has the renal problems. This was true of the unit in which I worked. We openly encouraged parents to bring members of their family with them, few however brought children – possibly because at the time of most appointments the children would be in school. If children attended an outpatient appointment they were offered the opportunity to come into the consultation. However, their inclusion in the conversation would be affected by many factors including the attitude and skills of the health professional undertaking the consultation, the wishes of the parents and how vocal the child was willing to be. The education sessions were run during the week; at a time children would be attending school. The timing of the sessions – 11am – 1pm was initially fixed to allow those attending to make the best use of travel concessions. This reflects the age of the majority of participants; however it was not good timing for those in employment. As an experiment, one series of education sessions were run between 3pm – 5pm. The group had a very different feel to it because of the age of the attendees, however, it potentially made childcare issues worse as the sessions extended beyond the end of the school day. The information provided very much focuses on the adult perspective, with acknowledgement of the needs of adult family and carers. For parents with CRF we have a complex situation

– the patient is also a parent and, as well as requiring information themselves, they may wish to share the information with their children and their children may want to understand what is happening to their parent. In exploring the influence that CRF has on the family and the information needs of the children I have had to make an assumption in relation to information giving. This is that the parents are able to assimilate information and then have the ability and inclination to pass this information onto their children in an appropriate form and at an appropriate time. It is to how we, as a society, view children and their need for information that we now turn.

1.7 Children

There are moves within society to improve the information given to children, essentially driven by legislation i.e. the Children Act (1989). The NSF for Children – Standard for Hospital Services (Department of Health 2003) argues that children are different to adults and therefore need distinct and tailored services. It also describes how children, young people and parents should be partners in care with access to appropriate and accurate information. This NSF urges that there should be a partnership with parents, children and young people to plan and deliver services. The NSF for Children (Department of Health 2003) is written with children who need to use hospital services for health issues in mind. However, the principles it enshrines are applicable to this research as a model to encourage participation and partnership to ensure that appropriate information is available.

A variety of approaches may be taken regarding what and how children are told about the impending changes because of parental illness. Advice sought from nurses by parents has often been given on instinct rather than an evidence base. For example, two nurses, Black and Hyde (2002) when discussing what to tell children when a parent has colorectal cancer, write about the lack of specific resources aimed at children and how they therefore used their extensive experience as healthcare professionals and parents to guide the information giving. Some evidence exists to guide information giving for children, however most of this comes from the adult perspective. In an article reviewing paediatric-nursing practices when helping children understand health and illness, Rushforth (1999) supports the view that information has been proven to reduce stress and anxiety in adults. However, within

paediatric nursing these ideas appear not to have been incorporated into practice because of the way children's development has been viewed. She supports the idea that children should be offered 'full, clear and appropriate explanations which they are capable of understanding' (p 684). However, Sartain *et al.* (2000) feel that children are still predominantly seen as passive recipients of health-care rather than active users of a service. It could be argued that this is the case here, where the focus is on the adult, whilst the children are very much second in line for care. Recent publications indicate that there appears to be more research being undertaken that includes the child's perspective. Smith and Callery (2005) interviewed nine children aged 7 –11 years regarding their information needs prior to admission for planned surgery. They concluded that these children had received little information directly from the hospital or the healthcare professionals. The children were however, quite capable of identifying the types of information they required and could therefore contribute to the development of information. Similarly children expressed a desire to be consulted and given information which helped them to understand their illness (Coyne 2006). All of the research discussed above relates to the sick child requiring information and explanation. However, it appears that the needs of the well children in families where an adult has CRF have, to date, been largely ignored. Therefore assumptions have to be made. I have presumed that the well child with a parent with CRF would be no different, and would want to be provided with information that they could understand. Children's views are a potentially rich source of data (Coyne 1998) and this source could be utilised to provide information for children in a form relevant to them. This is congruent with the Research Governance Framework (Department of Health 2001b)⁸ and the NSF for Children (Department of Health 2003) as indicated above. This leads onto the role of the family, and indeed how the family is defined. This then moves us towards the concept of family centred care which is more usually found within the paediatric nursing domain.

1.8 Families

The term family is an everyday term, and as such could be thought of as a simple concept to understand and define. However, within the discipline of sociology, as

⁸ This document has been superseded by the 2nd edition of the Research Governance Framework (Department of Health 2005c). However, the first edition has been used during the write-up as it was current when the data collection took place.

Thompson and Priestly (1996) describe, it is a concept that occupies much time and is a topic of lengthy debate. This is not the occasion to embark upon a lengthy discourse on the family and its variety of forms and functions. However, it is important to be clear and set down an understanding of the family as used in this research. As indicated defining the term family is not a simple task (O'Donnell 2002). The term family may mean different things to different people. It does however appear that in most cultures the family is seen as an important social grouping, however the function which it serves may vary (O'Donnell 2002). This may go some way to explain why the family, as used by researchers, appears frequently to be ill defined within the research context. Within the renal setting many studies appear to focus on the effects of CRF on the family – see for example Flaherty and O'Brien (1992) and Brunier and McKeever (1993). However, closer examination reveals that the family is often not well defined and frequently children are specifically excluded from studies unless they are adult children. Brunier and McKeever (1993) highlight this in the following statement:

‘research has been based on the mistaken assumptions that the “family” can be clearly defined and that there is a standard of “normal family functioning” against which “problem” families can be measured and subsequently “treated.”’

Brunier and McKeever (1993 p 657)

Many definitions of families do exist. There is, for example, the definition provided within the 2001 census:

A family comprises a group of people consisting of a married or cohabiting couple with or without child(ren), or a lone parent with child(ren). It also includes a married or cohabiting couple with their grandchild(ren) or a lone grandparent with his or her grandchild(ren) where there are no children in the intervening generation in the household. Cohabiting couples include same sex couples. Children in couple families need not belong to both members of the couple.’

(Office for National Statistics 2001)

There are also the concepts of the ‘nuclear family’ and the ‘extended family’, which are frequently seen in the literature. A nuclear family is described as a man and woman in a steady relationship with each other, who also have children, whilst an

extended family refers to a number of nuclear families who are related to one another (O'Donnell 2002). Within the current research the family is a key concept, however, the research focuses on the individuals within the family, the adults and their children, and their views on the effect CRF has on family life. The research is not principally about the relationships within the family and family bonds, even though these are important for family life. The definition of family used within this research is therefore deliberately loose and derives from the work of Smith *et al.* (1998), reflecting their belief that there is a wide variation in family types.

‘The family – a household consisting of one or more adults and one or more children, the adults being parents or *in loco parentis*.’
(after Smith *et al.* 1998)

1.9 Family Centred Care

Family centred care is a concept that has evolved over a number of years, particularly within the paediatric setting. In a recent publication, Shields *et al.* (2006) consider the concept of family centred care by critically reviewing 11 qualitative research studies which were identified during a Cochrane review. The studies were considered unsuitable for statistical analysis because of their qualitative approach, however the authors felt their content would further illuminate the concept of family centred care. Shields *et al.* (2006) suggest that family centred care is a cornerstone of paediatric practice, however its efficacy is unknown. They also highlight that no single definition of family centred care exists, rather, a list of elements or characteristics tend to be given. These have been suggested by others to include the notions of involvement, participation and partnership, with information-giving an important part of the process (Smith *et al.* 2006). Shields *et al.* (2006) define family centred care as:

‘Family centred care is a way of caring for children and their families within health services which ensures that care is planned around the whole family, not just the individual child/person, and in which all the family members are recognized as care recipients.’

Shields *et al.* (2006 p 1318)

Normally, family centred care is applied to professional nursing care within the paediatric setting, where the child is sick. However, in this study, family centred care is being approached from a different angle where it is the adult who is sick, but the

family, as a whole, still require care. The definition offered by Shields *et al.* (2006) would therefore seem appropriate to either situation.

1.10 Clarifying the need for this research

Families where there is parental chronic illness and children do not appear to have been a focus of research interest. Mukherjee *et al.* (2002a) corroborate this and state that, at the time of their research, studies which considered the experience of being a parent and having a chronic illness were sparse and usually exploratory in nature. They undertook a study looking at the experience of parents with inflammatory bowel disease (IBD), a topic which had received no consideration prior to their study. Mukherjee *et al.* (2002a) consider that there are numerous reasons why this type of research should be undertaken. These include: helping parents rise to the challenges of parenting whilst coping with a chronic illness, reassurance if the findings were positive, and evidence on which guidance and advice for families and health care professionals can be based. A second paper from the study, Mukherjee *et al.* (2002b) looked at the experience of the children in the families where a parent had IBD. Here again, the rarity of published research which considers the experience of children in families where there is parental chronic illness is stressed. These papers add weight to the need to undertake this study in a group whose experiences and needs appear to have been largely disregarded to date. Additionally, in a letter to the editor of the *Journal of the Royal Society of Medicine*, Frank (2002) considers the impact of chronic illness on the family. He acknowledges the burden that partners carry and would support research into this area, but adds that the impact crosses generations. He highlights the under-researched areas of child carers and the profound effects on children of parental disability and states that these would provide challenging areas of study. This study therefore seeks to cross some of the generations and consider the impact of a chronic illness, CRF, on the family from the perspective of both the parents and the children. It also aims to look specifically at the information needs of these children.

1.11 Summary and structure of the remainder of the thesis

This chapter has considered the background for the research and how the research question came into being. It has looked at various key areas, from policy to practice

within chronic illness in general and for CRF in particular. It considered various assumptions that have been made within the research and has set out key issues which are approached from a different angle within this project. The next chapter, presented in the form of a literature review, specifically considers how parental renal failure may affect the children within a family. This provides the background for the research, has helped clarify ideas, and has also influenced the thought processes and design of the research. After that, the ethical issues surrounding this project are discussed within Chapter three. This is a potentially challenging area, where children are to be involved in research, and the chapter therefore discusses the development of ethical frameworks in general, but also looks specifically at the issues surrounding involvement of children in research. Chapter four describes the methodology, the philosophical underpinning of the phenomenological approach used and how this affected the methods used to gather the data. This leads into Chapter five where the choice of data analysis tool is described and justified and the data gathered are presented. The concluding chapter covers the discussion, limitations of the study, application to practice and the final conclusions. A full reference list is offered and appendices lend support to the thesis.

Chapter 2

The potential effects on children of having a parent with chronic renal failure: a review of the literature

2.1 Introduction

The previous chapter has considered the aims of the study and the clinical context in which it is set. A literature review was undertaken to illuminate the area further. Some proponents of research using phenomenological approaches suggest that no literature review should be undertaken until after data collection. The methodologies behind this research project will be explored in more detail in the next chapter; however, the position of the literature review here requires clarification. Whitehead (2004), using what she described as a Heideggerian phenomenological approach tempered by Gadamer's philosophical hermeneutics, suggests that the validity of the research idea can be enhanced by an early literature review if it can be shown that little is known about the topic or if the research around the topic has been undertaken within another discipline. This is because use of Gadamer's approach enables the researcher to acknowledge their place within the research and the knowledge they bring to the situation. Undertaking a literature review will therefore not compromise the data analysis. On the other hand studies which are said to take a Husserlian approach, and so involve bracketing, may be compromised if a literature review is performed initially as this may influence the researcher's view of the topic and potentially hinder the final description. As the former position has been taken within this project the literature review was undertaken to support and give focus to the initial part of the research. The question posed for the review was

‘what are the effects on children of having a parent with chronic renal failure?’

The literature search was undertaken using the following databases CINAHL (1982 – January week 5 2003), MEDLINE (1966 to January week 2 2003), British Nursing Index (BNI, 1994 – January 2003), AMED (Allied and Complementary Medicine, 1985 to January 2003), EMBASE (1980 to 2003 week 8) and PsycINFO (1872 – February Week 1). In addition the issues available in the local education provider library of the American Nephrology Nurses Association – (ANNA) Journal, called the

Nephrology Nursing Journal since 2000, were hand searched from 1994 onwards when the subscription to the Journal commenced. Reference lists of the identified articles were scanned to provide access to further material.

The search parameters are given in Table 2.1. All the hits were scanned on the screen and material deemed relevant was saved. It was at this stage that much of the information was rejected as the majority of matches for child related topics, and indeed parental feelings related to CRF were related to the child having the CRF and dialysis, not the parent.

Table 2.1
Search Parameters

<p>Search Terms</p> <p>Children, child, family, parents, children of impaired parents, carers, family care, caregiver support, family centred care, professional family relations, family nursing, caregivers, chronic renal failure, kidney failure, peritoneal dialysis, renal dialysis, hemodialysis (sic), haemodialysis and dialysis.</p>
<p>Inclusion criteria</p> <p>The only time limits imposed upon the searches were those of the database dates – this was because initial searches had revealed little published material in the area. The search was, for pragmatic reasons, limited to articles in English. Articles were only considered if the primary focus appeared to be of the effects on the children, rather than the family.</p>
<p>Exclusion criteria</p> <p>Children with CRF, parental experience of having a child with CRF.</p>

2.2 Children and parental chronic renal failure

Seven articles were identified from the documented literature search that related to the search question. Six of the articles are North American in origin, the remaining one South African. These papers are summarised in Table 2.2 on the pages that follow. They are listed in chronological order to highlight the dated nature of the material. Further information on the studies is given in Appendix 1. The literature was reviewed in a critical and systematic fashion. Critical review of the literature plays an important role in establishing the need to undertake research and can help to ensure that the end result is in a form that can be incorporated into practice. The analysis is based on the format given in Appendix 2. This template for critical evaluation (after Hek 1996) is essentially for research material and was therefore used mainly as an

aide mémoire to ensure that all material was approached in a methodical and consistent way. Due to the dated nature of the material found it was not amenable to a more prescriptive form of critical analysis. This was particularly noticeable with respect to ethical issues. Far reaching changes to the ethical requirements inherent in undertaking a research project, as well as new expectations of documentation relating to these procedures means that this section of these dated articles is frequently below current standards. The typology of evidence used to classify the material can be found in Appendix 3. A synthesis of the seven articles additionally includes a small amount of extra, mainly descriptive, literature relating to the caring role that children undertake when a parent has CRF. This extra literature also fulfilled the search criteria. This synthesis is presented under the following headings which essentially emerged from the review

- potential effects on children's development, health and well-being
- specific needs of children
- how children may cope

2.2.1 Potential effects on children's development, health, and well-being

There are many factors which may impinge on the development, health and well-being of children. The potential effects discussed within this section have come directly from the literature reviewed. In a project exploring family adjustments to long term HDx, Hoover *et al.* (1975) made some additional interesting observations which they felt were worth recording. This paper highlighted how much of the preceding research had considered how 'the family' adjusts to HDx, but that there was very little (and none quoted) that examined the adjustment of children who have a parent on HDx. It is important to note, as detailed earlier, that the focus of dialysis treatment has changed over the years – at this time the only options would have been home or centre based haemodialysis, and for a younger and fitter population.

Table 2.2
Summary of key articles

Study	Type of Supporting Evidence	Objectives	Characteristics of Article or Study	Conclusions	Does it help answer the question?
Hoover <i>et al.</i> 1975	D (Summary review articles and discussions of relevant literature)*	Considers the adjustment of children with a parent on HDx.	Written as reflections of observations and anecdotal notes from interviews with patients and spouses. Three in-depth interviews over a 10-month period – data essentially collected for another project. Data collection did not focus on the children. Random sample – 72 families, 36 of which had children – average 2.1 per family.	Need for data about how children develop in families where a parent has a chronic illness. Nurses' contact with patient and family provides opportunity for both assessment of the children and anticipation of stressful times. Children who are at risk need to be identified and interventions instituted to promote optimum growth and development.	Raises important points. Other life changes may happen to the family along with dialysis – these may also affect the children e.g. moving, changing school. Is the effect on the children different if it is the mother or father that require dialysis? Where do children get their support?
Tsaltas 1976	C1 (Descriptive and other research or evaluation)*	Motivation seemed to be that attention to the influence of home HDx on children may shed light on the area of depression in childhood. Insight into the psychological problems of the parent undergoing dialysis.	Approached 10 families (21 children) – Six families (15 children aged 6 – 18 years) agreed to participate. Group psychological testing (Minnesota Multiphasic Personality Inventory – MMPI) and family interviews designed to show <ul style="list-style-type: none"> • school achievement • socialisation • body functions and body preoccupation Children undertook drawing e.g. human-figure and draw your family – rationale – familiar to author. The drawings were also scored by another, named 'expert' and compared with 'control' drawings from friends' children. States highly motivated, self selected group. Parents aware that treatment would not be offered to children, but referrals would be made if appropriate.	Drawings – showed emotional constriction, anxiety, depression and bodily concern. All children showed depressive and hypochondriacal MMPI patterns. School achievement was felt to be affected in 10 of the 15 children. Parental concerns that the dialysis may interfere with the children's recreation and socialisation. Children showed minimal sleep disturbances. Parents very sensitive to psychomotor disorders – e.g. hyperactivity.	Children showed moderate to severe depression. Children with a parent on dialysis face real stresses and often cannot find the words to express themselves.

Study	Type of Supporting Evidence	Objectives	Characteristics of Article or Study	Conclusions	Does it help answer the question?
Evans 1978	D (Summary review articles and discussions of relevant literature)*	To debate the correctness of the Tsaltas (1976) paper To reflect on interviews the author has conducted with 'several' dialysis patients, families and dialysis unit staff members.	Unable to comment on the characteristics of the study as none are given. Number of participants is given only as 'several'. It is unclear if the children were directly involved in the study. No interview questions or topics for discussion were given	Dialysis is a family problem – not just a patient one.	Highlights parental wish to appear 'normal' in front of children. Children of dialysis patients actively involved in administering HDx at home. Suggests that the problems encountered by the children are moderated directly by the amount of social support available to them.
Goldman <i>et al.</i> 1980 – 81	C1 (Descriptive and other research or evaluation)*	Focus on the reactions of adolescent family member with particular reference to developmental life crisis and the stresses of having a parent on home HDx.	8 families had son or daughter (aged 12 –21 years) living at home. 6 agreed to participate. 16 adolescents of whom 15 agreed to participate. Interviews held with, patient, spouse, family as a whole and adolescents. Initial information obtained at clinic visits. Families were visited at home between 1 – 3 times. Visit 1 was the family as a whole interview – described as non-directed and free-flowing. Topics explored: <ul style="list-style-type: none"> • how home HDx had changed life • problems • how illness and treatment were discussed with children • impressions of effects on children's behaviour. Adolescents interviewed privately.	All the adolescents still relate to their father respectfully. Generally they were proud of how the illness was faced. Information about the illness was generally received from the mother. About 50% were specifically involved in father's dialysis treatment. Realistic about life expectancy of father.	Appears to enhance self-esteem of children as they gain confidence in helping their parent survive. Children have specific information and emotional needs in relation to dialysis which need to be addressed.

Study	Type of Supporting Evidence	Objectives	Characteristics of Article or Study	Conclusions	Does it help answer the question?
Friedlander and Viederman 1982	C1 (Descriptive and other research or evaluation)*	Impact of chronic HDx of a parent on the children living at home and on their relationship with the sick parent.	<p>Termed a pilot study – looked at children’s fantasy lives hoping it would give insight into the child’s perception of parental illness and treatment.</p> <p>Involved families of both centre and home HDx patients who had been on HDx for at least 6 months and had at least 1 child aged between 7 – 14 years.</p> <p>12 families participated – 7 home and 5 centre HDx, and 14 children.</p> <p>Semi-structured interview with parent – focus – how child was affected by the chronic illness.</p> <p>Children asked to draw a picture and tell the story of the picture. A standard set of questions were then asked of each child.</p> <p>6 children of physically well parents were asked to draw a picture and tell its story.</p>	<p>No quotes were given from the parental perspective however parents were said to express guilt over becoming ill, their limited employment and educational opportunities and their dependence on treatment which involved other family members.</p> <p>No significant differences were perceived between the centre and home HDx children. The analysis had to be taken on trust as there was no reproduction of any of the drawings although some descriptions were given.</p>	<p>Parents were not aware of what their children thought.</p> <p>Children showed aggressive tendencies, pseudomaturity and identified with the sick parent.</p>
Schlebusch et al. 1983	B3 (Individual well-designed non-experimental studies)*	To ascertain the psychological effect of parental in-centre HDx their on adolescent children.	<p>4 patients had adolescent children and were included in the study. 8 children (aged 13 – 18 years) matched against controls for age, sex and socio-economic status.</p> <p>Two standard psychometric instruments were used</p> <ul style="list-style-type: none"> • high school personality questionnaire • personal, social, home and formal relations questionnaire <p>A clinical interview was also undertaken.</p> <p>Wilcoxon matched-pairs signed ranks test used to analyse the psychometric tests.</p>	<p>Little personality change identified between experimental and control group, but marked changes in adjustment.</p> <p>Tended to score more highly on the areas related to self-sufficiency.</p>	<p>Dialysis is not just a patient – hospital problem but affects children too.</p> <p>Children of HDx patient appear more self-sufficient and sometimes have difficulty with social relations.</p>

Study	Type of Supporting Evidence	Objectives	Characteristics of Article or Study	Conclusions	Does it help answer the question?
Molzahn and Kikuchi 1998	C1 (Descriptive and other research or evaluation)*	To describe one aspect of the reported quality of life of a selected group of children and adolescents whose parents were being treated by dialysis therapy for renal failure.	Exploratory, descriptive design. 25 children and adolescents (8 – 16 years) chosen as a convenience sample were interviewed privately, in their homes once a week for 2 –3 weeks – a total of 65 taped interviews. Content analysis was performed on the data – categorisation was based on the Aristotelian-Thomistic conception of the good life.	Overall, that the quality of life of this group of children appeared to be good, but further research is required! Need for carefree family holidays.	Children appeared to need more ‘goods of the mind’ – information about how various family members were feeling and decreased fear in relation to parents’ condition and treatment. Literature review identified that the children’s and adolescent’s experience tended to be described either by the parents or with the family as the focus.

*for full typology please see Appendix 3.

The typology is adapted from the National Service Framework for Older People (Department of Health 2001c p 11).

Seventy-two families participated in the Hoover *et al.* (1975) study. Thirty-six of these families had a total of 75 children and it was comments made by mothers (fathers are not mentioned) and interviewer observation that made the researchers question how children adjusted. No indication is given regarding the questions asked in the in-depth interviews. The article stresses that children were not the focus of the data collection, indeed it is not clear how many of the 36 families with children are represented within these comments. There is no consideration of ethical aspects of the research documented within the article – this is particularly worrying as it would appear that the data were collected for one purpose and some of them were used for a secondary purpose. This article makes the point that when working with families it is important to be aware that other life changes may happen to the family along with dialysis and these may also affect the children, for example moving school or house. However, Hoover *et al.* (1975) felt that home HDx caused great changes for the whole family, particularly in the first year of the dialysis treatment. They cite psychological, sociological and physiological resources as well as time, money, space (p 1374). Families draw on these resources during home HDx treatment. Children often experienced stress as family life altered and parental resources were directed in new ways. The points were also made that parents may require help in understanding how the parent-child relationship may be changed by dialysis – this however needs to be understood before help can be offered. The authors also questioned where children obtained support.

In a smaller study involving 15 children aged 6-18 years where one parent was undergoing home haemodialysis, Tsaltas (1976) found that all the children were moderately to severely depressed and two thirds had been referred by teachers for behavioural problems in school. These are problems which can have a direct influence on the health, development and well-being of a child. A recent literature review by Waslick *et al.* (2003) concentrating on chronic forms of depression in paediatric populations estimate the prevalence of chronic depression in the child and adolescent population as between 0.1% – 8%. They therefore suggest chronic depression is a relatively common disorder.

A vast amount of literature (1741 articles) pertaining to dialysis related psychological problems was considered by Tsaltas (1976). None of this material is reviewed within

the final article. She drew the conclusion that none of the papers referred to the effect of dialysis of a parent on a child – a point contradicted by Evans (1978). The impetus behind her study appears to be a wish to discover more about childhood depression and it may be that this motivation has coloured the interpretation of the results.

Details pertaining to ethical approval and participant consent are not documented, although there appears to have been a consent process, as initially 10 families were asked to participate. Tsaltas (1976) states that six families consented to bring their children for the psychological tests (using the Minnesota Multiphasic Personality Inventory) and family interviews that formed the data collection. The author acknowledges that the participating group is highly motivated and essentially self-selected. There is no indication of the composition of the families, except the total number of children involved. It is unclear if they are a representative sample. The fact that these children, in this author's opinion, showed moderate to severe depression is a potential effect of having a parent on HDx. It is however made explicit that the exact cause of the depression is unknown, the possibilities that the child is identifying with a depressed parent or reacting to changes in home circumstances brought about by home HDx are both mentioned. In addition the stresses faced by these children are highlighted and how children may struggle to find words to express themselves.

In a small study, termed a pilot, Friedlander and Viederman (1982 p 100) looked at what they termed 'the fantasy life' of children hoping to gain insight into how the child perceived the parental illness. Only four references support this article which is sparse even given the lack of literature in the area. The children of both centre and home HDx parents were included in the 12 family sample. The assumption has to be made that some consent process took place, as 50% of the eligible centre HDx families declined to participate, but this along with other ethical issues is not documented. The authors do not consider whether this self-selection process affected the study results. The approach taken was that of a semi-structured interview with the parent. This focussed on how they perceive that the chronic illness has affected the child. From these interviews the researchers concluded that parents were not aware of what their children thought. The parents were often afraid the children would also develop renal problems, this was a source of guilt for the parents and in some instances altered the way in which medical attention was sought. Despite this

potential and understandable ‘over-protectiveness’ the parents were aware of the importance of family relationships and displayed a sense of pride at the coping mechanisms of their children.

The use of drawing as a research or therapeutic tool with children has been a subject of interest for a number of years. In a brief section in their book Greig and Taylor (1999) say that children’s drawings are believed to reveal the child’s inner mind. They do however sound a caution indicating that drawings are particularly susceptible to false interpretation and suggest that drawing should be used as part of a strategy where the interpretations can be linked with a variety of other sources of information. More recently Driessnack (2005) undertook a meta-analysis looking at how children’s drawings can help their voices to be heard, she concluded that there were ‘strong and definitive results supporting the use of drawings to facilitate communication’ (p 421). In her summary, Driessnack (2005), notes that ‘offering children the opportunity to draw appears to be a potentially exciting way of engaging and involving children as active participants’ (p 422) – in other words, encouraging drawing but also listening to and using the explanation the child gives to accompany their picture to enable fuller understanding. The 14 children (aged 7-14 years) who participated in Friedlander and Viederman (1982) study were asked to draw a picture and tell the story relating to it. This technique worked well, and elicited good data from the authors’ perspective. The same drawing technique was administered to six children of healthy parents – it is not clear why this control group comprised six children or how they were selected or approached. A standard set of questions was also asked of each participating child – however the authors felt that this method did not ‘promote dialogue’ (Friedlander and Viederman 1982 p 101) in the same way that the drawing technique did. This is perhaps echoes of Tsaltas (1976) and children finding it difficult to express themselves using words. The results concentrate mainly on the children’s drawing, the interpretation of which is performed by the authors – there are no reproductions of the drawings, although some descriptions are given. The interpretation of the children’s drawings showed, amongst other things, aggressive tendencies. Several other authors have noted behavioural changes which may affect the long-term development, health and well-being of the children. Molzahn and Kikuchi (1998) indicated that six out of 25 participants were not performing adequately at school. Hoover *et al.* (1975) also noted lowered school performance but also documented

incidents of stealing and increased aggression at home and with peers. Schlebusch *et al.* (1983) described some of the adolescents they interviewed as having difficulty socialising, and Tsaltas (1976) documented parental concerns that home HDx may interfere with children's recreation and socialising with peers.

In an article paying tribute to carers of renal patients, Auer (2002b) puts in a paragraph about child carers – in the context of dialysis dependent patients, but offers no evidence from the literature to support her words. This is surprising as she writes about children often appearing to take everything in their stride, but highlights potential problems at school with behaviour or under achievement. These latter two problems were highlighted by the work of Tsaltas (1976). Auer (2002b) also mentions how children may receive less time or attention than they need because the parent becomes absorbed in their illness and treatment, a point made by Friedlander and Viederman (1982) and reinforced by Schlebusch *et al.* (1983). Evans (1978) describes the importance of social support in allowing children to adjust to parental illness and dialysis treatment. Children have specific needs which if met help them to grow and develop; the following section looks at these specific needs as identified by the reviewed research.

2.2.2 Specific needs of children

It is now acknowledged that the needs of children differ from those of adults (Greig and Taylor 1999). In an article written from professional experience Dingwall (2001) considers the social needs of patients with renal failure. He writes briefly about working with families where there is CRF and gives advice against trying to protect children from the realities of illness and treatment. However despite the relative abundance of literature considering psychosocial aspects of CRF and the impact on the family no evidence in support of this statement is offered. This article begins to give insight into the specific needs of these children, but does not identify or give advice about meeting these needs.

The needs of adolescents are explored by Goldman *et al.* (1980 – 81). The investigation focussed on the adolescents' reactions to a father on home HDx. It should be noted that there is a discrepancy between the title of the published paper and the original definition given below for inclusion within the study. This arises

because the researchers wished to include any family with a parent on HDx, however, in the event in all the families recruited to the study it was the father on home HDx.

The term adolescent is defined within the context of the family:

Families were asked to participate in the study if the family included at least one son or daughter between the ages of twelve and twenty-one years who was living at home (or who had lived at home within five years prior to the study) while a parent was on home dialysis.

(Goldman *et al.* 1980 – 81 p 236)

This article is unusual in containing a definition, since most of the articles lack key definitions, for example, of the term family, leading to ambiguities. Eight families met the Goldman *et al.* (1980 – 81) criteria for inclusion within the study however only six of these families agreed to participate. The authors view the family as central to the work. The presented literature review was minimal but did highlight the dearth of information relating to the effects on children of parental dialysis. The two studies cited were Tsaltas (1976) and Evans (1978), both of which are considered within this review. Nearly 50% of the text is used to present a cameo of each participating family, and also in providing tables allowing comparisons of the participating families and the two that did not. Within the six families there were 16 adolescents, who then, it appears, underwent a separate consent process, as only 15 chose to complete the study. Interviews were undertaken, with the family as a whole, the patient, the spouse and the adolescents. The adolescents were interviewed privately for between one to two hours. Some of the topics explored within the interviews are given. Goldman *et al.* (1980 – 81) identified that this group of adolescents had specific emotional and information needs in relation to their father's dialysis. An additional observation worthy of note was that information about the illness was generally given by the mother – within this study the spouse – not the patient.

It is suggested by Evans (1978) that many of the needs and problems encountered by children are moderated directly by the amount of social support available to them. The motivation behind this article appears to be a desire to contradict the Tsaltas (1976) publication. Evans (1978) feels that there is literature that relates to children and parental dialysis that should have been considered by Tsaltas (1976). In addition he presents 'reflections on interviews I have had with several dialysis patients, families, and dialysis unit staff members' (Evans (1978) p 343). This paper is

essentially an opinion paper looking, at a superficial level, at the adaptation of children to parental HDx. The number of participants is unknown and it is unclear if children were directly involved.

A study described as exploratory and descriptive in design set out to report the quality of life of both children and adolescents who had a parent on dialysis (Molzahn and Kikuchi 1998). In this study both HDx and Continuous Ambulatory Peritoneal Dialysis (CAPD)⁹ are considered. The children were chosen as the focus of the study as, from their literature review, the authors concluded that although effects on the children were considered, these were usually from the parental perspective. This research was therefore seen to begin to redress the balance, and investigate the perspective of the child or adolescent. A convenience sample of 25 children between the ages of 8 and 16 years took part. Interviews were private, in their own homes and researchers returned up to three times. The theoretical framework for the study was the Aristotelian-Thomistic concept of the good life. Molzahn and Kikuchi (1998 p 411) describe this concept as ‘a compendious set of propositions about the real goods that must be attained and enjoyed in the right order and proportion for a person to have a good life.’ This then leads to their definition of quality of life for the study which is ‘the good life or happiness, in the ethical (rather than the psychological) sense.’ The Aristotelian-Thomistic concept of the good life defines seven types of goods that must be attained for a good life, they are real goods and as such meet human needs. These are given as

- goods of the body
- goods of the mind
- goods of character
- goods of personal association
- social goods
- economic goods
- political goods

Molzahn and Kikuchi (1998 p 412)

The above ‘goods’ are defined within the article and are also used within the data analysis to provide the themes and categories. The study concluded that these

⁹ Continuous Ambulatory Peritoneal Dialysis (CAPD) – A type of peritoneal dialysis carried out manually during the day, by the patient or their carer (Wild 2002 p 224)

children appeared to have what was necessary for a good life, however more information (goods of the mind), particularly in relation to how other family members were feeling and specifically regarding parental condition and treatment, would enhance their life. This is similar to the findings of Goldman *et al.* (1980 – 81) and highlights the need for relevant information which is accessible to the child. Giving children information may help them to cope with parental CRF and a variety of coping mechanisms have been identified from this literature, these are considered within the next section.

2.2.3 *How children may cope*

One study was identified which is not a product of North American research, that of Schlebusch *et al.* (1983) working in South Africa. The study group chosen were adolescents with an age range of 13 – 18 years. Potentially, therefore these individuals were a very different adolescent group to those interviewed by Goldman *et al.* (1980 – 81). The study also had other features which set it apart from the studies considered so far. Schlebusch *et al.* (1983) chose centre HDx, not home HDx as the treatment. This was because during the course of their literature review Schlebusch *et al.* (1983) felt that the area of home HDx had received more attention. The study was also the only one that used an experimental approach. Four dialysis families from the centre met the criteria of having adolescent children. These families contributed eight children, four boys and four girls to the ‘experimental’ group. These adolescents were matched for age, sex and socio-economic class with control families who were said to have good physical and mental health. The small sample size is acknowledged. The authors used two standard psychometric tests and a clinical interview. No details were forthcoming regarding the content of the clinical interviews. Statistical analysis was performed using the Wilcoxon matched-pairs signed-ranks test, despite the small sample size. This test is frequently used in behavioural sciences research, as it requires paired data and the ability to rank the differences between pairs. It can be used with small sample sizes (Siegel and Castellan 1988). Schlebusch *et al.* (1983) stressed that dialysis is not just a patient-hospital dyad, but that the children are affected. They identified that the adolescents of haemodialysis patients can appear more self-sufficient than their counterparts with healthy parents. This can be seen as a coping mechanism.

Two of the studies considered in previous sections, Evans (1978) and Goldman *et al.* (1980 – 81) specifically mention children taking on a caring role and helping with parental dialysis. The latter study identified that 50% of the adolescents were specifically involved in helping with their father's dialysis treatment. This appears to have had a positive effect in promoting confidence and enhancing the adolescent's self-esteem. As Evans (1978) was considering the selection of dialysis setting – home or centre – and Goldman *et al.* (1980 – 81) looked specifically at home HDx patients with adolescent children, the finding and commenting on the involvement of children is probably not surprising.

Pseudomaturity and identification with the sick parent were described by Friedlander and Viederman (1982) when interpreting the children's drawings. These are potential mechanisms children can employ to help cope with chronic parental illness. In addition Evans (1978) described how parents wish to appear 'normal' in front of their children. This may sometimes influence where haemodialysis takes place. It has been noted by the researcher that parents frequently make the assumption that children will cope better if dialysis is based within a hospital, as the child does not then have to face the disruption at home. This effort to help children cope with parental illness may in some instances be misguided as Tsaltas (1976) indicates. Children and families cope differently with situations and for some children the separation that occurs with attendance for hospital based haemodialysis is harder to cope with than the disruption to the routine when dialysis occurs at home.

2.3 Discussion and conclusions from the literature review

This chapter has drawn on the available literature to consider the potential effects on children who have a parent with CRF. It has highlighted the lack of information surrounding this area. The material is dated, and in addition none emanates from the UK. In the light of Whitehead's (2004) comments, this project therefore has the potential to contribute to nursing knowledge. The review has answered the question posed at the beginning of this chapter. There do appear to be documented effects that could be attributed to having a parent with chronic renal failure. Most of the identified effects on children appear negative, specifically depression (Tsaltas 1976), behavioural problems and under achievement (Friedlander and Viederman 1982, Auer 2002b) and pseudomaturity (Friedlander and Viederman 1982, Schlebusch *et al.*

1983). However, there did appear to be some positive effects, notably enhanced self-esteem (Friedlander and Viederman 1982, Schlebusch *et al.* 1983) and the possession of a 'good life' (Molzahn and Kikuchi 1998).

In addition to answering the question posed, the review has been used to inform and shape the research project. The implications for the research project are documented in Table 2.3. Hoover *et al.* (1975) asked where children obtained their support, and this can be linked with Evans' (1978) proposal that the problems encountered by children are moderated directly by the amount of social support available to them. The needs of the children may not always be visible, particularly when attention is focussed on an adult member of the family. It is however, important to be aware of the needs of the whole family and offer support as appropriate. Goldman *et al.* (1980 – 81) identified that children had specific information needs in relation to dialysis, and more recently Molzahn and Kikuchi (1998) felt that the children and adolescents they studied had unmet information needs. The effects on children are often considered by a 'third party' as was evident in the work of Hoover *et al.* (1975). Given the finding by Freidlander and Viederman (1982) that nearly all the sick parents in their study reported 'a lack of awareness of their children's thoughts and feelings about chronic illness in the home' (p 101), it would appear that asking the parents about children's information needs is not necessarily the approach to take. However, eliciting information from children can be a challenge in itself. Techniques relying solely on the use of words may not allow the children to express themselves freely (Tsaltas 1976, Friedlander and Viederman 1982). The implications for practice of these findings are profound. Not only do we frequently ask the wrong questions of the wrong people, but in addition, the materials may not be available to provide the information in the variety of forms suggested by the NSF for children (Department of Health 2003).

Table 2.3

Summary of the effects on children of having a parent with chronic renal failure and the potential influences on the research project

Effects on children of having a parent with chronic renal failure	Literature identifying effect	Influence on research project
Children could be at risk and therefore need to be identified to promote optimum growth and development.	Hoover <i>et al.</i> (1975)	Conversance with child protection procedures and the ability to make referrals if required. Awareness that some children may show psychosocial problems that will require referral – this provision must be built into the research design.
Children showed moderate to severe depression.	Tsaltas (1976)	
Behavioural problems and under achievement.	Hoover <i>et al.</i> (1975), Tsaltas (1976), Friedlander and Viederman (1982), Molzahn and Kikuchi (1998), Auer (2002b)	
Children face real stresses and often cannot find the words to express themselves.	Tsaltas (1976), Friedlander and Viederman (1982)	Consideration of the methodology used – ‘wordy’ techniques may not work well as some children may find it difficult to respond in this way
Children actively involved in helping with parental treatment at home.	Evans (1978), Goldman <i>et al.</i> (1980 – 81), Schlebusch <i>et al.</i> (1983)	That for some children there can be positive benefits of having a parent on dialysis – they may consider it ‘normal’ for them.
Children experience enhanced self-esteem by helping their parent.	Friedlander and Viederman (1982), Schlebusch <i>et al.</i> (1983)	
Problems encountered by the children are directly moderated by the amount of social support available.	Evans (1978)	Appropriate referrals may be required to support a child/children
Children have specific emotional and informational needs that need to be met.	Goldman <i>et al.</i> (1980 – 81), Molzahn and Kikuchi (1998), Dingwall (2001).	Appears to be a lack of material designed for children taken from a child’s perspective.
Pseudomaturity	Friedlander and Viederman (1982), Schlebusch <i>et al.</i> (1983)	That the children may appear mature in some areas but not in others – this may influence the age grouping of the children and the methodological approach.

This review has enabled clarification of ideas. It has indicated that the methodology requires careful application to ensure that the children are able to express themselves fully. It is hoped that this project will serve as an example of good clinical and research practice. It aims to unearth how parents feel that CRF affects their family and how they gained the necessary information, and then to progress to talk to the children of these families about their experiences. These children have a specific outlook and information needs, but to date, no research has been undertaken to identify and address these. Therefore, this project's goal in gaining the children's perspective would seem appropriate and in line with current policy whilst also making a unique contribution to knowledge in this area and having a clinical application. Children are important; frequently their views are not taken into account simply because they are children. Children often have a different view of the world to an adult, and it is therefore important that their views are taken into consideration when preparing a family for the challenges that chronic illness can bring. It is also important to acknowledge that the research reviewed has shown that children with a parent with CRF also have needs other than for information – these may be identified by this study, but are not the main focus of it.

The current study therefore proposes to approach a complex area of practice, considering how CRF impacts on the family – an area where there is some evidence to draw on to support practice. It then seeks to move on and look specifically at the information needs of the children within these families. This is an area where several of the papers (see for example Goldman *et al.* (1980 – 81) and Molzahn and Kikuchi (1998)) highlighted a problem which appears to have received little attention. Approaching these information needs from the child's perspective would appear to be in tune with current thoughts and legislation pertaining to children (Department of Health 2003). The next chapter considers the ethical issues surrounding this research project. Some of which have been highlighted by this literature review.

Chapter 3

Ethical considerations

3.1 Introduction

The conduct of a research project which proposes to include children as participants has the potential to be ethically challenging. However, Allmark (2002) concludes that to achieve optimal health care for children, ethically sound quantitative and qualitative research is required. He goes on to add that it is unlikely that there are any ethical issues which are unique to children, however the situations encountered tend to present in more unusual ways or with more force. This makes it essential to prepare thoroughly, particularly from an ethical perspective, for any research that intends to work with children for all or part of the project. This point is reinforced by Greig and Taylor (1999) who suggest that all potential ethical dilemmas should be considered before commencing the project. They do however suggest that even careful planning may fail and that this is more likely when the research participants are human, particularly children. This chapter will consider the origins of ethics in research and link this to the research in question with particular reference to the participation of human subjects, especially children. Given that it is only relatively recently that codes of research ethics have been developed that focus specifically on children the historical development of ethical codes for children is essentially identical to that for adults (Allmark 2002).

3.2 Professional regulation

From a nursing perspective the Nursing and Midwifery Council's (NMC) 'code of professional conduct: standards for performance, conduct and ethics' (2004) reflects the values nursing espouses. The code of conduct makes it clear that the laws of the country in which you are practising must be adhered to. The professional guidance for nurses appears clear, patients are to be respected as individuals and consent is to be obtained before any treatment or care is given. This has an impact not only on daily practice, but also on the nurse as a researcher, and therefore the code of conduct not only underpins clinical practice but should also guide ethical research practice.

3.3 Historical perspective

It helps to understand how the ethics of health care research have evolved to help set both the project and the ethical issues related to it in context. In addition there are legal principles which underpin healthcare research. These relate mainly to consent when human beings are involved as research participants, however an understanding of the law as it relates to data protection, privacy and confidentiality is also essential (Montgomery 2003). As Masson (2004 p 43) points out, although there is a close relationship between the law and ethics, not everything that is legal is ethical. The law is often seen to represent the minimal acceptable standard, whilst ethical aspirations are usually higher. Some areas of medical research have been the focus of media attention and therefore public concern. This has had implications for the research community and out of this has grown the Research Governance Framework (Department of Health 2001b), which draws on moral, ethical and legal principles. At the heart of research governance is the principle that ‘the dignity, rights, safety and well-being of participants must be the primary consideration in any research study’ (Department of Health 2001b p 8).

Prior to the Second World War there was little evidence of research ethics codes in a form that it is now understood. The assumption was made that self-regulation was sufficient as all were expected to follow the general principles of ethical and moral behaviour within the research setting. Alderson (2004) considers that the ancient professional codes, for example the Hippocratic oath, were the basis from which ethics were drawn prior to World War Two. However, with the ending of this war and the realisation of what had been happening within the concentration camps, efforts were made to attempt to ensure that systematic experimentation against basic ethical principles would be less likely to occur again. Since then regular reviews and changes have occurred to try to ensure the building up of an ethical approach to research which keeps in step with social and moral developments. These milestones in the regulation of research activity include the Nuremberg Code (1947), the Geneva Convention (1949) and the Declaration of Helsinki (1964). These will be examined in more detail in the paragraphs that follow. In addition two United Nations documents will be referred to, the United Nations Universal Declaration of the Rights of the Child (1959) and the United Nations Convention on the Rights of the Child (1989).

These have a specific bearing on this research project, as they are concerned with both protecting children and ensuring they have a voice.

3.3.1 The Nuremberg Code

The Nuremberg Code (1947), written by lawyers, gave 10 principles which were required to be satisfied before experimentation on human beings was deemed acceptable (Montgomery 2003). These included consent, the right to withdraw from the research, that experimentation on human beings would only occur when other avenues had been exhausted and the need for the benefit of the research to outweigh the risks to the research subjects. Although children are not specifically mentioned within this Code, they were part of the concern according to Greig and Taylor (1999) as children were involved in the Nazi experimentation. Children may have been part of the concern but Alderson's (2004) interpretation suggests that the Nuremberg code presumes that children are too immature to consent and are therefore unable to take part in projects that would not benefit them. Allmark (2002) reinforces this by underlining the problem of making the voluntary consent of participants at the heart of the code. This makes some research, for example on young children impossible.

3.3.2 The Geneva Convention

In 1949 the Geneva Convention added to international guidelines. The contribution this revision of the Convention made was that it could be related to civilians. Prior to this original forms of the Geneva Convention, dating back to 1864, were only applicable to combatants (Greig and Taylor 1999). The Geneva Convention (1949) also made specific provision for children as Greig and Taylor (1999) highlight. It allows for areas of safety to be set up for children under the age of 15, and mothers with children under seven. It therefore makes a statement about family life and goes on to prohibit inhumane treatment, including biological experiments. This therefore is a further indication that the rights of families and children are to be considered when planning and conducting research with these groups.

3.3.3 The Declaration of Helsinki

The final international statement to merit consideration within this section is the Declaration of Helsinki (1964); this has been reviewed and refined on numerous occasions since with the latest major amendments in 2000 (Montgomery 2003). The

Declaration of Helsinki (1964) was written by doctors and provides a standard for international ethics with research involving humans. It moved on from the Nuremberg Code and clarified the ten principles. More importantly for children as Greig and Taylor (1999) point out, it considered that children could be research subjects and looked particularly at the subject of informed consent. It regarded as essential obtaining the informed consent of the child as well as the legal guardian. The Declaration of Helsinki (1964) also provided the springboard for the setting up of independent research committees which have gradually metamorphosed into the research ethics committees we know today.

3.3.4 *The United Nations*

The United Nations Universal Declaration of the Rights of the Child (1959) also has implications for this research. It sets out fundamental human rights to which every child is entitled, like the Nuremberg code it has 10 principles which try to ensure that a child has a happy childhood. The United Nations Convention on the Rights of the Child (1989) is a much longer document which has been adopted by all countries except Somalia and the United States of America (Kellet *et al.* 2004). This latter document has particular bearing on this project. Article three is concerned with always acting in the best interest of the child, whilst Article 12 states

‘State parties shall assure to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child.’

(United Nations Convention on the rights of the child, 1989, Article 12).

It would appear therefore that researchers have been subject to increasingly strict controls since the Second World War. However, Allmark (2002) suggests that the effects of international regulation were not immediate and details the consternation which followed the publication of two reviews in the mid 1960’s suggesting that much unethical research, including research involving children, was still taking place and that some of the findings were being published in respected medical journals. It would appear that even today this may still be the case as when Bauchner and Sharfstein (2001) reviewed the publications relating to child health in five American journals they concluded that 40% of the papers reviewed did not report ethical

approval. This was an unexpected result, as all the journals in question specifically ask authors to include details of ethical approval in their manuscripts. This chapter now moves on to consider the ethical principles by which the research project will be judged. This looks at the science behind the project, the best interests of the participants and their autonomy.

3.4 The principles of ethical research

A knowledge and understanding of the history of ethics is important, however this has to be translated into a research project that is morally and ethically acceptable to all parties. The principles which lie behind judging how ethical a research project is can be couched in a variety of terms. Foster (2001) sees them as related to the areas of science, best interests and autonomy. Foster (2001) goes on to suggest that all healthcare research studies involving the participation of humans should be analysed and judged on these three points, although in different circumstances it may be seen that one point holds more sway than another, and this may change with the differing nature of research studies. These three terms – science, best interests and autonomy – link with the broad areas which research ethics committees are asked to consider, that is, the scientific validity of a project, the welfare of the participants and the respect for the dignity and rights of the participants (Allmark 2002). The three areas identified by Foster (2001) will now be examined and linked to the appropriate area that would interest the ethics committee, and also to specific issues relating to this research project.

3.4.1 Science

Science relates to the necessity for the research, its goals and the extent to which the research methods proposed will achieve the goals reliably, this is the scientific validity of a research project. The research should be seen as valuable, with clear objectives. The methods used to achieve these should be clear and reliable, and the means of disseminating the results should also be identified. The aim is to cause improved health with little harm. This notion is based on the principle of utility, first expounded by Jeremy Bentham (1748 – 1830) within his discourse on maximising happiness. Utilitarianism can help to identify the goals of the research and should help the consideration of the consequences of the actions. Within this philosophical idea of utilitarianism, it is the consequence of an action that is important, not the

action itself. This has the potential to cause problems as it may be seen to justify causing harm to some participants. However, it can be useful as part of the judgement regarding what makes a project ethical.

Alderson (2004) describes how there may be conflict between science and ethics, but feels that it should be possible to maintain high standards in both disciplines. It would appear however that the science behind qualitative research may be poorly understood and therefore has the potential to expose participants to undue risk. Within the Department of Health (2001d) guidance '*Seeking consent: working with children*' non-therapeutic research is mentioned where the child is unlikely to benefit from any proposed intervention. It considers that much nursing research will fall within this category and gives the examples of interviews with children or asking children to draw pictures. Legally the courts have decided:

‘that people with parental responsibility can consent to a non-therapeutic intervention on a child as long as that intervention is not against the interests of the child and imposes only a minimal burden’

(Department of Health 2001d p 25)

However the impact of qualitative research can be underestimated. It is generally thought of as ‘low risk,’ qualitative methods do not tend to cause physical harm, however it may unearth psychological issues for the children or their parents (Allmark 2002) or in the longer term policies may be developed using findings which ultimately offer no benefit and may indeed cause harm (Alderson 2004). Therefore it is essential that there is the provision to deal with these risks inherent within the research project. In this project a clear means of accessing psychological support was provided for both adult and child participants. The unit counsellor was aware of the project and more specifically that participants might wish to contact her as a result of their participation in the project. The information sheet (Appendix 4) provided the name and direct telephone contact details of the counsellor who could therefore be accessed without need to involve the researcher. For children the contact details of the consultant paediatric psychologist were given on the adult and teenage information sheets. All children met the consultant paediatric psychologist as she co-facilitated the focus groups. In addition the family doctor was informed by letter of the family’s participation in the study (Appendix 5), in case this was the route of

support chosen by the participant. The family doctor was given the contact details of the researcher as well as the contact details for the provision of psychological support for both adults and children. Participants were made aware that their family doctor was informed of their inclusion in this research study. In summary this project uses qualitative methods but the potential risks to participants have been acknowledged and provided for. It is also hoped that ultimately families and children will benefit from having a voice.

3.4.2 Best Interests

The moral obligations of the research are behind the concept of best interest, where actions are related to moral principles. This should ensure that the healthcare researcher always does what is in the best interest of the participant. This part of the triad is concerned with the actions, not with the results. Foster (2001) suggests that this part of the thinking process in relation to ethics can sometimes give a basis to intuitive feelings that something is not right with the research project. The duty of care should override the duty to achieve reliable research results. One issue with this area is that it can be seen as paternalistic in that the researcher determines what is in the best interests of the participant, rather than the participant themselves deciding. Both the United Nations Convention on the Rights of the Child (1989), which looks at the best interests of the child in article three and the Children Act (1989) have implications for the involvement of children in research. The two fundamental principles of the Children Act (1989) as identified by Montgomery (2003) are:

- the welfare of the child is paramount (i.e. the needs of the child)
- the best way to achieve welfare is to support care of children in their families

The Children Act (1989) encourages adults to be more aware of what children say about experiences, feelings and how they understand the world around them (Coyne 1998). There is therefore an argument that children should be involved in research to ensure that their best interests are considered and, in that case, asking children to participate should not be seen as paternalistic but should be seen as enabling children to give their opinion. This will only happen if children are asked questions about their

experiences - this research project gives children, as well as parents the chance to talk about the influence of CRF on their family life.

3.4.3 Autonomy

The consideration of the autonomy of the participant is the final requirement for an ethical research project, enabling the person to decide whether to participate or not. This area should look at the needs and wishes of potential research participants and leads into the areas of consent and confidentiality which are pivotal when considering autonomy. In turn consent moves into an exploration of the areas of competence and information giving whilst confidentiality incorporates data protection.

3.5 Consent

For consent to be gained and valid it must be

- given by a competent person
- adequately informed
- voluntary

(Foster 2001 p 57)

Issues of consent and confidentiality have the potential to cause concern in any study, and are vital for participants in assuring that their autonomy is respected. When children are involved these issues are likely to be multiplied. Obtaining consent prior to giving care, or enrolling a participant in a research project is fundamental to good practice (NMC 2004) and a requirement of the law (Department of Health 2001d). Within the Department of Health (2001d) guidance, *Seeking consent: working with children* there is a brief consideration of consent and the research process. This section of the document opens by stating, 'The lawfulness of research on children who lack capacity has never been explicitly considered by the English courts' (Department of Health 2001d p 25).

3.5.1 Competence

The issue of competence is relatively straightforward for adults – within the UK everyone over the age of 18 years is viewed as competent unless there are specific reasons to believe that they are not, for example an unconscious person (Foster 2001).

However, for children the issues are not so clear cut, children can be deemed competent to differing degrees and in differing circumstances. However, the guidance given by the Department of Health (2001d) states that if a child is competent to give consent for themselves, this consent should be sought, this reflects article 12 of the United Nations Convention on the Rights of the Child (1989). Good practice dictates that where possible, even when a child is competent, that families are also involved in the decision making process where possible. For a person to be deemed competent (have the capacity) the Department of Health (2001d) guidance states that they must:

- comprehend and retain information material to the decision, especially as to the consequences of having or not having the intervention in question, and
- use and weigh this information in the decision-making process

(Department of Health 2001d, p 4)

Under general law, a child (minor) is any person under the age of 18 years (Family Law Reform Act 1969). However, there are various grey areas particularly in the area of consent. The Department of Health (2001d) highlights the differing legal positions for children aged 16 and 17 years and those under 16 years. The Family Law Reform Act (1969) states that at 16 a child can consent to treatment as if she or he were an adult. It would appear that the use of the word treatment is open to some interpretation (Montgomery 2003). The landmark case that tested this principle was the ‘Gillick case’ (Gillick v. Wisbech AHA [1985] AC 112). This went to the House of Lords where a majority decision held that a child is capable to consent if the child ‘has sufficient understanding and intelligence to enable him or her to understand fully what is proposed.’ This ‘test of maturity’ needs to be considered for each child and with each procedure, it may be that a child is deemed competent to consent to some procedures, but not others. Interestingly this ruling predates Article 12 of the United Nations Convention on the Rights of the Child (1989), which echoes similar sentiments. The Department of Health guidance brings the matter up to date concluding ‘there is no specific age when a child becomes competent to consent to treatment: it depends both on the child and on the seriousness and complexity of the treatment being proposed’ (Department of Health 2001d p 5). This would seem to be a principle which could be transferred from the consent to treatment to the consent to

participate in research, however Foster (2001) sounds a note of caution. She feels that a court may take the view that a greater level of competence was required to consent to participate in a research project than to consent to treatment. This is on the grounds that to be deemed competent to participate in research a child may be required to understand concepts such as altruism or randomisation.

3.5.2 Information

To achieve a valid consent, information needs to be given in a format that is appropriate for the person receiving it. This is true for both adults and children. The United Nations Convention on the Rights of the Child (1989) article 13 discusses freedom of expression and the right to seek and receive information. Within the guidelines of the ethics committee the format for information giving appears to be strictly regulated. The information given to adults is within a set format, with some of the paragraphs for inclusion given verbatim. It appears biased towards quantitative research. Although this can present a challenge to the researcher using qualitative methods, it is surmountable when designing an information leaflet for adults. The adult information sheet for this research is given in Appendix 4. Children too need information on which to base their decision whether to participate in a research project or not. This information needs to be presented to them in an easily understood fashion. Coyne (1998) suggests that time is invested in the production of leaflets to ensure that they are well written, clear and that child friendly language is used. The Department of Health (2001d) suggest various ways of providing information other than the use of appropriate language. Pictures, toys and play activities and drawing on the skills of specialist colleagues may all be ways of enhancing the information given to children and their parents. The leaflets produced for this research project (Appendix 6) took the form of a flow chart, they were colourful, included pictures and were written in child friendly language. An example of such language was to say that the focus group would last as long as two average length children's television programmes.

As part of the ethics approval process for this research (see section 3.7) the ethics committee asked that written consent was obtained from all participants. According to Montgomery (2003) it is the reality of consent that matters, not its form, as there is no legal distinction for consent – be it written, oral or implied. However, having

written evidence is the clearest proof that consent occurred and it is therefore preferred by institutions as it provides good evidence should that be required. Within this research written consent was obtained from all the adults who participated (see Appendix 7 for adult consent form). Additionally, at the beginning of each interview, the verbal consent of each adult participant was recorded. The position taken with children was that the ethics committee requested that a parent, as well as the child signed the consent form (see Appendix 8 for child consent form). This is an interesting point. Coyne (1998) when writing about some of the ethical challenges of researching with children was put under similar constraints. The children involved in her research were aged between seven and fifteen and all felt that their consent alone was sufficient for participation. Indeed some of the parents declined to complete the form stating that their children would only participate in the research if they wanted to, regardless of the wishes of the parents. The Department of Health (2001d) guidance, *Seeking consent: working with children* states that

‘where children are competent to give consent for themselves, their own signature on a consent form is sufficient without the need for their parents also to sign. If parents have been involved in the decision, however, it may be appropriate for both the child and their parent to sign.’

(Department of Health 2001d p 16)

The request that consent was obtained from both the child and the parent was felt to be reasonable in the case of this research. The ethics committee had requested it, but in addition the research was looking at the whole family and therefore it was a family decision to participate. Indeed at least one family did not participate because, having discussed the research project with their children, one of the children did not wish to take part, and therefore the whole family declined to participate. A pragmatic point is also added by Allmark (2002) that there is often a practical necessity for parental co-operation, which was certainly the case in this research, as parents were asked to bring their child or children to attend a focus group.

3.6 Confidentiality

The respect for confidentiality that health professionals give has a long ethical tradition, and is enshrined in the Hippocratic oath (Montgomery 2003). For nurses it is within the NMC Code of Professional Conduct (2004), and is one of the

cornerstones of the nurse-patient relationship. Within the research setting, Allmark (2002) suggests that the principle underlying confidentiality is that the data generated can only be used for the purpose for which participants have given their consent. For researchers using qualitative methods, there are additional issues which require thought before embarking on the research process, and there are also specific confidentiality issues relating to children which need consideration. When undertaking qualitative research, the number of participants in the research is usually small, as it was with this research, just seven families. Care must therefore be taken to protect anonymity, thereby respecting confidentiality. In this research the families were all given a number and members within the family were also numbered. Allmark (2002 p 16) notes the possibility of unearthing 'unsought' data. This may be particularly pertinent to children if some evidence of abuse was uncovered. Here it is allowed to breach confidentiality, and to pass the evidence on to the appropriate authorities to enable the issue to be dealt with. However, it is important that knowledge of local child protection policies is gained prior to commencing data collection. Working with both parents and children also has confidentiality issues. The parents may ask about the content of their child's input into the focus group. Coyne (1998) details a father's request for information about his son's interview and her polite refusal to divulge the information. Montgomery (2003) expresses the view that children are entitled to the same level of confidentiality as adults. Coyne (1998 p 414) states categorically that 'confidentiality of all data is a fundamental part of respecting and protecting the participant in any study.' It appears clear that children should be afforded the same rights as adults with respect to confidentiality except in the case where specific information, such as relating to child abuse, has been revealed. Here the researcher has a duty to divulge the information for the future protection of the child. There are also issues of confidentiality within the focus group. The children were aware that the focus group was being recorded – as well as talking, some of the children made models, which they kept, or did drawings which they also kept – some showing them proudly to their parents. With the drawings the researcher asked permission from the child to take a photocopy to keep for future reference. It is possible that there were discussions within the family following either parental interviews or the child's attendance at the focus group. The children all seemed to relish the opportunity to talk about their family life.

3.6.1 Data protection

Data protection is governed by the Data Protection Act (1998), which incorporated established law on confidentiality and replaced a more piecemeal approach. Within this project data were recorded using a 'dictaphone' system – this meant it was only possible to replay the material through the dictaphone or via the transcriber. The material from the interviews and focus groups was transcribed by medical secretaries who have an understanding of the importance of confidentiality through their daily work. When not in use the tapes were kept locked in storage. Only the family or focus group number identified tapes. All transcripts were password protected and at the end of the project the tapes will be securely stored for 15 years.

3.7 The process of ethical approval

Within the institution in which the research took place, a pathway is in place to ensure that all research undertaken was known about, and was presented for review to appropriate places to fulfil obligations resulting from the Research Governance Framework (2001b). Initially a brief research plan was presented to the Directorate Research Committee for comments. Registration with the Trust Research and Development Office was then required to fulfil the Trust's obligations under its research governance strategy. Once the project has been registered, an identification number is issued without which the administrator of the research ethics committee will not accept the documentation required for submission to the ethics committee. This project was submitted for review by the ethics committee in July 2003. The ethics committee granted it approval subject to confirmation of the following points: It was requested that the focus groups for children should be during out-of-school time. This was not explicit within the submission and was an omission – the intention had never been to hold the groups within school time. Due to the standard nature requested for the information sheet the researcher had followed the guidance and, as requested, used headed paper for all three sets of information. This proved a specific issue with the child information sheet as it meant that the information went onto two sides of paper. However, following review by the ethics committee permission was given to use a 'small address' rather than headed paper, thus enabling the information to fit onto one page. A change in font was also recommended to make the information appear more child-friendly. After the changes were made and accepted the ethics administrator asked if it would be possible to use the information sheet

(Appendix 6) as an exemplar for other researchers, to help them to produce more child-friendly information. Other minor changes were requested to the remaining information sheets. A copy of the letter confirming that ethical approval had been granted is given in Appendix 9.

3.8 Summary

The discussion surrounding the ethics of this research project is particularly important because of the involvement of both adults and children. As Coyne (1998) indicates, our experience in involving children in research is still relatively new and therefore raises more concerns than research involving adults. These issues need to be debated both to help future researchers who wish to involve children in their research and to ensure that children's rights to be heard are protected. The next chapter moves on to discuss the methodology chosen to achieve the aims of the research.

Chapter 4

The study design

4.1 Introduction

This chapter covers the overall methodology, my own professional interest in the topic and the influences these had on the methods chosen to achieve the aims of the research. This linking of the philosophical origins of the methodology with the methods used is particularly important in qualitative research, as Whitehead (2004) indicates because it helps a reader assess the trustworthiness of the research. It is also important because none of the philosophers considered within this discourse developed research methods *per se*, they developed philosophies and it is these ideas that are used to underpin much qualitative research today (Fleming *et al.* 2003). Following discussion of the methodology this chapter moves on to describe and justify the methods chosen for data collection. This includes a discussion regarding sampling and recruitment strategies. Both parts of the research are considered. The chapter concludes with a reflection on the ways used to enhance rigour within this research.

4.2 Methodology

The methodology is seen by Van Manen (1990) as referring to the philosophical framework: the fundamental assumptions and characteristics. Lavery (2003) sees the methodology as a creative approach to understanding, using whatever approaches are responsive to particular questions and subject matter. The theoretical underpinning for this work is phenomenological as it seeks to unearth the experiences of families as they live with CRF. Phenomenology is seen by Annells (1999 p 6) 'as an interpretive, qualitative form of research, the study of a phenomenon.' Jones (2001) characterises phenomenology as seeking 'truth and logic through both critical and intuitive thinking' (p 65), he feels it can offer creative ways to investigate human experience. Within nursing, many of the phenomena studied are human experiences. The term 'lived experience' is often used. This approach would therefore appear to fit well with the aims of the research. The phenomenological approach is frequently used within nursing research. Van der Zalm and Bergum (2000) state that it contributes to a variety of knowledge types including empirical, moral and personal, but go on to

point out that hermeneutic phenomenology will not prescribe action for clinical practice. However, practice should be influenced by phenomenological research by, for example, promoting reflection on practice.

The term phenomenology is however often applied generically, frequently with little understanding of what lies behind it (Koch 1995), this can lead to a lack of clarity in the concept of phenomenology (Jones 2001). This notion is supported by Lavery (2003) and Fleming *et al.* (2003) who feel that the terms phenomenology and hermeneutic phenomenology are often used interchangeably with limited thought given to the essential differences between them. It is constructive therefore to explore the overall nature of phenomenology and identify the principles guiding this research. The roots of phenomenology, in a philosophical sense, are clear. However, it has developed, evolved and in doing so has become a complex construct with much to offer but also with pitfalls along the way. The fact that phenomenology is still evolving and dynamic is seen as important (Lavery 2003). A further caveat must be added before the discussion begins. Languages are living and meanings frequently change over time. As Geanellos (1998) points out, the works used by most nurse researchers on which to base their philosophical exploration of phenomenology have been translated into the English language, in a way they have already been interpreted. Gadamer (2004) puts this more strongly, 'for every translator is an interpreter' (p 389). This leads on to a point made by Fleming *et al.* (2003) who indicate that some assumptions, which are taken for granted, may not in fact be what was intended by the original writer. With these points acknowledged, within this work, where original sources have been used, they are translations into English with all the potential pitfalls that entails. There is a burgeoning literature that claims to draw on phenomenological principles, much of which contains obscure language. The overview that follows attempts to capture the main pathways of phenomenology, concluding with the guidance this philosophy has given the research.

The pioneers of phenomenology are seen by Jones (2001) as Franz Brentano, Carl Stumpf and Edmund Husserl with later developments by Martin Heidegger and Hans-Georg Gadamer. The movement progressed through Europe, beginning in Vienna, moving to Germany and finally to France with the involvement of John-Paul Sartre and others and the merging, as some see it, of phenomenology with existentialism.

4.2.1 Husserlian phenomenology

Edmund Husserl (1859 – 1938), who studied under Franz Brentano, is the acknowledged father of phenomenology according to Holloway and Wheeler (1996). Husserl gives guidance to researchers who wish to investigate phenomena but not make assumptions or judgements about them (Koch 1999). In essence the work is purely descriptive, attempting to uncover the meanings of experiences as they are lived through by the participants – it is an attempt to describe reality. Corben (1999) agrees that, in its purest form, phenomenology is a descriptive form of research. She goes on to state that it is important, when describing the phenomenon in question, to achieve a full description. This should be done by including a description of both the phenomenon itself and how it is perceived by the participant. This approach however has difficulties. Husserl advocated an objective approach, in keeping with the scientific traditions of the day (Fleming *et al.* 2003). This includes the notion of bracketing, terminology which probably reflects his move from a mathematical background into philosophy. Bracketing is seen as a fundamental principle within Husserlian phenomenology but the means of achieving it are frequently not discussed within published nursing research (Beech 1999). Beech (1999) goes on to describe bracketing as

‘a means whereby the philosopher could look at things as they actually appear, unencumbered by any preconceptions, biases or judgements. In other words, by adopting this presuppositionless approach of holding the world ‘in brackets’ in the mathematical sense, the philosopher can return to pure consciousness of the phenomenon.’

Beech (1999 p 36)

Bracketing is acknowledged as a controversial topic within nursing research that takes a phenomenological approach. Paley (1997) considers that many nurse researchers misunderstand some of the essential concepts at the heart of Husserlian phenomenology. Included within this is bracketing. Many of the techniques described by nurses as bracketing appear not to be true to the original concepts that Husserl described and understood. As Paley (1997) is at pains to point out this does not necessarily negate their usefulness but it does return to Koch’s (1995) point regarding understanding of the philosophy, its terms and its appropriateness.

4.2.2 The influence of Heidegger – hermeneutic phenomenology

The ideas of Husserl were developed by Heidegger (1889 – 1970), who at one stage was a student of Husserl (Moules 2002). Heidegger, who came from a theological background (Lavery 2003), incorporated ideas from hermeneutics into his development of phenomenology; this therefore adds interpretation onto the description advocated by Husserl, in doing this Heidegger moved as Fleming et al. (2003) puts it from knowing to understanding. Hermeneutics itself has a long and colourful history. Moules (2002) describes how hermeneutics, the practice of interpretation, has its roots in the interpretation of biblical and theological texts in the 17th century. The term itself originally derives from Hermes, the Greek messenger god, who put the words of the gods into a form that mortals could understand (Pascoe 1996, Moules 2002). In other words Hermes took the words of one set of people – the gods and put them into a form that another set of people – the humans could understand. Within the realm of hermeneutic phenomenology the researcher takes the words of the participants and describes and interprets them so that a deeper understanding of the phenomenon is available to be studied. This is different to the Husserlian approach where the researcher takes the words of participants and purely describes the phenomenon as seen by the participant. This too can lead to understanding, but potentially of a different form.

Heidegger did not feel that bracketing oneself from the situation under investigation led to a full understanding and interpretation. Heidegger used the term historicity of understanding and incorporated the idea of the hermeneutic circle. The exact origins of the hermeneutic circle are unclear (Geanellos 1998), however what does appear clear is that its conception predates Heidegger considerably. In attempting to interpret the historicity, Koch (1995) describes how when humans come into a situation, there is a common background and culture, something which has to be acknowledged but that cannot be removed or 'bracketed'. The background of both the researcher and the participants is therefore important and influences the understanding and the interpretation. The hermeneutic circle is the continuous process of understanding and interpretation between the researcher and the participant looking at the phenomenon in question in part and as a whole, from their worldview. However, Jones (2001) extols caution in the use of Heidegger's existential phenomenology which he feels is both 'pessimistic and subversive' (p 73) and provides little potential for change. An

important caveat must also be added before the ideals of Heidegger are espoused. Both Holmes (1996) and Jones (2001) discuss the political beliefs of Heidegger and the influence this had on the development of his interpretative phenomenology. Heidegger was apparently committed to Nazism, and Holmes (1996) suggests that nurses need to be aware of this fact before committing themselves to follow this methodology. The values attached to Nazism are not the values which nursing espouses. However, Holmes (1996) makes it clear that he feels it is acceptable to 'selectively scavenge' (p 586) from Heidegger's work being aware of the assumptions on which some of the techniques are based.

4.2.3 Gadamer – *the way forward?*

Gadamer (1900 – 2002) was influenced by the work of both Husserl and Heidegger. He developed the ideas of hermeneutic phenomenology, particularly the historicity, this being an historical awareness which is valued and enables knowledge and understanding (Fleming *et al.* 2003). This can therefore include the influence and interest that the researcher brings to the phenomenon being studied (Annells 1996) and can help to achieve the deep understanding of the phenomenon that those using a Gadamerian approach seek (Fleming *et al.* 2003). This, as Pascoe (1996) indicates, makes this evolution in hermeneutic phenomenology particularly applicable to nursing research. As a practice discipline, nurses are in a real world where they relate, interact and interpret within a value-laden culture. Language is seen by Gadamer (2004) as crucial in understanding, 'language is the universal medium in which understanding occurs. Understanding occurs in interpreting' (p 390). The bracketing which Husserl described is seen by Gadamer as not possible and ridiculous (Annells 1996). The lived experience is paramount to Gadamer and he adopted and developed Heidegger's view of the hermeneutic circle (Taylor 1995) and the concept of 'the fusion of horizons' appears.

A 'horizon' is a range of vision that includes everything seen from a particular vantage point. A person with no horizon, in Gadamer's view, does not see far enough and overvalues what is near at hand, whereas to have a horizon means to be able to see beyond what is close at hand.'

(Laverty 2003 p 2)

This term is interpreted by Laverly (2003) as the interaction between the interpreter and the text. It helps both to take a new look at a phenomenon and find new understanding.

4.2.4 *The influence of Van Manen*

Van Manen (1990) describes a human science approach to phenomenology and hermeneutics, in his book, 'Researching lived experiences – human science for an action sensitive pedagogy'. Human science, Van Manen (1990 p 4) states, involves using methods that allow 'description, interpretation, and self-reflection or critical analysis' and he continues 'human science aims at explicating the meaning of human phenomena and at understanding the lived structure of meanings.' Van Manen (1990) suggests a methodological structure for hermeneutic phenomenology. This consists of six 'research activities' which remain dynamic and feed off each other. These activities are:

- turning to a phenomenon which seriously interests us and commits us to the world;
- investigating experience as we live it rather than as we conceptualise it;
- reflecting on the essential themes which characterise the phenomenon;
- describing the phenomenon through the art of writing and rewriting;
- maintaining a strong and orientated pedagogical relation to the phenomenon;
- balancing the research context by considering parts and whole.

Van Manen (1990 p 30 – 31)

Van Manen (1990) cautions over using these steps mechanistically, and acknowledges the somewhat artificial nature of the divisions. They do however provide the researcher with some structured form of approach to the data, written by the person propounding the approach. This is useful to the novice in the field of phenomenology, particularly when there is little written about the process of data analysis.

4.3 Application to the research in hand

The pathways through phenomenological philosophy are complex and, as Miller (2003) describes, at times confusing. It however appears important that the journey is

made to ensure that a depth of understanding is achieved with the complex phenomenon of families living with CRF. Holmes (1996), as stated above feels that parts of a particular phenomenological approach can be used without necessarily being dependent on the whole, whilst Taylor (1995) described her search for a form of phenomenology that suited her research requirements. This view, that it is possible to use a part of a phenomenological approach without necessarily embracing the whole reflects the definition of a methodology given by Lavery (2003) and quoted earlier. The use of this approach is perhaps put more poetically by Moules (2002) suggesting that in an enquiry there will be voices, influences and writings from the past, some of which will speak more loudly than others. For my research project it seems that the phenomenological hermeneutics described by Gadamer is the loudest voice with the work of Van Manen (1990) providing guidance with the follow through of the research and hints towards the data analysis.

The lived experience is paramount to Gadamer. This allows the researcher to acknowledge their own position and influence on the research whilst describing and interpreting the phenomenon, thus dispensing with the complex and sometimes controversial notion of bracketing. This is important; I have an interest in the effect of CRF on the lives of the people I work with and have worked in this area of nursing for many years gaining much experience, this also reflects the first research activity suggested by Van Manen (1990). In addition I have three young children, which could influence the way I think and deal with families and their children in the course of my work. I feel it would be impossible to distance myself from this knowledge and life experience and the influence of this on the research needs to be voiced.

The work of Gadamer also advocates active involvement of the participants within the hermeneutic circle. This is again an important facet of this approach that makes it particularly appropriate for work with people in health care settings. Encouraging participation and partnership in research is in tune with the Research Governance Framework (Department of Health 2001b) and may help to deliver an altered service to families which is more applicable to their needs.

Having completed the exploration of the philosophical underpinning of the research, this chapter now turns to justify the methods chosen to gather data. It considers each

phase of the research individually. The research project was structured as a two part project, with part one involving adults and part two the children of these adults. This reflects the desire of this project to move from a topic about which there is some knowledge – the effects of CRF on the family, to an area where there is no knowledge on which to base practice. Planning the project in two parts also gave a means to access the children who participated. In addition for me it involved a move from working with adults, where I have a great deal of clinical experience and some research experience, to an area which was unfamiliar, working with children, also in a research capacity, and where there are acknowledged challenges. The two parts of the project and the two aims were also dependent on each other in the sense that both parts of the project were required to try to shed light on the phenomenon under question, how family life is affected by parental CRF. To try and uncover the meaning of this phenomenon I felt that it needed to be approached from both the perspective of the parents, and of their children so that the picture drawn by the exhaustive description was as full and meaningful as possible.

4.4 Part 1 of the study

Aim: To explore the influence that a parental diagnosis of chronic renal failure has on the family and the information needs of the children within these families from the perspective of the parents.

4.4.1 Data collection – part 1

In taking a phenomenological approach to this research the experience of the participants and their view of how CRF affects their family is paramount. Interviews were chosen as the means of data collection. The interview is seen by Holloway and Wheeler (1996) as the most common form of data gathering. It is often used within the course of the day-to-day practice of nurses; therefore most nurses have some experience of this tool within the practice setting, if not for research purposes. However, this does not mean that the skills honed for practice are always readily transferable to the research field. The quality of the interview data depends to a great extent on the abilities of the interviewer and their main task is to ensure that the participant is relaxed and able to express their opinions honestly (Polit and Hungler

1987). Interviews are classified into one of three types by Holloway and Wheeler (1996):

- unstructured, non-standardised
- semi-structured
- structured or standardised

I chose to adopt the middle ground of a semi-structured interview (Appendix 10 gives the interview schedule). This was for a variety of reasons. I am new to the use of qualitative research methods; previous research experience has been within the quantitative domain. As indicated above, although many interviews are carried out within the course of daily professional practice, I have limited experience of using interviews as a research tool. The presence of an interview guide would, it was hoped, aid confidence as well as acting as an aide mémoire. Whitehead (2004) when discussing her research looking at the lived experience of chronic fatigue syndrome felt that she needed to use unstructured interviews but comments that there were disadvantages as participants covered different areas and the analysis was more time consuming because of the unfocussed nature of the data. The interview schedule used was developed to ensure that the topics covered were pertinent to the research aim of this part, in order to try to understand the effect parental CRF has on the family. This may seem at odds with the phenomenological stance taken, in trying to guide the interview in a particular direction. Review of the transcripts shows that the interviews, although covering broadly similar areas because of the prompt questions, were closer to the unstructured end of the structured/unstructured interview continuum. In addition the schedule helped to keep the focus of the study in mind. It was intended that guiding the direction of the interview would ensure that data analysis and the description of the phenomenon were also more manageable within the constraints of the project.

Participants were interviewed within the outpatient setting. This location was chosen for pragmatic reasons. Participants are all very familiar with the renal outpatient setting and interviews were undertaken to coincide with other booked appointments, thereby minimising travelling times for both the researcher and the participants. Interviews were tape-recorded. In addition to written consent, verbal consent was

obtained and recorded at the beginning of each interview. Tape recorders may well provide a distraction for both the researcher and the participant, however Whitehead (2004) concluded that if the researcher is engaged in observation or note taking they make a judgement about what to record and what to omit, in phenomenological research this may well influence the outcome of the description. In a family unit where there are more than two adult members it was decided that all adults would be interviewed, however no families had this extended family living at home. It was not envisaged that an individual interview would continue longer than approximately one hour. If the interview was over-running there were plans to offer a second visit, as Field and Morse (1985) suggest this is often more effective than one long interview. However, no second interviews were necessary. Brief notes were made following the interview to describe the feeling of the interviewer and any other pertinent factors relevant to the conduct of the interview.

4.4.2 Sampling and recruitment strategy – part 1

As I have an interest in part of the treatment plan for potential participants it was important to avoid coercion. Therefore the recruitment strategy approved by the ethics committee was for a poster (Appendix 11) to be placed within the renal outpatient setting asking interested family members to contact me for further information. This method also has the potential to reduce selection bias (Corben 1999). In addition provision was made to approach those families who had shown an interest in the work by contacting them via an approved letter (Appendix 12). In the event all families were approached using the letter, no one responded to the poster within the unit.

Some of the issues in sampling in phenomenological research are discussed by Corben (1999). Obviously the sample must include people who have experience of the phenomenon under investigation, additionally she suggests that potential participants need to have understanding of the topic and be articulate. Phenomenological samples are by their nature purposive and are often small in size. Corben (1999) indicates that this is not a problem as the data produced are not generalisable but as Annells (1999 p 6) points out nursing is a practice discipline and therefore nursing research should be able to ‘inform wise and prudent nursing action.’ For this research the potential pool of participants was large, as family units with a

patient at any stage in their renal treatment were considered for selection. Involving only participants who were still in the pre-dialysis phase could potentially restrict the sample size and the quality or usefulness of the data, since this phase varies widely in duration, and is dependent on many variables including, for example, the time of diagnosis and the progression of the disease. It is possible for a family to go from pre-dialysis to dialysis to transplantation within the space of a year, leading to much change and uncertainty for both the individual and the family as a whole. The information needs of the children may also vary as the parent moves to a different form of treatment. In addition some renal diseases, for example autosomal dominant polycystic kidney disease, are hereditary. A conscious decision was made to allow families to participate however the parent came to be in renal failure. Given the lack of information available for children about parental renal conditions to limit the sample in any way was felt to be inappropriate.

Initially it was hoped to recruit 10 families to participate in the study, 14 families were approached and 7 agreed to participate. The decision was made that this would constitute a suitable sample size following the interim assessment and discussion with supervisors. This revision was made because of the quantity of data that had been generated from the interviews which had already taken place. Saturation is not necessary in terms of interpretation (Whitehead 2004) and as Geanellos (1998) indicates from an hermeneutic standpoint interpretation is never final or complete.

Families who were willing to consent to inclusion were, at the time of asking, willing to allow their children to participate in the study. It was recognised that parents might wish to reconsider the participation of their children after the initial interview. However, no parents withdrew their children from the study after their interviews were complete. Consideration was given to the possible scenario that one adult member of a family would wish to be included but another would not wish to participate. It was decided that this would exclude the family from the proposed research, as there is unlikely to be agreement at the initial stage over participation of their children.

4.5 Part 2 of the study

Aim: To explore the influence that a parental diagnosis of chronic renal failure has on the family and the information needs of the children within these families from the perspective of the children.

4.5.1 Data collection – part 2

Within part two of the study the method chosen for data collection was focus groups. Central to the data collection were the children of the families involved and it was their voices that needed to be heard because although the parents talked about their views of the influence of parental CRF on the family, children are different and as Hart and Chesson (1998) indicate the assumption that parents' perceptions of their child's response may not reflect an accurate picture of the child's feelings and needs. The following section considers why focus groups were considered to be the best method of achieving the aim, stated above, of this part.

There is a debate regarding the use of focus groups in phenomenological research. Priest (2002) states that the most usual source of data is verbatim transcripts from interviews, however she does acknowledge other potential data sources, including group discussions. Webb and Kevern (2001) suggest that there is a methodological incompatibility between focus groups and phenomenology. However, they appear to draw on the work of Giorgi for their philosophical understanding of phenomenology and have perhaps fallen into the trap of failing to distinguish the different genres of phenomenology. The work of Giorgi draws on Husserlian principles (Whiting 2001) and as such is purely descriptive, whilst this project appeals to the hermeneutic phenomenological stance. This includes interpretation in its aims and Gadamer (2004) speaks of hermeneutical conversations and stresses that no one can know in advance what will come out of a conversation. Jones (2001) interprets this as understanding through dialogue. A focus group, it would appear, could therefore be an appropriate way in which to conduct a conversation, particularly when the participants are children who are likely to respond well to the technique, and interact in such a way to take the lead in the dialogue.

The use of focus groups with children requires careful consideration, particularly as much that is written about this data collection method reflects experience with the

participation of adults (Kennedy *et al.* 2001, Morgan *et al.* 2002). Greig and Taylor (1999) suggest the use of focus groups as they help put the children at their ease and enable them to set the agenda. This is important in order to ensure that children give their views. As with any data collection method there are advantages and disadvantages that have to be taken into consideration. Kennedy *et al.* (2001) suggest that focus groups are good for initially exploring a topic and gaining understanding. They corroborate the ideas of Greig and Taylor (1999) reiterating that focus groups enable the child's perspective to be captured and add that the focus group gives time for insights and original ideas which would not normally be heard. In addition they mention the fact that data can be gathered without limitations that may be encountered due to the literacy levels of the children involved. Hart *et al.* (2002) also highlight the freedom of expression that focus groups give to children, but on the negative side, do note that sometimes children can give short, succinct answers which do not lead to an in-depth understanding of the topic under investigation. It would have been possible to undertake interviews with the children as well as with the adults. There is a growing body of research to support the use of interviews with children (Kortesluoma *et al.* 2003) and Miller (2000) successfully used conversational interviews as part of a phenomenological study with children who have diabetes. However, there were a number of reasons why I chose to use focus groups. I have no formal training in paediatric nursing or specific communication skills required to elicit information from children and therefore felt that using interviews would be inappropriate. In addition the method of data collection had to be approved before recruitment to the study commenced. I therefore needed a strategy that had the potential to cope with children from a wide age range and differing backgrounds, and more importantly to be able to cope with an, as yet unknown, number of children. The focus group strategy was therefore also a way of limiting the amount of data, to ensure that the analysis would be thorough and of ensuring that the voices of all the children from the families involved in this research could be heard. Above all, I felt that focus groups might be more fun for the children involved. CRF is a relatively rare disease and it is unlikely that the children meet others with the same issues within their daily lives.

Kennedy *et al.* (2001) looked specifically at the use of focus groups in children in the 6 – 12 year age range. This range was picked because most work appears to have been undertaken with either pre-school children or adolescents, a point also made by

Greig and Taylor (1999). In terms of group size they suggest a maximum of six to eight adolescents, while with younger children (their age range here is six to ten years) they suggest four to six children. They stress that to obtain the best chance of full participation, and therefore potentially to enhance the quality of the data, groups should be carefully selected to match age (maximum two year age span), gender and behaviour characteristics. Hart *et al.* (2002) successfully used similar criteria to those mentioned by Kennedy *et al.* (2002). They involved 114 children in 23 focus groups to look at children's awareness of food and nutrition. The children in the study were aged between seven and 11 years and the focus groups were separated by age, gender and socio-economic status. With regard to the timing of the groups, Morgan *et al.* (2002) give some guidance, suggesting for the younger children groups, about 45 minutes, with the older children, about 90 minutes, with appropriate breaks. Morgan *et al.* (2002) suggest that timing is essential to maintain the quality of data and that after 45 minutes responses are deteriorating. They suggest refreshment breaks to divide sessions, but that the tape recorder be kept running during the breaks. Interestingly the focus groups in Hart *et al.*'s (2002) study were only 20 minutes in length. A condition of ethical approval was that these focus groups would not take place within school hours in term time.

I led the groups, but Kennedy *et al.* (2001) suggest a co-moderator is always present, to help with the children's needs, additional observation, field notes and any technical support. A consultant paediatric psychologist was the co-moderator. This is in line with a suggestion made by Hart and Chesson (1998) that liaisons with those who possess expertise in child development and communication could benefit the overall aim of allowing children freedom of expression in their views. As with the adult interviews the focus groups were recorded to allow verbatim transcriptions to be made. Coyne (1998) expressed fears that children may be inhibited by the use of a tape recorder, however she found that in practice this was not the case. In this project the children were interested in the tape recorder and how it worked, and being allowed to switch it on, but then appeared to settle down and ignore its presence. Debriefing notes were made in order to record any other necessary information.

A variety of techniques were used during the focus groups with the children. These were designed both to elicit information and to keep the interest and concentration of

the children. We took the stance that the children were experts about knowing what it was like to have a parent with CRF. We were not experts, and therefore needed the help of the children to gain insights into how to help other children who also had a parent with CRF. After initial introductions and an explanation of the research we talked to the experts – the children – and the discussion flowed from there. For example, we asked the children if there was anything that they thought we needed to know, and if they could tell us how they had become experts. Subsequent questions came from comments the children had made. In addition, constant efforts were made to ensure that all the children in the group had the opportunity to participate if they wished, sometimes therefore questions were directed to try to achieve this. For example, we might have asked one or more of the children if their experiences were similar to those just described by one of the other children in the focus group. The children proved willing to contribute and to listen to others. We also asked the children to help us write a story about a family where one of the parents had CRF. Each person contributed a sentence in turn, until the story came to its conclusion. Indeed, in one of the groups the participating children suggested telling a story before we did. In addition to the tape recorder, which the children helped to operate, each of the focus groups had access to drawing materials and play dough for modelling which they could use if they wish. Drawing is one technique suggested by Kennedy *et al.* (2001) and also endorsed by Coyne (1998). The latter used drawing techniques as part of relaxation techniques whilst establishing a rapport with the children in her study, as did Miller (2000). Some of the limitations of using drawing techniques are noted within the literature review. Within the focus groups some children chose to draw. It was essentially used as a relaxation technique; however, some children took up a suggestion to design a family coat of arms or draw a picture of their family. All children were given the opportunity to explain the pictures they had drawn and these explanations were noted. At the end of the focus group the children took their work home with them and were sometimes heard explaining it to their parents. Permission was asked of each child that drew a picture to take a photocopy of the picture, all children were happy for this to happen. Squash, water and biscuits were also provided.

4.5.2 Sampling and recruitment strategy – Part 2

The children in part two were identified as a result of parental participation in the first part of the research. Willingness on the part of the parents for the second part to occur was essential and the child must also want to participate. The children should be aware of the parental renal problem. In the end, the seven participating families had 11 children who were eligible and willing to take part in this part. At the time of the focus groups, the children ranged in age from four to 12 years, 10 were boys and there was one girl. Three focus groups were held, which attempted, within the given sample, to meet the suggestions discussed earlier, in order to encourage a successful group. For practical reasons siblings were grouped together. It is a mark of the dedication and willingness of the parents and children, that all children attended their allotted group, there were no dropouts and no need to reschedule groups. As a token of appreciation all children were given a five-pound book voucher, which was well received. A similar strategy had been used successfully by Morgan *et al.* (2002).

4.6 Rigour in qualitative research

The topic of establishing credibility in qualitative research remains a contested area (Cutcliffe and McKenna 2004), and the debate surrounding terminology used to establish the veracity of qualitative research within nursing continues. The position of rigour, reliability and validity are, amongst other concepts hotly debated. Tobin and Begley (2004) suggest that because quantitative research has a longer history, the terms used within this paradigm have essentially become the language of all research rather than applying only to quantitative research. Since I come from a quantitative background the concepts of validity and reliability are familiar to me, but since my interest in qualitative research has developed the difficulties in applying these concepts to qualitative methods have become apparent. Holloway and Wheeler (1996 p 162) discuss what they term ‘the search for truth’ in qualitative research, which seems an apt description. It is clearly important that qualitative research is rigorous, however, it is difficult to see how the concepts of validity and reliability would transfer directly. This view is supported by both Cutcliffe and McKenna (1999) and Tobin and Begley (2004) who discuss issues relating to methodological rigour within a qualitative framework and argue that transferring terminology from one paradigm to another is not appropriate. However, although the transference of terms and specific

definitions may not be appropriate, the ideas within the concepts can nevertheless prompt the researcher to ensure that the rigour of qualitative research is maintained. Tobin and Begley (2004) conclude that qualitative researchers should be explicit regarding the criteria they use to ensure that their research is robust. This section therefore considers the issues relating to rigour within this research.

A variety of terms have been suggested that could equate to terms used within the quantitative paradigm, however the exploration here will focus on trustworthiness and the demonstration of a decision trail, as these were used to establish rigour within this research. This is after the work of Koch (1994) who equated the trustworthiness of the research with rigour and developed these ideas in her work looking at hospitalised older people. She used an interpretive phenomenological approach which was based on the ideas of Heidegger tempered by Gadamerian hermeneutics which is similar to the methodology which underpins this research. Commenting recently on this paper Koch (2006) feels that the concepts involved in rigour in qualitative research are still evolving but there is still a relevance in her much quoted paper.

The discussion of methodology and methods that precedes this section attempted to show the decision trail within the work. Koch (2004) argues that if the research process and its decisions are well documented, the reader can decide if the work is credible or not. To help establish trustworthiness, Koch (1994) drew on the earlier work of Guba and Lincoln (1989), and considers the criteria of credibility, transferability and dependability, all of which contribute to trustworthiness. Koch (1994) suggests that the credibility of the research is enhanced when researchers describe and interpret their experience as researchers, requiring researchers to have a degree of self-awareness. Cutcliffe and McKenna (2004) question the use of decision trails suggesting that they do little to enhance the credibility of the research, however Koch (2004), in a commentary on this article, feels that they use a very narrow application of decision trails and remains convinced that decision trails can be a useful tool in enhancing rigour and demonstrating this rigour to others. This is a debate which is set to continue. I have found it useful to set out my thoughts and ideas in, what to me, seems a logical fashion, and therefore find the idea of a decision trail a useful one.

Paley (2005), looking specifically at research within nursing that purports to use a phenomenological approach, levels a number of criticisms which it is important to be aware of. Phenomenology is looking at perceptions and meaning, Paley (2005) sees it as a self-report method with perspectives and accounts from individuals. This means that the research is subjective and should be acknowledged as such at all stages. The study is also not generalisable, sample sizes are too small and are usually taken from one place. This leads on to questioning how transferability can be demonstrated with qualitative research studies. The suggestion from Koch (1994) is that sufficient contextual information be given to allow the reader to make judgements regarding how interpretation could and should affect their practice. This point is reiterated by Annells (1999) who, when discussing how nurses should undertake the evaluation of published research using a phenomenological approach, should ask themselves if the findings are 'relevant and useful for your practice of nursing' (p 11). It would appear that rather than make undue claims about how the research could be used by others, the reader is enabled to enter into the world described by the researcher and draw from that an interpretation of their own which prompts reflection on their own practice.

When discussing dependability, Koch (1994) again returns to the notion of a decision trail. Here, again, she argues that the provision of a decision trail helps both the researcher and the reader. Explicit discussion of the decisions regarding theoretical, methodological and analytical choices are shown within this thesis. The exact interpretations of the results may not be identical for researcher and reader, but as Koch (1994) indicates, the reader should always be able to follow a pathway through the research and the way an interpretation has been reached.

4.7 The Decision Trail

The considerations specifically related to rigour within qualitative research have been explored in the previous section of this chapter. However this thread, which is the decision trail, runs through the thesis to help establish the methodological rigour of the research. The listing of the decision trail in Table 4.1 seeks specifically to support this section and to clearly expose the decision trail. Here, personal reflections and

underlying assumptions are highlighted in an endeavour to support the decisions made within the research.

When considering the development of the research I made various assumptions that highlight the perspective from which I approached this research. These assumptions are fundamental in phenomenological work as they can influence the way the research moves forward and the interpretations that are made. In choosing to follow a Gadamerian approach, the need for bracketing is obsolete, but acknowledging the history of both the researcher and the participants is important.

Summary

Within this chapter I have documented a brief history of the development of phenomenology and its influence on this research project. I have also detailed my limited previous experience within the field of qualitative research and my interest in the working with families who have CRF. In addition the research setting has been described, the articulation of these areas, and the provision of a tabulated decision trail, should enable a reader to make a judgement regarding the trustworthiness of this research. As yet, the choices in relation to the data analysis have still to be considered, so they too can play their part within the decision trail. It is to this consideration of data analysis that I turn in the next chapter.

Table 4.1
The Decision Trail

Decision and rationale	Discussion in thesis – cross reference
<p>The research aims There were professional, personal and pragmatic reasons, which led to the formulation of the research aims. The topic also fulfilled the first of Van Manen's (1990) research activities.</p> <p>Professional The majority of my professional life has been spent working with people with chronic renal failure or educating nurses to work with them. As such I have a great deal of professional experience in the area. I moved to the pre-dialysis area in July 2000 and took up a nurse consultant post with a remit to develop the service and nursing practice. It is a challenging area, helping people to understand their chronic renal failure and to make decisions about their future treatment, but one that is well suited to use nursing skills. I believe that people should have access to information so that they are able to make decisions that are right for them. I also think that a team approach, which includes the patient and their family as part of the team, is a model which fits well with chronic illness where long-term associations will be formed. However, it became apparent that, as an adult speciality, we did not cater well for the needs of families where there were younger children. Brief literature searches and a discussion with nurses in a paediatric renal unit revealed that there appeared to be little information to guide practice in this area.</p> <p>Personal My third child was born in May 2001. During my pregnancy families with renal problems asked me for advice about their children, what to tell them about the parental chronic illness and how to approach the subject. The fact that I was pregnant seemed to break down some of the professional barriers that may exist and appeared to make it possible to ask these questions. It also caused me to reflect on my family and think about how I would approach the situation if I had to talk to my children about something which would change our family life.</p> <p>Pragmatic I had completed an MSc in 1992 – this was the minimum academic requirement for a nurse consultant appointment within the institution in which I worked. There was however, an expectation that Doctoral level studies would be undertaken in the future. Around the time of my appointment I began to look into taught Doctorate programmes and began this course in October 2001. I needed to undertake a research project as part of the programme. Looking at the influence of parental chronic renal failure on the family would help me, but would also help the families with whom I worked and therefore potentially have direct implications for practice. It was also an area where very little research had been undertaken.</p> <p>Assumptions Parents in the study would want to talk, or would have talked to their children about the potential influence chronic renal failure could have on their family life.</p> <p>Parents would be the main provider of information.</p> <p>Children would want information about their parent's condition.</p>	<p>Section 4.2.4 The influence of Van Manen.</p> <p>Section 1.5 Development of the research aims</p> <p>Section 1.10 Clarifying the need for this research</p> <p>Section 1.5 Development of the research aims</p> <p>Chapter 2 Literature review</p> <p>Section 1.6 Information revisited</p> <p>Section 1.7 Children</p>

Decision and rationale	Discussion in thesis – cross reference
<p>The study design</p> <p>The realisation that to undertake this research project I was going to have to move from, what to me was the relative safety and comfort of quantitative research and numbers was a shock, although in many ways I felt I wanted to try and undertake something different. However, it would be a journey into the unknown. The work was, by its nature, exploratory and a phenomenological approach seemed to fit with my initial ideas. The complexity and language of phenomenological approaches was a challenge through which I waded, gradually becoming more confident that this approach could be used to achieve the aims I had set myself within the research. I wanted to understand, but also be able to reflect on what I had described and alter my practice to provide a more complete service to these families. Therefore hermeneutic phenomenology seemed to best fulfil the needs of wanting to describe and understand. However, I needed an approach which would allow me to be me within the research and which would acknowledge where I had come from as well as where the participants were coming from. Therefore the Gadamerian approach was chosen, with some influences coming from the work of Van Manen (1990), which gave direction.</p> <p>Assumptions</p> <p>That I would be able to make the transition from a very quantitative research background to undertake a phenomenological study</p>	<p>Section 4.2 Methodology, including 4.2.1 – Husserl, 4.2.2 – Heidegger , 4.2.3 – Gadamer and 4.2.4 – Van Manen.</p> <p>Section 4.3 Application to the research in hand</p>
<p>Choice of methods</p> <p>Part 1 of the study</p> <p>The methods used need to be congruent with the philosophical stance of the research, but I also needed some familiarity with the method to give me confidence. Interviews are usually used within phenomenological research, usually unstructured interviews. However, although I used interviews within my professional work as a means of gathering information, I had not used them in the research setting. In addition the aims of my research were focussed on the influence of CRF on the family and the information needs of the children. I therefore felt it necessary to guide the interview to attempt to ensure that the data were relevant to the research. This was, I felt, particularly important given my initial time scale and the constraints of the write-up. I hoped that the interview schedule would also give me confidence and keep my focus during the interviews. I can get very interested in people's stories and it would be easy to stray down a different path within the interview, fascinating but perhaps not relevant to the topic under question. However, a balancing act needed to be undertaken to ensure that the interviews flowed and were not interrupted by the rigid following of the interview schedule, and the possibility of relatively closed responses to the pre-prepared questions. This did not prove too much of a problem in the end.</p> <p>Assumptions</p> <p>That I would be able to transfer my interviewing and information gathering skills from practice to the research arena.</p> <p>Parents would be willing and able to discuss the influence of CRF on their family life and their views and ideas on giving information to their children.</p>	<p>Section 4.2 Methodology Section 4.4.1 Data collection – part 1</p> <p>Section 4.4.1 Data collection methods – part 1</p>

Decision and rationale	Discussion in thesis – cross reference
<p>Choice of methods</p> <p>Part 2 of the study</p> <p>I was nervous about this part of the study, apart from dealings with my own children and their friends my experience of working with children was limited, the presence of a person who was extremely experienced in working with children was therefore both a necessity and a reassurance for me. The fact that she was very positive about the research was also important. For the second part of the study I chose to use focus groups. Again this could be seen as incongruent with a phenomenological stance, however, the focus groups were treated as a conversation with a small group of children. In addition, at the planning stage of the research I was concerned that I might be dealing with a wide age range of children. This however, proved not to be the case. All children were in a relatively narrow age span. It also meant coincidentally that the ages of the children in the group were broadly comparable to the ages of the children I was most used to dealing with. This was a confidence booster. The fact that the children obviously enjoyed participating in the groups and were willing to talk and interact with each other was also a big plus.</p> <p>Assumptions</p> <p>The children would be aware of the parental CRF and have received some information about it.</p> <p>The children would be willing to take part in the groups and speak in front of their peers.</p>	<p>Section 4.5.1 Data collection – part 2</p>
<p>Data analysis</p> <p>The data analysis proved to be a big challenge within the research – the quantities of data generated by the interviews and focus groups seemed vast to me and I was at a loss where to begin. For me a structured approach to data analysis was imperative and was backed up by the documented experiences of other researchers’ who were new to analysing phenomenological data.</p> <p>I chose to use the procedural steps described by Colaizzi (1978) as this appeared to give me a structured approach but left some room for flexibility. The steps were also congruent with the overall research methodology which is seen as important.</p> <p>Assumptions</p> <p>That the transcripts of the interviews and the focus groups will hold the meaning of the phenomenon.</p> <p>That I would be able to interpret the data and create something meaningful from it.</p>	<p>Section 5.2 Analysis of phenomenological data</p> <p>Section 5.3 Colaizzi’s (1978) procedural steps.</p>

Chapter 5

Findings

5.1 Introduction

In this chapter I will set out the reasoning behind the choice of tool to aid data analysis – the procedural steps described by Colaizzi (1978). This choice, as indicated previously, forms part of the decision trail. The chapter then moves on to look at brief profiles of all the families who were approached to participate in the project. The major focus of this chapter however, is the data presented from the 13 adult interviews and the three focus groups with children. The data from the two phases are initially treated separately, before being combined to give descriptions, from these seven families, of the effects of CRF on the family and a description of the information needs of the children.

5.2 Analysis of phenomenological data

The analysis of phenomenological data is a topic about which many published studies provide limited detail. This is a potential weakness, as it is only the presentation of data that allows readers to evaluate the quality of the research (Annells 1999) and helps in the assessment of its trustworthiness (Whitehead 2004). Corben (1999) identifies some specific issues that are often missing from published reports, these include the frequent absence of raw data, a lack of a clear explanation of the framework of analysis, and also an indication of how the data categories were arrived at. In an interesting paper which expounds the idea of the ‘expert’ researcher, Cutcliffe and McKenna (2004) explore the notion that the methods of data analysis employed by expert and novice researchers are different. They suggest that the procedures used by expert qualitative researchers are not easy to articulate, analytical principles are no longer relied upon, and these experts appear to have an intuitive grasp of data analysis. By contrast, the novice qualitative researcher requires structure, or step-by-step guides to aid the data analysis process. Interestingly Cutcliffe and McKenna (2004) add that students coming from a positivist background or with a greater familiarity with quantitative research strategies often need the thought processes to be sequential and logical with clear boundaries, which is what some data analysis frameworks try to achieve. Examples of these latter experiences

can be found within the literature. Miller (2003) used the six activities given by Van Manen (1990) detailed within the methodology section to guide her research with children, but at the data analysis stage felt that more guidance was required and therefore used Colaizzi's procedural steps. Whiting (2001) corroborates this, suggesting that novices of phenomenological methods are helped by using a structured approach like those devised by Colaizzi or Giorgi. In addition she considers that within nursing a 'pick and mix' approach towards phenomenology has been taken and therefore this same approach can be used with the data analysis. This is to an extent probably true, however if the full impact of the data is to be gained, the data analysis must be congruent with the philosophical stance taken to guide the research. This means that the philosophical underpinnings of these structured approaches to data analysis must be examined. Koch (1995) feels that frequently nurse researchers have embraced methods of analysis without fully exploring their derivation.

5.3 Colaizzi's (1978) procedural steps

5.3.1 Philosophical underpinning

In the light of the above, the choice to use Colaizzi's (1978) procedural steps as a framework, would appear appropriate given my previous research background and my lack of experience within the qualitative field. However, the origins of this framework must be explored to consider the fit with the Gadamerian phenomenological stance taken to guide this research. Koch (1995) states that the method of analysis expounded by Colaizzi (1978) is underpinned by Husserlian principles. This is an important and interesting point particularly as later within the same article Koch (1995) says that Colaizzi (1978) claims that his framework derives from Heideggerian principles. This therefore highlights the importance of returning to the primary source, to interpret the work in the light of this research and my understanding of phenomenological principles.

The chapter, 'Psychological research as the phenomenologist views it' written by Colaizzi (1978), a psychologist, makes interesting reading particularly when trying to discern the philosophical underpinnings of the procedural steps he describes. Initially the importance of studying experience as part of psychology is expounded. However, the precise philosophical underpinnings of the work are not stated clearly. Colaizzi

(1978) refers to a number of philosophers from whose philosophies he appears to take various parts, and then forms his procedural steps from an amalgamation of these ideas. It would seem that the 'pick and mix' approach suggested by Whiting (2001) has been used *par excellence*. This may be deliberate in an attempt to encourage readers to use phenomenological principles to underpin their research, to develop the steps, and use them 'freely and flexibly' as Colaizzi (1978 p 59) suggests. However, it may also reflect both changes in writing style and the continuing evolution of qualitative research in general, and phenomenology in particular in the nearly thirty years since the chapter was written.

Colaizzi (1978) refers to Heidegger on a number of occasions and his seminal work, 'Being and Time' is quoted in the reference list. Colaizzi (1978 p 52) discusses the phrase 'Experience is in and of the World.' This is akin to Heideggerian use of the word *Dasein*, a literal translation of which is 'being there.' Heidegger is named in relation to the phenomenological method of description, which Colaizzi (1978 p 53) states that the remainder of the chapter will be devoted to exploring. It is presumably from this statement that the assumption is made that it is Heideggerian principles underpinning the procedural steps. However, this is not clear and the chapter contains numerous references to other philosophers. The notion of intentionality is discussed (p 54), but this is not attributed to Husserl and notably there is no mention of Husserl in the reference list. The notion of approach and presuppositions, in the phenomenological sense, is discussed. This again is interesting. However, the conclusions that Colaizzi (1978 p 55) draws is that a state of absolute disinterest cannot be achieved, it therefore seems that Colaizzi (1978) does not believe that phenomenological reduction (bracketing) can be achieved, and this is substantiated in the footnote attributed to Merleau-Ponty, although Husserl is also mentioned. The use of Merleau-Ponty is in itself worthy of note as Koch (1995) states that his work is derived from both Husserl and Heidegger.

Colaizzi (1978 p 55) uses the phrase 'without some personal interest he could never follow through in completing or even initiating a research project.' There seems to be a Gadamerian perspective in this and it certainly links in with the work of Van Manen (1990). Later, Colaizzi (1978 p 56) discusses what he terms 'an understanding-descriptive method' as opposed to and distinct from 'a technological-experimental

method.’ This is again an important point, for two reasons. First it tells us a little about the research climate in which the chapter was written, - these were early days of the exposition of the uses of qualitative research even within the more accepting realms of psychology, but secondly it links the ‘description’ of Husserl to the ‘understanding’ of Heidegger.

A discussion of presuppositions occurs (Colaizzi 1978 p 58), this notion of presuppositions according to Taylor (1995) is found in both the work of Husserl and Heidegger but is not attributed by Colaizzi (1978) to either. Taylor (1995) suggests that Husserl advocates that presuppositions are identified so that they may be bracketed, whilst Heidegger suggests that the presuppositions are used to help illuminate the subject under study. The latter case would appear to be true for Colaizzi (1978) as he used presuppositions he identified to guide his research questions.

Other philosophers are mentioned briefly within the text, Giorgi whose work derives from Husserl, Paul Ricoeur who acknowledges the influence, amongst others, that Heidegger had upon his work and Nietzsche, an earlier German philosopher who is said to have influenced the work of both Heidegger and Merleau-Ponty. It would seem that the philosophical roots of this method of phenomenological analysis are far from clear and are not clearly articulated. It would appear that the main influence is the work of Heidegger, however there are certainly other philosophies at work. Given the amalgamation of ideas that have clearly influenced the development of Colaizzi’s procedural steps (1978), the Heideggerian influence, tempered by the influences of Gadmerian interpretation and personal interest, amongst other modifications, it would seem that this tool is appropriate to use to aid the data analysis. The presence of a robust data analysis tool is, I feel, all the more important to me given my novice status with qualitative research.

5.3.2 Application to this research

The procedural steps themselves are given in Table 5:1, the table giving my adaptation of Colaizzi’s work. Analysis of the procedural steps gives further insight into the origins of the work. The term protocol, which is used by Colaizzi (1978) in his original work, has been replaced by the term transcript, as protocol has a different

Table 5:1

Adaptation of Colaizzi's (1978) procedural steps

	Description of the 7 procedural steps (order may vary)
Step 1	The first task of the researcher is to read the subjects' transcripts to acquire a feeling for their ideas in order to make sense of them.
Step 2	The next step involves the researcher in extracting phrases and sentences relating directly to the phenomenon under study. This process is termed ' <i>extracting significant statements.</i> ' Colaizzi notes that several transcripts may contain the same or similar statements and duplications can be eliminated.
Step 3	The researcher then attempts to <i>formulate meanings</i> for each significant statement. Here Colaizzi extols caution as the researcher moves from what the subject says to what they mean – he terms this a precarious leap involving creative insight.
Step 4	The researcher repeats this process for each transcript and arranges these formulated meanings into <i>clusters of themes</i> . The researcher then returns to the original transcript to validate the themes. Colaizzi notes that there may be contradictions among or between the groups of themes. The temptation to ignore these data or themes which do not fit should be resisted.
Step 5	The researcher then integrates all the ideas into an <i>exhaustive description</i> of the phenomenon under study.
Step 6	The exhaustive description of the phenomenon is then reduced to an essential structure. Described by Colaizzi as an <i>unequivocal statement of identification of its fundamental structure</i> .
Step 7	In the final stage the researcher can return to the participants in the research for a further interview to elicit their views on the findings and to validate them.

(after Colaizzi 1978)

meaning within today's research community. There is no suggestion within the steps of a reference to bracketing, this would be consistent with its perceived Heideggerian origins. The analysis includes aspects of hermeneutics in formulating meanings and also the dialogue between parts and the whole of the transcripts. In addition in step two, Colaizzi (1978) suggests that similar statements or duplications can be removed. I would interpret this phrase with caution, as it may suggest that this particular aspect of the phenomenon is actually very important to the participants and this emphasis may need to be reflected in the final description. Colaizzi (1978 p 59) states that there is some overlapping amongst the steps, and that the procedures should be used 'flexibly and freely.' This enables the researcher to modify the steps to suit their own approach and the phenomenon under scrutiny. Step three, Colaizzi (1978) involves

attempting to ‘spell out the meaning of each significant statement – known as formulation of meaning’ (p 59). Colaizzi (1978) states that this stage considers what the participants say and moving from this to what they mean. This, he suggests is a ‘precarious leap’ which involves ‘creative insight’ (p 59) and whilst the meaning may be different to the statement, the two should still remain connected. Within his work Colaizzi (1978) gives clear examples of how he would analyse a transcript. In the text he goes through each step detailing how to undertake the analysis at each stage and refers the reader to a worked example. It is interesting to note however, that all the steps are present within the worked example except step three, the formulation of meaning. The reader is therefore given no insight into how this step can be achieved. It is evidently a difficult step to commit to paper and this reiterates the point made earlier in this chapter that many published works provide limited detail regarding the analysis of phenomenological data even within a step by step process. Therefore even with a scheme for analysing data the novice researcher is left somewhat in the dark with this stage. In a study where children were the research participants Miller (2003) takes the reader through her use of Colaizzi’s (1978) procedural steps. She acknowledged the overlapping nature of some of the steps and her need to adapt them. At the formulation of meaning stage Miller (2003) states that she aimed to describe the meaning derived from the significant statements and then phrase it as simply as possible, so that the meanings were accessible. This appeared to be a good principle to follow in my study.

It would seem that step seven is optional, and in my research analysis I chose not to return the transcripts to participants. The reasons why I made that decision were both practical and philosophical. Geanellos (1998) suggests that researchers using a Gadamerian approach do not need to return to participants to check interpretations, this is partly because each interpreter will come to a text with different experiences which will by their nature affect the interpretation but also because what Gadamer invites the researcher to do is to act as a mediator between the text and what it implies, not necessarily what the research participant meant. On a more practical note Koch & Harrington (1998) note the potential difficulties that can arise in returning the data to participants for comment. It is possible that a participant has died, and therefore the returning of data for comment could cause undue upset to near relatives. Often, transcripts are long and many participants are unwell, so they may find the

thought of reading and commenting on numerous pages of text tiring. Also in some cases, the final construct contains multiple sources of data and thus it may be difficult, if not impossible for the reader to identify their individual contribution. With my study the data collection took place in 2004/2005 – although the intention was to complete the analysis earlier this did not happen for a variety of reasons and I was left uneasy about returning the data to participants, some of whom I knew had been through health crises in the interim. My feeling is also that the data are temporal, a snapshot in time; if the data are returned at a later time, experiences have changed and life has moved on, and it may be very difficult to untangle the beliefs, values and knowledge of today from those of yesterday.

It is also pertinent to examine now a criticism laid at the door of the products of phenomenological research by Paley (2005). He feels that frequently phenomenological researchers have adopted these analytical procedures ritualistically and from them emerge common themes in which all uniqueness and lived experience completely disappears, to be replaced by an ‘all embracing blandness’ (Paley 2005 p 109). There is an acknowledgement that data does need to be classified but it would seem that the outcome perceived by Paley (2005) is very different to that of Koch & Harrington (1998). They speak of skilled writers where ‘the final research project resembles a thoughtfully constructed tapestry. Its appreciation will rely upon each needle point and the craft of its makers’ (Koch & Harrington 1998 p 889) or of Denzin and Lincoln (2005 p 4) who describe ‘the qualitative researcher as *Bricoleur* and Quilt Maker.’ The key must lie within step five of Colaizzi’s (1978) analysis to ensure that the final product is well crafted and gives insight to the reader.

Having justified the choice of data analysis tool, a brief profile of the 14 families who were approached to participate in the study is given. Table 5:2 gives the profiles of families who chose to participate, while Table 5:3 gives the characteristics of those families who chose not to participate, including, if known, the explanation for declining to take part. This is followed by an overview of the data collected.

Table 5:2
Profiles of participating families

Family	Ethnicity	Number of adults	Current treatment	Previous treatments	Children	Hereditary Condition
1	White	Two	Functioning Cadavaric transplant	PD and HDx	1 child, male – aged 8 at time of focus group	Yes
2	White	Two	Functioning Cadavaric transplant	HDx and PD	3 children, all male – aged 10, 12 and 17 at time of focus group Oldest child did not participate in the research as undertaking ‘A’ levels	Yes
3	Mixed race, White and Afro-Caribbean	Two	Home HDx – on transplant waiting list	PD and hospital based HDx, also had 2 failed transplants	1 child, female – aged 9 at time of focus group	No
4	White	Two	Functioning living donor transplant from friend	PD	4 children, 2 male (oldest) and 2 female (youngest) – aged 6mths, 3 6 and 8 at time of focus group	Possibly
5	White	Two	Failing cadavaric transplant – on transplant waiting list – went back onto PD during the research study	PD	3 children, all male – aged 4, 6 and 8 at time of focus group	No
6	White	Two	Started PD during research study – on waiting list for kidney pancreas transplant	None	1 child, male – aged 9 at time of focus group	No
7	White	One	Living donor transplant from father – pre-emptive	None	1 child, male – aged 8 at time of focus group	No

Table 5:3
Profiles of non-participating families

Family	Ethnicity	Current treatment	Children	Reason for non participation	Hereditary Condition
A	White	Living donor transplant from partner	2 children at least one of whom has the same renal condition	Response by telephone, followed by a later face to face conversation. Parents felt unwilling to participate because at the time of the study one of the children was having problems coming to terms with their renal disease and difficulty attending hospital follow-up. The parents felt participating in the research project would not help the situation. It is unclear if this was discussed with the children.	Yes
B	Afro Caribbean	Started HDx during course of research study	3 children	Not known	No
C	White	Living donor transplant from neighbour – pre-emptive	1 child, female – 4 at time of study.	Child was at the limit of age acceptance. After initial information it was felt by the parents that the child was too young to participate as they felt she had little understanding of what was happening within the family. A conversation then ensued during which a comment was made that seemed to indicate clearly that the child did have some understanding of the changes that were taking and had taken place within family life. At a meal time the child questioned if certain food could be eaten by the parent with respect to the level of potassium contained.	No

Family	Ethnicity	Current treatment	Children	Reason for non participation	Hereditary Condition
D	White	PD	2 children	Not known	No
E	Southern European	Pre-dialysis	2 children, both male – aged 11 and 16 at time of research	Family unwilling to participate, older son had GCSE's approaching. Unclear if children had been involved in the decision not to participate in the project.	No
F	Mixed race, White Afro-Caribbean	PD – had no preparation for potential treatment options as presented to unit requiring dialysis	2 children, one male – 17 at time of research, one female – 10 at time of research.	Both parents and the older child indicated that they were willing to participate in the research, however the younger child was still angry about what had happened to the family and was unwilling to be involved. The family therefore chose not to participate.	No
G	Mixed Race, White Afro-Caribbean	Pre-dialysis	3 children	Not known	No

5.4 Overview of data collected

The data collection took place between February 2004 and October 2005. This was longer than initially intended. Eleven of the 13 adult interviews took place between February 2004 and August 2004, with all except one of these interviews happening before the three child focus groups. The two remaining adult interviews took place in February 2005 (family five – patient) and October 2005 (family four – partner). This was due to the availability of participants. One recommenced dialysis treatment and the other had a newborn baby around the main data collection period. I was initially quite nervous about undertaking the interviews with the adults, worrying about the tape recording and concerned about the whole procedure. However, the interviews all seemed to go well and the participants talked freely during the interviews. Having an interview schedule worked well for me, as it gave my confidence a boost and did not appear to restrict the flow of conversation. It did ensure that the interviews remained focussed on the important subject areas for the research. Reviewing the transcripts there are a few times when, in my enthusiasm, I seem to try to direct the conversation too much, or on occasions put words into the mouths of the participant. On reflection that is, I feel, part of the learning curve, I would have found it extremely difficult, if not impossible to remain uninvolved in the interview process, and therefore using a Gadamerian approach and a dialogue about the topic was right for me.

The three child focus groups took place in July 2004, August 2004 and September 2004, the first two being in the school holidays and the final one on a Saturday morning. This therefore fulfilled the requirements of the ethics committee that the focus groups be outside school hours. The child focus groups were fun. The children obviously enjoyed them, and enjoyed meeting other children who could ‘speak the same language’ as them. The data collection strategies worked well, except for the story telling, which the children enjoyed and gave an outlet for their imaginative and creative talents, but provided little useful data. The groups were small, and the children generally listened to each other speaking, which made the transcription task easier. There were times when the conversation did not reveal anything about the topics of interest, except that these children talked about the same sort of things my children did, the books they read and computer games they played, the pets they had. The children talked freely and expressed themselves confidently despite not knowing me or the co-moderator. The presence of drawing materials, play dough and refreshments helped the general smooth running of the

groups and the family shields drawn and explained by some of the children gave a further insight into their family lives.

The adult interviews lasted between 19 minutes and just over 60 minutes. The three focus groups lasted approximately 60 minutes. Verbatim transcripts were produced from all the tapes with the majority of transcription being undertaken by medical secretaries. I finished transcribing two of the tapes. One tape from an adult interview (family six – patient) and one tape from a child focus group (focus group two – August 2004) were not transcribe because the microphone did not pick up the voices well. In both cases notes were available, as well as copies of the drawings the children produced. The fact that this interview and focus group were not transcribe did impinge on the data analysis. Whilst the notes contributed to the overall feel of the data and its interpretation, no direct quotes attributable to these participants could be analysed. The notes that existed contributed to the overall feel of the data and its interpretation. However, there are no direct quotes attributable to these participants included. Despite this there was still a considerable amount of material with which to work and build up an understanding of the phenomenon.

Notes were made immediately after the adult interview, however, these were remembered points to the interview questions. Memory is the ability to recall thoughts (Marieb 1992). Holloway and Wheeler (1996 p 70) indicate that notes should be written ‘as soon as possible after the interview to capture the flavour, behaviour and words of the informants.’ They felt, from personal experience, that note taking during an interview, particularly if a tape recorder was used, was disturbing to the participant. In making my notes my memory may have been influenced by previous interviews and points made by other participants. This may have subconsciously influenced what I remembered and therefore documented in my notes. Potentially then, material that I had ‘heard before’ from other participants may have been noticed more than new, perhaps just as valid views. In many respects notes made after an interview have already been interpreted and this reiterates the importance of the use of the tape recorder in obtaining raw data so that the influence on the final description is minimal at this stage (Whitehead 2004). The adult interview that was not transcribed lasted about 20 minutes, and was therefore one of the shorter interviews and proportionally within the data constitutes a relatively small amount of data. However, for the focus group, the loss of about a third of the raw data

had the potential to be more significant. This was balanced by the availability of copious notes for analysis taken during the focus groups and the availability of the pictures drawn by the children. The notes were made as the focus groups progressed – this was easier to achieve with the presence of a co-moderator, as both could take notes. It is however impossible to make verbatim notes, as Holloway and Wheeler (1996) acknowledge, but taking notes at the time, rather than being made after the event probably made them less selective. There is still the potential to record what you wish to hear thereby again affecting the final description.

5.5 Analysis of data

The data were analysed using the framework of Colaizzi's (1978) procedural steps, given in Table 5:1 as a starting point. Figure 5:1 shows a flow chart which attempts to represent the processes I undertook with the data I had gathered from both the adult interviews and the child focus groups. It is shown as a linear process, which is the best approximation of the process I undertook, however at certain points there may be some blurring of the steps. As a novice to qualitative research, this linear model seemed a logical way to represent the analysis and the uncovering of the meaning of the data. However, Figure 5.2 more probably represents the actual process, but is both difficult to represent and harder for a novice to grasp.

For the adult interviews the verbatim transcripts were read on numerous occasions and the significant statements relating to the effect CRF can have on family life or the parental view on information were highlighted and extracted. From these significant statements the clusters of themes were derived. These themes have been identified trying to use headings which come from the data, although not each transcript contained all the clusters. Each theme has a shorter title, which indicates the meaning I gave to the theme. This highlights my interpretation of the data. Putting the phrases together like this and effectively giving two titles to each theme highlights both the participant's view – giving them a voice – and my interpretation, with the two forming parts of the whole. It also emphasises that the meaning is a co-construction between the participants and the researcher. However, it has to be acknowledged that another person may interpret the findings differently. The meaning that I have attached to the data is shaped by my life experience and my extensive professional

Figure 5:1

Flowchart representing data analysis process

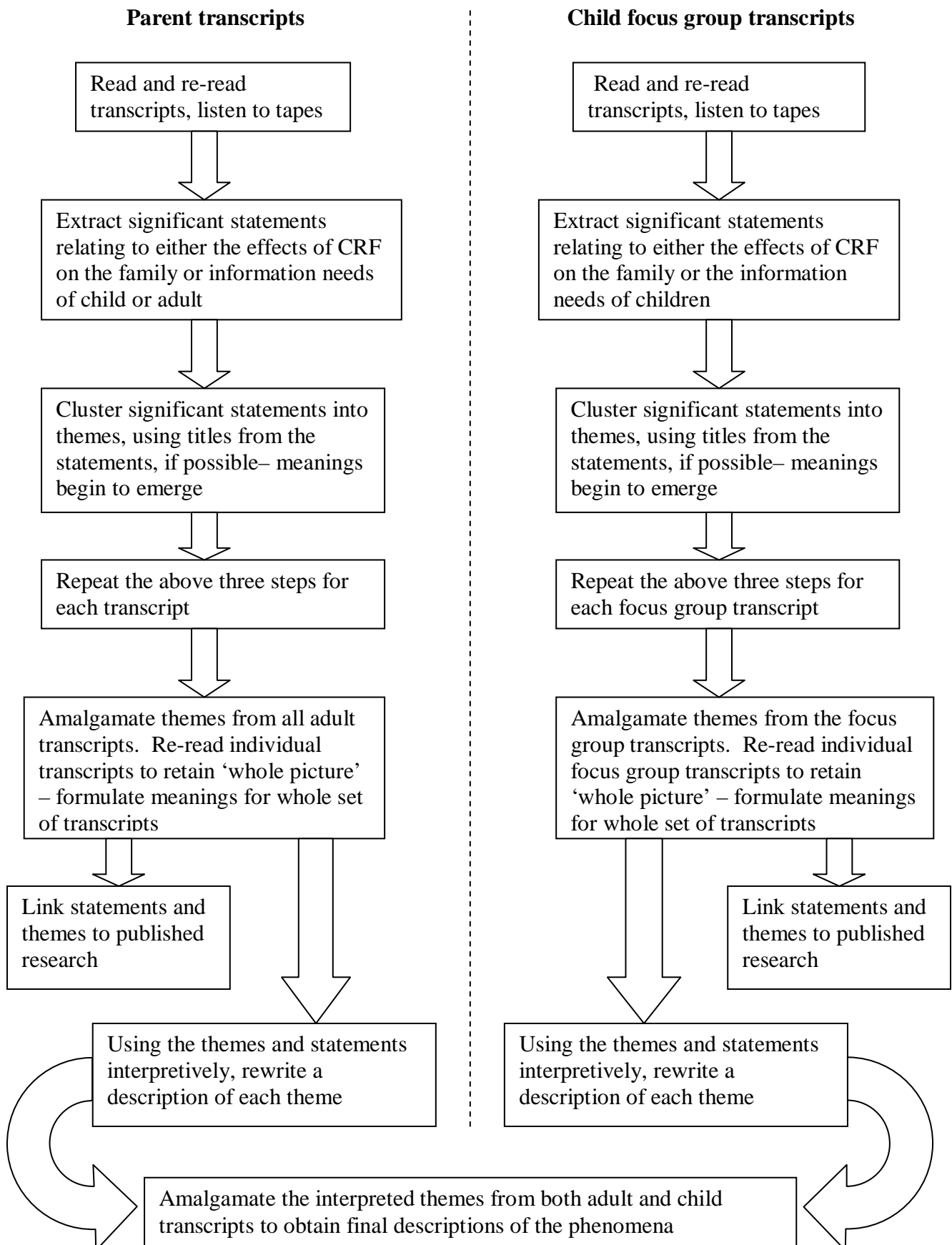
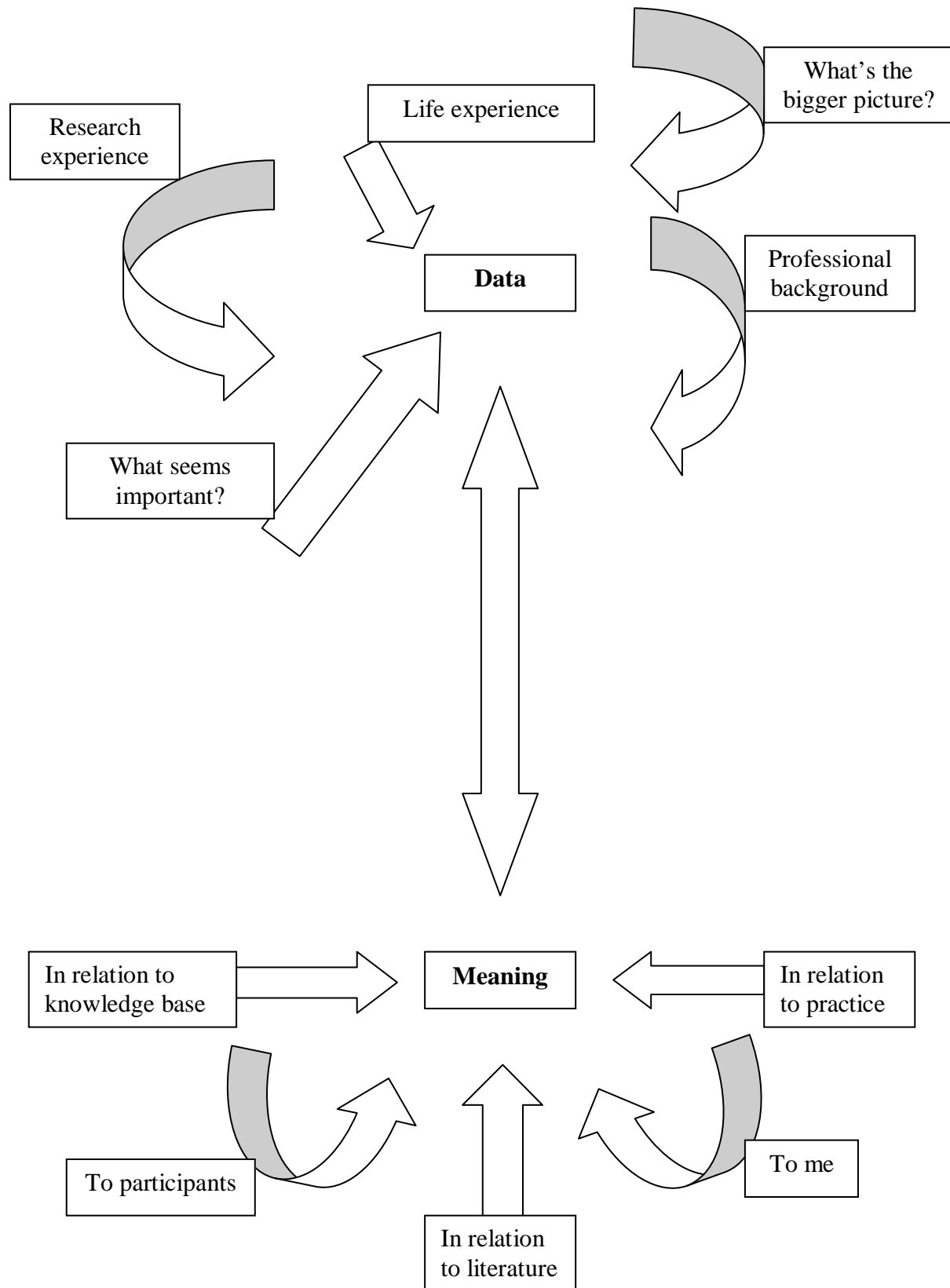


Figure 5.2
Diagrammatic representation of data analysis



experience with people who have CRF, another coming to the data would bring different experiences and their interpretation would reflect this. Significant statements were highlighted on a copy of the transcript; these statements were then cut and pasted into a separate document for each participant. These statements were then read through several times and pencil jottings made alongside the statements, which explored what I thought these statements meant. This formulation of meanings is the step not well documented by Colaizzi (1978) where the term ‘creative insight’ is used. The use of these words is interesting and suggests to me that the researcher requires knowledge of the topic under scrutiny and the creativity to use language – the universal medium of Gadamer to further understanding. These meanings were then taken and placed into clusters; there were clusters specific for both adults and children as at this stage the data was being treated separately. From both the clusters and the meaning the exhaustive description was fashioned, putting the statements and meanings together to form the tapestry of rich description using predominantly the participants’ words to reflect how they experienced chronic renal failure affecting their family lives. The essential structure came out of the clusters and was used to help give a structure to the exhaustive description. In my study the two, the essential structure and the exhaustive description, feed from each other. Steps five and six have not been amalgamated as such, but happened more in parallel than as distinct steps. The meaning of the statements is explored further within the discussion of chapter six. Table 5.4 gives a worked example of what eventually became hereditary conditions sitting within living with uncertainty. The meaning initially attached was connected to differences in families and values and linked closely to certainty and uncertainty. Some of the significant statements which were analysed are shown in Table 5.4 giving the analysis and the meaning taken from this.

Originally when the significant statements were extracted from the transcripts these statements seemed to be saying something about differences in families, this was when the transcripts were viewed as individual entities. The meaning behind what the participants were saying seemed to be linked with an amalgam of family values which were instilled by parents and childhood experiences, there were also elements of anger and some uncertainty. However, when the significant statements were viewed as a whole it became clear that these significant statements only occurred in

Table 5.4**A worked example of formulation of meaning**

Statement	Key words	Meaning
I'm not quite sure how you're going to interpret this but one of the things I was thinking this morning as I was preparing for this is that I do think that there is an issue between the hereditary people perhaps and the comes-as-a-thunderbolt (F1P)	Issue, hereditary, comes as a thunderbolt	Different families may need different approaches and this may be related to the presence or absence of a hereditary disease.
The more information I have the better informed I am and I have always wanted that and because of my past experiences, children you never cried in front of, you said everything was gonna be okay but its not to be honest and that's my point now, be honest with your children (F3P)	Information, past experiences, honesty	Information and past experiences are important, as these shape how we deal with our own children, but it is most important to be honest.
That doesn't mean that every family is the same and that every family will have gone through the same experience but it doesn't mean that you can't glean something of value from having that information (F1Pt)	Differences in families, experiences, information	There are different families with different experiences but information will usually help them.

the transcripts of families who knew they had a hereditary disease or where there was a possibility that the renal disease may be hereditary. This appeared to change the meaning of the phrases and therefore perhaps only relate to families with hereditary conditions. The theme therefore changed meaning from looking at differences amongst families to be more specifically related to the presence or absence of hereditary disease.

Two examples of transcripts and then the clusters of significant statements are given in the Appendices. A transcript from a patient is given in Appendix 13 with one from a partner in Appendix 14. In addition an amalgamation of the significant statements from one of the clusters, parental interpretation, is given in Appendix 15. A similar process was undertaken with the transcripts from the child focus groups. A transcript from one of the focus groups is given in Appendix 16. Data from the focus groups will be considered later within this chapter before combining the adult and child data to give the exhaustive description of the phenomenon under study.

5.6 Parental data

Eleven clusters of themes were identified from the adult transcripts. The clusters have two titles, one taken from a quote which is a significant statement taken directly from the data. The second, a shorter working title that helps to explain the cluster and reflects the meaning which I attached to it. Some of the themes appear quite closely related. This will be explored further in the discussion.

- “I think they just think this is our life, this is what it's about, and you know they get on with it” – family life
- “It just seemed to coincide with the time things started to go wrong” – changes in behaviour
- “I will have to lean on them more” – caring role
- “You don’t always want to read all the down side” – information giving to adults
- “I think it’s one of those things you deal with it as you go along” – information giving to children
- “How do I get inside a 9-year-old’s head?” – parental interpretation
- “I think seeing mum taking pills every day is no longer a threat because it’s just a routine and it's almost a security” – security
- “I think you almost have to live for the best and plan for the worst” – living with a chronic illness
- “The new kidney is doing very well but may not last a lifetime” – transplantation
- “How am I going to deal with the fact that he may have this?” – hereditary conditions
- “Really forget about it and just get on with our lives” – life view

5.6.1 “I think they just think this is our life, this is what it's about, and you know they get on with it” – family life

This cluster is at the heart of the study which, as a whole, explores the influence of CRF on the family. Many examples were given by the parents to describe how the diagnosis and various treatments had changed their way of life and impinged on

family life. However, above all, the families strove for ‘normality’ although this was expressed in a variety of ways.

“I think they just think this is our life, this is what it's about, and you know they get on with it.”

F2P¹⁰

“not allowing the condition or disease to encroach on what I perceive as my life”

F5Pt

“We just try and be normal.”

F6P

However, despite the perceived normality, there were still effects on the family that were described by the parents. For some they continued even after, what was considered to be, a successful transplant. The often overwhelming tiredness and also the lasting effects of surgical operations combined, at times, to limit the physical side of the parent-child relationship. The fact that the parent generally looks well also contributes to the situation. Their children, and other acquaintances, may find it difficult to remember, and understand, that the parent was actually ill.

“when we play rough and tumble, there's still the "you have to be careful of my fistula" He knows that it would be horrific if he kicked me in the new kidney. He can't be totally uncontrollable if we have a tickling session or something like that but it's much better than it was. Physically I'm a much fitter person than I was pre-transplant.”

F1Pt

“I've got the fistula and it's buzzing away and they'd maybe laying up me and they can actually hear it up in my arm, up in my shoulder.”

F2Pt

“The fact that he doesn't look unwell ... That he works and all the rest of it you know there is a normality to our life but what she does see is a very tired man”

F3P

¹⁰ Throughout the document the following abbreviations are used:

F – family, followed by a number denoting the family in the study

P – partner

Pt – patient

C – child, followed by a number denoting the child's position in the family i.e. first child – 1, second child – 2.

“they were playing in the garden and its really hot and of course F4Pt had his tube coming out and F4C1 wanted him to play in the padding pool with him and F4Pt did get in and it was me, I was panicking F4Pt and then he said “ooh no, let’s get out” but F1C1 he would go “come on daddy, come on daddy, come back in” but F4Pt would go obviously “I can’t”

F4P

“the fact that dad got tired very easily so they would have to, calm down a little, not jump on him.”

F5P

“he knows, but I don’t think he totally comprehends because she is so fit and well, looks so fit and carries on, and she is there day after day getting up, looking after him”

F6P

Family 1 described how dialysis had ‘impinged considerably’ on their family life and described how, as a family; they found HDx very difficult, whilst PD for them gave them a better family life. Many of the families managed to integrate their dialysis into their life and continue working, although this sometimes put pressure, or made changes to, other areas of life.

“He carried on working throughout. He can’t then go to the theme park all day on the Saturday. They have to understand that.”

F2P

“I managed to work full-time so if you like the regular life-style didn’t change.”

F2Pt

“I run my own business and I still have a social life”

F5Pt

“We want a life and therefore, if F3Pt wants to go out for a work do on a Friday night when he normally dialyses then we do an overnight. Then he can have a couple of beers and we get rid of them on the machine. So we do to a certain degree move it around where we can but we actually lead very busy lives and sometimes we’re not able to be that flexible”

F3P

“through dialysis, through everything I’ve worked, I’ve not stopped working. So I was lucky really compared to some people but I found that three months (on dialysis) not hell, but it wasn’t good,”

F4Pt

Holidays were a topic that were considered by most of the families involved. Two families ensured that they had taken a holiday before they commenced dialysis; one family, family one, took a Summer holiday over the Easter period prior to commencing dialysis, while another family, family five, negotiated two weeks out of school for their children to enable them to have a holiday before dialysis recommenced after around 15 years of a successful transplant. It is clear that the time spent together on holiday can be a precious time for families and therefore extra effort is exerted to ensure these holidays can happen. However, the descriptions also show the limitations that are put on family holidays where HDx is the treatment, as described vividly by family three.

“we went to Centre Parcs for a week, with the bags”

F2P

“we can’t go on holiday abroad because Daddy can’t fly because he needs his machine’ it wasn’t like a punishment, but sometimes it felt like a punishment”

F3Pt

“I tell you even if it was France or Spain or just Bruges or something for a week, we just flew away, have a bit of fun and have a family, where we actually enjoy it as a family, don’t care where it was, fly to Isle of Man for all I care dialyse over there”

F3Pt

“But I mean it does affect family because F3C and I go abroad, F3Pt's family have to come and cover me when I go for those two weeks with F3C. I would love my family abroad to meet F3Pt. I'd love him to be able to go out there and he resents the fact not that we go, but that he can't come with us. And even if we paid for dialysis out there he's still got a long flight and that's what we don't want to risk.”

F3P

Interactions with schools are obviously a large part of the lives of the children within the families. Most of the parents had talked with the school about their renal problems, usually just so that the school were aware and could support the families. The schools seemed willing to offer support and this gave children additional avenues outside the family where they could discuss issues, if they wanted. The support of the school nurse was offered in one case and an educational psychologist in another, although at the time of the research neither had been used.

The impact of CRF on the family is also seen as having an impact on the size of the family, although this is only made explicit within one family with this group of families.

“I mean she has really resented the fact that we haven't had another child, yes, and so does F3Pt. I've just said no, I work, you work, I can't do it. There's got to be boundaries somewhere. No, it's because of the dialysis machines. I couldn't. It's hard enough. I don't work full-time, well I do, I work full-time in a part-time post but I do that because I wanted to be a mummy on a Thursday and a Friday and obviously because of dialysis as well. So to add another child into that equation was just horrific but she definitely does resent that. As she's got older now the idea of sharing with a sibling is not quite so lovely but you know even up to probably a year ago it was "It's not fair, I want a brother or a sister"

F3P

The time at which the father in family four was diagnosed with CRF also had a profound impact on the life of that family, particularly from the mother's (the partner) perspective. She still expresses concern and regret about her way of dealing with the situation at the time.

“F4C3 was only 3 months old, she was really, really little. I don't actually remember a lot of F4C3's first year which is very sad. It is awful really but I can remember the exact date that F4Pt went to the doctor's and I can remember the exact date that he got his results. That year I can't remember how F4C3 grew up but I can tell you how many times I was up here, when I look back at that, I'm not saying it's awful but it overtook especially my life far too much and I became sort of obsessed with it. F4Pt went from diagnosis to dialysis to transplant within one year and that was quick and, like I say, I can't remember that year”

F4P

There are clearly many effects on family life that are attributable to the fact that one of the parents has CRF. However, listening to the tapes and reading through the transcripts, the overwhelming feeling is not one of sadness or gloom, but there is a sense of vitality, of wanting, as far as possible to enjoy life and live it to the full.

5.6.2 “It just seemed to coincide with the time things started to go wrong” – changes in behaviour

Some families remarked on changes in behaviour in their children that they attributed to the effects of parental CRF. These usually appeared to coincide with a change in

health of the parent. Often it just seemed to mean that the child, or children wanted to be physically closer to each other, or to the adults in the family. None of the changes mentioned by the parents appeared long-lasting. In addition, there was no indication from the parents that the schools attended by the children had reported often on changes in behaviour or, at the time of data collection, that the parental illness was having an effect on academic achievement.

“But within class, I think it was pre-dialysis, he started wanting to go to the toilet a lot in class. And I thought that was probably a sign of nerves. His teacher didn't see it like that and was very strict with him, even though they were aware of the situation so I don't think that helped and the more the teacher said you can't go, it was a psychological thing he had sort of a few weeks of that but it did gradually ease up.”

F2P

“When F5Pt first got his diagnosis earlier in the year they started all sleeping together. When F5Pt started to feel unwell there was quite a lot in our house, because then I took a long time to get used to the idea and F5Pt did as well and they all started sleeping together at one point, 3 of them in a single bed. Two of them share a room anyway but they started getting in the same bed and then they started off just in the same room. F5C2 would go back to his bed and F5C1 swapped I think from one bed to another. F5C1 is the eldest and then eventually now he is back to his own room. They get a lot of comfort from each other really.”

F5P

5.6.3 “I will have to lean on them more” – caring role

Some of the families talked about a caring role that their children undertook within the family, or some families expressed a concern that their child might have to take on more of a caring role in the future. Certainly with the two families who had dialysis taking place at home the children were involved in parental care at this level.

“they like to get involved in pressing the little arrows on the APD machine,¹¹ wash their hands and things like that”

F5Pt

However, the parents expressed concern about the possibility of having to ask them to do more in the future, they seemed confident that the child would be able to do what

¹¹ APD machine – automated peritoneal dialysis machine. An APD machine automatically controls the fill volume, dwell time and length of treatment the patient receives. APD is most often carried out at home, whilst the patient sleeps (Wild 2002 p 225).

was asked, but did not wish to impose upon them as this quote from family three indicates.

“I mean there is a real risk you know if F3Pt doesn't get another transplant that as she gets older I will have to lean on her more, or he will, or we will expect more of her and then your child comes into the caring role. But as I say, we haven't and we consciously have not done so, so far.”

F3P

5.6.4 “You don’t always want to read all the down side” – information giving to adults

The statements in this cluster were usually in response to specific questions asking about how information had been gained. This is important to the study, as the assumption has been made that parents are the main providers of information for the children. It is therefore encouraging to see that the parents in this study had obtained their information in a variety of ways. For some, the memories of parental dialysis was the beginning of their quest for information, for others, information was gained from books, staff, other patients and carers, information groups, the library, local and national support groups and more recently, the internet. Some participants were nurses, or worked in hospitals and used this to gain information. However, providing the right information at the right time can prove a problem as the situation and treatment can change frequently.

“he had 6 operations, or 5 operations in 6 months, something like that. It was all sort of one a few weeks after another so it all was a bit of turmoil for them”

F2P

“I had dialysis starting probably March/April 2002 and then went onto the transplant list in October. I had my problems with, you know, with various bits and pieces but I had the transplant mid-November”

F2Pt

When thinking about information these parents appeared keen to obtain a positive perspective. They also wanted time to receive and digest information for themselves, before moving on to give information to their children as the quotes below show.

“you don't always want to read all the down side. We used to try and get a positive sort of perspective.”

F2P

“they didn’t come up with us to a visit to the dialysis, mainly because F5Pt and I weren’t sure what we were doing and we like to know so that we make it quite relaxed for them”

F5P

However, not surprisingly, different attitudes to the gathering and importance of information could be seen in the parental approach to information, varying from the “voracious information consumer” in family one, to families where the parents had different attitudes, to each other, for example in family four.

“She’s been the one that’s liked to get all the information but I’ll deal with it as it happens.”

F4Pt

“I would sit in every consultation, F4Pt would sit there like my son. I would be going well tell me this or tell me that whereas F4Pt didn’t really want to know.”

F4P

5.6.5 “I think it’s one of those things you deal with it as you go along” – information giving to children

This cluster is seen as key as it links in with the aim for the second part of the research. There were many significant statements from this cluster, partly because, amongst other things, the interview guide asked questions about how the parents dealt with giving their children information. Importantly parents appeared to want to share information they had gained about their CRF with their children. This linked in with one of the assumptions that was made before beginning this research.

“The idea that you can’t tell the children is not an option in my view. What you tell the children and how you tell the children is problematic to say the least.”

F1P

They wanted to approach the subject truthfully and honestly, however there were some caveats to the information giving. Parents talked about trying to ‘hide the down side – at least trying to’ (family two) and ‘keeping back the full brunt’ (family four). In approaching the topic, parents also appeared more likely to talk on a ‘need to know’ basis, or by answering specific questions rather than regurgitating all they knew about the subject. If parents did not know the answer to a question they would attempt to find out and bring the information back to the child (family three) and the

parents also took on a 'translator' role, putting the information that they were given into language the children could understand (families four and five) and adapting this as the child grew (family three).

"I've sort of tried to explain it as I've gone along on a need-to-know basis and when they've asked me a question then I've been honest - I feel I have - as best I can"

F2P

"She'll tell them the truth and what it's all about, but generally it's everything that happening is there for my well-being and that's how it's put across."

F2Pt

"She's asked a question and we've told her, we've been up front because we'd rather she hears it hopefully the right way from us,"

F3Pt

"I think it's one of those things you deal with it as you go along. I think I'd give him the information that I thought was appropriate at the time"

F4Pt

"if they want to know anything I will tell them absolutely anything, but because at the moment F4Pt is fine and everything is going okay. At the moment I don't feel I wanna sit down and blast them with science when there is no reason to."

F4P

"I think the best protection they can have is being told the honest truth about what's going on"

F5Pt

The parents appeared to undertake a careful balancing act. They wanted to answer questions honourably, which they felt would help to establish a trusting relationship between them and their children. They also hoped this would offer protection to their children in helping them to understand the family situation. However, this openness and building of trust had to be set against not wanting to worry the children unnecessarily, or make them feel responsible for the parental illness and family situation.

“I sort of showed them what I was doing and told them what it done - it sort of cleaned the kidney and cleaned everything out - sort of kept them involved but not giving them too much to worry about. I didn’t want to sort of worry them”

F4Pt

“I always say to F4C1, ask me whatever you want and I will tell you and I will be as honest without trying to be hurtful but I don’t want to ever frighten him”

F4P

“basically or else it becomes too heavy doesn’t it. You just want to inform them really I think. You don’t want to make them feel responsible.”

F6P

In family one, the parents described themselves as the ‘information managers,’ a term which seems apt, and although not specifically called that by other parents the concept was alluded to. There was a general expectation and hope that the parents would be the main source of information for the child, they wanted to do this, and felt a responsibility to the children, however this did not mean that they were not willing to accept help or guidance with the matter, or that they thought that their children would not look elsewhere for information. However, the parents wanted to foster an environment of trust where the children could ask any questions and expect an honest answer. The following quote captures this well and leads into the difficult subject of discussing the possible death of a parent with their children.

“I don’t believe in hiding things either and I would much rather help my children to cope with things than I would for them to think that I had lied about something or hidden something from them – that trust really and to foster environments like that I think it enables an environment where the children can really ask me something like “does this mean dad’s going to die?” I would much rather they asked me about it than worry about that, when I can give as honest an answer as I think I can at that time.”

F5P

The topic of discussing death with their children was touched upon by some of the families. Most of the adults were aware that in some cases their early death was more likely than within the average population. It was also a specific issue for family one as they were, as they termed it, ‘older parents.’ The parents were understandably reticent about talking about the possibility of death. It is not really clear if this is because they have difficulty facing their own mortality, and therefore discussing this

subject with their children, or if it is thought of as a means of offering further protection to the children from the full impact of the disease. It may also be because we as health care professionals frequently avoid this difficult subject and offer limited advice.

“I don’t think, pheww, I suppose the big thing would be death you know how that was portrayed or put over, No, no, she hasn’t spoke to me about it but I think that would be my main, main concerns I think everything else would be OK, I think that would be the only main concern”

F3Pt

“I say it’s hard to remember now really but we didn’t really tell them the full “I could die” or anything like that.”

F4P

“its just once I reassured F5C1 that he couldn’t die from this. You know, that’s a bit of a rash kind of thing to say but when F5C1 means are you going to die, he means are you going to die tomorrow, he doesn’t mean are you going to die in a number of years time because of the condition, he means tomorrow and the answer to that is no, he is not dying tomorrow, he can survive with dialysis until a time when a transplant comes along and that’s exactly what I meant.”

F5P

On a lighter note, most of the children were actually quite interested in all the paraphernalia to do with dialysis. This meant it was easy to involve the children in the process of dialysis and to answer questions as the procedure moved along. It was also noted that when other children visit the house the parent and the machinery could become an interesting talking point. Family three described how, prior to a first visit, they always spoke to parents of visiting children before they came to the house. They would talk about the presence of the haemodialysis machine, and try to gauge parental and child reaction to attempt to prevent upset at the time of the visit.

“It sounds like a horrible thing to say but they found F2Pt’s tubes as being quite interesting. And that seems really awful, F2C2 likes the drains and he just thought, “Oh, Dad’s got something really cool”, and I suppose we just laughed at it. “Oh you want a drain on your trousers, look at me”. But obviously you knew they were all aware of the machine but they were quite involved because they used to come up and sit with F2Pt on the bed when he was going on it.”

F2P

“she can actually explain when her friends come in that colour takes it out, so she’ll point to my arm and say that line will take it out and it goes round there, cleans and comes back to daddy”

F3Pt

There was some concern expressed by parents that frequently they think the children have understood a particular piece of information, but then something is said that clearly indicates that it has not been understood, or at least not in the way that the parents had expected or intended. Linked with this is the knowledge that telling and hearing are two separate activities and that in any situation they do not necessarily follow each other.

“What we tell them and what they hear, as I say, are probably two different things.”

F5P

As noted earlier parents were perceived as the main source of information and clearly wanted to be that. However, various other potential sources of information or questioning were cited, school, cubs, tablets, but the television appears to stimulate most interest and questioning. Children gained information from television programmes, particularly about transplantation, and this could then lead in to further questioning of the parent, but also relates to the points about hearing and understanding as these quotes illustrate.

“She’s seen programmes on it because obviously there’s quite a few of them around and then she’s sort of sat down with F3Pt sometimes to watch it but I don’t know fully how much she really understands. She knows that you get a kidney from somebody else and of course she loves Casualty, they have had transplantation on there in the last year and she was “Erm you put a kidney from a dead person in a live person”. That bit horrified her. She can quite cope with a live-related but not with a dead and I said well Daddy’s first two kidneys have come from dead people and she said “ooh” but she didn’t really go into it. She just said “ooh”.”

F3P

“so far as they think they can go to the shop and get one and that when dad comes into hospital then “is he having a transplant today?” They don’t really understand. They do understand that they have got to wait, they understand that I was tested to be a donor and they understand the business that as a live person, you can give someone a live one Then there was a discussion about having a dead person’s kidney which went a bit over their heads really. I don’t think they can get the concept of that at all and they just kind of went “oh yeah” and

“oh right, okay”. So they didn’t ask anymore. I don’t think they could understand it and they just kind of moved on with it.”

F5P

The parents gave various ideas that they thought might be useful to families to provide information to their children. Not surprisingly many ideas centred on the provision of a fun computer-based learning package. However, books and leaflets, perhaps with some activities in them were also popular ideas. The caution was added that anything produced would need careful piloting.

“I’m rather concerned about hard copy being ambiguous, ambivalent and unclear. There’s a lot of people out there who think they can write it as leaflets and I fear that little of it has been piloted, so I think that whatever does come out needs careful testing and maybe with the consumer being the audience, because I think that some of the stuff that’s been written for kids by adults has just come out as if it’s for adults.”

F1P

Some families also suggested an information session that was aimed at the whole family. It was envisaged that all family members would attend, not only to listen, but also to meet other families in similar circumstances. Another suggestion was an individual session for a family with a nurse, where again the whole family would have the opportunity to be together and ask questions. I want to bring the discussion of this cluster to an end with a final quote, which I hope sums up what the parents are trying to achieve when providing information.

“I think he needs to hear it from me because if he doesn’t hear it from me, he won’t trust me. Does that make sense?”

F7Pt

5.6.6 “How do I get inside a 9-year-old’s head?” – parental interpretation

Parents were asked some specific questions which invited speculation about what their children thought. The emergence of this category is therefore not surprising. However, there were also additional instances in the conversations where parents did try to interpret what their children thought. This appeared to be in a positive way, trying to understand what the parental illness meant to the child and hoping that, as parents they were dealing with the situation in the ‘right’ way. Most parents made the point that they were not always clear about what their child meant or wanted and

they were also explicit that they were giving their interpretation of the situation as the following excerpts indicate.

“So... I don't think you can ever get inside somebody else's head. You can know them pretty well but I think there's always a little space that's private so he does have anxieties about that”

F1Pt

“If you can do that I think it might be an eye-opener because our interpretation of what we think he thinks is maybe wholly erroneous.”

F1P

“I suppose I would be quite fascinated to hear what F3C does actually say because I'm sure they'd be quite a lot we don't know, just how she feels in herself, who she's actually spoken to, what her fears are, what her concerns are, and generally is she happy. I suppose the other thing is, does she think it is holding her back?”

F3Pt

“I think that what bothers her most is and that it will be interesting to see when you talk to her... as I perceive it's the fact that”

F3P

“I suppose he wants to know everything but then I don't know. How do I get inside a 9-year-old's head?”

F3P

Children's interpretations of situations do not always match those of adults and this cluster highlights some of these differences well. Within family one it is in terms of the child's view of the number of tubes his mother has. The child's measure appears to be the more tubes his mother had, the more ill she was. He was therefore unsure how positive the transplant was as the number of tubes had increased significantly. With family five it was issues around a child wanting his father to have one of his kidney's to make his father better.

“F5C1 wanted to give a kidney at one point. He made me choke quite a lot early on, cos as children do they see things in black and white, he spent a long time asking “why do we have 2 kidneys.” “Why do we have them if we just need one, why can't he have mine then, is it too small?” “oh it's too small” and then his killer line was “I will just have to eat a bit more”

F5P

Many of the assumptions made by the parents related to the sort of information that they thought their child might want. Again this is attributable to the interview

technique. It also seems to be a conscious decision on the part of the parents of the need to protect the child, as far as is possible, from the full impact of the disease. This was often the pattern seen when the parent with CRF needed to be in hospital, either for HDx or as an inpatient. The reasons for not encouraging the child to visit appeared many. There were perceptions about hospitals in general and the visiting of children in particular. There were the practical issues about what to do with the children when they were visiting, and there was the presence of other sick people. This involved a worry that the child might assume that their parent could soon become like that. However, visiting hospital was more 'normal' for one family and another family felt it was better to see the parent and know they were well, than to leave things to the imagination. A selection of quotes are given to illustrate these points.

"They never saw me on haemodialysis because we felt that possibly could freak them out. Not because of seeing me but because of seeing everybody else."

F2Pt

"To be honest with you I don't like them up here seeing me ill and when there's other people ill it's a bit harrowing on them to be honest with you"

F4Pt

"I think it's better for him to see her than not, because it's scarier I think not to see her."

F6P

"They associated hospitals with where I work so they are not frightened about hospitals."

F5P

Parents also seemed to make other assumptions about the need to protect their children. There were concerns expressed about the possibility that children would worry too much and, in one case, a decision was taken to remove a child from specific lessons at school related to kidney problems to protect them from what they assumed would be old information.

"sometimes I worry that she's taking too much on even though we don't tell her actually half so much about it"

F3Pt

“They do know a lot of the down side, I don't know but I feel that I don't want it to take over their lives and to be worrying.”

F2P

“I thought I don't want him to learn about it at school. You don't know and it could be frightening to suddenly show somebody on this old-fashioned machine so I told the school I would sit and go through it with him myself, which is what I did. I had the book and we went through it together”

F2P

There was an almost unanimous reaction to the question asking about what the parent thought the child wanted to know, all initial responses were along the lines that they would just want the parent to be all right. Which seems a totally understandable response.

“Well I suppose really all they want to know is, “am I going to be all right?”

F4Pt

“So, I think he just wants to know his mother's going to be all right.”

F6P

5.6.7 “I think seeing mum taking pills every day is no longer a threat because it's just a routine and it's almost a security” – security

This cluster has emerged from the data and has the potential to be important in describing family relationships. Having security is an important part of a child's life. In this study the parents expressed the child's need for security in various ways. It is the security the child has in knowing that mum will be there at the end of school - or not, if she is on hospital based HDx, which is a cause of anxiety. The security of seeing the parent take tablets daily and knowing they help keep them well, and security of having mum and dad around, and the emotional pain and anxiety when, for whatever reason the security is taken away, perhaps because of an hospital admission.

“Well I think that parents are security blankets, aren't they? Your security is based around that”

F1Pt

“it will definitely be an issue when I'm ill. He'll want to know what's going on and I think that what will upset him most is that I'm in

hospital. If I've got a cold he can come upstairs to make sure I'm OK, but if I'm not there, I'm away from him."

F7Pt

"But then just telling him isn't the same I suppose as... because when it happens there'll be a big absence"

F6P

"I think seeing mum taking pills every day is no longer a threat because it's just a routine and it's almost a security."

F1P

Doesn't like to be away from either of us and that definitely is probably one of the effects of dialysis is that she's a very confident little girl but she's very clingy to both of us.

F3P

5.6.8 "I think you almost have to live for the best and plan for the worst" – living with a chronic illness

Some participants discussed the unpredictability of living with a chronic illness. The fact that, even as an adult, you had no control over the course of the illness contributes to the uncertainty experienced by these families and can make it harder to know what to say or do when trying to plan for situations.

"when it started, when you're first told about it, they make it sound like you need a transplant but seven years later here we are still waiting, It's a very slow process, You just become immune to it after a while. You know it's going to happen but you just get on."

F6P

However, the presence of children appeared to make living with a chronic illness harder to deal with, as there were the needs of the whole family to be considered. This was particularly pertinent to family five who were moving from the relative stability of a working transplant back to dialysis, but other families were aware that there could be change in their situation just around the corner.

"The hardest bit definitely, obviously its different this time around cos last time around I just had myself to worry about, this time I have got the children to worry about and it has taken me quite a long time to get "my" head around F5Pt being ill again."

F5P

“They ask questions about when I’m going to get better and of course the only answer I have got is that I haven’t any ideas on that, just have to wait and see what happens.”

F5Pt

“Oh is it failing, is it going wrong?” That’s one of my main worries - how to deal with that when it happens; and I got a feeling in my head I’m not going to deal with it very well. I don’t know, just the thought of it dreads me now so that’s my main worry, how am I going to deal with it and tell the kids and that.

F4Pt

Living with a chronic disease appears to suffuse many aspects of family life. It is perhaps summed up quite simply with this quote.

“I think you almost have to live for the best and plan for the worst”

F1P

5.6.9 “The new kidney is doing very well but may not last a lifetime” – transplantation

It is evident from the conversations that for the families the area of transplantation presented many issues to be dealt with. These were different, not unsurprisingly, for those who had a functioning transplant and those who were waiting for a transplant. Families were aware of the positive side of transplantation, but this is tempered with the waiting and the feeling of when would it be our turn or the fact that the transplant will not last for ever and how would they and their children react to the possibility of coping with dialysis again.

"What I need to know is, is Daddy better now?" and I thought, "Oh I've never actually sat and said, well I can't say better but I've never actually said this is the end to it hopefully for a little while."

F2P

“her new kidney is doing very well but may not last her lifetime”

F1P

With a transplant there are still the routine hospital checks, the maximum time between appointments being 12 weeks. These checks can provide reassurance for the family that all is well, but they can also raise the possibility of problems.

“The first year I've always been frightened, his creatinine was, I feel it should be lower than it is, you read up and I suppose because I've read up, I've read that a higher creatinine level means that the kidney

doesn't always last as long as a lower creatinine. But there's nothing we can do about that anyway.”

F2P

“Five years down the line, we have had a really good outcome and yet today, I hate today. He won't let me phone up because he doesn't want to know, he says “if it is bad news they will phone me.” But I would rather know the results cos I'm waiting for that phone call, that's why I do it and then for 12 weeks I can rest, in some ways we can both rest.”

F4P

For those participants who were waiting for a transplant the issues were different. They talked about not knowing when the call for a transplant might come, whether it will happen at all and the life changing potential a transplant may bring, although the knowledge that the transplant may not work or may not last long is also clearly expressed. The waiting proved stressful for many.

“I think it would make a big, big change, a very big change, it's just important and I suppose for anyone you can't guarantee that the damn things going to work but on the positive side, feeling good, being able to do things, travel, just things in general, not that routine of three days on a machine and I know you still have to come up for clinics and things like that but that's little.”

F3Pt

“Because we don't believe it's ever going to happen so I've got to the point where it's there in the back and it's just like it's not going to happen. I'd love it to happen. Even if it only lasted a year it would be a year of what is reasonable health and no machine.”

F3P

5.6.10 “How am I going to deal with the fact that he may have this?” – hereditary conditions

With hereditary conditions a number of factors seemed to be at play. There were understandably elements of worry and regret at the unknown, as these quotes indicate.

“It does keep worrying me, how am I going to deal with the fact that he may have this.”

F1Pt

“I probably think he probably has got it because the history is too strong to suggest he hasn't got it and that's my biggest regret. “

F2Pt

However, hereditary conditions also presented other dilemmas. The presence of an unknown, has the child inherited the disease, led to uncertainty regarding how, what and when to talk to the child about the possibility they might have the disease and also affected planning for the future, perhaps in financial terms. There was also some anger, directed at the medical world in general, regarding the inability to provide an early diagnosis.

“I think that a number of improbables and implausible and unpredictable are quite extreme in this case and I think that probably affects the guarded way in which we talk to F1C. We try to be open but we try not to be threatening”

F1P

“I do think that there is an issue between the hereditary people perhaps and the comes-as-a-thunderbolt”

F1P

None of the adult participants appeared to blame their parents for their lack of knowledge, rather there was an acceptance that generations have different views, and in some cases an awareness of the fact that the parents may not have passed on information simply because they did not have the information. There appeared to be a recognition that perhaps the paternalistic views of medicine are changing, albeit slowly. There is also a view expressed of the societal changes that have taken place in the way that childhood is viewed. What this theme does seem to illustrate is how childhood experiences, of hospitals, or their own parents' illness appear to have influenced how the parents wish to treat their children in terms of giving information about their CRF to try to ensure that it is a more positive experience.

“I don't think my parents talked to me at all about what was going on but then I don't think they talked to each other about it. I think when F1C came along or when my renal disease came along I decided to deal with it differently with F1C but, life has moved on, life has changed. The way you deal with children I think has changed.”

F1Pt

“but we can only try and help him through it as much as we can and I would like to hope that I would give him a lot more support than probably what my parents gave me, but then they probably didn't understand it as much as what I understand. They were probably, and I'm probably being unkind here, but they were probably ignorant about

it "Oh well, just treat me, don't worry about it, what do I need to do now". They never asked questions"

F2Pt

"I've always with F2C1, I've never denied that he wouldn't get it. I've always from day one because I remember it being such a shock for F2Pt to suddenly find out that his uncle had died from kidney problems, and that's how we started to piece it together and then it was all a big mystery about all these relatives that had died. It was never openly talked about in his family so I always thought, "well no".

F2P

"The more information I have the better informed I am and I have always wanted that and because of my past experiences, children you never cried in front of, you said everything was gonna be okay but its not to be honest and that's my point now, be honest with your children."

F3P

5.6.11 "Really forget about it and just get on with our lives" – life view

This cluster seems to reflect what I have termed a 'life view'. This has a possible connection with personality, if someone is optimistic or pessimistic for example. However, the way somebody is, the life view that they hold appears to affect their coping mechanism and how they deal with illness in the family.

"So apart from that we'd deal with it quite well, I think. I mean as I say we're sort of pretty of what's the word - take it for granted. Really forget about it and just get on with our lives which as I said before I think is the way it should be so and if anything happens then we would deal with it, deal with it as a family group then."

F4Pt

"the only way that we coped with it so far is by just not letting it take over cos it very easily could and I'm sure there must be unfortunately some people who just can't handle it and it does become the biggest thing in their life and their life evolves around their illness. What that would unfortunately mean, if you look at it on a bigger picture, is you've got the illness in the middle and then the person standing next to it and outside the circle of them and their illness, is their family and they'll start to block out the family because they feel that they are more concerned, they become more protective of the disease, than they do of their families it's like completely on its head to how it should be."

F5Pt

The picture given by the patient in family five is I feel particularly pertinent in trying to describe how CRF could affect the family. With the family in mind I now turn to the presentation of the data from the children's focus groups.

5.7 Children's data

The data from the focus groups were analysed using the same techniques as the adult data, except for the drawings which were explained by the children; no further analysis was undertaken with these pictures. The significant statements relating to family life or to information were extracted from the transcripts and when reviewed gave five clusters. These clusters, like the adult clusters have two titles, with the shorter title reflecting the meaning that I attached to the cluster. The emphasis of the themes was slightly different but some similarities could be seen.

- “You kind of need to be a bit up front and a bit sort of laid back about it” – information
- “We didn't have much time with him” – family life
- “Because if you, sort of, talk about it too much, your friends just get bored to death” – friends and school
- “We could go more places” – holidays
- “He had to go back in hospital the next day” – worry

5.7.1 “You kind of need to be a bit up front and a bit sort of laid back about it” – information

The children talked about the information they had received in quite a factual manner. One child knew for example that the average waiting time for a kidney transplant was two years. It appeared that most of the information they had was given by the parents. They could explain the type of dialysis that their parent had and knew about transplants. They made some very interesting points about what they think they should be told and why, but also showed a mature understanding of some of the difficulties that must face their parents. They appeared to enjoy the focus group as it gave them chance to interact with other children whose parents had the same illness, so the information that they were not alone appeared important to them.

“Well one thing I did um is because well what I did like about our families.... my mum and dad do like me to know umm about.... they wouldn’t lie and say like no, if someone’s body was like a bit wrong or something and I asked they would say this is how they were born and stuff or they wouldn’t just say like that ... they would say what it was and how you get it, its just nice to know what is actually going on. It probably is hard to tell you what is going in a way that you understand like, umm, like umm, you couldn’t say it like you would say it to an adult cos you are quite little and you wouldn’t understand really. You have to say it like a children way, you know, how children think.”

F3C

“Sometimes it does sort of happen in that sort of case because you’re, its sort of, if someone gets the news before you and then you get the news sometime you don’t get the umm exact what was said and sometimes you’re not really sure about what was actually said so sometimes I do sort of ask my Mum a few questions about what happened”

F1C

“you kind of need to be a bit up front and a bit sort of laid back about it because, yeah because sort of if you are a bit too up front you get so far into it if you sort of get some bad news you will get very sad about it. If you are a bit laid about it sort of, you’re sort of in the middle of it and you don’t know much about it, so if something goes wrong you can ask about it and you don’t really get as sad as you would if you were so up front. I know. You have got to think about what you’re doing as well as, sort of, what is happening to your parents. The laid back you sort of, you don’t really talk about it much but you’re being very laid about the matter. And also you need to be a bit, sort of, upfront asking your parents questions but not very many questions.”

F1C

5.7.2 “We didn’t have much time with him” – family life

This cluster appeared to have two main strands to it. On the one hand the children talked about the influence dialysis has upon their daily life, and on the other it was clear that as far as possible life carried on. Family life went on in that for one family the call for a transplant came the evening before a school residential trip. The child had a sleepover at a friend’s house and went on the trip the next day. The need to remember that kidney problems may not be the only issue within the household was also made. One child has one parent with CRF and the other with another chronic illness and at the time of the focus group felt that the kidney disease was easier to deal with and impinged less on their life. There were some interesting comments

about the impact of dialysis on daily life, for example a different routine, necessitated by the time it took for the parent to perform their dialysis. There were limits to the amount of time these children wanted to spend in front of the television or with a computer game. However, there were also implications for trips out – to the cinema as illustrated below.

He had like a tube from his stomach, to drain the blood or something, then we had to drain it out in the bath. My dad took it out (of the bath) cos he only needed it at night and then we had to have our baths and showers in the day but..... like my mum sterilised it to get rid of all the... I don't know what it is but.....

F2C2 and F2C3

“We didn't have much time with him but he had to do it for about an hour and a half and he said the bag was really slow. I don't know how slow it was but it was really slow. Well, we were just doing stuff together. F4C1 was playing on the play station and I was watching telly. It was like really boring.”

F4C2

“I sort of just sat there sometimes and sometimes I resorted to doing nothing because maybe Dad was doing some job in the garden while Mum was doing dialysis and sort of there was really nothing much to do.”

F1C

“It takes up a lot of time.”

F4C1

“You couldn't actually really do stuff much because you needed to do dialysis sometimes. That kind of got a bit annoying. (*Did it?*¹²) Yeah because sometimes if we were sort of like if we wanted to go to the cinema and sort of maybe Mum needed to do dialysis sometime she would go out into the car and actually do dialysis and put the bag on top of the car and do it that way and me and Dad could stay in the cinema so sometimes it would get.....”

F1C

5.7.2.1 Descriptions of pictures

During the focus groups some of the children drew pictures. Some of them drew family shields which we asked them to explain. They give further insight into family life from the child's perspective. Photocopies of the pictures are given in Appendix 17.

¹² Words in italics spoken by one of the adults leading the focus group.

F2C2

Umm, well, first size is like my guitar and like cos my big brother plays guitar as well and like I...Umm, my little brothers might like play like a bit of guitar and like you see it and then Yeah! Right there's my first section with all my guitars, umm, my second section is like a Lift Company, like my dad's work and my next section is like a CD collection and vinyl. Well, when I'm home from school, about 80% of day (listening to music). Well I just put it on and then do other stuff in my room the whole house but like my mum has her music downstairs and my big brother has his music and my little brother has his music and I have my music. My next section which is nearly finished but is all dedicated to Jack Black, the biggest legend in the wild. It's my dad's and mine favourite actor in the house and he has got his own band. He's in things like Ice Age and School of Rock, And he's got like years and years of films planned out like Shark Tale and..... lots of stuff. and I'm just about to draw Curt Cobain, the biggest legend in music, from Nirvana, as you can see there. (Yes!) Unfortunately 10 years ago he committed suicide. (Right) Because people knew his name when he didn't want them to.

F7C

Yes, I've nearly finished my hospital but – I'm mainly colouring in my important picture. Laughs. – Cos I was born in here. (*Oh right.*) And my mum had her operation PAUSE....kidney tablets.... Books and.....(*Books?*) And my very, very important Game Boy Advance. I like a rude type of story called Captain Underpants and he had a little red cape!

F2C3

Umm yeah, there is music cos our whole family likes music and holidays. And sports. Yeah and, like, everyone in our family likes sports. Baseball bat! and there's a cricket bat and then baseball and football net, cricket stumps, tennis racquet and tennis ball and American foot ball – and a rugby post – Yeah I'm signing up for..... last year I couldn't get into the football team, I signed up for that and I signed up for rugby and my last section is entertainment like TV

F3C

Well the first one is just our faces because we are all happy in our family and second one is umm like a rollercoaster cos we do like rides. We go to Lego Land every year and sometimes maybe even twice and um we just go on all the rides. The third one is well all like sports, like, we were watching the Olympics and one thing that we didn't like was that the second week of the Olympics we were on holiday and the people we stayed with didn't have a TV. (*Oh dear!*) We were listening to the radio but their dad had the TV laughs And then we all like music really. We got all our different types of music. Like, me and my dad maybe sometimes we like reggae and my mum likes all this old stuff like Genesis and Meatloaf and everything.

F1C

It's about a person with a runny nose. (all laugh) Because umm, my family's had a few illnesses but they are still happy. Because, my, all my sort of, at the moment, as my Dad has got Parkinson's disease and we have just sort of found out that it, sort of, that's really, sort of, not the most popular thing at the moment. Sort of the most popular thing at the moment is the three teeth he got taken out on Monday. And the, sort of, kidneys getting less talked about. That's pretty much been and gone.

As discussed in the literature review in Chapter two, the interpretation of children's drawings can be fraught with difficulty. Greig and Taylor (1999) suggested that drawing can disclose the inner mind of the child; whilst Driessnack (2005) concluded that using a drawing technique, when the pictures are explained by the children, helps to encourage children to become more active participants in the research process. In my study, the drawing materials were available for the children if they wanted to use them, drawing was used to relax the children and to try and maintain their interest, much as Kennedy *et al.* (2001) and Coyne (1998) suggest. The descriptions of the pictures have therefore been left deliberately in the words of the children. I would not know how to interpret them. However, I think that the combinations of pictures and words contributed by the children enhance the overall view of the family life of these children and highlight the normality of it.

5.7.3 “Because if you, sort of, talk about it too much, your friends just get bored to death” – friends and school

The children in the groups obviously had many friends, however they also often found it difficult, and in some cases did not talk about their parents’ health problems with their friends. The main reason for this seemed to be that their friends did not understand the medical terms that to these children were becoming second nature. One or two children talked about the importance of friends knowing about the parental illness, so that if you needed to talk to someone at school you could. It was noticeable in the groups that children did talk freely about parental illness in the groups. This is perhaps understandable, they knew that was one of the things they had come to talk about, but also they knew that they would be understood, not just by the adults but by the children too because they spoke the same language.

“Well sometimes I’ve got close friends when they come to my house like, umm, they know about it already as we have told them but sometimes... sometimes we don’t know what their mums want us to tell them about it so we have just have to sort of not let them in that room.”

F3C

“I kept it a secret. Yeah I didn’t want no one to, like, know that my Dad was on kidney transplant..... I told very few cos No they don’t, not at all. No! No, I just keep it right to myself cos, umm, all of my other family know, like my Granddad.... yeah, all of them and I just keep it to myself and they most probably keep it to themselves.”

F4C2

“Because if you, sort of, talk about it too much, your friends just get bored to death.”

F4C1

“Well, I told him that my Mum had a transplant and umm.... Yeah, he knew what a transplant was, he pretty much knew what a kidney was, but when I went on to the stuff like fistula and haemo and, sort of, dialysis he was completely baffled”

F1C

School was talked about briefly in a couple of the groups, mainly in the context of whether the teachers knew about the parental renal problems. Most children thought their school was aware, however, they appeared to be unsure if specific teachers knew, for example at the beginning of a new school year. The children did not seem

concerned whether the school knew or not and no children mentioned it as a source of support or of difficulty.

5.7.4 “We could go more places” – holidays

Holidays were talked about in all the focus groups. This could have been influenced by the time of year that the groups took place; two were in the summer holidays and the final one just after the start of the new school year. The children talked about the influence dialysis had on their holidays, how in some cases it restricted where they could go and what they could do. Others talked of their different experience now the parent had a transplant, but how it had still influenced their holiday.

“A few years ago we went to Center Parcs when our dad was on the machine and we had to like get someone to bring it over... We got to do everything was gonna do except our dad wasn’t around to go swimming. Umm, I’m not sure, just that I think he had loads of scars and stuff and he couldn’t get wet otherwise he would just make it worse so occasionally we came out and just kept him company. But you can like get a bag or something.”

F2C2 and F2C3

“Yeah, but we got put into a hotel about seven.... about six in the morning but luckily because all like young children and like medical needs had to go first so umm we got there, like, the first people in there so like we virtually got the best room and umm, like a lot of people got there about 10. If you was at the back of the aeroplane they done it by seat numbers so was quite lucky there. But we didn’t think we was gonna have that long a delay, in fact, we didn’t think we was gonna have a delay at all so umm my dad packed all his tablets in the suitcase and then when we had the delay, he didn’t have them so he had to go right to the hospital. Of course they don’t have like the NHS, you have to pay for them. And that was like, something in England that is really hard to get hold of. I have no idea what the tablets are called but umm luckily he got it and made the flight as well.”

F2C2 and F2C3

“Well, we could go more places, like, when my mum goes abroad every year but my dad can’t come obviously cos of his dialysis so he has to stay behind but if we could go and see him it would be quite fun cos we could all go out together not like me and my mum going somewhere and me and my dad somewhere... us not getting to go somewhere cos my dad Yeah.... well my dad has... he has been on an aeroplane, like we’ve been to Ireland but we only stayed for about 2 days”

F3C

5.7.5 “He had to go back in hospital the next day” – worry

The children expressed some worries that they had. Sometimes these related to knowing that their parents were worried about something, but not being fully aware what that was. Sometimes it was because something had happened and the child was concerned that it was going to happen again, like a hospital admission. Sometimes it seemed to be related to a lack of information.

“One night when I was 5 my Dad had just came home from the hospital and when he was going to bed he was frightening me cos he was really coughing and umm, he had to go back in hospital the next day cos he wasn’t feeling well”

F4C1

“I used to when my Mum was actually doing the dialysis on the machine at one point and also (*the one where the blood goes around*) It looks a bit gruesome, and umm, I thought also when she came in for the transplant sort of it feels, sort of, sometimes a bit worrying sometimes because almost you are actually in there and you don’t know what they are doing to your Dad or your Mum. It seems sort of worrying quite a lot.”

F1C

“Because, sort of, knowing that your parents worried and you don’t really know much about it, you want to investigate it but your parents don’t really want to talk about it because maybe the other one’s worried about it and you don’t want to sort of put them in tears or something. Sometimes my Mum was kind of a bit worried and sometimes she got very happy about what had happened and sort of that’s because also she mostly talked about it to my Dad so I didn’t really get the full info on what was happening which kind of made me a bit unsure but pretty much now its been pretty much explained to me.”

F1C

“Well, when my, umm, when my Dad went to find out what his blood levels were, my Mum was really worried in case they were high because my Dad’s blood levels need to be low, and err, and she, and my Mum was all worried about it but when my Dad knew his blood levels and he phoned my Mum up and he said, and err, he said that they were alright and I was happy and then my Mum was happy”

F4C1

The children’s data clearly shows that they have their own views and perspective of the parental illness. They want to be consulted and involved in the decisions that are made about family life.

5.8 Summary

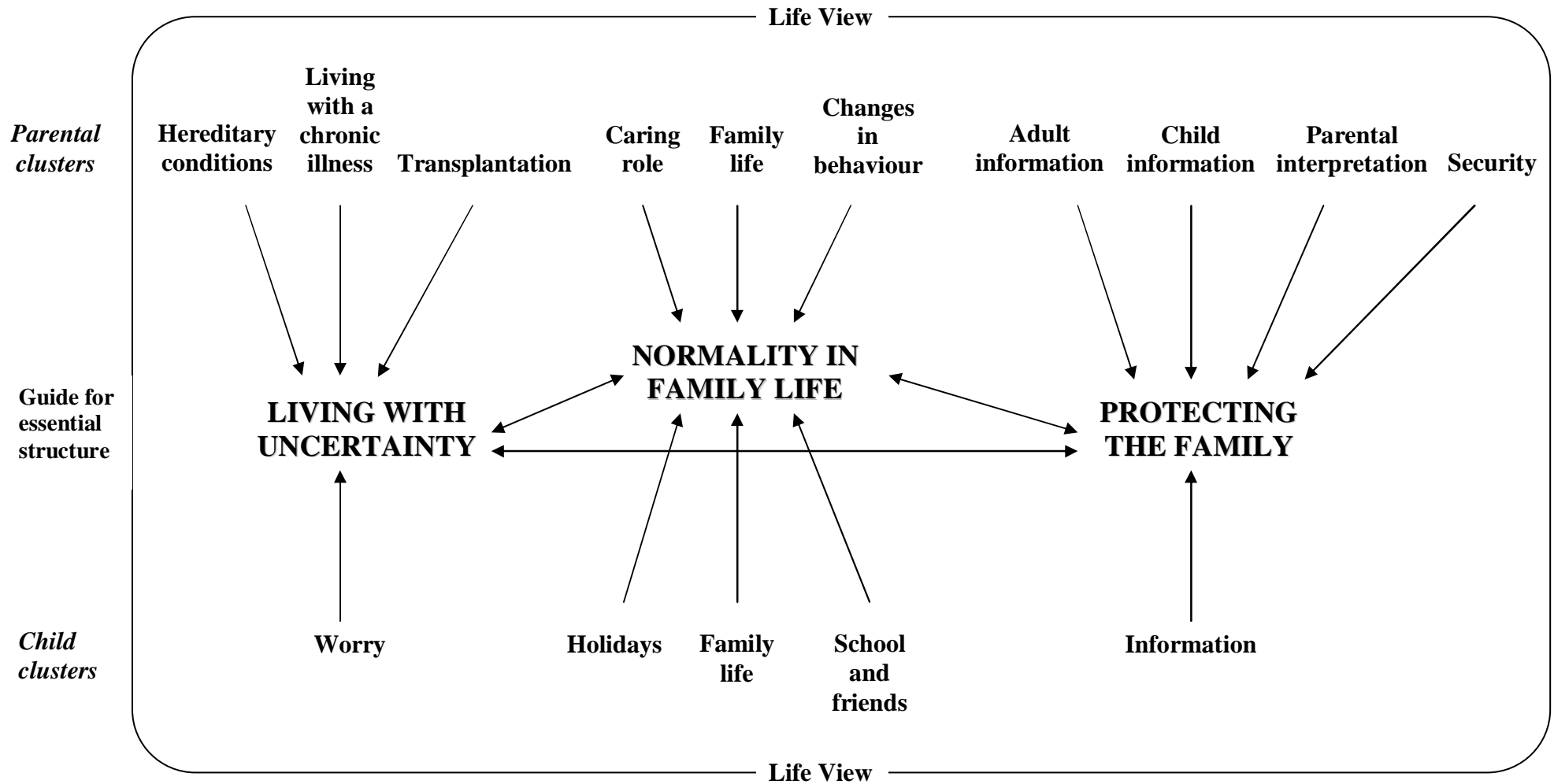
Data from both the adult interviews and the child focus groups have been presented. A diagrammatic representation of the parent and child clusters is given in Figure 5.3. Here they are grouped and shown feeding into a theme which is common to all the clusters in that group. These three themes guide the formation of the essential structure and are:

- **Normality in family life** – normality is in itself a difficult concept, as what is normal for one family, may not be for another. However, essentially the families appeared to concentrate on a pre-treatment lifestyle and worked to maintain that. Within that the children kept their normal routine with school, friends and to an extent holidays.
- **Protecting the family** – here the parents try to protect their children from any effects of CRF to provide security for their children. This is often achieved by using information. The children also wanted information to help them understand what was happening to their family.
- **Living with uncertainty** – within this core theme both parents and children identified the uncertainty and unpredictability of living with a chronic illness, even when transplant was available the uncertainty pervaded all.

The life view – “Really forget about it and just get on with our lives” is entwined within all three themes and essentially seems to drive the way the parents deal with life. Their desire for normality, how they try to protect their family and how the differing levels of uncertainty are dealt with. The clusters will be discussed in Chapter six and linked within their themes with reference to recent published literature.

Figure 5:3

Linkage of the parental and child clusters with the essential structure of living with chronic renal failure



However, before Chapter six commences the data is drawn together in the form of the exhaustive description, this is a pre-requisite in Colaizzi's (1978) procedural steps. This highlights the meaning of the phenomenon to the participants, as it describes how the parents and children in the families see CRF impinging on their family life. It also ensures that, the data having been deconstructed as part of the analysis, it is then reconstructed to give a view of an interpretation of the whole. The exhaustive description aims to draw together the findings of the research using the participants' significant statements, linked together with some of my own words. I have chosen to write the exhaustive description and present it here, and in this way to give voice to the phenomenon from the participants' perspective. It is therefore the amalgam of their voices that speaks. In this way I hope I have created a thoughtfully constructed tapestry, as suggested the product of phenomenological research should be by Koch and Harrington (1998) and mentioned earlier in the chapter, rather than the blandness described by Paley (2005) where all the uniqueness and lived experience has been removed. Using the participants' phrases linked by my connecting words ensures that their view of life with chronic renal failure is presented – not mine – I have not had to live with this disease, only cared for people with CRF. Reading the exhaustive description should help focus the reader's mind on the living of family life when a parent has chronic renal failure. This is what spoke to me as an experienced practitioner working with people who have CRF and exploring with them how their CRF affects their family life. It is given as a summary of the findings, prior to the detailed discussion.

5.9 Exhaustive description – the effects of chronic renal failure on the family

Normality in family life

“We just try and be normal” (F6P), while I try “not to allow the condition or disease to encroach on what I perceive as my life” (F5Pt). The parents believed that the children “just think this is our life, this is what it's about, and you know they get on with it” (F2P). However, the children, at times, saw things differently. They felt “We didn't have much time with him but he had to do it for about an hour and a half and he said the bag was really slow. It was like really boring” (F4C2), and “It takes up a lot of time” (F4C1). Whilst another “resorted to doing nothing because maybe Dad was doing some job in the garden while Mum was doing dialysis and sort of there was really nothing much to do” (F1C).

“We want a life and therefore, if he wants to go out for a work do on a Friday night when he normally dialyses then we do an overnight. Then he can have a couple of beers and we get rid of them on the machine. So we do to a certain degree move it around where we can but we actually lead very busy lives and sometimes we're not able to be that flexible” (F3P). The freedom and relaxation to do what you want are restricted by dialysis regimes but “we went to Centre Parcs for a week, with the bags” (F2P). However, if there was a transplant “we could go more places” (F3C).

At school the children were selective about who they told about their parent's CRF, concerned perhaps at the potential reactions of their friends “because if you, sort of, talk about it too much, your friends just get bored to death” (F4C1). While “I kept it a secret. Yeah I didn't want no one to, like, know that my Dad was on kidney transplant.....” (F4C2) but me “well, I told him that my Mum had a transplant and umm.....yeah, he knew what a transplant was, he pretty much knew what a kidney was, but when I went on to the stuff like fistula and haemo and, sort of, dialysis he was completely baffled” (F1C).

Parents were concerned that “I will have to lean on them more” (F3P), but appreciated that “they like to get involved in pressing the little arrows on the APD machine, wash their hands and things like that” (F5Pt). Additionally parents looked for changes in behaviour that “just seemed to coincide with the time things started to go wrong” (F5P).

Protecting the family

“Well I think that parents are security blankets, aren't they? Your security is based around that” (F1Pt). The parents wanted to protect their family so “they never saw me on haemodialysis because we felt that possibly could freak them out. Not because of seeing me but because of seeing everybody else” (F2Pt). Others thought “I think it's better for him to see her than not, because it's scarier I think not to see her” (F6P). The parents used information to help provide this protection but even they “don't always want to read all the down side. We used to try and get a positive sort of perspective” (F2P). Some wanted all the information “I would be going well tell me this or tell me that” (F4P) whilst others “deal with it as it happens” (F4Pt).

Giving children information could prove difficult because “how do I get inside a 9-year-old’s head?” (F3P) and sometimes “what we tell them and what they hear, as I say, are probably two different things” (F5P). Parents wanted to give their children the information because “I think he needs to hear it from me because if he doesn’t hear it from me, he won’t trust me. Does that make sense?” (F7Pt). Parents therefore tried to “deal with it as you go along. I think I’d give him the information that I thought was appropriate at the time” (F4Pt) because “the idea that you can’t tell the children is not an option in my view. What you tell the children and how you tell the children is problematic to say the least” (F1P). So when “she’s asked a question and we’ve told her, we’ve been up front because we’d rather she hears it hopefully the right way from us” (F3Pt) because “I think the best protection they can have is being told the honest truth about what’s going on” (F5Pt).

Children developed their own strategies “you kind of need to be a bit up front and a bit sort of laid back about it because, yeah because sort of if you are a bit too up front you get so far into it if you sort of get some bad news you will get very sad about it” (F1C) because they knew “my mum and dad do like me to know about.... they wouldn’t lie and say like no, if someone’s body was like a bit wrong or something and I asked they would say this is how they were born and stuff or they wouldn’t just say like that ... they would say what it was and how you get it, its just nice to know what is actually going on. It probably is hard to tell you what is going in a way that you understand like, you couldn’t say it like you would say it to an adult cos you are quite little and you wouldn’t understand really. You have to say it like a children way, you know, how children think” (F3C).

Living with uncertainty

There is however, much uncertainty about living with a chronic illness – “you know it’s going to happen but you just get on” (F6P) but life is more complicated with children in the equation “obviously its different this time around cos last time around I just had myself to worry about, this time I have got the children to worry about” (F5P). There is the uncertainty that “the new kidney is doing very well but may not last her lifetime” (F1P) and for some families “it does keep worrying me, how am I going to deal with the fact that he may have this” (F1Pt). The children too have their own worries and concerns because “it looks a bit gruesome, and I thought also when

she came in for the transplant sort of it feels, sort of, sometimes a bit worrying sometimes because almost you are actually in there and you don't know what they are doing to your Dad or your Mum. It seems sort of worrying quite a lot" (F1C). At other times "when he was going to bed he was frightening me cos he was really coughing and umm, he had to go back in hospital the next day cos he wasn't feeling well" (F4C1).

But despite all this we "really forget about it and just get on with our lives which as I said before I think is the way it should be so and if anything happens then we would deal with it, deal with it as a family group then" (F4Pt). After all "I managed to work full-time so if you like the regular life-style didn't change" (F2Pt) while "I run my own business and I still have a social life" (F5Pt). With a chronic illness "I think you almost have to live for the best and plan for the worst" (F1P).

Chapter 6

Discussion

6.1 Introduction

Within this chapter of the thesis the findings presented in the previous chapter will be set in the context of the available knowledge, although the published literature is somewhat limited. The discussion will be presented using the three themes identified in Figure 5.2, and with the overarching link of the 'life view.' The chapter also includes a brief comparison of CRF and cancer. The thesis is then drawn together by critiquing the methods used within the research, considering implications for practice and by drawing final conclusions.

6.2 Normality in family life

Parents appear to try to minimise the effects of CRF on their family life by trying to keep their family lives as normal as possible, that is, family life as close as possible to how it was before the parent had to begin RRT. This may mean different things to different families, as what is normal in one family, may not be in another. However, it does link in with an observation of Evans (1978) that parents wish to appear normal to their children and that this may influence their choice of RRT. Children, in their turn, have the normality of school and friends, holidays and the routine of family life. All of which is probably subtly different to the experience of their peers.

Wanting to continue to live life normally when a person has CRF has been clearly identified within the literature. Although it should be noted that this normality is usually linked to the individual's life in general rather than, as here, specifically to normality in family life. This 'wish for normality' was identified by Lindqvist *et al.* (2000 p 293) who described the struggle people undergo to try and maintain their life as much as possible in a pre treatment state, whilst Polaschek (2003), in a study of six Caucasian men established on home HDx, identifies that these patients describe having a relatively normal life within the confines of their dialysis schedule. However, Polaschek (2003 p 50) goes on to argue that although these patients describe a normal life what they are actually verbalising is the 'dominant professional discourse' and the interviews in fact show how many limitations and negotiations are

accepted by patients to achieve this. In a study looking at 41 patients being treated by HDx, Hagren *et al.* (2005) used a qualitative methodology which was not described, and examined life on HDx, focusing on patients' experiences of care, and on the time-consuming nature of the treatment. Some patients talked about a desire to live life normally, however, they also knew that for them, this was effectively impossible; this was also acknowledged within the interviews undertaken for this research. All of these studies express the patient's wish to be free of the constraints that RRT, particularly HDx, imposes on their life. However, none of the studies specifically considered the needs of the family. It would appear that many patients, with or without families, attempt to combine dialysis and their normal routine. This can be seen in this research in the way that families three and five approach their dialysis treatment and their desire to integrate dialysis into family life, rather than allowing dialysis to dictate to them what family life should be like. This integration has been noted by Polaschek (2007) and he describes how negotiation with health care professionals will take place so the patient achieves a balance in their life, rather than complying with advice and directions unquestioningly. This can lead to a modification of treatment regimes to try and maintain a normal lifestyle while living on dialysis and this is acknowledged by Polaschek (2007). However, interestingly Polaschek (2007) also indicates that when a young family were present there appeared to be a strong motivation to continue undertaking the treatment carefully. This has to be interpreted with caution, the term young family was not specifically defined, but it did appear to include caring for children.

The physical limitations that can come with CRF and its treatments can also have an effect on family life. The fact that patients with ESRD frequently look relatively well, and many within this younger age range continue working, can hide the fact that, particularly for people on dialysis, there is a general lack of energy (Polaschek 2003) and physical limitations (Lok 1996). Anaemia is a common problem in many with CRF or ESRD (Chalmers 2002). These limitations were shown by the families in this study. Particularly noteworthy were: the lack of freedom to indulge in physical activities with their families, for example, not going in a paddling pool with their children in order to protect their PD catheter; and the fatigue experienced due to a combination of the CRF and the effort involved in trying to maintain some semblance of normality. In their work with families where a parent has IBD Mukherjee *et al.*

(2002a) identified that physical limitations can affect family life. They found that parents with IBD described how their family's social life was restricted by, for example, tiredness (Mukherjee *et al.* 2002a).

Family three had taken the decision to have only one child because of the constraints haemodialysis puts on family life. Mukherjee *et al.* (2002a) noted similar findings in their sample, here families chose to have only one child, or perhaps ensured a longer gap between children so that there was only one very young child to look after at a time. The child in family three, with a father on home HDx, had until recently frequently asked for a sibling. This was all within the context of the parents ensuring that she had a very full and active social life to try to avoid what they perceived were the drawbacks of being an only child.

Families with hereditary CRF also respond by making choices about their family make up. Both family one and family two had taken the decision to have children knowing that the disease could be passed on to them, both families had also sought help from genetic counselling. In an editorial comment, Levy (2001) identifies that although genetic testing is possible for hereditary renal conditions it will not calculate the age of onset of the renal disease, or the severity of the condition. In my clinical experience I have met couples who have not had children because they did not wish to pass on their renal disease to a future generation. This observation is supported by Levy (2001) where he mentions that some couples, where there is an inherited renal disease, choose to remain childless. The decision to have children or not, is not taken lightly within these families.

Children and parental views on the restrictions dialysis can place upon family life did not always coincide. Parents appreciated that undertaking dialysis was a time-consuming procedure and tried to ensure that children were occupied whilst dialysis took place. However, for many children this meant being given the chance to watch television or play with computer games. Parents appeared to think that the children were quite happy with this arrangement, and particularly with younger children, parents felt that they did not notice the absence of the parent while dialysis was performed. However, the children saw this situation very differently. They talked about how time-consuming dialysis was, and of how they did not see much of their

parent, of the boredom of having to watch television or having no one to talk to as one parent was away doing their dialysis and the other parent was occupied undertaking another task. This particular facet of the data may be more prominent in these children because of their age range. Some of them were old enough to remember life before the parental transplant and therefore were able to compare life on dialysis and life with a transplant. However, they were not yet teenagers who would be gaining more independence and perhaps the ability to occupy themselves more fully.

Holidays are an important part of family life and an activity considered normal by most families. However, for families where a parent has CRF the reality may be somewhat different as Polaschek (2003) points out. Not only is travelling difficult, particularly when on HDx, but the main feature of many holidays, the freedom and relaxation to do what you want, are also restricted by a dialysis regime. White and Grenyer (1999) also highlighted the lack of opportunity for holidays when a dialysis patient. The children in my study talked about the places they had been on holiday, both with and without dialysis. They also included pictures related to holidays and days out on their family shields. Molzahn and Kikuchi (1998) identified that children need carefree holidays, which they acknowledge is difficult to arrange when a parent is on dialysis. It was clear that there was more freedom to holiday as the family wanted to when the parent had a successful renal transplant. However, even this was not without problems as family two illustrated. The father's anti-rejection medication was all packed and then a flight was delayed causing an anxious, time-consuming and expensive trip to obtain replacement medication from a local medical centre. Generally however, the parents tried in a variety of ways to ensure that their children had a normal holiday, even if it meant obtaining special permission to be absent from school. Holidays are part of normal life, part of sharing family experiences together, and being like their friends, all of which are important to families and their children.

All parents had told their children's school about the parental CRF. The children however, were more selective about who they told. Many of the children did not tell their friends about the parental illness. This appeared to be for a variety of reasons, mainly to do with understanding – the children felt that their friends would not understand the terminology or the effects on their life. Molzahn and Kikuchi (1998) noted that children often did not talk to their friends about the parental CRF, or if they

did, it tended to be only to their best friend, because of worry about their friends' reactions. In their study looking at the effects of parental IBD on children Mukherjee *et al.* (2002b) also commented that children were often reticent about talking to their friends because of a lack of understanding.

School is obviously an important part of children's life, and happily, they did not appear to experience significant problems in this area. It was suggested by Hoover *et al.* (1975) that there should be a tripartite arrangement for communication whereby the child's school, the renal unit and home should all be able to contact each other easily to share information and therefore be able, in stressful times, to unite to support the family. Parents in my study were aware of additional support mechanisms available via the school such as the school nurse or an educational psychologist, although these had not been used at the time of the study. Interestingly, when Chalmers *et al.* (2000) looked at the needs of adolescents whose mothers had breast cancer, they remarked that the adolescents only appeared to contact the school counsellor for support if they had done so before for other issues. The parents in Mukherjee *et al.*'s (2002a) study acknowledged the help and support offered by schools when they were aware of the parental situation. This help appeared to be on a practical support and understanding level, much as was described by the patient in family five in my study, where the school understood the need for a term-time holiday and the possibility of lateness in the morning because of the extra dialysis related tasks that had to be performed in addition to the normal pre-school morning routine.

Chalmers *et al.* (2000) suggest that schools can potentially be a source of information and support for children, although in relation to cancer, their topic of study, they note that the information provided is likely to be of a generic, rather than a specific nature. Additionally, Chalmers *et al.* (2000) noted that the provision of up-to-date information was an issue in schools. The decision taken by family two to withdraw one of their children from specific lessons in school on CRF because the information he would receive might be dated can therefore be taken to be an appropriate point of concern.

Notwithstanding the general lack of problems at school, Auer (2002b) mentions that some changes in the behaviour of children may be seen. She like others, for example

Friedlander and Viederman (1982) and Molzahn & Kikuchi (1998), noted the potential for under performance at school. This latter potential problem was not highlighted by any of the parents in my study. Mukherjee *et al.* (2002a) documented incidents of difficult behaviour in children. They gave an example when a parent described how the difficult behaviour correlated with exacerbations of the parental illness and a general feeling of anxiety within the home. The parents in my study appeared to take a pragmatic view of the behaviour changes they had noted. They tended to be attributed to the child or children's way of dealing with the situation and were usually not long-term changes. As changes in behaviour were asked about in the interview it is therefore no surprise that this cluster appears within the data. The questions related to this topic were asked because of the findings from the initial literature review, documented in Chapter two. However, for these seven families behavioural changes were not an issue and this perhaps reflects on the parental view of what is normal, and the expectation that there will be some changes in behaviour when there are alterations in the normal pattern of family life and that the child should be given time to work things through.

Within this cluster there appear to be two levels of caring that parents identified: firstly a demonstration of a caring attitude and a caring role, perhaps towards their parents or others (as indicated in family two), but secondly, at a deeper level, the possibility, acknowledged by the parents (for example in family three), that in the future the children might become young carers. Interestingly, there was no particular acknowledgement of the caring role of spouses. The families which talked about the potential for their children to become young carers were the families where dialysis took place at home, and in addition in family one, where the parents were older and both had a chronic illness. The visibility of the treatment for CRF, in the form of machines and supplies at home, and the heightening of awareness of dependency on this machinery perhaps account for this facet of the data. When the parent is attached to the dialysis machine they become more visibly dependent on others. By contrast, in the families where a parent had a functioning transplant, the influence of the treatment (tablets) was much less visible; although there was a knowledge and understanding on the part of the children of the need for the tablets, they did not usually impinge so directly on family life and the parental ability to undertake tasks for themselves.

In their study looking at the parental experiences of living with IBD, Mukherjee *et al.* (2002a), parents reported that they felt their illness had a positive effect on their children in terms of fostering compassion, not only towards the parents, but also for people in general. This is similar to the experiences in my study given by family two, who discussed how one of their children took a particular interest in the health needs of others and offered help and support where he was able. The parents in Mukherjee *et al.*'s (2002a) study also described how their children helped around the house and the support they gave, particularly when the parent was unwell. Interestingly, when the children's views were obtained (Mukherjee *et al.* 2002b), the children saw the role they undertook as voluntary, the children did not see themselves as carers. Molzahn & Kikuchi (1998) also noted that children helped with both housework and dialysis. Within the Aristotelian-Thomistic concept of the good life used as the framework for their study, helping around the house was categorised as developing 'goods of character' Molzahn and Kikuchi (1998 p 412). This caring role was therefore seen to be strengthening and developing the child's moral faculties. In addition Molzahn & Kikuchi (1998) described how the caring role helped decrease the overall anxiety the child experienced about the parental CRF.

Within the interviews, families three and five commented on the involvement of their children in the routines. These families were using home dialysis. This was usually because the children wanted to help. This links well with Auer's (2002b) comments that children should be involved in helping with parental treatment for renal problems as this can help make them less anxious and less excluded, and also the observation of Molzahn & Kikuchi (1998). However, the issue of young carers is an interesting one and one which it is appropriate to consider briefly here. Families usually have a rehearsed response to an episode of acute illness (Byng-Hall 1997), whilst these are appropriate mechanisms for an acute illness and children may have a caring role to play, Byng-Hall (1997) goes on to caution that these mechanisms should not be used in the chronic illness situation, and that children should not become permanent carers. It would appear that there is a grey area between helping around the house, as is usual for most children, and becoming a young carer and, in addition, concepts of caring are different in different cultures. Kellet *et al.* (2004 p 36) writes that, in what they term, 'the majority world', the concept of young carer is an alien one. Caring for your family is the rule, rather than the exception, so it is seen as natural that help comes

from within the family. Children who care for others are therefore seen as taking part in normal life, rather than undertaking a special task. It is also suggested by Kellet *et al.* (2004 p 36) that within ‘the minority world’, which would include the UK, the concept of carers who take the burden of caring away from the state is relatively new, and with it has come the notion of young carers.

The topic of young carers in the UK has received more attention recently. In the third national survey of young carers, Dearden and Becker (2004) found that the average age of young carers was 12 years, and they comment on the positive steps that have been taken to improve the lives of young carers. The publication of a report from the children’s charity Barnardo’s “Hidden Lives, unidentified young carers in the UK” (2006) offers further insights into the lives of young carers. Barnardo’s (2006) are concerned that although a significant number of young carers have been identified – it is estimated at 175,000 children – there are probably more who remain unidentified and therefore potentially isolated. The report recommends improved support for young carers by ensuring that schools have a strategy to support them, and the working together of various statutory agencies. This latter point is particularly pertinent given the lack of joined up thinking demonstrated by a recent news item (Stickler 2007). Within this article, the assistant director of the Princess Royal Trust, Alex Fox, is quoted. A situation is described in which adult and child services within many local authorities are disjointed, and where practitioners consider that issues pertaining to children and parenting are beyond their remit. This can mean that questions which could be asked of those with serious illnesses which could lead to an amelioration in the situation, for example, “Do you have children?” are not being asked.

6.3 Protecting the family

Parents want to protect their family, and particularly their children, wherever possible from the effects of CRF. They want to provide security within the home. They seem to try to achieve this by processing the information that they receive and then passing it on to their children to help them to understand about CRF and its different treatments. They appear to offer the information on a piecemeal basis, providing information when questions are asked or because of a potential, or actual change in circumstances. The parents draw on their own life experiences and cues from their

children, and use these to further guide, direct and interpret information and actions. The children in these families affected by CRF also expressed a need for information to help them understand what was happening to their parent and family. Table 6.1 shows the information needs of both the adults and the children as identified by this research. These clusters of adult and child information giving and receiving, security and parental interpretation all work together, linking and overlapping to offer a web of protection to the children in particular.

Individuals have different responses to their need for information; this can be seen clearly in the families in the study. The couple in family one, and the partner in family four, for example, would accept all the information given, continue asking questions, and still search for information from their own sources, whilst the patient in family four, and the partner in family six were much more pragmatic, preferring to deal with issues as they arose, and being content with partial knowledge. In many ways, these latter two displayed a certain ambivalence to information, which runs counter to all that is purported to be held dear about information giving in the health service today. However, it is important to recognise and understand that there are many coping mechanisms and responses which can be seen in people who are dealing with life changing issues as Coupe (1998a) indicates. The way health professionals respond can help with the longer-term acceptance of the patient and planning for their future.

It is important to remember that giving information is not a one-off event, but should be a process (Department of Health 2004b). This would appear to be particularly pertinent in families where there is CRF, as for some families many changes may take place within a short space of time. Educational programmes have been found to have a positive effect on functional and emotional well-being in people with CRF (Klang *et al.* 1998), however these authors go on to suggest that patient education should be ongoing. Suet-Ching Luk (2004) also noted the need for ongoing education in her transplant patients. They particularly appeared to require continuing education on aspects related to diet and exercise because of their immunosuppressive medication.

Table 6.1
Identification of the information needs of the children when a parent has chronic renal failure

What parents identified	What children identified
<p>Individuals and families have different information needs.</p> <p>These parents wanted to pass on information to their children.</p> <p>Parents did not want to worry or frighten their children, or make them feel responsible for the parent's CRF.</p> <p>Information giving is an on-going process, treatments will change and therefore the need for information will also change.</p> <p>The children's information needs change over time as they become older and are able to understand more or as the parental treatment changes.</p> <p>Parents find some topics harder to discuss with their children, for example the possible death of a parent.</p> <p>The parents wanted to be the main provider of information about CRF for their children.</p> <p>The parents often wanted to obtain a positive outlook on life and wanted to assimilate information for themselves before discussing it with their children.</p> <p>A lack of materials to help their children understand the parent's CRF.</p> <p>Children do not always understand what the parents tell them in the way that the parents anticipate.</p>	<p>Children want to ask questions and receive information about their parent's CRF.</p> <p>The children understood that there were times when it was difficult for their parents to give them information.</p> <p>The children value being able to approach their parents for information and trust their responses.</p> <p>The children knew that their parents had to 'translate' the information that they had received into a language that the children could understand. "You have to say it like a children way, you know, how children think" (F3C).</p> <p>The children enjoyed meeting other children with whom they shared a common experience and language.</p> <p>The children were selective with which of their friends (if any) they shared this information about their parent's CRF.</p>

Parents wanted time to digest the information they had been given, and then decide how and when to pass on the information. Families, for example, family two, wanted to stress the positive aspects, and did not always wish to know about the negatives. In various ways, families described how they filtered the information given to their children. This was to ensure that they knew what was going on, but were also protected from the potential negative aspects of having a parent with CRF. These interpretations appear to be similar to findings described by Helseth and Ulfsæt (2005) who looked at parenting experiences during cancer. Considering purely the parental perspective, Helseth and Ulfsæt (2005) talked to ten families with children aged 0 – 18 years, where one of the parents had a serious cancer disease. Parents in the Helseth and Ulfsæt (2005) study looked for the right time to discuss information with their children and were conscious of the need to adapt the information for children of different ages. In addition parents were aware of trying to stress the positive experiences in life.

The parents in my study seemed willing to pass on information about their health and the potential impact on family life to their children. However, information was often only given when questions were asked, rather than all the information being volunteered. It would appear that parents based this decision on a wish to protect their children, not wanting to worry or frighten them or make them feel responsible for the parental illness. Fitch *et al.* (1999) note that parents tried to balance the inclusion of the child in discussions, with concern that they could cause the child to worry or be frightened. This paper is again cancer related, and considered the impact of a maternal cancer diagnosis on the family, specifically looking at role changes. In Mukherjee *et al.*'s (2002a) study, some of the parents decided to restrict the information they gave their children about IBD, others however chose to be open about the illness. The comment was made that children were more understanding of the parent when the information had been shared with them. Helseth and Ulfsæt (2005) concluded that parents chose to be open about their illness, cancer, in the hope and expectation that the children would continue to feel safe. It would appear that similar thought processes are at work in the seven families in my study.

Parents did face a number of difficulties when trying to share information with their children. In family five, for example, the partner was clear that what children were

told and what they understood were two different things. This was not said as a criticism of the children, more of a statement, or perhaps an acknowledgement that the information given at the time was not required by the child and therefore not processed. This notion of being unsure of what information had been absorbed was also noted as an issue by some of the parents in the study by Helseth and Ulfset (2005). Some booklets have been written either to advise parents about discussing their illness with their children for example, breast cancer (Breast Cancer Care 2001) or for children who have ill parents, for example Parkinson's disease (Goodall 2000). However, there is no information written for children that parents with CRF can use to support the verbal information they are giving. This means the child has nothing to refer back to, when perhaps they want to revisit something their parent has told them. This observation was also made by Mukherjee *et al.* (2002a) in relation to IBD. Here the parents identified a need for information on the effects of IBD on the family and would have liked a booklet written for children about IBD. When the children were asked about their views, some did say they would like more information about their parent's illness and others wanted the opportunity to meet other children who had a parent with IBD (Mukherjee *et al.* 2002b). Certainly within the focus groups I held, the children seemed to enjoy meeting other children who had parents with CRF. These children, although they had not met before, shared a common experience and language which their regular friends did not have.

The partner in family one expressed a concern that much information for children is written by adults who think they know what, and how, to write for children. Given the policy guidance (Department of Health 2003) it would seem more appropriate in the current climate if children themselves were enabled to define their information requirements. We know that Smith and Callery (2005) found that children, if given the opportunity, are able to identify their own information needs. The ideas of the children, collected with suitable guidance and assistance, could then be used as a basis to develop information which could then be piloted with them and their parents.

Children do need and want information about their parent's illness. Molzahn & Kikuchi (1998) noted this in their study with adolescents. The children in the focus groups clearly wanted information, however, the quote from F1C probably sums up the information they want - "You kind of need to be a bit up front and a bit sort of laid

back about it.” The children want to ask questions and get information, but they also know that there are times when their parents are more willing to talk about their illness than at other times. In addition, sometimes the child does not want all the information given, or does not want to know any more – they have heard and coped with enough at that stage. Having access to written information may help both the parents and the child in this delicate balancing act, since these provide a source of information that is not dependent on mood or knowledge. However, both parents and children appreciated the trust and open channels of communication that appeared to exist in all these families.

One of the most difficult topics about which to give information is the possible death of a parent. Families, for example, family three, were concerned how this information might be put across to their children. It was not something that was discussed freely within the families, as is probably the case in most families. However, if asked by their children, parents tried to give an honest answer, without trying to dwell on the topic or be negative. Family five highlighted this issue, and also illustrates how children’s concepts differ to those of adults, in this case with respect to timescale. Again drawing on the cancer literature, parents wanted to know how best to give their children information about the illness, but they particularly needed help and support to discuss the issues surrounding their possible death (Helseth and Ulfset 2005).

In contrast to the views expressed in the work by Friedlander and Viederman (1982) where the authors considered that parents were not aware what children thought, these seven families appeared to be more than aware that they could be misinterpreting their children. However, the parents did appear to use their views and experiences to decide what information the children wanted, although this might not always be correct. Children have very different concepts of, for example, hospitals and illness to those of adults, as Hart and Chesson (1998) indicate. Parents were often in a dilemma about visiting a sick parent in hospital. Some took the view that it was better to see the parents, sick or not, than to be at home imagining what was happening to them (family six), others appreciated that the children needed to see their parent, but were concerned about the lack of things to do once in the ward (family seven), or the effect on the child of seeing other sick people with CRF (families four and two). This is a very real issue for these parents but, interestingly, one that they did not often seem to

talk to their children about, they appeared to make a decision on their beliefs alone. Mukherjee *et al.* (2002a) noted a similar quandary for people with IBD who required admission to hospital.

The parents in this study wanted to provide a secure environment in which to bring up their children. In many ways this is no different to the aims of many parents, however, within these families there are many more sources of uncertainty, as discussed later, which have the potential to disrupt feelings of security. In Helseth and Ulfset's (2005 p 43) study, parents expressed that 'the overall aim of parenting was to protect the children and to make the illness situation as secure and normal as possible for them.' This would appear to be what the parents in my study were also trying to achieve. Attachment theory can provide a framework for the development of security in childhood but most of the work appears to focus on the mother-child relationship and there has not been a great deal of study of how attachment is disrupted when a parent is ill (Altschuler 1997).

6.4 Living with uncertainty

The uncertainty of living as a family with CRF seems to have many effects on family life; and appears to affect many decisions that adults make. There is uncertainty and guilt regarding the possible transmission of the condition to their offspring, the impact of the uncertainty of transplantation, both in the waiting for a transplant and the continued good functioning of the transplant and the general unpredictability of living with a chronic illness over which you have no control. The children worry about their parent's illness, about hospital visits, and about when a transplant might be available if the parent is waiting for one. Therefore, for both the parents and the children, there are many sources of uncertainty within their lives. Uncertainty ran through many of the conversations. The concept of uncertainty is one that has attracted some interest within nursing, as a recent publication indicates (Penrod 2007). Using a phenomenological approach this study explored the concept of living with uncertainty from the perspective of family caregivers. More specifically for renal patients the loss of control and general uncertainty that people with renal problems face is identified as an issue (Dingwall 2003). Within my study, all the families mentioned uncertainty in some form, however, as noted, the uncertainty seemed to relate to different issues, sometimes with more than one type of uncertainty being present in a family. In an

interesting paper written from a philosophical standpoint, which, he concedes, could be challenged, Bevan (2000) writes about the uncertainty that treatment for ESRD brings. He describes the experiment that is dialysis, how in its infancy it really was seen by all as an experiment, and this perhaps explains why initial selection criteria for dialysis, mentioned in Chapter one, were so stringent, so as to ensure the best possible chance of success. However, Bevan (2000 p 438) contends that 'dialysis remains an experiment, an experiment in prolonging life, not knowing what will happen next.' Bevan (2000 p 440) goes on to explain how the patient with CRF attempts to be a 'healthy-ill person.' He describes this as follows

'This is a non-role as it is not legitimated either by medicine or society. The individual should be either sick or well with no room for ambiguity.'

Bevan (2000 p 440)

This 'non-role' is seen by Bevan (2000) as the beginning of uncertainty. This concept can be seen within the lives of the seven families, trying to maintain normality in the face of circumstances which for most families are abnormal, living with uncertainties that many do not face, working fulltime to continue the pre-treatment life and lifestyle, but being so tired that evenings and weekends with the family are spent resting.

For people with CRF there is an anxiety surrounding the uncertainty of their health. This has been identified from a patient's perspective (Lok 1996, White and Grenyer 1999) and uncertainty in the time leading up to dialysis has been noted by Harwood *et al.* (2005). However, having children alters the equation, a fact that does not appear to be dealt with in published material. This lack of certainty impinges on many decisions, including financial planning and discussions about the future. This would appear to link with Harwood *et al.* (2005), who interviewed 11 haemodialysis patients about their preparations for dialysis, and described how some individuals actively sought to 'get their houses in order' (p 297). It also appears to echo the sentiments expressed by Delmar *et al.* (2005) who, looking at 18 people's experiences of what it means to live with a chronic illness, identified what people described as swings between feelings of self-control and loss of control, and between hope and doubt and hopelessness. Delmar *et al.* (2005) describe how in trying to achieve reconciliation with living with a chronic illness there is much uncertainty, anxiety, frustration and some difficult choices.

Not surprisingly, issues surrounding hereditary conditions only appeared within the families where there was a known inheritance pattern. The presence of a hereditary disease in a sense affects all members of the family and Levy (2001) identifies that it should therefore be treated as a family issue. However, the lack of provision to achieve this within the present health care system is also highlighted (Levy 2001). Two of the families within the study knew they had a hereditary disease, polycystic kidney disease. There are a number of cystic diseases of the kidney, however it is autosomal dominant polycystic kidney disease that is one of the most common genetic disorders which accounts for approximately 10% of patients with ESRD, and if one parent has the condition then any offspring have a 50% chance of inheriting the disease (Chalmers 2002). Another family was unsure if the condition causing their renal failure could be passed on to their children. There was uncertainty because, at the time of data collection, the parents did not know which of their children had inherited the disease. Levy (2001 p 2) writes of an 'anxious uncertainty' which parents have regarding their offspring and the possibility of having the parental renal disease. Interestingly, Friedlander and Viederman (1982) noted in their study that half the parents worried about passing their disease on to their offspring regardless of whether the disease was known to be hereditary or not. There was no indication here of that type of concern, other than in families where the familial nature was recognised. However, it has been noted with other chronic illnesses. In the study which considered IBD, Mukherjee *et al.* (2002a), parents also expressed concern that their children might suffer from the same health problems as they did.

The positive which seemed to come out of this uncertainty, was that the parents drew on their childhood experiences of hospitals and receiving information, and used these experiences to shape their values and ideals about how children should be given information about illness. In the case of both family one and family two the individuals, who are now patients, were given very limited information in their childhood. These families therefore approached the situation differently, and tried to give their children information in a relatively open fashion, so that the children did not experience the same shock when they learned that the CRF was hereditary. This desire to give children information is also a reflection of the changing views about the position of children in society as a whole. An interesting walk through the changing perceptions regarding childhood is given by Kellet *et al.* (2004 p 27) in their chapter

entitled 'images of childhood' which considers both the historical and present context from a variety of perspectives.

Different uncertainties arose depending on whether the parent had a functioning transplant, or was on the waiting list for a transplant. As indicated, from a professional standpoint, transplantation is seen as the most clinically and cost-effective treatment for many patients with ESRD (Department of Health 2004a). It is also the treatment option that most renal patients would choose, if they were able, as they perceive it will give them the best chance of a return to a more normal lifestyle. A small-scale study did indeed find that quality of life was significantly higher for patients following transplantation (Fallon *et al.* 1997). More recently it was noted that quality of life scores were consistently higher for transplant recipients than people who were on PD or HDx (Niu and Li 2005), whilst a study looking at health related quality of life in 31 transplant recipients in Hong Kong reported an increase in physical functioning (Suet-Ching Luk 2004). The families in my study were aware of the better quality of life they had because of their functioning transplant. For example, the patient in family one remarked how much better she felt physically because of the transplant. However, in spite of the increased feeling of wellness, the people who have transplants continue to experience uncertainty.

This fear and uncertainty can be seen in the families in my study. With, for example, the wife in family two, expressing her concerns about the level of her husband's creatinine. She hoped it would be lower, as she had read a lower creatinine helped the kidney last longer. Family four were clearly anxious around the time of each clinic visit. These concerns have been documented within the literature. Fallon *et al.* (1997) identified worries prior to clinic visits and the fear of rejection as stressors, which affect renal transplant patients. Concerns about the possible rejection of the renal transplant were also noted by Niu and Li (2005), whilst (Suet-Ching Luk 2004) described how transplant recipients were constantly aware that rejection could occur. Family three regretted that, with their second transplant they had not fulfilled various travelling ambitions. They had really tried to look after the kidney transplant, feeling that this would ensure that it lasted longer. They now wished they had just gone out and enjoyed having it. If they got another transplant they would look after it, but would combine this care with travelling. Although families do appear to have more

freedom to enjoy a more normal lifestyle because of a transplant this does not remove the source of uncertainty from their lives. The CRF is still there, no cure is available, just respite from dialysis. Bevan (2000) using his 'healthy-ill person' concept gives an example in relation to transplantation. Here the person with CRF is essentially seen as healthy, they have a functioning transplant, but what is often forgotten, although probably not by the person themselves, is that they still have an underlying chronic disease which has not been cured or gone away. Transplantation is mistakenly seen as a cure by many, this can therefore mean the removal or reduction of supportive measures. This was identified as an issue by the patient in family one who remained on Fluoxetine¹³ despite a functioning transplant. The need for an antidepressant was questioned, as the transplant was meant to cure all, however it is important to remember that people have lives outside their CRF and we do not always know what else they are dealing with.

Life on dialysis brings with it its own uncertainties which have been identified in the limited published work available. Polaschek (2003) identified the 'ongoingness and uncertainty of life on dialysis' (p 47) and described how one of the ways these men coped with this uncertainty was by hoping for a kidney transplant. Molzahn & Kikuchi (1998) noted how children hope for a transplant for their parent. This hope was clearly visible in families three and five where both fathers were on dialysis. For family members uncertainty was also linked to the availability of a kidney transplant for their loved one by Pelletier-Hibbert and Sohi (2001), they wondered if and when a transplant would be available and whether it would work.

The children in my study worried about their parents. As they got a little older they were more aware of parental anxiety, for example around the time of clinic visits. This therefore caused the children to become worried. There were worries expressed about when the parent stays in hospital, particularly if this was unexpected. The children also expressed concern that they did not always know what was happening to the parent, again this related to a hospital admission. The implication here was that more involvement and appropriate information at the time would perhaps alleviate some of this worry. According to Mukherjee *et al.* (2002b) when children were asked

¹³ Fluoxetine (prozac) – an anti-depressant (British National Formulary 2007)

about what parental IBD meant to them, worry was frequently mentioned, particularly in relation to hospital appointments and admissions. Here the children also identified that being given information helped the situation.

6.5 “Really forget about it and just get on with our lives” – life view

This cluster overarches all the clusters and runs through the three themes. The attitude to life reflects and affects the desire for normality within family life, how the families cope with uncertainty and how particularly the parents use information, and their interpretation of a situation, to protect their family. Altschuler (1997) notes that there is a range of coping mechanisms and strategies which have been identified as responses to an illness. Many people use a combination of styles to cope. It has been suggested by Kotchick *et al.* (1996), following a study looking at coping styles in families where the father was chronically ill with haemophilia, that there may be a connection between parental and child coping styles. In addition when looking at coping styles, Kotchick *et al.* (1996), felt that parenting styles and the home situation need to be considered too. The predominant ‘life view’ of the families in my study appears to be – ‘we’ve got it, we deal with it and we get on with life’, this is clearly expressed within the data – ‘really forget about it and just get on with our lives’ (F4Pt) summarising the parental view and from the child’s perspective ‘It’s about a person with a runny nose because my family’s had a few illnesses but they are still happy’ (F1C).

Models have been used within the context of nursing to try to represent reality. However their use is not unproblematic. Aggleton and Chalmers (1986 p 4) describe a model as ‘a device which attempts to explain something and by doing so facilitates a better understanding of it.’ Models are therefore not reality, merely a representation of it. When they try to represent, for example, life with a chronic illness, the reality is usually much more complex to grasp and put clearly and simply onto paper. However models can be useful, alongside theories, which are themselves limited and incomplete. We are all unique individuals. No model or theory will fully cover the complexity of life with or without chronic illness but these models which are attempting to capture a complex reality can be used to help deepen our understanding of a situation. Within nursing they can act as a guide to help change practice. In this study I feel that my data, showing the attitudes expressed by the families connects not

only with the work of Bevan's (2000 p 440), a renal practitioner, and the notion of the 'healthy-ill person' he expresses (as discussed in section 6.4), but also with the 'shifting perspectives model of chronic illness' which Paterson (2001), a researcher with an interest in chronic illness, developed. This latter model was developed by Paterson (2001) from what she terms a metasynthesis of 292 qualitative research papers which related to chronic illness. From this, Paterson concluded that the models which existed, and were used to describe the trajectory of living with a chronic illness in a linear fashion, did not fully represent the complex situation these individuals find themselves in. Many of the families in this study describe a number of changes of treatment, all for the same underlying disease, but each requiring a separate set of adaptations which cannot be viewed easily in a strictly linear fashion other than by the progression of time. In a paper which considers the use of metasynthesis within qualitative research Zimmer (2006) suggests that this relatively new technique offers a way of using qualitative findings to gain further insights and develop knowledge. The importance of the Gadamerian concepts of the hermeneutic circle, fusion of horizons and dialogue with the text, are seen by Zimmer (2006) as key to help uncover further meanings within the process of qualitative metasynthesis. However, there are potential issues with the methodology. Zimmer (2006) questions whether metasynthesis can be used across qualitative methodologies. She concludes that its use across different qualitative methodologies, such as phenomenology and grounded theory is possible, and may give new insights when approached with the right combination of analytical and interpretative skills. From the Paterson (2001) article it was impossible for me to judge the quality and trustworthiness of the literature used within the metasynthesis, although the criteria used to qualify for inclusion were given. This is because the majority of the 292 articles are not directly quoted within the published material regarding the shifting perspectives model. Metasynthesis aims to give a further interpretation and is made by someone coming to data that has already been interpreted. By its nature the interpretation is made from published data, which is only part of the original data. It is therefore selective and this might be considered a weakness of metasynthesis.

From the metasynthesis, with its potential pitfalls, Paterson (2001) went on to develop and describe the shifting perspectives model of chronic illness in which she sees aspects of both health and ill-health, which continue as the person learns to live with

the disease; the disease trajectory is no longer represented as linear. This type of non-linear representation of chronic illness has also been described by other researchers using qualitative methods. Kralik (2002) referred to Paterson's (2001) work when she looked at transitions in chronic illness, which she described as 'non-linear, sometimes cyclical and potentially recurring' (Kralik 2002 p 146). Kralik (2002) took a feminist perspective and a narrative approach and corresponded with 81 women for a year. The women were asked to tell their story of living, midlife, with a chronic illness. The correspondence was thematically analysed and provides, as does the shifting perspectives model of chronic illness, a way for nurses to consider life from a different perspective and thereby encourage holistic care. Telford *et al.* (2006) in a non systematic literature review looked at the concepts of acceptance and denial and how this can influence adaptation to chronic illness. In their paper they discuss the shifting perspectives model of chronic illness at length as an alternative and more appropriate model to the more traditional linear staged adaptation process. Paterson (2003) describes this model as follows:

'The shifting perspectives model of chronic illness depicts living with a chronic illness as a process of continually shifting between the perspectives of wellness in the foreground and illness in the foreground in order to make sense of one's world at the time.'

Paterson (2003 p 988)

This seems to fit particularly well with Bevan's (2000) concept of the healthy-ill person with CRF, again this concept contains elements of both health and ill-health. It also captures the essence of what the families in the study described, that at times the illness was the focus – (for example at diagnosis or a change of replacement therapy) but that at other times the illness takes a back seat – perhaps whilst focusing on career development or while on holiday. Bevan's concept of 'healthy-ill' also bears a similarity to the description given by the patient in family five and typifies that of the others and is quoted again here.

"the only way that we coped with it so far is by just not letting it take over cos it very easily could and I'm sure there must be unfortunately some people who just can't handle it and it does become the biggest thing in their life and their life evolves around their illness. What that would unfortunately mean, if you look at it on a bigger picture, is you've got the illness in the middle and then the person standing next to it and

outside the circle of them and their illness, is their family and they'll start to block out the family because they feel that they are more concerned, they become more protective of the disease, than they do of their families it's like completely on its head to how it should be."

F5Pt

The shifting perspectives model of chronic illness (Paterson 2001) is essentially an explanatory model of how people move through life with a chronic illness. It certainly rang true with my long experience of working with people with CRF and appears very perceptive. It is reflected in my data, for example in the quote from patient five given above. It suggests why after many years of living with a chronic illness some people still do not appear to have adapted and still express anger at their condition. Life is linear, we all move from birth to death. Therefore linear models can be seen to represent the progress of a disease, however, as Paterson's model suggests, and as others such as Kralik (2002) have suggested, this may not always be the most appropriate way to think about a chronic illness. Within my data the constant struggles which the families experience in attempting to keep the normality of family life during the uncertainty associated with CRF whilst trying to protect the integrity of family life is seen as at times illness or wellness is to the fore. When a transplant comes along for example, as described by family two, even though the family appear generally to try to keep wellness to the fore during this time illness occupied their minds. Indeed, as described by the partner in family two, illness still featured in her mind with clinic visits and creatinine levels. The children also experienced this change in perspective. In family one the child described, using his family shield, how he felt that for his mother, with a successful transplant, illness to the fore in terms of CRF had 'pretty much been and gone' (F1C). This is allowed for in Paterson's model, in which the perspective can shift from illness in the foreground to wellness in the foreground and back again. The perspective is defined as:

'a representation of beliefs, perceptions, expectations, attitudes, and experience about what it means to be a person with a chronic illness within a specific context.'

Paterson (2001 p 23)

It is suggested by Paterson (2003 p 988) that each person will have a 'preferred perspective'. This is the perspective that they prefer to keep to the fore; however, events that occur in life can cause the perspective to change. When illness is in the

foreground the person concentrates on being ill, they home in on many of what are seen as the negative aspects of the illness, the burden, the loss and suffering. Paterson (2001) suggests that this perspective is usually seen at the time of diagnosis and suggests it can offer protection at this stage. Some however, continue with this perspective to the fore as it maintains the sick role and is perhaps what society generally expects. Paterson (2001) also suggests that when something new occurs with the chronic illness, so perhaps a change of RRT for a person with ESRD, this concentrating on the illness assists coping. When wellness is in the foreground the person as an individual, rather than the illness is seen. People can achieve wellness in the foreground in many ways. These can include finding out information about the illness, ensuring supportive networks and by learning new skills. During the course of a chronic illness the perspective can of course change, and either illness or wellness can move to the fore, and there are paradoxes within the model, which Paterson (2001) acknowledges. For example she suggests that to keep the wellness perspective to the fore it is actually necessary to continue to pay attention to the management of the illness to ensure, as much as possible, that wellness stays to the fore. Additionally Paterson (2001) considers that self-help groups may cause illness to be brought to the fore as the group tends to focus on the sickness. Paterson's shifting perspectives model of chronic illness was envisaged as a model for use with individuals, those with the chronic illness but it is clear that although the chronic illness may affect an individual in terms of physical symptoms, those around them also experience challenges and changes. Telford *et al.* (2006) exhort health care professionals to reconsider their views on chronic illness and linear models which focus on acceptance and denial and to listen to the stories that people tell. This should enable a client focussed response which looks at not only the individual and their medical condition, but also at the bigger picture of the individual's life. If Paterson's model were to be used, but applied to families rather than just the individual this may help the practitioner look beyond the individual in front of them. However, it would appear that it could be applied to groups of individuals, to families. The life-view perspective taken by the parents appears to be dependent on whether illness or wellness is to the fore, and therefore how family life is held together. For example, when illness is to the fore there tends to be more contact with hospitals and this precipitates a need for more information in the children. When life settles down again and 'normality' returns the questioning becomes less both for the

adults and the children, information needs therefore change and maintaining family life is perceived as easier.

Telford *et al.* (2006) suggest that using the approach taken by the shifting perspectives model of chronic illness encourages the health care professional to listen to the unique perspective of the individual and encourages a wider view of their life than just the medical facts of the case. In understanding the wider context, the health care professional can then choose an approach which will facilitate the adaptation of the chronic illness in to an individual's life, or indeed, as Paterson (2001) indicates, the person with the illness may well choose to consult primarily with a practitioner who takes their perspective. A person who generally works with wellness to the fore would look for a practitioner who used a holistic approach, whilst a person who usually has illness to the fore would wish to consult someone who would concentrate on the symptoms of the disease (Paterson 2001). This could also be true, therefore, of sharing information with people; to ensure that the information is processed and useful it will need to be in tune with their perspective of not only their illness, but of their life view.

6.6 Drawing the discussion together

There are many effects a parental diagnosis of chronic renal failure has on the family. The seven families in this study strove, despite their CRF, to have normality within their family life. This was clearly expressed by both the children and their parents. This air of normality in family life appears to exist to protect both the parents and their children from the uncertainty of living with CRF. The parents keep this normality by holding on to their wellness despite the renal failure. In doing this, family life goes on, holidays are taken and friends visit, but the parents are ever watchful. They are wary of putting too much of a burden on their children. They note the children's behaviour and wonder if problems could be related to the influence of CRF on the life of the family signifying perhaps that the protective mechanisms are no longer functioning as they had been.

There was much uncertainty acknowledged within the lives of these families. This was dealt with in a variety of ways. The parents tried to protect their families from the stress of living with CRF by providing security for the children and an amalgam

of interpreting and giving information. However, these do not stand alone, they too are interrelated and help to make up the complex web which is family life lived out in the presence of CRF. Running through this web is the parental life view, which, for these families, is not predominantly an attitude of mute acceptance, but an acknowledgement of the impact that the illness has, combined with a wish to minimise the effects of the illness on the family. This appears to link with the wellness in the foreground of Paterson's (2001) shifting perspectives model of chronic illness, which can be applied to any chronic illness. It also connects with the healthy-ill person with CRF of Bevan (2000) and the images of the family and illness spoken about so eloquently by the patient in family five.

The values these families espouse are not those of their grandparents' generation when children were often unaware what was happening within a family, particularly where illness was concerned. These families have chosen a different path, one where they try to be honest and open with their children, but even then there are issues concerning how much should be told to the children and when. These parents choose to share information about their CRF with the children. However, they interpret the information to try to ensure that both they and the children focus on the positives of family life and keep hoping. Despite all the setbacks, the uncertainty, the worry that children experience when, for example the parent is admitted to hospital, the children want to know about their parents' CRF, and to hope for them, for good health, for a transplant, for normality. Living with a chronic illness inspires hope amid the uncertainty. The parents too hope for the best each day, hope for a transplant, hope the transplant will continue to work, and above all hope that the CRF has not been passed on to their children to impact on the next generation.

Helseth and Ulfsæt (2005 p 45) concluded that 'nurses aim to care for patients as whole individuals, yet the needs of the children and the challenges of parenting with cancer are rarely addressed in hospitals'. It would appear to me that this conclusion could apply equally to families where there is parental CRF, and that it is as applicable to the community situation as to the hospital. Whilst Mukherjee *et al.* (2002a p 361) suggested in their discussion that parents with IBD did not appear to need or want specific support for their children, 'by supporting parents, professionals will in turn be supporting their children.' The seven families in my study appeared to

want support too, and indeed seemed keen on the provision of information specifically for their children, to cover amongst other things, the effects of and treatments for CRF, in one form or another. The dilemma for the health care professional is how best to go about supporting these families in their everyday lives. I would concur with Telford *et al.* (2006) and suggest that listening to people using an understanding of the shifting perspectives model of chronic illness (Paterson 2001) would lead health care professionals to take a more holistic approach to caring for people and their families. Optimal care and support for families with CRF may thus be achieved through integration of the principles of the shifting perspectives model of chronic illness (Paterson, 2001) within the approach to family centred care as described by Shields *et al.* (2006). Using this definition of family centred care, the emphasis is on the whole family as recipients of care and therefore support is planned around the needs of the whole family. This would encourage the practitioner working with adults to take into account the needs of all members of the family. Parental CRF clearly has effects on the whole family and therefore requires an approach that will take into account these needs.

However, coming from an adult perspective on nursing and undertaking day to day practice that involves predominantly adults there are potential problems which require consideration. Traditionally adult nursing models focus on the individual as the recipient of care, for example Orem's self-care deficit theory of nursing (Eben *et al.* 1989). The care given therefore tends to be patient rather than family centred. If practitioners were enabled to use their experience and expertise in renal nursing and this was enhanced and supplemented by using insights gained from both a family centred approach and the shifting perspectives model of chronic illness, the patient could be listened to and their children involved and informed in the planning for their care. The focus of care would still be the individual patient, but a wider picture may be obtained. This would enable the care to be more holistic, considering both the needs of the individual, and those of their family, including the need to provide information. There are challenges which could face the practitioner in this situation. The children within a family are often not seen by the health care practitioner working with adults in the hospital setting. Out patient appointments are usually within school hours, meaning that the child is not visible so it is easier for both the parent and the practitioner to ignore the needs of the child. This is even more likely if the parent

does not want, for whatever reason, the child to know about their condition. This may be because of a conflict within the shifting perspective of chronic illness model – the parent may be focussing on wellness and carrying on with life relatively normally, whilst the child may be concentrating on the illness and require information to be able to shift their perspective to coincide with that of their parent. This situation would make it difficult for the practitioner to work within a philosophy that also incorporated family centred care. However, if children are involved in the consultation, be that a discussion about their needs in their absence, or with the children actually being present, this brings other issues to the fore. Many adult nurses have little training in communication with children or an understanding of child development. They may have experience of dealing with, for example, their own children and their friends, but they may not feel confident imparting information to children, particularly when the information could be seen as sensitive in nature. This was a similar challenge to that encountered by Black and Hyde (2002) in the world of adult colorectal nursing where they felt that they drew on their extensive experience as healthcare professionals and parents. These challenges can be overcome as Damboise and Cardin (2003) illustrated when describing how they were involved in implementing family centred care within a critical care environment. Here the preparation focussed on education, revising the visiting policy, rewriting the information booklet and increasing the frequency of what they termed interdisciplinary family conferences.

6.7 Cancer and chronic renal failure – a comparison

Much of the literature that has been referred to in this discussion is related to the impact of cancer on the family. In the introduction I described how I was not convinced that this comparison of cancer and chronic renal failure was appropriate. I remain unconvinced, but in the light of the paucity of published literature relating to the impact of any chronic illness on the family, it is, in the main, the only research to draw on. Dealing with cancer within a family does not seem analogous with dealing with CRF within the family. However, what can be said is that for dialysis patients life expectancy is reduced – dialysis patients live about one quarter as long as an age-matched population who do not have renal failure and the survival of people with renal failure is comparable or worse than for many types of cancer (Moss *et al.* 2004). This is something that, in my experience, many people with CRF do not know, often

because they are not told by health care professionals, in the potentially misguided assumption of protection.

6.8 Critique of the methods used

The use of a qualitative approach was appropriate for this research, as was its phenomenological methodology. This can particularly be seen in the light of a recent article by Rapport and Wainwright (2006), which considers phenomenological methodology and the 'metaphor of movement' (p 229). In this paper Rapport and Wainwright (2006) explain that, in their view, much of the phenomenological research undertaken by nurses could be examined in a new way if the similarities between Husserlian and Heideggerian phenomenology were considered, rather than always focussing on the differences. Rapport and Wainwright (2006) argue that phenomenological research is well suited to approach many issues that nurses wish to address. Within the discussion they state that:

'nursing and nursing research must make sense of the constantly changing states of health and illness of the patients and constantly changing perspectives of the nurse and patient.'

Rapport and Wainwright (2006 p 234)

With hindsight, the linking of the findings of this study to Paterson's (2001) shifting perspectives model of chronic illness and the view of Rapport and Wainwright (2006) expressed above, highlights the need for a methodology that accepts and allows for movement and change both within the researcher and the participants. This flexibility could not and would not be seen in quantitative domain.

However, Paley (2005) describes what he sees as inherent problems within phenomenological methodology and it is important to avoid these pitfalls. Paley (2005) criticises much research in nursing that calls itself phenomenological. This appears to be because although many published reports align themselves with a phenomenological approach, within the methodology, they fail to remain true to the principles. This frequently leads to attempts to generalise the findings. Therefore instead of presenting a unique representation of feelings and perceptions, they often appear to have categorised the findings. Thus the reported results could, in fact, apply to many concepts Paley (2005). I have tried to avoid falling into these traps. The

findings were presented in categories, however the headings given for the clusters tried to use participants' words to describe them. In addition, the findings concluded with a full description of the phenomenon under study to draw that chapter to an end and to present an interpretation of the participants' experience of CRF and its effects on the family. The reader is left to their own interpretations and reflections to take ideas to apply to their own practice, as the implications for practice are my reflections on how undertaking this research project has influenced my practice.

The sample recruited for the study – seven families – was small. However, it is comparable with other studies using a phenomenological approach. Paley (2005), from his overview of the literature, suggests that sample sizes in these studies appear to range between six and twelve. Certainly the 13 interviews and the three focus groups I undertook generated a vast quantity of data. The sample was not totally homogenous as it included a single parent family and a mixed race couple. The other families who were approached, but declined to take part, would also have contributed to the diversity. In terms of the recruitment strategy, the poster did not succeed. No families contacted me as a result of the poster placed within the unit. All families that agreed to take part did so after a personal letter of invitation. This latter strategy may well be the best method to employ for this type of study. However, the families in this study obviously communicated well, both in terms of their interviews – which is imperative for phenomenological research, but also within their family and in the approach they took towards their children. It would be interesting to encourage families who did not share so openly with their children to participate however, this could prove difficult from an ethical perspective. As the parents and children had an awareness of the disease and its impact on the family, and appeared to cope with this, it has provided opportunity for me to reflect on how I approach families and encourage them to involve their children in this aspect of family life.

The semi-structured interview technique employed for the adult interviews worked well for me, as a novice to qualitative research, it also appeared to channel the interview to ensure that much of the data gathered was relevant to the research, and this in its turn did make data analysis easier. Reviewing the interviews in general, it was a learning experience for me; if the interview was flowing, the question prompts were not really necessary and much information was gained. However, I feel that I

sometimes interrupted too much, and at others times perhaps tried to put words into the participant's mouth. Husserlian phenomenology, with its use of bracketing would have been very difficult for me. My interpretation of Gadamerian hermeneutics is that the process of data gathering and data interpretation is a conversation, which to me is a two way process, this should contribute to the fusion of horizons and a greater understanding, which is what I feel that the interviews achieved.

The focus groups for the children would be the most likely part of the research strategy that I would change if further research was undertaken. The focus groups worked well and the children did enjoy them. I think it was also appropriate given that fact that when the project was designed the number of participants who were children was unknown. However, I think using an interview approach with the children could also work well. The children were generally very willing to talk and were knowledgeable about their parents' kidney problems and had definite ideas about how the CRF had an impact on the family and what they wanted to know. However, I am not convinced that I would have the research and communication skills required to undertake this type of interview. In addition the children would not have had the opportunity to meet other children whose families were facing similar situations.

A limitation of the sample, that was not inherent in the initial design of the study, but occurred because of the families who took part. All the children who participated in the focus groups were aged 12 years or younger; therefore the results can only be interpreted for this age group of children, despite the study design catering for children up to the age of 18 years. A further study would need to be undertaken which targeted families with children in the age range 12 – 18 years to be able to make any comments on the views of this age group of children.

As I have made clear throughout the study, I was a novice to the qualitative research approach in general and phenomenology in particular. The data analysis therefore provided specific challenges. As discussed, there is still very limited published material to guide the novice researcher with the analysis of data gathered using a phenomenological approach, which I found a problem. I would endorse the ideas of Cutcliffe and McKenna (2004) discussed in Chapter five, and very much needed to

take a sequential and logical approach to the data analysis. It is likely that a more experienced researcher in the qualitative field would approach the data in a different fashion and at a different level. However, I have learnt from the experience and am now able to appreciate more fully some of the subtleties of qualitative research.

6.9 Implications for Practice

As Paley (2005) indicates, he does not feel it is possible to generalise from work which uses a phenomenological approach. However, nursing research should be undertaken to impact on practice, and there is therefore a necessity to reflect on practice and to integrate research results into practice. Dissemination of the results of this study would allow others to read about the research and interpret it for themselves, thereby stimulating reflection on and application in their own practice. This is congruent with the advice of Koch (1995) and Annells (1999). They both suggest that providing sufficient contextual information and presenting the findings in an easily accessible form, help readers decide if the research is applicable to their practice. The presence of the exhaustive description allows readers to enter in to the research and so perhaps to concur with the implications for practice.

For me this research has emphasised the importance of involving the whole family in the planning of care and information giving – in taking a family centred approach. Currently we have an adult focus, rather than a family focus. We do encourage people to bring their family with them, both to consultations and the education sessions, however the focus is usually on the adult members of the family. This could be explained because of the age at which people, on average, commence RRT – currently standing at 64.7 years (UK Renal Registry 2005). However, it is important to ensure equity of provision of the service and not to disadvantage families with young children from the advice and information and support that we offer to the majority of our population. It is important that we engage with these parents, who are dealing not only with the impact of CRF on their life but also with the potential effects the treatment for this chronic condition could have on their young family. This will present challenges, however it should be possible to offer a range of resources that would help the parents to prepare their children for the changes ahead. This would provide the encouragement that parents need to support their children (compare Mukherjee *et al.* 2002a, as discussed in chapter 1 section 10). It was clear

from the seven families who participated in this study that they felt strongly that information about their renal condition should come from them the parents – amongst other reasons so that trust and openness were facilitated within the family. However, the parents wanted reassurance that they were going about this task in the ‘right’ way. In a consultation with parents or a parent it is therefore important that the health care professional makes time to ask about the whole family, not just the member who is the patient. This time could be used to encourage the parents to talk through issues relating to their CRF with their children, to highlight when more input might be needed, for example if a change of treatment has become necessary. The parents could be encouraged to use the naturally inquisitive nature of most children to ask questions and to emphasise that as the children become older their need for information will change. The parents felt that they would be helped if there were, for example written or computer based resources to provide a platform for questions and to enable them to sit with their child or children and discuss their family situation. Development of materials to support these families in sharing information with each other is required. Certainly it would appear that children would be capable of identifying key information points which could be incorporated into material for piloting with children and their families.

In addition it should be possible to offer a one off visit service to families with younger children, similar to the one I offered to families where there were older individuals, for whom attendance at hospital was difficult because of mobility or transport issues. A convenient time is arranged either for a home visit or a visit outside normal clinic hours where there was time to spend talking about treatment options and the potential impact on family life. This model could be applied to families with young children and this research has identified some topics that it might be appropriate to cover in such a visit. For example it would be possible for the families to examine an APD machine or a haemodialysis machine, to see it at first hand and ask questions. If the parent is having a transplant then perhaps the staff in the outpatient department could be introduced, so that the children and parents know who will be looking after them. These activities and topics could be used as a starting point for discussion or to highlight ways in which other families have dealt with situations.

Following the focus groups the consultant paediatric psychologist expressed an interest in organising a group for these children, run on similar lines to the focus groups two or three times a year. This would enable children with a parent with CRF to get together and talk. This has the potential to be useful and supportive to the children who, other than siblings, are often isolated from other children in the same situation, partly because of the relative rarity of the disease in the younger adult population.

The suggestions made so far are all relatively simple ways to include the whole family in care. However, the real challenge, as I perceive it, will be to encourage the parents with CRF who do not appear to want to involve their children in this aspect of family life. The care within an adult renal unit is designed to cater for an adult population, as such it is relatively easy to hide or ignore the needs of children, both from the point of view of the health care professional and the parent. This therefore, is where the culture of the unit needs to change; to incorporate a family centred care approach within its philosophy. If this family centred care also incorporates an understanding of the shifting perspectives model of chronic illness (Paterson 2001) this would value both adults and children within a family. If a definition, such as the one offered by Shields *et al.* (2006) were utilised, the whole family would then be seen as requiring care. This should encourage all health care professionals to think beyond the adult in front of them, to the wider situation and the life that a person has apart from CRF. For example, in the current study, the children clearly wanted information to help them deal with the family situation and also wished to be consulted and involved in decisions regarding family life. As practitioners recognise the need to consider the individual as part of a greater whole, the family, this should change for the better the care given to many, and make it easier to encourage parents who are not keen to discuss their CRF with their children to consider taking that step. This study gives us encouragement to take up this challenge. The children in the study clearly wanted to know about what was going on in the family and wished to be involved. One of the core themes indicated that the parents wanted to protect their children. One way of trying to achieve this protection and involvement was to give and receive information. This study suggests that this information should be given in a way that is congruent with the perspective on chronic illness that is held at the time, as this will also contribute to holistic care, helping the parents to understand the information and

enabling them to pass this on to their children. Incorporating new care routines to keep the perceived normality of family life was a challenge, but achievable for many, and dealing with the multitude of uncertainties that these families faced appeared easier when the channels of communication were kept open.

6.10 Conclusions

This study set out to explore the influence of parental CRF on the family and to describe the information needs of the children. In doing this the involvement of two groups of people whose care needs are often ignored were considered. These were younger adults with CRF and the children of these adults. The former are not often a focus of attention because the majority of people who have CRF are older and therefore if they have children in their family they are usually correspondingly older. This group also often have a functioning transplant, are therefore deemed relatively well and not in need of major input from health care professionals. The latter group, children, frequently receive little attention, because they are not often seen or asked about.

The study was also different because instead of focussing on the disease in hospital it chose to consider the impact on family life, thereby acknowledging that there is a life being lived with chronic renal failure. The data generated three interlinking themes:

- Normality in family life
- Living with uncertainty
- Protecting the family

These themes could in theory apply to family life in general. However, parents made many attempts to normalise their family life despite the time consuming presence of CRF and its attendant treatments. Children appreciated the relative normality of their lives but discussed some of the areas where their lives were not like those of their peers – for example in terms of holidays or the dialysis machine at home. The parents wanted to protect their family from the worst effects of the disease and in doing so provide security for their children. This happens to an extent by trying to continue the normality of daily living but also through an amalgam of giving and

receiving information and of interpreting their child's situation, questions and wish for information. This involves a blend of truth and trust established to protect the family.

These families face more uncertainty than many families and this gives a certain edge to life, a daily walk with the unknown which again is managed by trying to maintain normality and protect the family. These three themes are themselves interlinked, and this web of connection is made stronger by the overarching life view of the parents. Through the generic work of Paterson's (2001) shifting perspectives model of chronic illness and Bevan's (2000) renal specific work the influence of the parental life view on these themes, and the research aims, was explored. The life view guides and directs the way the parents approach their illness and their life. In the cases where hereditary CRF was present the parental life view appeared to have been directly influenced by their parents. The shifting perspectives model of chronic illness (Paterson 2001) with its movement between either illness to the fore or wellness to the fore showed how these families tried to keep wellness to the fore and as such were likely to search out strategies and health care professionals who would support this view and help maintain this state.

I have argued that the information that adults receive is more likely to be effective if it is given in a manner which corresponds to their view of their CRF. These seven families expressed a clear desire to share the information they received with their children and as such the assumption, made in the introduction that this would occur held true for these families. Within the study these parents were also clear that they felt they were the best people to share information about how their CRF may affect family life with their children. Therefore a strategy is required that supports the parents, and will then, in turn support the children as Mukherjee *et al.* (2002a) suggested. The concept of family centred care, usually seen within the paediatric setting, appears to be an appropriate model of care to be used, with the important difference in this case of putting the adult at the centre of family centred care rather than the more usual situation of the child being central. This involves a culture change within adult focussed renal units by accepting a definition of family centred care such as is offered by Shields *et al.* (2006) which emphasises the needs of the whole family, not just the central figure with the illness. If such a strategy is adopted,

of considering the individual's perceptions of their illness and tailoring the information strategy to meet their needs within an environment where family centred care is paramount the implications for practice are profound. This should lead to a more individualised and family led service, thereby meeting more fully the information needs of the children.

Appendix 1

Further information on the seven literature review articles

Adjustment of children with parents on Haemodialysis (Hoover *et al.* 1975)

Type of Supporting Evidence	Objectives	Characteristics of Article or Study	Conclusions	Does it help answer the question?
D	<p>Considers the adjustment of children with a parent on HDx.</p> <p>NB Part of a larger study – ‘Home Dialysis Project’ – which had as one of its aims exploring family adjustment to long-term home dialysis.</p>	<p>Written as reflections of observations and anecdotal notes from interviews with patients and spouses.</p> <p>Three in-depth interviews over a 10-month period – data essentially collected for another project.</p> <p>Data collection did not focus on the children.</p> <p>Random sample – 72 families, 36 of which had children – average 2.1 per family.</p>	<p>Need for data about how children develop in families where a parent has a chronic illness.</p> <p>Nurses’ contact with patient and family provides opportunity for both assessment of the children and anticipation of stressful times.</p> <p>Children who are at risk need to be identified and interventions instituted to promote optimum growth and development.</p>	<p>Raises important points. Other life changes may happen to the family along with dialysis – these may also affect the children e.g. moving, changing school.</p> <p>Is the effect on the children different if it is the mother or father that require dialysis?</p> <p>Where do children get their support?</p>
<p>Additional notes</p> <p>American study.</p> <p>Identified lack of literature addressing the adjustment of children when a parent is on home HDx.</p> <p>Literature review and relationship to literature is minimal – presumably due to identified lack of literature within this area.</p> <p>No operational definitions – notable in absence is a definition of family – as later it becomes clear that the original study does not require participants to have children.</p> <p>The assumption has to be made that the data presented relates to the 36 families with children.</p> <p>No indication of the questions asked within the in-depth interviews is given.</p> <p>No indication if all families completed study</p> <p>Lack of consideration of ethical procedures. It is unclear if the participants were aware that the data they provided might be used for other purposes.</p> <p>It would not be possible to replicate this study.</p>				

Children of Home Dialysis Patients (Tsaltas 1976)

Type of Supporting Evidence	Objectives	Characteristics of Article or Study	Conclusions	Does it help answer the question?
C1	Motivation seemed to be that attention to the influence of home HDx on children may shed light on the area of depression in childhood. Insight into the psychological problems of the parent undergoing dialysis.	<p>Approached 10 families (21 children) – Six families (15 children aged 6 – 18 years) agreed to participate.</p> <p>Group psychological testing (Minnesota Multiphasic Personality Inventory – MMPI) and family interviews designed to show</p> <ul style="list-style-type: none"> • school achievement • socialisation • body functions and body preoccupation <p>Children undertook drawing e.g. human-figure and draw your family – rationale – familiar to author. The drawings were also scored by another, named ‘expert’ and compared with ‘control’ drawings from friends’ children.</p> <p>States highly motivated, self selected group.</p> <p>Parents aware that treatment would not be offered to children, but referrals would be made if appropriate.</p>	<p>Drawings – showed emotional constriction, anxiety, depression and bodily concern.</p> <p>All children showed depressive and hypochondriacal MMPI patterns.</p> <p>School achievement was felt to be affected in 10 of the 15 children.</p> <p>Parental concerns that the dialysis may interfere with the children’s recreation and socialisation.</p> <p>Children showed minimal sleep disturbances.</p> <p>Parents very sensitive to psychomotor disorders – e.g. hyperactivity.</p>	Children showed moderate to severe depression. Children with a parent on dialysis face real stresses and often cannot find the words to express themselves.

Additional notes

American study.

Literature search identified 1 741 articles on psychological problems related to use of dialysis treatment but states that none referred to the effect of dialysis of a parent on a child. This literature is not considered within the article.

No operational definitions.

Initial motivation for study appears to be observation of children who have a parent on dialysis – seen to be quieter, more inhibited and less spontaneous in play. Children seemed insecure and the parents expressed concerns.

Detail is given regarding methodology – incomplete.

Some consideration of ethical issues – participants agreed to allow publication of results provided anonymity was maintained.

Data analysis appears descriptive and not linked to any literature.

It would be difficult to replicate this study.

Children of dialysis patients and selection of dialysis setting (Evans 1978)

Type of Supporting Evidence	Objectives	Characteristics of Article or Study	Conclusions	Does it help answer the question?
D	To debate the correctness of the Tsaltas (1976) paper To reflect on interviews the author has conducted with 'several' dialysis patients, families and dialysis unit staff members.	Unable to comment on the characteristics of the study as none are given. Number of participants is given only as 'several'. It is unclear if the children were directly involved in the study. No interview questions or topics for discussion were given	Dialysis is a family problem – not just a patient one.	Highlights parental wish to appear 'normal' in front of children. Children of dialysis patients actively involved in administering HDx at home. Suggests that the problems encountered by the children are moderated directly by the amount of social support available to them.

Additional notes

American study.

Identifies that in his opinion Tsaltas (1976) is misleading – gives four references which he states discuss the role of children when a parent is on dialysis. One of these Hoover *et al.* (1974) – is considered within this review, the others appear to focus on changing family relationships or on relatives and are therefore outside the scope of this review.

No operational definitions given – no elaboration of the term family.

No indication of the number of participants is given and there is no interview schedule. It is not clear if all groups of participants were of equal size, or if they were asked similar questions at interview.

There appears to be no consideration given to ethical procedures.

Discussion appeared to focus on general points derived from other literature – there appeared to be little input from the writer's own work – it in some ways appears to attempt to review literature in the area of children's adaptation to HDx, but at a superficial level.

It would not be possible to replicate this study.

The family and home hemodialysis: Adolescents reactions to a father on home dialysis (Goldman *et al.* 1980 – 81)

Type of Supporting Evidence	Objectives	Characteristics of Article or Study	Conclusions	Does it help answer the question?
C1	Focus on the reactions of adolescent family member with particular reference to developmental life crisis and the stresses of having a parent on home HDx	<p>8 families had son or daughter (aged 12 –21 years) living at home. 6 agreed to participate. 16 adolescents of whom 15 agreed to participate.</p> <p>Interviews held with, patient, spouse, family as a whole and adolescents.</p> <p>Initial information obtained at clinic visits. Families were visited at home between 1 – 3 times. Visit 1 was the family as a whole interview – described as non-directed and free-flowing.</p> <p>Topics explored:</p> <ul style="list-style-type: none"> • how home HDx had changed life • problems • how illness and treatment were discussed with children • impressions of effects on children's behaviour. <p>Adolescents interviewed privately.</p>	<p>All the adolescents still relate to their father respectfully. Generally they were proud of how the illness was faced.</p> <p>Information about the illness was generally received from the mother.</p> <p>About 50% were specifically involved in father's dialysis treatment.</p> <p>Realistic about life expectancy of father.</p>	<p>Appears to enhance self-esteem of children as they gain confidence in helping their parent survive.</p> <p>Children have specific information and emotional needs in relation to dialysis which need to be addressed.</p>

Additional notes

American study.

Literature review minimal but did highlight the dearth of information relating to the effects on children of parental dialysis. The 2 studies given were Tsaltas (1976) and Evans (1978).

Term adolescent defined as used in this study.

Detailed demographic detail is presented for all the participating families and is compared with the two similar families who declined to participate. It was not initially envisaged that the sample would contain only fathers as the person undergoing home HDx, but that is what the sample was. The families were all described as Caucasian and 'middle class' – this may have influenced their perspective on illness, treatment or perceptions of family responsibility.

Some of the areas covered within the different interviews are given.

It was stated that written consent was obtained to tape record interviews. It appears that adolescents underwent a separate consent process. However, if the patient declined to participate it appears that adolescent family members were not approached. Agreement for use in scientific publishing was agreed by participants. The study had received ethical approval.

It would probably be possible to replicate this study.

Children of Dialysis Patients (Friedlander and Viederman 1982)

Type of Supporting Evidence	Objectives	Characteristics of Article or Study	Conclusions	Does it help answer the question?
C1	Impact of chronic HDx of a parent on the children living at home and on their relationship with the sick parent.	<p>Termed a pilot study – looked at children’s fantasy lives hoping it would give insight into the child’s perception of parental illness and treatment.</p> <p>Involved families of both centre and home HDx patients who had been on HDx for at least 6 months and had at least 1 child aged between 7 – 14 years. 12 families participated – 7 home and 5 centre HDx, and 14 children.</p> <p>Semi-structured interview with parent – focus – how child was affected by the chronic illness. Children asked to draw a picture and tell the story of the picture. A standard set of questions were then asked of each child. 6 children of physically well parents were asked to draw a picture and tell its story.</p>	<p>No quotes were given from the parental perspective however parents were said to express guilt over becoming ill, their limited employment and educational opportunities and their dependence on treatment which involved other family members. No significant differences were perceived between the centre and home HDx children. The analysis had to be taken on trust as there was no reproduction of any of the drawings although some descriptions were given.</p>	<p>Parents were not aware of what their children thought. Children showed aggressive tendencies, pseudomaturity and identified with the sick parent.</p>

Additional notes

American study.

Identified lack of literature in the area, literature review covered 4 studies (one unpublished) but only one, Tsaltas (1976) – reviewed earlier looked specifically at children with parents on HDx.

No distinct operational definitions were given, however defining characteristics of the sample were given.

The standard set of questions used with the children was not given – perhaps because in the researcher’s opinion it did not given them as much information as the drawing and story telling technique.

A comparison with 6 children of well parents was made – it is unclear why 6 were chosen, or how other characteristics compared with the sample group, for example age representation – the number of children in the study was 14.

There was no documented evidence of ethical consideration, written information or referral to an ethics committee. However, some element of choice must have been given as half the eligible centre HDx patients declined to participate. The effect of this on the study was not considered.

Acknowledges small scale of project (but was seen as a pilot) and suggests follow up studies – there is no evidence that these were undertaken.

Referencing is limited – but probably reflects the lack of material within the area.

It would be difficult to replicate this study particularly as the standard set of questions asked of each child is not documented within the methods.

Psychological effects of in-centre haemodialysis on the dialysand's adolescent children (Schlebusch *et al.* 1983)

Type of Supporting Evidence	Objectives	Characteristics of Article or Study	Conclusions	Does it help answer the question?
B3	To ascertain the psychological effect of parental in-centre HDx their on adolescent children	<p>4 patients had adolescent children and were included in the study. 8 children (aged 13 – 18 years) matched against controls for age, sex and socio-economic status. Two standard psychometric instruments were used</p> <ul style="list-style-type: none"> • high school personality questionnaire • personal, social, home and formal relations questionnaire <p>A clinical interview was also undertaken. Wilcoxon matched-pairs signed ranks test used to analyse the psychometric tests.</p>	<p>Little personality change identified between experimental and control group, but marked changes in adjustment. Tended to score more highly on the areas related to self-sufficiency.</p>	<p>Dialysis is not just a patient – hospital problem but affects children too. Children of HDx patient appear more self-sufficient and sometimes have difficulty with social relations.</p>

Additional notes

South African study.

Acknowledged small study size.

Considered the literature in relation to psychological implication of HDx – previous studies have tended to focus on the effects of home HDx, this study therefore chose to consider the effects of centre-based HDx.

No operational definitions given – the age of adolescents appears by default and it is unclear if other children were available whether they would be eligible for the study.

No indication of the content of the ‘clinical interview’. It is unclear if this was a private interview with the adolescent.

No documented consideration of ethical procedures – however, a senior medical superintendent was acknowledged for permission to publish.

It would be possible to replicate some parts of the study.

**Children and Adolescents of Parents Undergoing Dialysis Therapy: Their
Reported Quality of Life (Molzahn and Kikuchi 1998)**

Type of Supporting Evidence	Objectives	Characteristics of Article or Study	Conclusions	Does it help answer the question?
C1	To describe one aspect of the reported quality of life of a selected group of children and adolescents whose parents were being treated by dialysis therapy for renal failure.	Exploratory, descriptive design. 25 children and adolescents (8 – 16 years) chosen as a convenience sample were interviewed privately, in their homes once a week for 2 –3 weeks – a total of 65 taped interviews. Content analysis was performed on the data – categorisation was based on the Aristotelian-Thomistic conception of the good life.	Overall, that the quality of life of this group of children appeared to be good, but further research is required! Need for carefree family holidays.	Children appeared to need more ‘goods of the mind’ – information about how various family members were feeling and decreased fear in relation to parents’ condition and treatment. Literature review identified that the children’s and adolescent’s experience tended to be described either by the parents or with the family as the focus.

Additional notes

Canadian study.

Identified and described the theoretical framework – the Aristotelian-Thomistic philosophical theory of the good life – that underpins the research.

Identified the growing body of literature that considers children’s and adolescents responses to personal health problems, but puts this study in the context of the limited number of studies that consider the impact of parental illness on the child which take the child’s perspective. The literature review follows a logical sequence and considers most of the material presented here.

The research question was clearly identified.

There are no specific operational definitions given, but eligibility criteria for the study are considered.

Ethical approval is documented, as is the process of gaining consent from the participants including the children. 16 families were eligible to participate but only 13 chose to – it is not clear why these families chose not to participate or if they were from a different population.

This sample considered centre based HDx, home HDx and CAPD –The interviews were semi-structured and the broad areas for consideration were given. Younger children were asked if they wanted to draw, in an effort to reduce anxiety. The drawings were not used for data analysis. The data analysis methods are briefly described and appear appropriate for the study.

The findings were presented in logical fashion structured around the theoretical framework.

The discussion is made with reference to earlier work in the area and the incongruence of these results – good adaptation – is noted.

Limitations of the study are identified – only exploring one aspect of quality of life, small sample from homogenous population (white, middle class).

This would probably be the study that would be the easiest to replicate of those considered.

Appendix 2

Template for critical evaluation

Template for critical evaluation

Stage 1

Obtain article and verify that it is original research.

Stage 2

Read the article in its entirety

Stage 3

Re-read article but consider it in sections

Stage 4

Examine each section identified at stage 3 in depth – balance positive and negative features.

Make detailed notes.

Usual sections include:

- Introduction and background to study – *Clear identification and explanation of the research problem, rationale and purpose of research. Limitations. Significance, relevance and benefit of study in context. Operational definitions.*
- Review of the literature – *Relevant to study, thorough and logically presented.*
- Research design and approach – *Approach should be explained together with any underlying theoretical or conceptual frameworks. Research design linked to research question.*
- Data analysis and results – *Adequate description, appropriate for data collected.*
- Ethical considerations – *Documented within report. Research should be ethically justified. Written information available for participants. Reference to appropriate ethical boards. Data safety. Confidentiality.*
- Discussion – *Drawing research together and formulation of recommendations (including for further research). Relationship to research question. Discussion in relation to literature.*
- Presentation – *Unambiguous title. Clear, jargon free text. Logical structure. Consistent, accurate referencing. Appropriateness of researcher to undertake this research. Acknowledgement of sponsorship if required.*

Stage 5

Consider each of the above sections in relation to the whole study.

Stage 6

Re-read the entire article – by this stage a judgement regarding the appropriateness and usefulness of the study to the initial question should be able to be made.

(after Hek, 1996)

Appendix 3

Typology of evidence

Typology of supporting evidence

Evidence from research and other professional literature

- A1 Systematic reviews which include at least one randomised control trial (RCT) (e.g. systematic reviews from Cochrane or Centre for Reviews and Dissemination).
- A2 Other systematic and high quality review which synthesise references.
- B1 Individual RCT's.
- B2 Individual non-randomised, experimental/intervention studies
- B3 Individual well-designed non-experimental studies, controlled statistically if appropriate; includes using case control, longitudinal, cohort, matched pairs, or cross-sectional random sample methodologies, and well designed qualitative studies: well designed analytical studies including secondary analysis.
- C1 Descriptive and other research or evaluation not in B (e.g. convenience samples).
- C2 Case studies and examples of good practice.
- D Summary review articles and discussions of relevant literature and conference proceedings not otherwise classified.

Evidence from expert opinion

- P Professional opinion based on clinical evidence, or reports of committees.
- U User opinion from reference groups or similar.
- C Carer opinion from carer's focus group or similar.

Adapted from National Service Framework for Older People
(Department of Health 2001c, p 11)

Appendix 4

Adult information sheet

Adult information sheet Version 2 – August 2003

1. Study title

When a parent has kidney problems: what children want to know.

2. Invitation paragraph

You and your family are being invited to participate in a research study. It is important for you to understand why the research is being done and what it will involve before you decide whether to participate. Please take time to read the following information carefully, discuss it with friends, relatives and your GP if you wish. Ask me if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Consumers for Ethics in Research (CERES) publish a leaflet entitled 'Medical Research and You'. This leaflet gives more information about medical research and looks at some questions you may want to ask. Please ask us for a copy, or if you wish, a copy may be obtained from CERES, PO Box 1365, London N16 0BW.

Thank you for reading this.

3. What is the purpose of the study?

This study aims to improve what children are told when a parent has kidney problems. Relatively little work of this kind has been done. Most of what has been done considers the family as a whole, rather than asking what the children might wish to know. This study would help us to understand what children like yours would like to know about their parents' kidney problems. It should also help us to improve our care for these children. It is hoped that the end product would be leaflets that can be used with children to give them information about their parent's kidney problems.

4. Why have I been chosen?

You have asked for further information about this study after you saw a poster within the renal outpatient area that asked for families to volunteer to participate or you may have received a letter telling you about the study. You also have a child or children between the ages of 5 – 18 years old who know that you have a kidney problem. There will be about 10 families taking part in the study.

5. Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. This will not affect the standard of care you receive.

6. What will happen to me if I take part?

If you wish to participate in this study we will make an appointment to meet for an interview which I expect to last about an hour. This will take place at the hospital. The research project as a whole will last between 2 – 3 years. I am hoping that your children will also want to take part in the study. This means that you will need to bring them to an appointment, probably between 6 months to 1 year after your appointment. If you have more than one child their appointments may be on different days. Your children will be involved in some group activities with other children of a similar age who have a parent with kidney problems. I hope by taking part in the activities and talking to them that I will learn more about how to help children understand their parent's kidney problems. There are no extra blood tests or other tests involved in this study.

7. What do I have to do?

If you want to participate in this study when you have considered the information here I will discuss the study with you a little more and we will discuss and sign a consent form. You will be given a copy of the consent form to keep, as well as having the information sheet to refer to. After this we will arrange a mutually convenient time for us to meet at the hospital and talk about how you feel your kidney problems affect your family life. This discussion will be tape recorded and will probably last about an hour. At a later date, after I have talked to all the adults in the study I would like to be able to talk to the children from these families in groups. This will be to discuss what the children want to know about their parents' kidney problems. It is therefore important that your children know that you have kidney problems.

8. What are the side effects of taking part?

There should not be any physical side effects of taking part in this study. However participation in this project may cause either you or your children to consider areas of life that you may not have thought about deeply. If you want to talk about this with someone who is not involved in the study this can be arranged either for you, or your children. The contact details are at the end of this sheet and you can either contact them yourself or ask me to do it. Your family Doctor also has these details.

9. What are the possible disadvantages and risks of taking part?

There should be no disadvantages in taking part in this study, except having to spend about an hour extra in the hospital, and needing to bring your children for a separate appointment, which would be out of school hours. As mentioned in point 8, there may be a risk that you might think more about how your kidney problems are affecting your family life. Again, if you want to talk about this with someone who is not involved in the study this can be arranged either for you, or your children. The contact details are at the end of this sheet and you can either contact them yourself or ask me to do it. Your family Doctor also has these details.

10. What are the possible benefits of taking part?

There is not intended to be a clinical benefit from participating in this study. However participation may help you to understand more about how kidney problems may affect your family life. You may find it becomes easier to talk about your kidney problems to your children. This may help them in the future.

11. What if new information becomes available?

New information about how we help families with children may become clear while the study is running. I would hope to use this information in later interviews to explore some of the issues further.

12. What happens when the research study stops?

When the study stops I hope to have information which will help me change the way we work with families and their children to help them cope with kidney problems.

13. What if something goes wrong?

If you are harmed by taking part in this research project, there are no special compensation arrangements. If you are harmed due to someone's negligence, then you may have grounds for a legal action but you may have to pay for it. Regardless of this, if you wish to complain about any aspect of the way you have been approached or treated during the course of this study, the normal National Health Service complaints mechanisms may be available to you.

14. Will my taking part in this study be kept confidential?

All information which is collected about you during the course of the research will be kept strictly confidential. The tapes and written copies will be kept safely within a locked cabinet when not in use. At the end of the study I will return the tape and written copy to you if you wish. If you do not want to have the tape it will be destroyed. Any information about you which leaves the hospital will have your name and address removed so that you cannot be recognised from it.

15. What will happen to the results of the research study?

The study will be written up to form the research part of taught Clinical Doctorate at the University of Southampton. In addition I would hope to publish the findings and present them at conferences. If you want to discuss the results with me and see how we have changed what we do then please let me know. You would not be named or identified under any circumstances.

16. Who is organising and funding the research?

This study is part of a taught Clinical Doctorate level programme run by the University of Southampton. The fees for this course are paid by the Charitable Foundation who also pay some travel expenses and a small equipment grant.

17. Who has reviewed the study?

The study has been reviewed within the renal unit and also by the ethics committee. In addition it has been reviewed and commented upon by both my supervisors within the University of Southampton.

18. Contact for Further Information

For further information please contact
Frances Coldstream – extension 2887

If psychological support is required please contact
Adults: Psychotherapist – extension 5613
Children: Consultant Paediatric Psychologist, Contact via Secretary –
extension 5672

Thank you for reading this information sheet.

Appendix 5

Letter to General Practitioner

Dear Dr

Re:

Your patient and their family have agreed to participate in a study entitled 'When a parent has kidney problems: what children want to know.' This study has been scrutinised by the ethics committee of the hospital.

It will involve the parents being interviewed about the effects of chronic renal failure on family life and their perceptions of what their children want to know. These findings will be used as the basis to explore what the children want to know using focus groups.

It is possible that participation in this study may cause the family to think more deeply about areas of family life that they may not have discussed. It is possible that further support may be required. All the participants are aware that they have access to the following psychological support services if they are required.

Adults: extension 5613

Children - Consultant Paediatric Psychologist: Contact via secretary: extension 5672

If you would like further information about the study please contact me on extension 2887.

Thank you for your support.

Yours sincerely,

Frances Coldstream
Nurse consultant – pre-dialysis management

Appendix 6

Child information sheet

Child information sheet Version 2 - August 2003

Study Title

When a parent has kidney problems: what children want to know



What is this about?

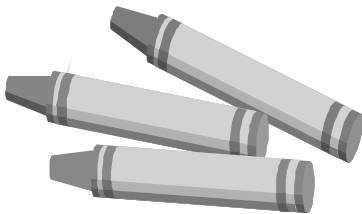
I am a nurse and I like to learn new things to try to help the people I look after. I go to something like school. Here I am doing a project. This sheet gives you information about my project and how you could help me if you wanted to.

Do I have to take part?

No. You do not have to take part. If you say you would like to help me, then change your mind that is OK. I do not mind, but we will still look after your Mum or Dad.

What will happen to me if I take part?

I will ask your parents to bring you to meet me. Then we will meet some other children who are about your age. We will talk together and perhaps do some drawing and some games.

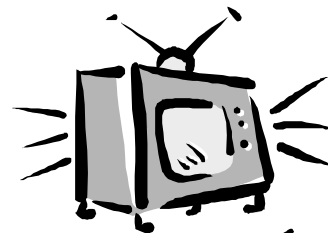


What do I have to do?

You would be part of a small group of children who meet together and talk about what it means to have a Mum or Dad who has kidney problems. When we talk a tape recorder will listen to your answers. We might ask you to do some drawing - if you would like to.

How long will it take?

About 30 minutes to one hour. That's somewhere between one and two episodes of your favourite T.V. programme



Who will know?

Any information you tell me will be confidential. That means that I will not discuss it with anyone except my teachers. I will write up the project for my school. The people who read the project will not be able to tell which children have helped me with my work - your name will not be used.

Thank you for reading this information sheet

Appendix 7

Adult consent form

LREC Study Number:
Patient Identification Number for this trial:

CONSENT FORM (ADULT)

Title of Project: When a parent has kidney problems: what children want to know.

Name of Researcher: Frances Coldstream

Please initial box

1. I confirm that I have read and understand the information sheet (Version 2 – August 2003) for the above study and have had the opportunity to ask questions. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected. ☐
3. I understand that sections of any of my medical notes may be looked at by Frances Coldstream. ☐
4. I agree to take part in the above study. ☐

Name of Participant

Date

Signature

Researcher

Date

Signature

1 for participant; 1 for researcher; 1 to be kept with hospital notes

Appendix 8

Child consent form

LREC Study Number:
Patient Identification Number for this trial:

CONSENT FORM (CHILD)

Title of Project: When a parent has kidney problems: what children want to know.

Name of Researcher: Frances Coldstream

Please initial box

1. I confirm that I have read and understand the information sheet (Version 2 – August 2003) for the above study and have had the opportunity to ask questions. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected. ☐
4. I agree to take part in the above study. ☐

Name of child

Date

Signature

.

Name of Parent

Date

Signature

Researcher

Date

Signature

1 for child; 1 for researcher; 1 to be kept with hospital notes

Appendix 9

Letter documenting ethical approval

07 August 2003

REC Ref: 03/07/07 *Quote reference in all correspondence*

R&D No: RJ1 03/0114

Guy's Research Ethics Committee

3rd Floor Nuffield Annexe
Henriette Raphael House
Guy's Hospital, London SE1 9RT

Mrs Frances Coldstream
Department of Nephrology, Transplantation and Urology
Renal Outpatients Department
4th Floor Thomas Guy House
Guy's Hospital

Chair: Professor Steven H Sacks
Administrator: Mrs Valerie Heard
Direct line: 020 7955 4559
Fax: 020 7955 4303

Email: valerie.heard@gstt.sthames.nhs.uk
Website: www.corec.org.uk

Dear Mrs Coldstream

Re: 03/07/07 When a parent has kidney problems: what children want to know

Documents seen at first review	Documents subsequently approved (new or amended documents marked with an asterisk)
Application signed 3 July 2003 Adult information sheet Version 1 dated July 2003 Teenager information sheet Version 1 July 2003 Child information sheet Version 1 dated July 2003 Letter of support from supervisor dated 21 July 2003	Application signed 3 July 2003 <i>Adult information sheet Version 2 dated August 2003 *</i> <i>Teenager information sheet Version 2 dated August 2003 *</i> <i>Child information sheet Version 2 dated August 2003 *</i> Letter of support from supervisor dated 21 July 2003

Thank you for your letter of 6th August 2003 confirming that focus groups involving children will be held in out-of-school time, and enclosing amended documents listed above. This meets the committee's concerns and the study has Guy's Research Ethics Committee approval.

Permission is granted on the understanding that:

- Any ethical problem arising in the course of the project will be reported to the Committee;
- Any change in the protocol or subsequent protocol amendments will be forwarded to the Committee using the enclosed form (available in electronic format). The principal investigator should see and approve any such changes and this needs to be indicated in the forwarding letter to the Committee.
- A brief report will be submitted one year after commencement, thereafter annually, and after completion of the study. Continuing approval is dependent upon this report.
- You do not undertake this research in an NHS organisation until the relevant NHS management approval has been gained (R&D)
- Approval is given for research to start within 12 months of the date of application. If the start is delayed beyond this time, applicants are required to consult the Chairman of the Committee. **If the study does not start within 3 months of date of this letter, please notify the Committee of the date of commencement for record purposes.**

A list of members in attendance at the 23 July 2003 meeting is enclosed.

Yours sincerely



Steven H Sacks
Chairman of the Guy's Hospital Research Ethics Committee



Appendix 10

Adult interview guide

Interview guide for adult participants.

Tell me a little about your family – the people that are in your household?

- and your child/children?

How long have you known about your (your partner's) kidney problems?

Could you tell me how you got information about your kidney problems?

Do you share this information with your child/children?

Do your children ask questions about your kidney problems?

- are they interested in your hospital visits?
- have they been to the hospital with you for an outpatient visit?
- have you been an inpatient with your renal problems?
- did your children visit you then?

What bothers your child/children most?

Have you noticed (or has anyone else noticed) changes in your child/children since you found out about your kidney problems?

(if someone has changed RRT explore if they have noticed changes at these times too.)

What do you think your child/children want to know about your kidney problems?

Where do you think your child/children get their information from?

What ways do you think your child/children would like to receive information?

Do you have any concerns about your child/children knowing more about your kidney problems that they do?

Appendix 11

Poster

Are you interested in finding out what your children want to know about your kidney problems?



I am interested in talking to families about the effect kidney problems can have on their family life.

If you have one or more children between the ages of 5 – 18 years and you would like further information

Please contact:

Frances Coldstream extension 2887



Appendix 12

Invitation letter to potential participants

Dear

As you may be aware I am planning to undertake a study called 'When a parent has kidney problems: what children want to know.' You may have seen a poster about the project displayed in the unit.

We have talked in the past about what your children might want to know. I therefore wondered if you would be interested in obtaining more information about the project.

If this is the case I would be very grateful if you would contact me on extension 2887, when we can talk a little more about what the project aims to achieve and I can provide you with some written information.

Thank you for taking the time to read this letter,

With best wishes,

Yours sincerely,

Frances Coldstream
Nurse consultant – pre-dialysis management

Appendix 13

Patient's transcript

Family 5 – interview with patient

I would just like to check first F5Pt if you are happy for the interview to go ahead.

yes, I am. Fine.

Thank you. Can you tell me a little bit about your family, who is actually in your nuclear family, to begin with.

erm, close family is wife F5P and three sons, F5C1 aged 9, F5C2 aged 7 and F5C2 aged 5.

so they're all school age now. What a change.

They're all at the same school, so it's good.

that makes it easier

not too much hassle

Right, good. And how long have you known about your kidney problems?

probably 20 years (*twenty years?*) in total, since I was 19.

right, so was it a shock then at all?

yeah, pretty much so when it all happened but over the course of time you just get on with it. It doesn't really encroach too much on my life at all. (*right*) In fact as little as, it's the treatment and things like that certainly take a lot of time but it's not something I try and change my life around. I'd rather work the treatment around my life.

yep, well I would say that's the right way to try and do it, to try and make sure that you carry on as normal as possible. Ok, so about 20 years ago when you were 19. And can you remember, I mean it's quite a long time ago now, but how you got information about your kidney problems?

Do you mean about the consultations with doctors when they told me something was wrong or....

anything really. So the doctor tells you something's wrong and perhaps he used lots of long medical terms and you think, you know, where do I get information and did you just ask them?

as far as I remember, it was a matter of just asking the nurses and doctors, you know, what the layman's terms were for any technical things that they were talking to me about, what they actually meant, getting timescales for them for when it would potentially would happen, how long would it be before I would need to have dialysis and that sort of thing. I was told initially it was about two years.

and were they right?

and it worked (*both laughing*) and then I was on CAPD-type dialysis for around about ten months and had a transplant so in that intervening period any information came from the CAPD unit and as I say, the doctors and I suppose, the lucky thing I've got in terms of F5P being medically or her professional side is medical anyway. That, that makes it easier to understand.

but do you actively go looking for these? I mean would you get books out of the library or ...

no, not particularly. I am quite happy to know what, in layman's terms, potentially caused the problem that I've got. Erm, I know what happened and I know what treatment I've got to go through and basically like get on with it and will eventually get back round to having a transplant again and all this will disappear for a set period of time. In the back of my mind, it'll probably resurface again at some stage further down the line but so could lots of things. So there's no point dwelling on it on a daily basis and worrying about it or trying to plan for it because you don't know what's going to happen.

yeah, yeah, ok. So obviously you didn't have your children when you were first diagnosed...

no

and they came along at a later stage as it were but can you remember what you told them or how you shared information with them or what was the specific point when you thought 'I got to do this' or did you tell them as soon as they were old enough to understand or...

no, 'cos of the fact the children were all born after I had my transplant, they never, and my transplant was great so I never had any problems with it at all. I just got up in the morning and took my tablets and had an absolutely normal life for 15 years until Christmas 2003 when it all started to go awry again and the only sort of intrusion into our lives that kidney disease had was the fact that I took tablets in the morning and the boys just used to ask 'what are you taking tablets for?' And at that point, we just basically told them I had a kidney transplant and told them that I had an operation before they were born. I told them basically everything that they asked questions about. I was quite happy to share the information with them. They took it on board quite easily and as I said, it didn't have any effect on the day-to-day living 'cos I was living a normal life with no treatment required or anything. The odd visit to the hospital but then that didn't even concern them and then in this last year, with the renal function disappearing and going onto dialysis, they got more involved in things and we actually told them that I would have to go through another operation and things like that and they again just accepted it as dad's not very well and he'll get another kidney at some point and they were quite happy with that. The concept was set in their mind that that's what happens (*right*) they've got no, I don't think they have any reasons to question what we tell them 'cos we've told them the whole truth about it and luckily, they understand what we've managed to do is put it in terminology they understand.

Did you find that difficult?

no, not at all. Just, throughout the years, just a matter of lots of people that I knew in my industry and friends and things, because of the fact I was living a normal life it was a bit of a shock to them (*right*) to hear that I had kidney problems because they just they didn't contemplate anything like that could have ever happened and when it happened it's a matter that you have to start at the beginning and tell them the things that happened and ermm, it's quite a well versed script as it were (*yeah*) it's there, and over the course of time I've probably honed it into a situation where it's very layman's speak and everyone is quite happy with it.

'cos I suppose you find you probably it's not just your children you have to explain to it's

Yes

other people

lots of people

Yes, OK - so do they still ask questions?

err Yeah, they, they ask questions about what's happening, what's the machine's doing, they like to get involved in pressing the little arrows on the APD machine (*emm*) emm wash their hands and things like that err, they ask questions about when I'm going to get better and of course the only answer I have got there is that erm I haven't any ideas on that, just have to wait and see what happens, there are no direct timescales involved. ermm and you know they are quite happy to accept that (*right*) and they, and they, the treatment doesn't actually encroach on their life either because I go to bed about the same time as they do (*right*) so they're (*yeah*) gone off to bed, and I'm doing it overnight so there's nothing really happens in their life as far as my treatment is concerned.

OK, now I think I probably know the answer to this one, they've come up on outpatient visits haven't they?

Yes,

Yeah, and do the, did they go in the room with you?

Yes, Yeah,

and do they ask questions in there? Or do we let them ask questions in there perhaps more to the point?

Well, the, the, the kids are all very, what they're children so, they, they're inquisitive (*emm*) and ermm, yeah, they ask questions about the environment that they are in all the time, they ask questions about how everybody is feeling, so they like to gauge reactions from people ermm and again just like we've always done with any particular subject, whether it's a serious subject or whether it's you know, something not quite so serious, something down to humorous type thing, we will tell them the truth about things ermm and it's not a matter of saying you know talking about some round about fashion how something happens it's quite straight and blunt to the point and mostly factual (*emm*) and they take it on board (*emm*) and they are quite happy with the information and I think that is the best way to be.

yeah, yeah. have you ever been in hospital whilst you, as it were had the children?

yes, ermm, cos I had to come in for a renal biopsy and I've also had to come into hospital for insertion of a catheter (*right*) and they came to hospital, they came up to the hospital to see me. (*uh huh*) ermm Again, just the inquisitiveness of children on their environment as I said, the whole ward scenario is an interesting thing for them and they, also they can relate to the fact that it's like going to Mummy's work (*right*) as well so (*OK*) there's not, it's not such a huge culture shock for them (*uh huh*) because they know that F5P works in a hospital (*emm*) and they're quite au fait with hospital type terminology, as it were (*right*) they're not, they're not going to be phased by the surrounding, the environment, the amount of people going about, the fact that there are other people who are not very well (*right*) err as well doesn't seem to bother them and they're more concerned, as children would be, in their own little world (*uh huh*) ermm and the influencing factors round there and when they were with me they were quite interested in how I was feeling (*uh huh*) yeah the usual thing within about 5 minutes they're quite happy to sit doing their drawings or eat the fruit (*game boy?*) get the game boy out and it's sort of, yeah OK this is what's happening just now let's accept it and then when they had to go, they went, quite OK (*right*) ermm, you know they knew that I was coming out the next day or (*uh huh*) ermm they weren't, they didn't fear for me put it that way.

Right. Do you feel ever any need to protect them in any way?

err, no I don't, I think the best protection they can have is being told the honest truth about what's going on (*emm*). ermm, I don't think that this ermm, it's the way the I handle the condition that I've got, disease, condition, whatever you want to call it, I'm pretty honest with myself about it, ermm it's not the nicest thing for anyone to go through (*no*) and I wouldn't wish it on anybody (*no*) ermm but by the same token it's not life threatening because I can alter (*uh huh*) my life around and, you know the treatment works fine (*uh huh*) ermm and you know, as of yet I haven't been told I've got some sort of life threatening condition that I've got x amount of time left, (*emm*) if that was the situation then I would have to reassess that and talk to the kids (*yeah*) at that point (*yeah*). ermm, just going back on your original question I can't really answer it

'til you're there?

Until I'm there. yeah.

OK. Do you, and it might be different for each of your children because they are at different stages, different ages, is there anything that you think bothers them about this whole kidney business as it were?

I think that, I just think that the only potential thing that bothers, that bothers them is that they just have natural feelings for me (*uh huh*) and they want me to be well, that's all and that potentially there's a little bit, the same way that I sometimes think about it, there's probably a

little bit of anger somewhere there, that something's happened to their Dad and they want me to get, you know and then leading on from the initial tension, anger, then there's their loving and kindness that they just want me to get better again.

Do they show that in any particular way?

Err yes, they come give me hugs and cuddles and tell me that they hope I'm going to get better soon, yeah so that's the nice things that happen.

OK, So just perhaps just a bit of anger about?

Not, not a huge amount, it's just you can tell that they, that they have some, may be a bit of anger, may be a wee bit of confusion as well, I'm not sure, but then by the same token they don't know any different because ermm, the situation they've always been in, you know it's not something that just cropped up, (yeah) it's something that's been there for quite a while (yeah) ermm and they begin to live with it as well as we do.

OK Around the time that either you started to realise that there was something going wrong with your transplant, or just recently now you've started peritoneal dialysis have you or have perhaps the school or anybody else mentioned that they'd been perhaps changes in your children's behaviour or anything, have you noticed anything that might have changed?

No absolutely nothing. They're quite, (right) quite ermm sort of can't get on with their life as much as possible and I think probably one of the contributing factors to that is that I am quite happy to push myself to the limit (uh huh) as far as physical things that I can do (mmm) and as I mentioned earlier on not allowing the condition or disease to encroach on (emm) what I perceive as my life (emm) ermm I run my own business (emm) and I still have a social life and we talk about booking up a holiday and things like that (emm) you know I don't, I don't have any fears about treatment (emm) and to be quite honest with you if it was a matter of having to circumvent it somehow then, then I'll do that (emm) ermm because I don't want it to ever to encroach on our (yes) family life, well obviously it will do to a certain extent (yes) but I don't want it to go over any, I haven't drawn any invisible lines or anything but there is, is a point where I don't want it to get too much involved (emm) ermm and I'd keep it back (emm) there as much as I could, ultimately if I'm not physically strong enough to do something then I can't do it. But I'd make a good effort towards doing it, and keep it away. (yeah)

Out of interest do the school know about your health problems?

yeah, they do. The school are great, absolutely fine ermm, they understand that sometimes I'll, if I'm taking the kids into school they'll be 5, 10 minutes late in the morning, (uh huh) they're quite happy with that (emm) because they know that I've got to do more things than the normal person (uh huh) in a morning when I get up, ermm, if, like last year when we went on holiday they allowed the kids to have 3 er, 2 weeks off from school, at the end, at the end of term (uh huh) because at that stage we were booked to come in to have the, I was booked to come in and to have the PD catheter done (uh huh) and it would have, it was advisable to go on holiday prior to the insertion of the catheter rather than wait until it was done (umm) ermm so the school were very understanding on that, quite happy to (right) play ball as it were. (uh huh) Headmistress is very much up to date on it ermm (ermm) they're quite, I wouldn't say concerned, for they're concerned with everyone's welfare, welfare that's you know to do with the school but they are, every time I see them they all ask questions how am I feeling and (right) how's it, how's it getting on and when F5P is at school most of the teachers and things will ask how I'm getting on, ermm, it's not a hidden fact it's (emm) there it's out in the open and everyone

and there's a genuine interest?

Yeah, (yes?) yeah

OK. What do you think your children want to know about your kidney problems? Perhaps a bit different.

Ultimately they want to know when it's gonna disappear (*right*) that's (*OK*) that's the thing that I think is there, when's it, when are you gonna get better, (*uh huh*) that's, that's the primary thing. What they want to know is ermm, in addition to that, how, how it potentially started? How ermm is it sore? (*uh huh*) you know (*ermm*) they are interested in whether it is painful or not. ermm they're, yeah, probably that's about as much, as far as it goes, when is it going to stop and how is it painful (*emm*) and cos they don't understand that ermm it has an effect on other sides of, of life (*right*) and the only, because their life isn't as complex as an adult's life, they will relate to what they (*uh huh*) they themselves would find err changed in their life (*emm*) if it was happening to them and I can only see that firstly, as I say, they want to get better as quickly as possible (*emm*) and like any normal person that you talk to them about any sort of illness, disease or you know even, cut in your foot, (*emm*) one of the first questions you ask them is, cor, is that sore? (*emm*) That looks really painful. (*emm*) It's a natural question and everyone will ask ermm and how long is it going to take to get better? and that's all that they're, that they're really interested in, you know, they have ermm, well we've gone through how your, what your kidneys do (*right*) err they quite understand the fact that you've got 2 kidneys and that you don't need to have the whole 2 to survive and ermm, they've accepted all of the, the sort of anatomical, I would suppose, (*Uh huh*) discussions that we've had and you know they've asked questions about it whilst we're talking about that side, side of things and again luckily because F5P background is medical while she is able to describe it in quite layman's terms as well ermm and those, that's the crucial factor about all this, getting it all down into layman's terms (*emm*) so that, so that they don't feel as, so that there's no big spectre of fear (*emm*) in as much as, you know, a dark shape of kidney disease is creeping (*emm*) into their life. It's kept away from them (*emm*) as purposely as possible.

So how do you deal with the fact that at one level it isn't going to get better?

Errm With the children? or with

With the children, well I suppose with you as well but I suppose I am interested in the children, but yeah, with you as well.

ermm As I, as I said earlier on just getting to the point where if like today coming here and having an iron infusion (*emm*) is just one of these things I've got to do (*emm*) so go to work this morning, do some phone calls (*emm*) that I have to do, tell people I've got some guys I need to phone back later, letters I need to do later, I'll be back in the office 3, 3.30, (*uh huh*) talk to people saying sorry I've got to go to hospital (*emm*) and if anyone asks, Are you OK, yeah I'm fine (*emm*) and carry on with that ermm, there's always going to be contact with the medical profession somewhere down the line (*emm*) ermm, in the back of my mind, it could well be probably something that is revisited at a later stage, but if it's 15, 20 years time then we'll get on with it whatever's our personal circumstances at that time then we'll just make the most of it.

Are you back on the transplant list now?

yes

And do the boys know that?

Yeah, yes, they're quite aware.

And they know what it might mean?

yeah, they're quite aware of the fact. ermm, I think they are also aware of the fact that F5P had offered to (*right*) ermm be a donor (*uh huh*) but unfortunately it didn't work out, well she was a match with me but the ermm transplant kidney that I had (*uh huh*) introduced too many antibodies against her (*right*) so me, both me and her were OK (*yeah, yeah, but*) but the third thing (*emm*) into the equation didn't make it work out. (*right*) so they were quite OK with the concept, (*right*) it's not as if, in fact they don't have any perceptions that we're turning to

some new person or something like that (*uh huh*) erm and they're quite, just waiting to get me back so that I can shout at them even more and,

surely you don't shout at them!! laughter! Where do your children get their information from about the kidney problems?

Primarily from Mum and Dad (*uh huh*) ermm secondary sources from erm I would guess they've had a look on the internet, F5C1 certainly has, (*uh huh*) the older one, he's had a quick look on the internet (*uh huh*) about kidney things (*right*), they have books, ermm encyclopaedias and the like (*uh huh*) that they have got and they are able to look at how different organs function, not just the kidney (*yes*) ermm and that's probably their only sources I don't think they would ask anyone at school about it (*right*) ermm, other family wise, they don't see my parents very often, they still live in Scotland (*uh huh*) and to be honest they don't know too much about what's happening on (*right*) my side anyway, well, the others, they know (*yes*) what's happening, but they're not involved in a day to day basis (*emm*) because they're still live, they live that far away and it doesn't encroach on their life either. And then, erm from F5P's sister, that's their other, or sisters and brothers who live close by to us (*uh huh*) they may well get some information from them, but again I doubt if they would ask them (*right*) they'd primarily come and ask me or F5P.

Good, OK, and in a sort of an ideal world how do you think they would like to receive information?

ermm, I just trying to think, you've just got your normal channels of, of information provision so word of mouth probably (*umm*) the parents is the primary source, then ermm they would, you know depending as I say F5C1's old enough to go and have a search on the internet himself (*umm, umm*) within certain boundaries, (*yes*) that he's not allowed to step over (*yes*) ermm and to his, to his credit he doesn't ermm, the other two aren't old enough really, (*umm*) they're, they know what the internet is about and they sit with F5C1 when (*umm*) he's doing it but he's the one (*umm*) who's driving things (*umm*). ermm, I think some sort of interactive, computerised ermm, sort of explanation as it were (*uh huh*) that would be very helpful, in some kind of presentation (*right*) that they need to click on a couple of things, (*uh huh*) or you click on something and it opens up and (*umm*) and you know there are some words (*umm*) there to say this is what this does and this is what that does and when kidney failure comes along this doesn't work (*umm*) and that's why you need to have (*yes*) and then you know, go in leading through from the very beginning stages of how normal kidneys work to how the disease affects what parts of the kidney (*umm*) and then moving on to the treatments that are there (*umm*) so looking at haemodialysis, peritoneal dialysis, ermm you know the normal CAPD and then the APD type (*umm*) thing ermm and then ultimately looking at what happens at the point of a transplant (*uh huh*) and to be honest with you I think that would probably be quite a, a useful tool, not just for children

right, no for the adult population as well

Yep, just to see how the cycle works, I mean everyone's gone through it in their own lives ermm and whether, whether you take it on board at the time because sometimes it probably affects people very quick or (*umm*) quickly there's ermm a sort of a phasing of (*umm*) you know too much information or too much, not too much information but too much ermm, negative information to take (*umm*) on board at one time (*umm*) and a lot of people will probably shut it off and say it's not happening (*umm*) whereas I think you've got to accept the fact that it is there, and get on with it (*umm*) and make it as open as possible (*umm*) and work your way round it, in addition to that you could have some sort of complimentary work book (*uh huh*) type thing ermm which has got you know some sort of text in it, same concept as the (*umm*) multimedia type approach but, you know has little things like a poster for example, (*yes*) you know just little things (*yes*) like that in it, but may be not as complex as that, but in a fashion that the kids could colour that in (*yes*) you know, (*umm*) and whilst they're colouring something in, if they had a picture of a house and they coloured the house in (*yes*) then they would know what a house was, (*yes*) afterwards same thing, if they get the general shape of what a kidney is, (*yes*) knowing whereabouts in your body your (*umm*) kidneys are and just some general awareness of physiology or the like, where, where things actually are and the

sort of side effects of what kidney disease does to you (*umm*) the fact that my, your ankles swell up, (*umm*) and what happens, how that happens, (*yes*) a bit, a bit of a more simplistic approach to say the workbooks that we were given when we got the APD machine (*right*) you know something along those lines ermm I think maybe, the other, the only other aspect that is not really taken on board, from the hospital's point of view, is if, if, if errm, I'm sure that there are lots of families that just run with their hospital appointments on their own and they don't discuss what goes on (*umm*) ermm, it might be a worthwhile consideration to, to when somebody is at the point of diagnosis or just after, to arrange some kind of err meeting in a hospital environment but not in a ward situation, (*umm*) you know a comfortable type environment with their closest family members (*umm*) to just talk through what their hopes and fears are as regarding potential treatment, (*umm*) or do they even know what their potential treatment is, (*yes*) most of the time people don't, (*umm*) they just accept it ermm and get on with it, they don't (*umm*) know why they are doing something, how long they are going to have to do it for (*umm*) ermm there's still mystic, well not mystic, but there's still a lot of ermm (tape2) there was a different kind of errm attitude towards the medical profession (*uh huh*) you know it's like the doctor, your doctor, the GP, (*emm*) which most people actually saw was sort of revered in the (*emm*) in the community and the doctor, people wouldn't call the doctor, my Grandfather wouldn't call the doctor out (*right*) because he didn't want to disturb him because he was the doctor. What was the point, you're ill, that's his job, (*emm*) his job (*emm*) is to try and make you as comfortable (*emm*) as possible if he can't help you (*emm*) ermm or help you get rid of whatever is affecting you ermm and I think there still tends to be, but as I say, to a lesser extent that errm distance between patients and doctors (*right*) and the, the, the professionals that doesn't help itself too much because you've got the situation where lots of people are called professor (*emm*) or Mr (*emm*) or (*emm*) Sir (*emm*) I think you've got that so there is, and quite rightly but that's the way that they progress through their profession (*emm*) ermm, but I tend, when I attend doctors, I'll end up talking to them by their first name (*emm*) and I think it's quite nice that they can relate back (*yes*) to me in that way, I've never had anyone say how dare you call me (*emm*) John or (*emm*) whatever it is and everyone who I've talked to on a level basis, they're quite happy to (*emm*) expand information and you end up getting more out of the doctor if you can have a conversation (*yes*) with them but then not everyone is able to do that (*no*) and obviously not everyone wants to do it as well.

Going back to this idea of getting, would it be specifically families together with the children present? or

yes, I think, I think the perfect example of it would be perhaps if, if you go back in time and it happened to me then at some point afterwards, after the initial diagnosis (*emm*) is, would be to have arranged a meeting whereby I would have been in a situation with F5P and the children (*uh huh*) and we were there (*emm*) and to sit down and somebody ermm, whether it be a doctor or whether (*emm*) it be a senior nurse or somebody (*emm*) who, who's pretty compassionate like what they, what, how they present themselves (*emm*) ermm because you don't, you wouldn't want to have somebody there just saying these are the blatant facts (*emm*) and these are the things you've got to (*emm*) get on with, it's got be, a nurse is fine their nature are compassionate people (*emm*) so it works quite nicely (*emm*) on that side ermm and that would be just a, a discussion (*emm*) half an hour's worth of (*emm*) as I say what your fears are and what your hopes are ermm and what your impressions of, of the treatment you may have had up to (*right*) a certain point have been as well, and I think that would be very helpful to a lot of people. Put their mind at ease.

And perhaps meet another family in the same

Yes, I think so, going back to when it all kicked off with me, yes, as I say when I was first announced to me that I had something wrong with me (*emm*) I was probably the worst person in the world that you would want to meet for about 4 or 5 days (*emm*) ermm because I just became very insular (*emm*) and it was the situation of I was 19 years old and starting out on a career and thinking I've got quite a lot to potentially give back into society and you see these down and outs sleeping on doorsteps and drug addicts (*emm*) and all this sort of stuff and it was just a natural thing (*emm*) and I am sure that anyone (*emm*) starts questioning why is this happening to me when its not happening to these guys (*emm*) and it took me 3 or 4 days to

just kick myself around and all, all of a sudden, but not, not persuade myself but just come to the conclusion that well it's happened, get on with it and make it, make it as best as you can. You're not going to change it, (emm) and there's no point in saying I wish it happened to somebody else, it was, it was, a matter of accept it (emm) and then make the most of what goes on in the future, and I think that works quite nicely (right) when it happened ermm nobody came and really talked to me on a patient's side of things (right) but what I do remember is when I went onto CAPD at first, cos nurse was (yes) working here back then as well, I've know her for a long time, or nurse was working here a long time ago and she asked me if I would talk to one of the, some young guy who'd (emm) just been diagnosed and I said yes, that's not a problem (emm) and I sat and talked to him and then basically told him a lot of stuff (yes) that I've told you now, (yes) because my attitude hasn't changed (yes) it's just you can take me back 20 years and it would be exactly the same, except for that first 4 or 5 days (emm) that's the only thing that err happened.

And do you think the children would perhaps benefit from meeting other children who are in a similar, whose parents are in a similar situation

Well, I'm absolutely positive it wouldn't have a detrimental effect on them (emm) how positive it would be I don't know because it all depends on how the children communicate with each other (emm) and whether they would be err you know if they met other children I'm sure the last thing on their mind would be to ask them a question about (emm) kidney disease or something (emm) like that, they've got kids things that (emm) they want to talk about, (emm) they want to talk about the latest power rangers or whatever it is (yes, yes) you know, car trump cards, top trump cards that sort of thing, that's what children (emm) do and that's what children will always do (emm) so I don't, as I say no detrimental effect on them (emm) actually meeting up with children whose parents are in similar situations (emm) but how beneficial it would be I am not really certain,

Right, OK. If your children did find out more information by whatever way, would that bother you that they knew,

Absolutely not (no) quite happy with it, err I, I would find it very difficult to errm believe that they could find out anymore than they actually know (right) that's the issue of it unless of course they suddenly became errm master medics themselves (emm) because as far as we told them in layman's terms (emm) we've given them as much information as they can, they can probably take in (emm) errm we haven't held anything back (emm) so the only way I think that they could find out more about it is going into the actual, how it works and more technical, technically aware of what has gone wrong (emm) errm the easiest way to explain to them what's happening is they are there, what your kidney's do (yes) at that age, show them a tissue, bit of tissue paper and run some water on it (emm) and the tissue paper starts to, well first of all the water will go through slowly, I'm not talking about gallons of water, (emm) but a drip of water (emm), it will go through slowly and then eventually the tissue will rip (emm) because the pressure of the water, and it breaks and that's the explanation of what's happening to the (yes) filtration things inside your kidney, (yes) that's what we told them (yes) and I'm sure they are aware of how it works, maybe they'll just flick back in their mind to a vision of a tap dripping on a tissue or a bit of filter paper, and that, that's what your kidney does (yes) so, yes, and as I say if you take that as an example of what you need to go into in more detail

Yes, sure, sure, that's the end of my sort of specific questions, but I don't know whether you've got anything you think I haven't covered, or that you want to add, or something that you've thought of that

err, no, just the only, only way that we coped with it so far errmm, is by, as I mentioned all along, just not letting it take over (emm) cos it very easily could (emm) and I'm sure there must be unfortunately some people who just can't handle it (emm) and errm it does become the biggest thing in their life and everything that their, you know their life evolves around their illness as it were (emm) errmm and what that would unfortunately mean if you look at it on a bigger picture is you've got the illness in the middle and then the person standing next to it and outside of the circle of them and their illness is their family (emm) and they'll start to

block out the family because they don't, they feel that they are more concerned, they become more protective of the disease, (*emm*) than they do of their families (*yes*) it's like completely on its head, (*yes*) how it should be.

Yes, that's really useful

That's the only way that I think it could happen err cos obviously somebody in that position where they are really, really caught up in something (*emm*) they're going to leave (*emm*) the rest of it to its own devices (*emm*) and they really couldn't care (*emm*) whether they understood it, what effect it has on them (*emm*) errm and not, not maybe care is the wrong word but they wouldn't have, they wouldn't be able to understand that the other people on the outside of their little world (*emm*) which is them and their disease actually does care about (*yes*) what goes on, (*yes*) but that is as much as I think I can.

OK thank you very, very much, it's really useful. Thank you.

Family 5 – patient

Life view

I'd rather work the treatment around my life.

I don't think that this, it's the way the I handle the condition that I've got, disease, condition, whatever you want to call it, I'm pretty honest with myself about it, it's not the nicest thing for anyone to go through and I wouldn't wish it on anybody but by the same token it's not life threatening because I can alter my life around and, you know the treatment works fine

the only way that we coped with it so far is by just not letting it take over cos it very easily could and I'm sure there must be unfortunately some people who just can't handle it and it does become the biggest thing in their life and their life evolves around their illness. What that would unfortunately mean, if you look at it on a bigger picture, is you've got the illness in the middle and then the person standing next to it and outside the circle of them and their illness is their family and they'll start to block out the family because they feel that they are more concerned, they become more protective of the disease, than they do of their families it's like completely on its head to how it should be.

Information – adults

it was a matter of just asking the nurses and doctors, you know, what the layman's terms were for any technical things that they were talking to me about, what they actually meant, getting timescales for them for when it would potentially would happen, how long would it be before I would need to have dialysis and that sort of thing

any information came from the CAPD unit and as I say, the doctors and I suppose, the lucky thing I've got in terms of F5P being medically or her professional side is medical anyway. That, that makes it easier to understand.

I am quite happy to know what, in layman's terms, potentially caused the problem that I've got. I know what happened and I know what treatment I've got to go through and basically like get on with it and will eventually get back round to having a transplant again and all this will disappear for a set period of time.

Uncertainty

In the back of my mind, it'll probably resurface again at some stage further down the line but so could lots of things. So there's no point dwelling on it on a daily basis and worrying about it or trying to plan for it because you don't know what's going to happen.

They ask questions about when I'm going to get better and of course the only answer I have got there is that I haven't any ideas on that, just have to wait and see what happens, there are no direct timescales involved. and you know they are quite happy to accept that

Information - child

I just got up in the morning and took my tablets and had an absolutely normal life for 15 years until Christmas 2003 when it all started to go awry again and the only sort of intrusion into our lives that kidney disease had was the fact that I took tablets in the morning and the boys just used to ask 'what are you taking tablets for?' We just basically told them I had a kidney transplant and told them that I had an operation before they were born. I told them basically everything that they asked questions about. I was quite happy to share the information with them. They took it on board quite easily.

With the renal function disappearing and going onto dialysis, they got more involved in things and we actually told them that I would have to go through another operation and things like that and they again just accepted it as dad's not very well and he'll get another kidney at some point and they were quite happy with that. The concept was set in their mind that that's what happens they've got no, I don't think they have any reasons to question what we tell them 'cos we've told them the whole truth about it and luckily, they understand what we've managed to do is put it in terminology they understand.

they ask questions about what's happening, what's the machine's doing, they like to get involved in pressing the little arrows on the APD machine, wash their hands and things like that and they, the kids are all very, what they're children so, they, they're inquisitive

I think the best protection they can have is being told the honest truth about what's going on

we will tell them the truth about things and it's not a matter of saying you know talking about some round about fashion how something happens it's quite straight and blunt to the point and mostly factual and they take it on board and they are quite happy with the information and I think that is the best way to be.

Again, just the inquisitiveness of children on their environment as I said, the whole ward scenario is an interesting thing for them and they, also they can relate to the fact that it's like going to Mummy's work as well so there's not, it's not such a huge culture shock for them because they know that F5P works in a hospital and they're quite au fait with hospital type terminology, as it were they're not, they're not going to be phased by the surrounding, the environment

They want me to get better as quickly as possible and like any normal person that you talk to them about any sort of illness, disease or cut in your foot, one of the first questions you ask them is, cor, is that sore? That looks really painful.

we've gone through how your, what your kidneys do, they quite understand the fact that you've got 2 kidneys and that you don't need to have the whole 2 to survive

Primarily from Mum and Dad, secondary sources I would guess they've had a look on the internet, F5C1 certainly has, he's had a quick look on the internet about kidney things, they have books, encyclopaedias and the like that they have got and they are able to look at how different organs function, not just the kidney

I think some sort of interactive, computerised explanation would be very helpful, some kind of presentation you click on and it opens up and you know there are some words there to say this is what this does and when kidney failure comes along this doesn't work. Leading through from the very beginning of how normal kidneys work, to how the disease affects what parts of the kidney and then moving on to the treatments, so looking at haemodialysis, peritoneal dialysis and ultimately looking at a transplant and to be honest I think that would probably be a useful tool, not just for children

you could have some sort of complimentary work book, which has got text in it, same concept as the multimedia type approach but, has little things like a poster for example, but may be not as complex as that, but in a fashion that the kids could colour that in and whilst they're colouring they get the general shape of what a kidney is, knowing whereabouts in your body your kidneys are and just some general awareness of physiology. The side effects of what kidney disease does, the fact that your ankles swell up, and what happens, how that happens, a more simplistic approach

would be to have arranged a meeting whereby I would have been in a situation with F5P and the children and to sit down and somebody, whether it be a doctor or whether it be a senior nurse or somebody who's pretty compassionate, how they present themselves because you wouldn't want to have somebody there just saying these are the blatant facts and these are the things you've got to get on with, it's got be, a nurse is fine their nature are compassionate people so it works quite nicely. It would be just a discussion, half an hour's worth of, as I say what your fears are and what your hopes are and what your impressions of the treatment you may have had up to a certain point have been as well, and I think that would be very helpful to a lot of people. Put their mind at ease.

so the only way I think that they could find out more about it is going into the actual, how it works and technically aware of what has gone wrong. The easiest way to explain to them what's happening is they are there, what your kidney's do at that age, show them a tissue, bit of tissue paper and run some water on it and the tissue paper starts to, well first of all the water will go through slowly, I'm not talking about gallons of water, but a drip of water it will go through slowly and then eventually the tissue will rip because the pressure of the water, and it breaks and that's the explanation of what's happening to the filtration things inside your kidney, that's what we told them and I'm sure they are aware of how it works, maybe they'll

just flick back in their mind to a vision of a tap dripping on a tissue or a bit of filter paper, and that, that's what your kidney does

Family life

not allowing the condition or disease to encroach on what I perceive as my life I run my own business and I still have a social life and we talk about booking up a holiday and things like that you know I don't, I don't have any fears about treatment and to be quite honest with you if it was a matter of having to circumvent it somehow then, then I'll do that because I don't want it to ever to encroach on our family life, well obviously it will do to a certain extent but I don't want it to go over any, I haven't drawn any invisible lines or anything but there is, is a point where I don't want it to get too much involved and I'd keep it back there as much as I could, ultimately if I'm not physically strong enough to do something then I can't do it. But I'd make a good effort towards doing it, and keep it away.

It didn't have any effect on the day-to-day living 'cos I was living a normal life with no treatment required or anything. The odd visit to the hospital but then that didn't even concern them

the treatment doesn't actually encroach on their life either because I go to bed about the same time as they do so they're gone off to bed, and I'm doing it overnight so there's nothing really happens in their life as far as my treatment.

they come give me hugs and cuddles and tell me that they hope I'm going to get better soon, yeah so that's the nice things that happen.

they begin to live with it as well as we do.

The school are great, absolutely fine they understand that sometimes if I'm taking the kids into school they'll be 5, 10 minutes late in the morning, they're quite happy with that because they know that I've got to do more things than the normal person in a morning when I get up, if, like last year when we went on holiday they allowed the kids to have 3 er, 2 weeks off from school, at the end, at the end of term because I was booked to come in and to have the PD catheter done and it was advisable to go on holiday prior to the insertion of the catheter rather than wait until it was done so the school were very understanding on that

Ultimately they want to know when it's gonna disappear, then it's, when are you gonna get better, in addition, how it potentially started? How is it sore? They are interested in whether it is painful or not. Probably that's about as far as it goes, when is it going to stop and how is it painful

Parental interpretation

they didn't fear for me put it that way.

I just think that the only potential thing that bothers them is that they just have natural feelings for me and they want me to be well, that's all and that potentially there's a little bit, the same way that I sometimes think about it, there's probably a little bit of anger somewhere that something's happened to their Dad and then leading on from the initial tension, anger, then there's their loving and kindness that they just want me to get better again.

so that there's no big spectre of fear in as much as, a dark shape of kidney disease is creeping into their life. It's kept away from them as purposely as possible.

I would find it very difficult to believe that they could find out anymore than they actually know that's the issue of it unless of course they suddenly became master medics themselves because as far as we told them in layman's terms we've given them as much information as they can, they can probably take in we haven't held anything back.

Appendix 14

Partner's transcript

Family 3 – interview with Partner

OK so it's the 28th Apriland interview with F3P and I'd just like to check firstly that you're quite happy that we proceed with the interview.

Yes, that's fine.

Thank you. As I say, it's fairly non-structured and it's whatever comes to mind really but erm... and there's no right or wrong answer so don't get worried. If you tell me first a little bit about your family – who's actually in your household.

Right, I've got my husband who's on haemodialysis and has been for as long as I can remember practically and then I've got an eight-year-old daughter.

And how long have you know about your husband's kidney problems?

Since the day I met him in 1983. At that point he was just on medication and he was working as a nursing auxiliary but ..

Is that where you met then, through work?

I'd come to do my training, yes. And so yes I mean he was quite open about it from day 1 I mean he was on meds and then obviously he got progressively worse, went on CAPD in 1984/85 – 85...

Just after you got married was that?

No we got married in 1987. So he was on CAPD up to 1986 and then he was having top-up haemo, got transplanted in 86, May 86, of which my flatmate died at the same time and had his kidney taken, the night F3Pt got his transplant so he probably sat next to the recipient of C's kidneys. *(Oh right.)* Very awkward time that was and erm so he lost that literally as we got married and the day before we got married he was rushed back up here and put on loads of frusemide and they took it out about two weeks after we got married.

Did you manage to honeymoon?

No we were [unclear] And then he was back on haemo in the hospital because we were renting and then we had a flat where it was one bedroom and there was no space and he got re-transplanted in 91 and while I was pregnant, he lost that kidney, so it's been very much a part of our lives.

And he's on haemo at home

Yes he's on haemo at home now. I was determined when we had the space that he was going to be at home. Best move ever. So, and you know it works fine.

It's part of your life.

I mean it's just that F3C's never know any different – she's never known him well, so.

And so even in terms of getting information about what was wrong with F3Pt's kidneys, I mean it's a bit of a while ago now and obviously you were both to a level at sort of nursing-type background so how did you get information? Did you go and look for it or was it given or?

F3Pt is the type of guy who likes to be in control. It's the only thing he feels he's in control of so most of the information I glean I glean via F3Pt and I know that sometimes it's not always right erm..

Like "I can drink 6 litres of fluid a day, dear, don't worry"?

Yes. So in fact we didn't actually have his proper diagnosis till... Do you know I can't even remember but I think it was after F3C was born and it was when he was coming home on haemo and I had much more contact with the unit than I had before that I was actually able to ask the questions saying I want

to know what it's called and you know so I could ask a lot more so it was only really when he was coming home as a haemo patient that I actually got a lot more information. Otherwise F3Pt tended to come to his clinic appointments on his own.

Is that because he didn't want you there?

He didn't want me there. It was the one thing that he could be in control of. He couldn't be in control of the thing that he was ill, but he could be in control of coming to the clinic and what information he imparted to the rest of the family.

Right, that's interesting it means he's in control, I mean I've known F3Pt since 88 perhaps a bit later, perhaps 89, but I've never met you before. I know I've had a period when I wasn't here but...

But that was him and I have to .. I mean the last time I came up to you was a year ago to when he was in to see the doctor because I insisted on coming but it causes too much hassle. And I just think fine, if that's what you want to do,

That's the way you want to deal with it.

Yes, that's fine. I mean I respect that that's how he feels. Yes, it's irritating, yes it's frustrating but it's not worth the fight about it. So, when it's really, really seriously I can always talk him round and I can come but he likes to... This is the one thing that's his and I don't come into that.

Interesting. But you feel if you like that you get an edited version. What about F3C? How do you tell her?

F3C from day 1 has just ... She just accepts the machine as part of F3Pt really. She knows that he can't do wee-wees, and that's how he has to get rid of his wee-wee through the machine. That's how we introduced it to her when she was really tiny and I mean she will obviously now talk about it as a haemodialysis machine obviously as she has got older but that is how we have always dealt with it so what I will say is that she has changed in the fact that she is more She doesn't like the machine so much these days because she realises that it does impede what we can do as a family. When she was younger she just accepted it, now she ... there's a little bit of resentment towards it. She knows it stops F3Pt from doing what he would like to do so she doesn't.... she will do as much as she wants, she'll want to stick his tape down and she'll want to put on gloves and she'll fiddle around with his gauze after he's gone on the machine but she's not really interested in the mechanics of it apart from "Oh Daddy", sometimes she wants to pull the blood back in the syringe but that's at her pace and I mean that could be once a month. Always when she's got friends round to tea and Daddy becomes a spectacle and we all have to come up and they sit on the bottom of the bed and they watch him go and And we always say to all our friends, you know her friends, the parents say, I mean all of them know now that he's on a machine and if it's dialysis night, or "plug-in night" as we call it you know the children just wander in and out. They're not fazed by the machine at all. The first time they were all really curious and they were fascinated to watch the blood go round but then it's just like "Oh he's up on the machine you, know where's his drink. So they're She accepts it, resents it, but isn't that keen to take a very active role whereas I know so children would be but she's just you know she'll run him up a drink and occasionally she might say, Oh can I stick your needles round or pull the blood back but not very often.

And what about ... I mean you say she understands that the machine is doing a job, getting rid of wee-wee effectively, does she know that her dad would die without it?

Yes, yes. Normally that conversation has come up when she's getting really cross about it. That's not how we introduced it at the beginning because I mean I am very very open with her and always have been and have always said that we're very lucky that we've got the machine and that without the machine Daddy wouldn't be here and we'd much rather have Daddy and a machine than not have Daddy at all. But that invariably comes up in the conversation when she's going "I hate dialysis" and then it will be "Look, without the machine, Daddy would be dead. There is no other option unless he gets another transplant and we are very lucky to have it and yes it is frustrating at times, but, you know that machine is there for a purpose".

And what about transplantation? Does she know, obviously she knows the word but have you talked to her about that at all?

She's seen programmes on it because obviously there's quite a few of them around and then she's sort of sat down with F3Pt sometimes to watch it but I don't know fully how much she really understands. She knows that you get a kidney from somebody else and of course she loves Casualty. Casualty is her absolutely all-time favourite programme and of course they have had transplantation on there in the last year and she was "Erm you put a kidney from a dead person in a live person". That bit horrified her. She can quite cope with a live-related but not with a dead and I said well Daddy's first two kidneys have come from dead people and she said "ooh" but she didn't really go into it. She just said "ooh".

Does she know that if he got a transplant the machine would possibly go?

To be honest know because we've not even been down that road because I don't want to raise her hopes. I mean F3Pt's been back on the list for the age of her.

So nearly 8 years.

Well more than eight years because he actually went on the list before I had her. But he didn't restart dialysis until just after she was born. So in fact it's 8½ nearly 9 years since he went back on. He went back on in the July before she was born.

And there's not been a peep.

Not a peep. Not even a hint. So I mean, why raise somebody's expectations when you know... I mean yeah we could get the call tomorrow and if we get the call tomorrow I'll deal with it but ...

Do you think she'll deal with it as well?

I think she'll be excited for him. I think she'll be really excited. I mean I talk to her about what happened when he had the transplant last time because the second one was really slow to get going. He was a month on the machine before he could go without the machine but that's as far as we've gone. We haven't gone any deeper. Because I, you know, rightly or wrongly I don't know but it's just that I don't want her hoping that whole time because we do enough of it for her. You know it I would love it at the age she's at that he got another transplant because she'd see him well. She'd see the fact that he could go out and do. And obviously he's getting long-term problems now from dialysis with being .. bone problems, joint problems.... He's definitely got some arterial disease going on, I mean his feet are as cold as ice. (Lovely.) And he's getting foot calluses and lots of other things happening. So and obviously without the minimum time dialysis continues those are probably going to still continue really.

How do you think dialysis affects the family?

[long pause]. It erm.. It probably, because she's never known any different from her point of view. I think if she had, she resents – I resent the machine, F3Pt resents the machine sometimes. The fact that we do home dialysis is that we do move it to suit ourselves, rightly or wrongly.

No, no. Far from it.

We want a life and therefore, if F3Pt wants to go out for a work do on a Friday night when he normally dialyses then we do an overnight. Then he can have a couple of beers and we get rid of them on the machine. So we do to a certain degree move it around where we can but we actually lead very busy lives and sometimes we're not able to be that flexible because we've got other things going on – meetings and bits. But I mean it does affect family, it affects family because F3C and I go to Abroad, F3Pt's family have to come and you know cover me when I go for those two weeks with F3C. I would love my family in Abroad to meet F3Pt. I'd love him to be able to go out there and he resents the fact not that we go but that he can't come with us. And even if we paid for dialysis out there he's still got a 12-hour flight you know and that's what we don't want to risk. There's times when you get really low and you go through a period when you think I hate this, I hate everything about it and then you bounce

up again and you think "no actually home dialysis is a lot better than hospital dialysis " and we've lost friends who have had transplants because obviously F3Pt was very active in the transplant games and we've lost friends who have had hearts and lungs and you know a good friend of F3Pt's they used to do the shop together for many years, when Alan died he was you know, it was his heart and there was no option. When it was failing he had to wait for another transplant or nothing and sadly he didn't get another transplant that time so at times like that you look back and thing well actually we're damn lucky we've got the machine and it's not the liver or something else that's going. You do try to stay updated but.. I mean F3Pt's gone through periods of depression and he's just come out of another quite long bout of it really. So I mean he's had two lots in the time that he's been on dialysis which since 83 is actually not bad going but the last period that he had he was the lowest that I've even seen him and that was hard. He didn't want to eat, didn't want to talk, and F3C found that difficult but he wasn't too bad with her – he would make an effort for her but he knew he didn't have to bother with me. (Right.) Typical. The inequities.

At least he does feel that he needs to make an effort.

Yes, I don't think he got... he got low but he didn't get so low that he was completely moribund so I got him up and that's when I came to see the doctor that time and I said "right, we've got to do something about this guy".

The doctor must know it's bad when you ... [laughs]. So F3C accepts F3Pt's kidney problems because she hasn't really got any choice I suppose. Does she know when he comes up to hospital and is she interested in the visits or?

She knows when he comes but no she's not interested. Typical 8-year-old.

Does she ever come up? Or wouldn't he bring her?

No no no no. He's brought her up. No

He'd prefer to bring her up than you?

Well no, normally it's because say we're covering childcare and he's got an appointment or he's coming up for something and then he would just bring her with him. Because I work Monday, Tuesday Wednesday and appointments of his tend to be Monday or Wednesday if it was holiday and he's still got an appointment he would keep it and he'd bring her with him. But I mean she doesn't come that often and obviously he's been in hospital since she was born when they took out his transplant when he had a nephrectomy and she's got vague memories of coming up when I'd come home from work, pick her up, bring her up when she was only toddling she was little

So she does remember

Yes. Coming up to see him on the ward and ..

Because he's not.. has he been in since then?

No, no.

It's pretty remarkably actually.

But you see she lives in a nursing family with hospitals and ... so she's.... she's not fazed by it at all.

So hospitals are almost part of not quite daily life but.

Yes, not I mean she sees them as exciting places and when she gets there she's bored. You know it's the idea of going, because my father's really unwell with two cancers and I take him regularly down to hospital and it's "I want to come with you and Granddad" and I'm saying "but you'll be bored when you get there because you'll just be sitting there waiting to go in" but she wants to. But fortunately we go when she's at school. So.

She's interested but not you know.

No, she'll know that he's coming up "oh is Daddy leaving early to go to the hospital?" or "Are you taking Daddy.." particularly because it usually affects her childcare arrangements.

Yes, that's what they're getting at.

You know I might be asking her childminder to have her that bit earlier so I can drop him up here on my way through to work and because she knows apparently that I can honestly say hand-on-heart I don't think I've ever heard her say to him "and how did you get on at the hospital".

Right, so it doesn't?

No, I don't think it would enter her head. Or maybe it does but she doesn't vocalise it.

But she connects the hospital and the kidney and the machine.

Yes, oh yes, I mean she's got no problems with knowing and like we were in Maidstone with a fishbone as a matter of fact a two weeks of ago and she said "Why don't you come here" for your hospital appointments" and Daddy said well, I've always been under Hospital and she said. "Oh. I was born here you know". And that's was it – the end of the conversation.

Did you get the fishbone out?

We did eventually but it took 40 minutes.

Oh dear. Poor thing.

Nearly made it to theatres. Me and the poor SHO, She's off mackerel now.

So what you do think bothers her the most?

I think that what bothers her most is that it will be interesting to see when you talk to her... as I perceive it it's the fact that she can't have quite as much freedom as she sees her friends having.

Freedom in what sense.

Freedom in the sense that if we wanted to go away for a week or a long weekend we could just go without...

"It's sunny today, let's go to..."

yes. Well we can go out for days but we just can't go for any length of time. You know even when we go down to.... my parents live in Whitstable, my best mate and obviously quite a few of my friends and my brother but when we go we only can go even if it's school holidays from a Wednesday to a Friday. Whereas I think she sometimes would like to go for the whole week. And I've said to her she could stay down there with my friend but she won't. She's very Doesn't like to be away from either of us and that definitely is probably one of the effects of dialysis is that she's a very confident little girl but she's very clingy to both of us.

Even in the respect of dropping her with your childminder?

No no I mean as in she doesn't like having nights away and things like that. Unless it's where it's just across the road or it's round at Grandma's but you know my parents, have always said "holiday time bring F3C down, let her stay and you come down on the Wednesday night" but she will not do it. It's being away and even abroad I had to ring F3Pt every day, morning and evening, for her to say good morning and good night. You know that's just always been there. Even when he goes away, if he goes to Cheltenham. I don't know. We've never had a conversation about why that's so important but she just wants to speak to her Daddy really. And whether that's part of dialysis or whether that's just part of daughter and father relationship I don't know but she's always wanted to do it and I mean the very

first time we went out abroad she took off when we came out of arrivals. If she could have flown she would have taken off there and then you know I mean suitcase and everything just got dumped she was just like "There's my Daddy" - boof, and she was off. So now, I mean she's very close to F3Pt and she's got closer as she's got older. When she was younger she was having to be very dependent on me. Even though F3Pt had her, because I used to work 1 weekend in two, but she was very dependent on me little but not now. She's very much Daddy's girl. Which is fine.

No it is but it's just well whether it would have happened anyway or whether it is?

Yes, don't know.

Well, never will, but... Interesting, interesting. Do you think her behaviour ever changes because of dialysis or ...?

That is probably one of the trickiest questions to ask me. Erm I probably expect too much of her and that's why I'm saying it's difficult. She's a very caring little girl and will always look out for others but I think she probably would have been like that despite dialysis. She's going through that horrible push-the-boundaries stage at the moment, delightful, and actually she's going through quite a selfish very insular stage and I've really had to sort of rein her in at the moment and therefore that's when we get a lot of the bad mouth about dialysis and life in general. "It's not fair", my favourite saying by F3C "It's not fair". I don't know. I actually can't answer that because I really do not know. At the times when she's really If something's come up and she can't go or we can't go I should say because obviously if she's going on her own it's not a problem then she's very, very resentful and she can be really quite a sulky little mare really. But you can normally talk her round and get her out of it. But you know the bottom lip comes out... but then F3Pt sulks so that's a family trait. They all do. You see the bottom lip come out with the hands. So I don't know.

Do the school say anything. I mean the school would know.

School thinks she is the wonder child. I mean I keep checking for her halo. The headmaster keeps telling me she's just such a wonderful child, your daughter" and I'm like "sorry? Are we talking about the right child her" but no she is a good kid. She is a very good kid. She's just pushing things at the moment but at school she's wonderful. She'll be the one to look out for the little ones. She'll be the first to put up her hand to help anybody else and she's in the top group you know. I mean they don't have to do a great deal with F3C.

But school obviously know about the ...

Yes, they know. I think they find it hard to believe because obviously F3Pt and I do quite a lot in the school you know and he looks so well he doesn't look how you would expect a renal patient to look and of course F3Pt puts up this wonderful façade for people which of course he's not like that at home but you know I think they find it very hard to believe he is as sick as he is really.

And do they have an awareness of if the transplant call came what that might mean.

No, I've never had a conversation with them about it. Because we don't believe it's ever going to happen so I've got to the point where it's there in the back and it's just like it's not going to happen.

Do you want it to happen.

I'd love it to happen. I would love it to happen. Even if it only lasted a year it would be a year of what is reasonable health and no machine. And I said to F3Pt right from day 1, you're off abroad with me mate. I don't care what it costs and if we have to take a loan, we're going, you know. Grab it while you can.

What do you think F3C wanted to know about F3Pt's kidney problems?

You'd have to ask her that one. I have always answered everything very openly and very honestly.

What sort of questions does she ask?

Oh sex, we've been down there but not about the kidneys but I mean anything as an example but she doesn't ask that much about his kidneys. Now maybe I haven't asked the right open questions with her. Maybe I haven't said is there anything about Daddy's illness you want to know? Because it just

Does she think you can't tell her.

[pause]. No I doubt whether she does because she knows I'm type of person

And you're a nurse

Yes, she knows I'm a nurse but she also knows that if I don't have the answer I'm the type of person I'll say. Look I don't have the answer but I'll go away and try to find out for you in as simplistic terms as I can find. I mean when we were doing sex we started off with various books and we did it at her pace. So no, no I don't think that I think she just sees it as part of normal life so it's not a huge, huge issue. It's a huge issue when it stops her from doing something or she can't... or Daddy's not well enough or something but otherwise no. Because you know we do go out. We go into Legoland. We have days out. We try to have the week away in Devon, like last year because we didn't do the nurse holiday I did the dialysis. She didn't like that particularly because obviously she's got to sit there the whole time he's on the machine but she know on the days that he wasn't on the machine we had a whale of a time so it worth the bit in the middle. And obviously she's older now. I think when she was little it would have been a worse nightmare but she knows that she can put her walkman on and she can take stuff with her trying to entertain a 3 or 4 year-old while he was on the was machine for that amount of time, about 5 hours. Would be horrendous.

Where do you think she gets her information from?

Every man. I don't think it's an, an exclusive, well my sister-in-law because, you know is a renal nurse, paed.

Oh right, she's the sister isn't she?

Yes. So probably between all of us really. So...And obviously from television of course. Not quite the perspective you would like to put on it sometimes but it's an opening for discussion isn't it and normally when they've had. I mean obviously they had transplants in Emmerdale – she loves Emmerdale so you know that came up a little bit but I'm not sure it's quite the right perspective but there we go.

Does she go to Sister-in-law without you knowing?

No I think I know. No I think Sister-in-law would tell us if she was asking questions. She might not tell us the content of the questions but... I'm very close to my sister in law and I think she would certainly saw oh F3C's been asking some awkward questions but you know but no. I don't think she does. I think it comes about just purely becauseF3Pt will go to Sister-in-law. He will definitely go to Sister-in-law because it's back to this control thing. Sister-in-law is that bit removed. He comes to me and then it's oh well you're the nurse, you think you know more than I do and he's got a real thing about this is the one thing that he has to be in charge of ... to the point I never fully set up the machine, ever. I line it, I can put it through the heat disinfect but he does the final bit and I've needled him, never. Assisted him but not needled him. You know and that's the one thing I mean if there's something he's not sure about he'll often go to Sister-in-law for something. He'll tell me about it afterward, " I've spoken to Sister-in-law ...[tape ends].

Tape 2 with F3P on April 28th and we just talking about where we think children get their information [laughs] and we've turned it round a bit. OK so he'll go to Sister-in-law and tell you afterwards. Something just crossed my mind there when you were talking about the machine and him always having to do the final bits. Do you think that's because I mean I know he's protective and if you like a control freak in that respect but it's his life.

Hmm. I don't question him about it. I don't net it. I just sit back and let him do it because he has always wanted to do it that way and that's just his bit. I mean we've had conversations in the past where he's said it's mine and so I've just "fine it's yours". I mean the problem would be if he was too unwell to do it but if he suddenly were I would be fiddle-faddling about in the last bit because I've never done that bit. There you go. We'd manage. He'd probably be able to talk you through it even if he couldn't do it.

If there was extra information available for F3C how do you think she'd like to get it? You know what would be most applicable to her.

Erm I don't think she..... At the age she's at now she reads beautifully and brilliantly but only yet what she wants to pick up as and when. Possibly a small leaflet with pictures and bits and pieces.

A video?

Possibly a video. Something that she hasn't got to work too hard at. She likes the idea of coming to the group very much so. So she's a very sociable child so she likes social interaction.

So possibly a group where children could mix and match and talk about, safely, what's happening at home but not wishing to exclude mum and dad but just somewhere where they can....

Her own peers, yes. Because I mean there is a real risk you know if F3Pt doesn't get another transplant that as she gets older I will have to lean on her more, or he will, or we will expect more of her and then your child comes into the caring role. Well so far she does not fit in to that category and she moans if I ask her to take a drink up. "It's your dad, and he can't come down and get one". But there is a real risk as she gets older that we could potentially lean on her more. But as I say, we haven't and we consciously have not done so, so far. There are probably other children that probably would be far more adept at doing things than her but she's you know would rather be downstairs with her music on or watching the telly than coming up, unless she's got a friend there then of course she's got a [unclear].

Would you be bothered if you had more information and that perhaps if you didn't have I use the word control but please don't take that in the wrong way control over it?

No...not at all. Not at all. Erm.... As I say we're as open with her as we can at the pace that she asks things. I mean yes you've got me thinking that maybe I should at least give her the opportunity. We've just made assumptions and that's made me think well actually perhaps I should sit down with her and say "Is there anything?", I mean I won't go rushing home tonight but at time when it presents itself. So no, F3C is well able and well vocal to say what she feels and what she wants and what she doesn't, so no.

Thank you. That's the end of my questions per se but I don't know whether you've got anything else that you want to say that you think might impinge or.?

No probably not. I mean I guess our circumstances might be different to others in the fact that I'm sure things would have been different had F3C had known F3Pt well.

Does she perceive him as unwell though, do you think?

I guess that because we've been so open and we do remind her that without the machine Daddy would not be here and he would be dead then yes, I think there's an element of that. The fact that he doesn't look unwell ...

That he works

That he works and all the rest of it you know there is a normality to our life but what she does see is a very tired man, you know, to the point that he'll go up, because his dialysis room is set up with a TV and video and his stereo and everything we used to have to be understand it was like "This is mummy's room, this is daddy's room and this my room". Now hold on a minute here that's mummy's and daddy's room here but you see he'll come in in the evening and he'll be shattered and he will just sleep up in the

dialysis room and of course by three or four o'clock in the morning he's up. So I mean she sees a man who is 9 times out of ten snoring his head off but not obviously at the weekend when they spend time together. So I think when she sees him like that she knows he's tired because of his kidneys, but it would be interesting, I don't know, I don't know what her perception would be of it because at the end of the day she has a fantastic social life and you know I'll get him on the machine and then I'll be whizzing her off here there and everywhere you know and then I'll leave here wherever I'm taking her and come back and ... so yes, her life continues. As I say it's just at times.

But do you think you've made a very conscious effort for that to happen.

I guess to a certain degree. I didn't want her ... Yes I probably have. I've always sort of made sure.. probably not because he's on the machine but because I think because she's an only child and I didn't want the only-child syndrome so I've always made sure she was very social. I've always got her going somewhere or people coming to us and I mean she has really resented the fact that we haven't had another child, right,

and does she know why that is?

Yes, and so does F3Pt and F3Pt has resented the fact that we haven't had another child and I've just said no, you know, I work, you work, I can't do it. There's got to be boundaries somewhere.

So it is because of work or is it because of kidney problems?

No, it's because of the dialysis machines. I couldn't. It's hard enough. I don't work full-time, well I do, I work full-time in a part-time post but I do that because I wanted to be a mummy on a Thursday and a Friday and obviously because of dialysis as well. Tuesday nights I don't get into bed until half-past one, two o'clock in the morning. I'm up at 6 and out the door again by seven. So to add another child into that equation was just horrific but she definitely does resent that. As she's got older now the idea of sharing with a sibling is not quite so lovely but you know even up to probably a year ago it was "It's not fair, I want a brother or a sister" and .. (*Has she got cousins?*) Yes, lots. Oh she's got her best friend because of my childminder's children. Kerry has been her best friend, there's 9 months between them, they go everywhere together and she's got her other best friend from school round the corner so..erm it's not quite the same as having a sibling to fight with at home and because I have always been very open and said I can't do it because of work and dialysis and everything else she has really resented that, but less so now.

OK, thank you very much.

You're very welcome.

Family 3 – partner

Uncertainty

I think she'll be excited for him. I think she'll be really excited. I mean I talk to her about what happened when he had the transplant last time because the second one was really slow to get going. He was a month on the machine before he could go without the machine but that's as far as we've gone. We haven't gone any deeper. Because I, you know, rightly or wrongly I don't know but it's just that I don't want her hoping that whole time because we do enough of it for her. You know it I would love it at the age she's at that he got another transplant because she'd see him well. She'd see the fact that he could go out and do.

Because we don't believe it's ever going to happen so I've got to the point where it's there in the back and it's just like it's not going to happen.

I'd love it to happen. I would love it to happen. Even if it only lasted a year it would be a year of what is reasonable health and no machine. And I said to F3Pt right from day 1, you're off abroad with me mate. I don't care what it costs and if we have to take a loan, we're going, you know. Grab it while you can.

Parental interpretation

To be honest no, because we've not even been down that road because I don't want to raise her hopes. I mean F3Pt's been back on the list for the age of her.

So F3C accepts F3Pt's kidney problems because she hasn't really got any choice I suppose.

I think that what bothers her most is that it will be interesting to see when you talk to her... as I perceive it it's the fact that she can't have quite as much freedom as she sees her friends having. Freedom in the sense that if we wanted to go away for a week or a long weekend we could just go without... Well we can go out for days but we just can't go for any length of time.

So no, no I don't think that, I think she just sees it as part of normal life so it's not a huge, huge issue. It's a huge issue when it stops her from doing something or she can't... or Daddy's not well enough. Because you know we do go out. We go into Legoland. We have days out. We try to have the week away in Devon, like last year because we didn't do the nurse holiday I did the dialysis. She didn't like that particularly because obviously she's got to sit there the whole time he's on the machine but she knows on the days that he wasn't on the machine we had a whale of a time so it's worth the bit in the middle. And obviously she's older now. I think when she was little it would have been a worse nightmare but she knows that she can put her walkman on and she can take stuff with her trying to entertain a 3 or 4 year-old while he was on the machine for that amount of time.

As I say we're as open with her as we can at the pace that she asks things. I mean yes you've got me thinking that maybe I should at least give her the opportunity. We've just made assumptions and that's made me think well actually perhaps I should sit down with her and say "Is there anything?"

Information – adults

F3Pt is the type of guy who likes to be in control. It's the only thing he feels he's in control of so most of the information I glean I glean via F3Pt and I know that sometimes it's not always right.

He didn't want me there. It was the one thing that he could be in control of. He couldn't be in control of the thing that he was ill, but he could be in control of coming to the clinic and what information he imparted to the rest of the family.

I mean I respect that that's how he feels. Yes, it's irritating, yes it's frustrating but it's not worth the fight about it. So, when it's really, really seriously I can always talk him round and I can come but he likes to... This is the one thing that's his and I don't come into that.

Information – child

I mean it's just that F3C's never know any different – she's never known him well, so.

F3C from day 1 has just, she just accepts the machine as part of F3Pt really. She knows that he can't do wee-wees, and that's how he has to get rid of his wee-wee through the machine. That's how we

introduced it to her when she was really tiny and I mean she will obviously now talk about it as a haemodialysis machine obviously as she has got older but that is how we have always dealt with it so

She's seen programmes on it because obviously there's quite a few of them around and then she's sort of sat down with F3Pt sometimes to watch it but I don't know fully how much she really understands. She knows that you get a kidney from somebody else and of course she loves Casualty, they have had transplantation on there in the last year and she was "Erm you put a kidney from a dead person in a live person". That bit horrified her. She can quite cope with a live-related but not with a dead and I said well Daddy's first two kidneys have come from dead people and she said "ooh" but she didn't really go into it. She just said "ooh".

she doesn't ask that much about his kidneys. Now maybe I haven't asked the right open questions with her. Maybe I haven't said is there anything about Daddy's illness you want to know?

Yes, she knows I'm a nurse but she also knows that if I don't have the answer I'm the type of person I'll say. Look I don't have the answer but I'll go away and try to find out for you in as simplistic terms as I can find.

I guess that because we've been so open and we do remind her that without the machine Daddy would not be here and he would be dead.

Family life

Normally that conversation has come up when she's getting really cross about it. That's not how we introduced it at the beginning because I mean I am very, very open with her and always have been and have always said that we're very lucky that we've got the machine and that without the machine Daddy wouldn't be here and we'd much rather have Daddy and a machine than not have Daddy at all. But that invariably comes up in the conversation when she's going "I hate dialysis" and then it will be "Look, without the machine, Daddy would be dead. There is no other option unless he gets another transplant and we are very lucky to have it and yes it is frustrating at times, but, you know that machine is there for a purpose".

She doesn't like the machine so much these days because she realises that it does impede what we can do as a family. When she was younger she just accepted it, now she ... there's a little bit of resentment towards it. She knows it stops F3Pt from doing what he would like to do

when she's got friends round to tea and Daddy becomes a spectacle and we all have to come up and they sit on the bottom of the bed and they watch him go and we always say to all our friends, her friends, the parents, I mean all of them know now that he's on a machine and if it's dialysis night, or "plug-in night" as we call it you know the children just wander in and out. They're not fazed by the machine at all. The first time they were all really curious and they were fascinated to watch the blood go round.

She accepts it, resents it, but isn't that keen to take a very active role whereas I know some children would be

We want a life and therefore, if F3Pt wants to go out for a work do on a Friday night when he normally dialyses then we do an overnight. Then he can have a couple of beers and we get rid of them on the machine. So we do to a certain degree move it around where we can but we actually lead very busy lives and sometimes we're not able to be that flexible because we've got other things going on – meetings and bits. But I mean it does affect family, it affects family because F3C and I go abroad, F3Pt's family have to come and you know cover me when I go for those two weeks with F3C. I would love my family abroad to meet F3Pt. I'd love him to be able to go out there and he resents the fact not that we go but that he can't come with us. And even if we paid for dialysis out there he's still got a long flight you know and that's what we don't want to risk. There's times when you get really low and you go through a period when you think I hate this, I hate everything about it and then you bounce up again and you think "no actually home dialysis is a lot better than hospital dialysis "

so at times like that you look back and think well actually we're damn lucky we've got the machine and it's not the liver or something else that's going.

gone through periods of depression and he's just come out of another quite long bout

she lives in a nursing family with hospitals so she's, she's not fazed by it at all.

She'll know that he's coming up "oh is Daddy leaving early to go to the hospital?" or "Are you taking Daddy." particularly because it usually affects her childcare arrangements.

I probably expect too much of her and that's why I'm saying it's difficult. She's a very caring little girl and will always look out for others but I think she probably would have been like that despite dialysis.

"It's not fair", my favourite saying by F3C "It's not fair". I actually can't answer that because I really do not know. If something's come up and she can't go or we can't go I should say because obviously if she's going on her own it's not a problem then she's very, very resentful, but you can normally talk her round and get her out of it.

The fact that he doesn't look unwell ... That he works and all the rest of it you know there is a normality to our life but what she does see is a very tired man, to the point that he'll go up, because his dialysis room is set up with a TV and video and his stereo and everything we used to have to be understand it was like "This is mummy's room, this is daddy's room and this my room". Now hold on a minute here that's mummy's and daddy's room here but you see he'll come in, in the evening and he'll be shattered and he will just sleep up in the dialysis room and of course by three or four o'clock in the morning he's up. So I mean she sees a man who is 9 times out of ten snoring his head off but not obviously at the weekend when they spend time together. So I think when she sees him like that she knows he's tired because of his kidneys, but it would be interesting, I don't know, I don't know what her perception would be of it because at the end of the day she has a fantastic social life and you know I'll get him on the machine and then I'll be wizzing her off here there and everywhere you know and then I'll leave here wherever I'm taking her and come back and ... so yes, her life continues.

I've always sort of made sure, probably not because he's on the machine but because I think because she's an only child and I didn't want the only-child syndrome so I've always made sure she was very social. I've always got her going somewhere or people coming to us and I mean she has really resented the fact that we haven't had another child, right,

Yes, and so does F3Pt and F3Pt has resented the fact that we haven't had another child and I've just said no, you know, I work, you work, I can't do it. There's got to be boundaries somewhere. No, it's because of the dialysis machines. I couldn't. It's hard enough. I don't work full-time, well I do, I work full-time in a part-time post but I do that because I wanted to be a mummy on a Thursday and a Friday and obviously because of dialysis as well. So to add another child into that equation was just horrific but she definitely does resent that. As she's got older now the idea of sharing with a sibling is not quite so lovely but you know even up to probably a year ago it was "It's not fair, I want a brother or a sister"

it's not quite the same as having a sibling to fight with at home and because I have always been very open and said I can't do it because of work and dialysis and everything else she has really resented that, but less so now.

I think they find it hard to believe because obviously F3Pt and I do quite a lot in the school you know and he looks so well he doesn't look how you would expect a renal patient to look and of course F3Pt puts up this wonderful façade for people which of course he's not like that at home but you know I think they find it very hard to believe he is as sick as he is really.

It probably, because she's never known any different from her point of view. I think if she had, she resents – I resent the machine, F3Pt resents the machine sometimes. The fact that we do home dialysis is that we do move it to suit ourselves, rightly or wrongly.

Security

Doesn't like to be away from either of us and that definitely is probably one of the effects of dialysis is that she's a very confident little girl but she's very clingy to both of us.

No no I mean as in she doesn't like having nights away and things like that. Unless it's where it's just across the road or it's round at Grandma's. It's being away and even abroad I had to ring F3Pt every

day, morning and evening, for her to say good morning and good night. You know that's just always been there. Even when he goes away, I don't know. We've never had a conversation about why that's so important but she just wants to speak to her Daddy really. And whether that's part of dialysis or whether that's just part of daughter and father relationship I don't know but she's always wanted to do it and I mean the very first time we went abroad she took off when we came out of arrivals. If she could have flown she would have taken off there and then you know I mean suitcase and everything just got dumped she was just like "There's my Daddy" - boof, and she was off. So now, I mean she's very close to F3Pt and she's got closer as she's got older. When she was younger she was having to be very dependent on me. Even though F3Pt had her, because I used to work 1 weekend in two, but she was very dependent on me little but not now. She's very much Daddy's girl. Which is fine.

Caring role

I mean there is a real risk you know if F3Pt doesn't get another transplant that as she gets older I will have to lean on her more, or he will, or we will expect more of her and then your child comes into the caring role. Well so far she does not fit in to that category and she moans if I ask her to take a drink up. But there is a real risk as she gets older that we could potentially lean on her more. But as I say, we haven't and we consciously have not done so so far.

Appendix 15

Amalgamation of significant statements

Parental interpretation - amalgamation

Family 1

F1C's earliest memory is F1Pt having to go to hospital in a hurry in an ambulance and I was chasing in the car because there wasn't enough room ...in the same ambulance. So F1C has lived a life which has always been on the assumption that F1Pt is not very well and is getting worse.

he used to be very worried about F1Pt going onto dialysis because he thought all these tubes - and it looks a bit like Casualty on a bad day - were serious and the number of tubes were a kind of mental score card as to how seriously ill F1Pt is. And of course she doesn't have any tubes any more - she just comes up here and most of the time he thinks about her being weighed and it's just a routine check, so as far as he's concerned I think F1Pt's attendance at hospital these days is a positive whereas it used to be a negative. Maybe I'm misjudging; maybe you should have this interview with F1C actually.

If you can do that I think it might be an eye-opener because our interpretation of what we think he thinks is maybe wholly erroneous.

Even at the time of transplant. That was when he got worried about tubes. He couldn't distinguish really... he hadn't got the technology or the technological understanding to understand whether this was different or the same as dialysis. I think it was difficult for him to understand why mother was getting apparently sicker when she was supposed to be getting better. So it's been quite challenging for him. And me.

I was going to donate a kidney, how he could have dealt with both parents being ill at the same time I don't know but it was getting so crucial as F1Pt was obviously deteriorating under the dialysis conditions that something had to be done so even at the risk of F1C's discomfort and thus my discomfort was the thought that F1Pt was going to deteriorate further.... we've just come back from a weeks' holiday and F1Pt's running out of steam and I think that that was worrying for all of us.

I think that F1C is an inveterate diplomat and he will tell you what he thinks you want to hear, I fear.

Well, it's also second-guessing what he thinks and knows which may be difficult to determine you may find.

So I don't think you can ever get inside somebody else's head. You can know them pretty well but I think there's always a little space that's private so he does have anxieties about that

Family 2

F2C1, yes I'm just keeping a low profile on that one at the moment, purely because obviously circumstances - he's going to go to University and he don't want hassle with me. I think he's got a fairly good idea that it's a 50-50 chance that he could have it.

They never saw me on haemodialysis because we felt that possibly could freak them out. Not because of seeing me but because of seeing everybody else. I mean the Unit, is a big, big unit and there are lots of people there - there's lots of elderly people there and there's lots of people there that are not very well. So we sort of thought you know with all the blood moving around etc. and plus seeing unwell people they're minds might get on overtime and start thinking well, you know, my dad could get like that. So whilst I was I sort of remained fairly healthy whilst I was on dialysis. So we left that one. We often thought about it, doing it, but you know just to actually get them used to the idea, but peritoneal dialysis wasn't a problem. They was fascinated by the tubes and so we didn't have a problem explaining it and showing them all that and we certainly explained how that sort of side of it worked.

I suppose every age... you look at a child... every age has got a different criteria. I mean going backwards if I look at F2C1 I mean he's coming up to adult. Well he is an adult but he's looking at university now is that the time I mean I'm talking about the kidney disease that I've got, polycystic kidneys, adult polycystic kidneys and it shouldn't affect him until 40,50 when he you know could be later. Erm so really does he need to know? I suppose he needs to have an idea but then... I think possibly 18-20 is possibly the right age that he should be encouraged to know what's going in his life.

I mean as you say he then becomes a responsible adult looking after his own life and I think anything before 18 I think you don't want to burden them with something and worry about it purely because of .. I think their life is so difficult as it is what with different examinations

but over all, I think if I look at it, I don't believe they've suffered that, well I don't believe they've suffered that badly. No, not at all. Purely because I think I've probably been I've been very, very fortunate.

knew dialysis was imminent it came up on his GCSEs, coursework, and they were going to show them films. Then I thought well it'll probably be a film out the ark with an old machine, you know these school films, so I had to phone up and stop him watching it at school.

I thought I don't want him to learn about it at school, he might burst into. You don't know and it could be frightening to suddenly show somebody on this old-fashioned machine so I told the school I would sit and go through it with him myself, which is what I did and that's how I talked it all through with F2C1. We just really I had the book and we went through it together

It's only F2C3 when he said that to me. It shocked me that he didn't realise now that that kidney was working and that was a good year down the line. And I was taken aback by that one. That's the only thing. I think the rest are pretty clued up. But he didn't go for that long, we were so lucky that he wasn't on dialysis for very long .

lucky if it came up in one of his GCSE questions about the diet because I thought no one knew more than him. They've all been aware of F2Pt's diet restrictions because the middle one gave up chocolate with F2Pt. You don't realise what they're taking in.

Obviously F2C1 I thought because he's older and he's very sensitive and very close to F2Pt I think I thought it would bother him that he might the prospect of him having it. Seeing F2Pt so ill but his attitude was, "I want to find out straight away - I want to know", but it's me holding back saying, "No, do your A-levels, then you can assess it."

F2C2 is thinking, "Oh it's cool - I wouldn't want a transplant but I wouldn't mind you know having a go at it," because he's so naïve.

F2C3 would worry terribly but he's too young and I think it washes over his head at the moment, and yet he did say to me today, going home in the car, he said, "A lot of things have happened in our family, more than other families sometimes", but he did list other things like we had a burglary yes he did say the transplant was the first thing he said.

he had six operations, or 5 operations in 6 months, something like that. It was all sort of one a few weeks after another so it all was a bit of turmoil for them but they certainly did come up and see F2Pt. I tended to leave it till he was a bit better and I took one at a time, I never brought them all up together because of a) the other patients and b) you know what children are like – have they got a cold, haven't they? You know you can't, you've got to make sure they're healthy. But F2C1 came up a lot obviously by himself.

they wouldn't want me to dwell, I don't think so too much on the down side but I'll always make them aware, especially when it's things this could happen, if it's very likely to happen.

I feel I told them as much as they really need to know. They do know a lot of the down side, I don't know but I feel that I don't want it to take over their lives and to be worrying. They've got enough little worries as they go along with the pressure I see children under at school. I feel you can do with one less, you know and even with F2C1 I feel that a bit I think. He's got so much pressure at the moment. Maybe next year or so, he can find out then if he wants to. That's his choice, I'm leaving that up to him but obviously we'll be there right next to him if he does decide to do that, and he's the spitting image of F2Pt so I'm pretty certain, but I don't know, it's horrible thing to say but you know I look at his tummy and I think it's slightly I don't want to say that but I've sort of always got that in the back of my mind.

I thought if they'd seen that they would have really worried. And I'm saying "Dad's tired, he's had enough now", they couldn't always see it. "Why can't you play football now" and you know if F2Pt gets irritable,

Family 3

I'm not too sure I think if we sat down, the thing is we've got to the stage I don't know whether lets say bore her or scare her I think we'll wait for her to ask the questions I think she's one of these people, child who'll take a lot on and I think if we sat down unless she asks about it I think she'll take a lot on, personally, I don't know

I suppose I must say I would be quite fascinated to hear what F3C, well what F3C does actually say because I'm sure they'd be quite a lot we don't know, just how she feels in herself, who she's actually spoken to what her fears are, if there's any fears what her concerns are, you know and generally is she happy you know. I suppose the other thing is now, does she think it is holding her back, I know she's at a young age but I think kids today they mature so young.

you look tired Daddy and things like that but she takes it to heart though she really does take it a bit, sometimes I worry that she's taking too much on even though we don't tell her actually half so much about it but I think she's the sort of person could be interesting she might say to F3C, err F3P a bit more than that I am sure they do talk more about it what they'll do, what she'll do one day

I think she has spoken to her class a bit about it, I think one of her books, her earlier books was about Daddy and being on dialysis so, but I don't think she scared or anything

I doubt it would be too much for her but she's, school it's so important, work at school, I think for me the concern is that she takes it on board and she starts worrying about it unnecessary and it starts interfering with work, well with school, her activities, life in general, but as I said, every time she asks something we actually give her an answer straight away, and I think if it was worrying her she would ask us if there was a question she didn't know, or she'd tell the childminder if it was that bad, like for instance the childminder, the childminder hears her talking to us, to her child about dialysis, the childminder would let us know so every subject we feel we need to actually explore we'll bring it, we'll bring it into conversation

well I'd be quite surprised if there was ever a question she felt she couldn't ask us you know about, very surprised but then you don't know, you don't know it depends how she's feeling

I think if she's getting concerned we will know about it, because I think she will ask to speak to someone

To be honest no, because we've not even been down that road because I don't want to raise her hopes. I mean F3Pt's been back on the list for the age of her.

So F3C accepts F3Pt's kidney problems because she hasn't really got any choice I suppose.

I think that what bothers her most is and that it will be interesting to see when you talk to her... as I perceive it it's the fact that she can't have quite as much freedom as she sees her friends having. Freedom in the sense that if we wanted to go away for a week or a long weekend we could just go without... Well we can go out for days but we just can't go for any length of time.

So no, no I don't think that, I think she just sees it as part of normal life so it's not a huge, huge issue. It's a huge issue when it stops her from doing something or she can't... or Daddy's not well enough. Because you know we do go out. We go into Legoland. We have days out. We try to have the week away in Devon, like last year because we didn't do the nurse holiday I did the dialysis. She didn't like that particularly because obviously she's got to sit there the whole time he's on the machine but she know on the days that he wasn't on the machine we had a whale of a time so it worth the bit in the middle. And obviously she's older now. I think when she was little it would have been a worse nightmare but she knows that she can put her walkman on and she can take stuff with her trying to entertain a 3 or 4 year-old while he was on the was machine for that amount of time

As I say we're as open with her as we can at the pace that she asks things. I mean yes you've got me thinking that maybe I should at least give her the opportunity. We've just made assumptions and that's made me think well actually perhaps I should sit down with her and say "Is there anything?"

Family 4

They come up when I had my transplant but when I've been ill, like I've had a couple of infections and things I've been in they didn't come up. I think they come up once when I was better and ready to come home, that day I was coming home, but apart from that. To be honest with you I don't like them up here seeing me ill and when there's other people in there ill you know, it's a bit harrowing on them to be honest with you. When you see people in with tubes hanging out and whatever. No I've said to F4P, "Don't fetch them up here". I'd prefer them not to, to be honest with you.

I think the only thing that really bothered them is when they saw me ill, they did see me looking quite sort of.

after when I've had like infections and that. A couple of times I've had to come in and I've looked quite rough and I think they worried then. I'd say that was the only thing that worried them when I actually come into hospital when I'm not well.

I suppose really all they want to know is, "am I going to be all right?" That would be their main worry, I would have thought.

I think that's the only thing they'd sort of want to know, you know, as long as Daddy's going to be all right that's the main thing. I don't think they are that interested in anything else. I mean what else is there to be interested in for the children, thinking about it?

the thing we've talked about before, "Is it hereditary?" and things like that. I wouldn't want them to think they could get it and then start worrying about this, that and the other. I suppose I wouldn't want them to know really too much and unless it possibly did happen.

Well, in case it worried them really. I wouldn't want them to really be worried, saying, "You could die", or "You could you know" Not for a child. Unless. I would deal with that if it happened. I think she did say it could be.

Family 5

they didn't fear for me put it that way.

I just think that the only potential thing that bothers them is that they just have natural feelings for me and they want me to be well, that's all and that potentially there's a little bit, the same way that I sometimes think about it, there's probably a little bit of anger somewhere that something's happened to their Dad and then leading on from the initial tension, anger, then there's their loving and kindness that they just want me to get better again. so that there's no big spectre of fear in as much as, a dark shape of kidney disease is creeping into their life. It's kept away from them as purposely as possible.

I would find it very difficult to believe that they could find out anymore than they actually know that's the issue of it unless of course they suddenly became master medics themselves because as far as we told them in layman's terms we've given them as much information as they can, they can probably take in we haven't held anything back.

Family 6

Well, exactly yes. I mean you know ... she's pretty short but then that's part of it and he knows it. I don't think he takes it to heart and he doesn't feel, you know like it's his fault. I think he just realises that Mummy is tired just like we all get, you know the pair of us. It just goes over my head.

I think it's better for her to see him than not because it's scarier I think not to see her. Because he's a 9-year-old boy and you know one minute your mum's here and the next minute she's not, the imagination just takes over doesn't it, so it's better just to see you and then you know so you can sleep at night or, you know, be happy. Know that she's still... nothing wrong so.

But apart from that, no not really. He's very outgoing still. It hasn't affected him at all in his, what do you call it, psychological development.

Sometimes when F6Pt's tired, I think, and he wants to go out. Like after school with some of his friends and like the mothers get together and go out. F6Pt can't always make that and I think that might hurt him. On a purely selfish level. But then you know 10 minutes later once he's had a bit of a tantrum it's fine so, I don't really think he seems upset about anything, really, He hasn't voiced anything as it were,

I don't know. Everything, or nothing. It's you know... I don't know really. I suppose he wants to know everything but then I don't know. How do I get inside a 9-year-old's head? So, I think he just wants to know his mother's going to be all right. At the end of the day, you have the bare bones later, afterwards you know explain everything so.. but I don't knowHe hasn't said that he wants to know more. I don't know

I don't know how he feels. Maybe. I think there might be times when he does. I think. Sometime I think he's only nine.

It's just he keeps worrying he takes it a little bit to heart. I just think, I don't know, whether he's building something up in years to come but it hasn't affected him at all he's still the same happy little boy he's always been.

Appendix 16

Focus group transcript

Focus Group 3 – 11.09.04

F – Right, well first of all thank you very much for all coming and giving up some of your Saturday morning. F3C has already had a busy morning cos she has been swimming. Perhaps we should all introduce ourselves first. Do you think that would be a good thing? My name is Fran and it is my fault that you are all here really because I wanted to talk to you as well as having talked to your parents because I wanted to talk to the experts but I will tell you a bit more about that later, and you are.....

F7C!

F – You're F7C!

F2C3.

I'm F2C2!

F3C!

Me – and my name is Melinda.

F – okay. Well who goes with who?

Me – Now we might just tell by..... but the thing is I don't know I don't know if is on the way but Fran does. Do any of you know each other at all? Have you ever met up with ach other?

F2C2 – He's my brother.

Me – You know each other, okay, okay! So you have met each other a few times then.....

F2C2 – Yeah!

F – and F3C is even more special because she is the only girl in the whole project. Everybody else seems to have had boys so you're really, really special F3C! How old are you F3C?

F3C – 8!

F – You're 8! F2C2?

F2C2 – I think I am 12. No, I am 12!

F – You're 12!

Me – Does that mean you're just 12 or nearly 13?

F2C2 – No, umm, I was 12 in umm ,early January so I'm like 12 ½.

Me – Yeah, don't forget the half, that's an important half. When are you 9 F3C?

F3C – November!

F2C3 – I'm about 10 ½ in late December.

F – Oh, so you are a Christmas baby?

F2C3 – Umm, no, I was born on New Year's Eve.

F – Okay so you missed all the celebrations... and how old are you F7C?

F7C – 8!

F – 8! Okay. Right as I said, thank you very much for coming and we wanted to talk to you the experts, cos do you know what I do for my job?

F7C – Talking to children?

F – I don't usually talk to the children which is why this is a bit different. Melinda does lots of talking to children.

F7C – Talk to people or.

F – Yeah I talk to people who know that they have got something wrong with their kidneys but who haven't actually had to have anything done about it like your mum's had a transplant hasn't she F7C, and you dad's had a transplant and your dad's on dialysis so I talk to people who don't really know anything about transplants or about dialysis and some of the people I talk to are quite old but some are quite young and some of them have children and some of them have sort of said to me well, what do we tell the children? and nobody really knows what to tell the children or how to tell the children so Melinda and I thought it might be quite a good idea if, after speaking to your parents and sort of finding out how they went about things or how they felt about things, that we actually spoke to, the experts, on what you children know or what you want to know or what you think is good about it, bad about it, nice about it, horrible about it, all those sort of things and we don't just have to do talking, what we have done before.... Oh as I say I have forgotten the play dough and I am really sorry about that because some people have done some nice models for us and things, umm, we can do some drawing or we could write a story or whether you have got anything to say that you want to, you know, you think might be important for us that if there was, say, one thing, that if I was talking to a mum or a dad, that you could really, really make sure that they tell their child this or that or whatever whatever because you're the experts, you're the people who have been there. I have talked to a lot of people but I haven't got kidney problems. What do you think? Does it sound like a reasonably idea to talk to the experts?

F7C – Yeah.

F – Yeah?

F7C – Yeah.

F – So have you got anything that you think I might need to know?

Me – Actually I just wondered how you became the experts cos I know you live in a family where you know either your mum or your dad had come to hospital and had some help with their kidneys but how did you find out about what was happening to your mum or to your dad and how did you learn about it, who sort of told you stuff. How did you find out?

F2C2 – My dad told me.

Me- Your dad told you. Did he talk to you both together or separately?

F2C2 – No, umm I think he talked to us separately like different times.....

F2C3 – Yeah cos like when he was in hospital we went up on different days...

Me – Was that your choice or just how it sort of happened?

F2C2 - I couldn't go because I was on a school trip for, like, a week.

F – Is that when he had the transplant?

F2C2 – Yeah, and when I came home I had a cold so I couldn't visit him.

F – Right! But before that had anything happened that they talked about with you?

F2C2 – Umm yeah, everything!

F – laughs. Everything! Right, okay! Like what?

F2C2 – Umm, like how dialysis works and stuff like that.....

F – uuh huh!

F2C3 – And like if anything is going to happen. (*Right!*) And umm, I'm not sure!

Me – Did your dad know when he was going to have the transplant or did he, like, just come back from a phone call and say “ I’m going in today for a transplant?”

F2C2 – Umm, yeah!

Me – It was just sudden?

F2C2 – Yeah, we wasn't expecting it!

Me – Right!

F – Well obviously not because you wouldn't have been on a school trip if you had been expecting it I suppose?

Me – Do you know how long your dad had been waiting to have one?

F2C3 – Umm, a few months.....

F2C2 - about 6 months I think. The waiting list was about 2 years... the average is about 2 years I think!

Me – So you heard when you came back from your school trip.....

F2C2 - No umm, because the night my dad got the phone call I was just about to leave for the school trip, umm, it was about, it was about 8, 9 and I was going to go.... and so I had to go around to a friends so I slept over there the night.

F – I wonder what it felt like when you heard that the phone call had come through?

F2C3 – He was just happy.

F – You were all happy, your dad was happy?

Me – Well, he had been waiting 6 months and you think he might be waiting up to 2 years, as soon as you get that phone call it must be very special.

F- What about you F3C, what's your story?

F3C – Well I don't actually remember when I actually got told about, I think I was really little I think. My mum just explained it to me and I was just... and every night I used to watch him on the machine and everything....

F – Do you want to tell the others what your dad does at home because I think they might not know.

F3C – Well he just umm... well he's got those lumps on his arms.....(*Yeah*) and he puts some needles in them and attaches the tubes and then attach it to the machine. He sort of then sets the machine up on different things.

F – Okay, cos I think your dad had a different type of dialysis, didn't he?

F2C2 – He had like a tube from his stomach, to drain the blood or something.....

F2C3 - then we had to drain it out in the bath.

F – Did you, so did that mean you didn't have any baths?

F2C3 – No cos umm my dad took it out cos he only needed it at night. *(Right!)* and then we had to have our baths and showers in the day but.....

F2C2 - like my mum sterilised it to get rid of all the... I don't know what it is but.....

F – Okay, so your dad has a special machine at home doesn't he, for cleaning the blood, a bit different to the one your dad has? What about your mum F7C?

F7C – Well, I don't really know a lot of it cos I wasn't even born. *(Right)* don't really know a lot.

F – But what do you know?

Me – Have you ever been at the hospital with your mum?

F7C – Umm.... Once or twice!

Me – You have, okay! So you have seen her coming into the hospital and maybe chatting to a nurse or a doctor?

F7C – Hesitates..... well, my dad picked me up from school and he told me the bad news and um a bit sad and umm That your mum might not be home because she is going to go to the hospital cos her kidney has gone a bit bad and.... can't really remember everything.

F – I think your mum's kidney is quite special isn't it?

F7C – Cos it came from my grandma's...Yeah.

Me – I can imagine that was a hard day for you getting picked up by your dad and being told that your mum might not be at home today cos she is not too well and she needs to go to hospital, so what did you do when you heard that?

F7C – I cried!

Me – Aah! It is upsetting to hear that, and did you have a chance to get to go in and visit your mum?

F7C – Yes! I brought her in some biscuits and stuff like that.

Me – and that always helps.... She must have been pleased to see you and the biscuits. Laughs.

F7C – I brought her favourites as well.

Me - Laughs. Oh did you!

F – Which are those?

F7C – Umm, chocolate digestives.

F – Chocolate digestives! Whoo!!

Me – and then what happened after that.

F7C – She came out and.....

Me – So it wasn't so bad after all?

F – And that was only when you were in Year 1 or 2?

F7C – Yeah, Year 1 or reception, I was quite little. 5 or 6.

Me – and before that you didn't really know anything much, no? Okay, thank you! You have all had sort of different experiences and named certain things at certain times. I wondered if you wanted to know, if you had questions about what was happening to your mum or to your dad, who would you ask? Would it be someone at home, would it be someone at the hospital, would it be someone at school.

F2C3 – My dad.

Me – You'd ask you dad

F2C3 – Or my mum, anyone really.

Me- And have there been, sort of, questions that you have wanted to know about?

F2C3 – Yeah like, when my dad was on, like, dialysis I asked him what it done and stuff like that!

F – Was that the dialysis at home.

F2C3 – Err yeah!

Me – Good. I think it is quite important to know what he is doing and why really! He is doing something that's a bit different at home than people would normally do.

F2C3 – Yeah!

Me – Come to think of it, what other questions you might have.... The question I would have had, does it hurt cos I think it might hurt a bit. Did you ever ask him that?

F2C3 – No!

Me – What other things do you like to ask? Hard to think back isn't it because you probably asked all those questions a long time ago.

F – Did you ask questions F3C? Are you an expert in setting that machine up?

F3C – No, not yet! My mum tried to teach me but I think I did ask him, I sometimes asked him cos when he puts the needle in, the blood comes out and I had to ask him does it really hurt.

F – What does he say?

F3C - Well he says it is sore sometimes but it depends what happens.

F – Right.... and what about with friends and people, do you talk to these people about if your mum and dad might be seen perhaps as a bit different?

F3C – Well sometimes I've got close friends when they come to my house like, umm, they know about it already as we have told them but sometimes... sometimes we don't know what their mums want us to tell them about it so we have just have to sort of not let them in that room.

F – Right, so you have got a special room, as it was, a dialysis room.

F3C – Yes!

F – Did you have that at home you two?

F2C2 – No I think.... Ma - no, it was all kept in and covered in our bathroom and in our mum and dad's bedroom and when like our friends come around we have to shut the doors. But like a lot of our friends were in the area and like every one of my friends cos I got like quite a lot of friends and they all came around, a lot of them came round and like my dad got a phone call for the transplant then... they all knew.

F – What about you F7C, do your friends know?

F7C – No! They probably don't remember. I remember! She takes tablets and my dad has to pick me up when I go to school but umm, I know!

Me – Do you reckon it helps having friends who know or do you think that's not so important?

F2C2 – Well it is important, like I haven't ever come across it yet but I might do later on but like if you ever need to talk to him or something at least you know you have got in, lets say, you are at school and you can't actually talk to your mum or dad because they are at work at the moment, like you have actually some people you can talk to.

Me – Yeah, okay. I agree with that.

F3C – Like when you're at school and your mum and dad are at work you can talk to.... I have only told a couple of my friends, I haven't told all of them.

F – Perhaps because they are special friends. Do your teachers know?

FC3 – Yeah, most of my teachers and my Head Teacher.

F2C3 – My Head Teacher knows and when my dad had it the teacher I had then knew about it. (*Right!*) I'm not sure about the Teacher I have got now. (*Right!*)- The teacher I had last year, I don't think she knew.

F – Right! Okay, what about you F7C?

F7C – In Year 1 I had Miss, that was when it was happening. None of the other Teachers knew.

F – But that Teacher knew?

F7C – Yeah.

Me - And did you ever want to tell any of your friends or did you just think it was it just too hard for them to understand?

F7C – Too hard to understand....

Me – I also think it is quite hard to explain to them about either dialysis or about having a transplant. I think it is really complicated isn't it. You have to ask your dad what the dialysis is for and you have asked your dad and found out things from talking to your dad as well. It is actually really hard to sort of know how to explain it to somebody in a way that they can remember cos its not something that you talk about everyday is it, its not like everyday stuff that people would understand and be able to talk about? It is quite hard telling friends..... it would be a quite special friend..... of all the friends that you have got now, would there be like a special friend who you would maybe in the future want to tell?

F7C – Umm.... Might be and might not! There might just be a couple something like that!

Me – Good, good! Would that be harder for you to ask somebody a little bit

F7C – Yeah!

Me – Thank you!

F - Would you like to do some drawing. Do you like drawing?

F2C3 - Umm, not very good at it.

F – It doesn't matter because I am absolutely hopeless at it. One of the things that some of the children that have come have done has been to draw a family shield, do you know what I mean?

F2C3 – Err, yeah....

F – Like a coat of arms!

Me – You have all seen the knights haven't you, where they all have their special shields and they have special pictures on the shields.

F2C3 – Yeah!

F2C2 – Yeah, I had to do one for RE....

F2C3 – Oh have you?

F – F7C, would you like a diagonal cross or as it were a vertical cross?

F7C – Vertical cross....

Me – If you had a family shield what would it tell us about your family. What sort of pictures would you need to have on your shield?

F – Cross like that or a diagonal?

F2C3 - Can I have a cross like that please?

F – They have either moved the floor or I have just shrunk (laughs)....

F2C3 – Thank you.

F – You have got colouring pencils here..... pause

Scribbling Or Drawing Sound

F2C3 – I am going to have to be different, I am going to have

F – well why not?

Me – I think it always helps to be different.

F – F3C, which one would you like?

F3C – I like that!

F – You like that, so you the different one, the individual?

Drawing Sound

F – This is getting more and more peculiar in shape! Here we are! Lots and lots of coloured pencils! You don't have to do it if you don't want to, if you want you can have blank paper and draw something else or you can just carry on talking to us, in fact you can carry on talking to us while you are doing this anyway. Doesn't feel too much like school work does it?

F3C – No.... I am glad to be out of school.

F – You have only gone back this week though haven't you?

F3C – I went back not last week....

F – You've been back 10 days haven't you? When did you go back boys?

F2C2 – I went back Wednesday about 1 o'clock.

F – So you have only had about 2 ½ days at school?

F2C2 – Yeah!

Me – And have you had enough already or is that.....?

F2C2 – Yeah!

F – So this is a new school for you this time?

F2C2 – No I am in Year 8 now.....

F – Oh, so you went to a new school last year was it?

F2C2 – Yeah.

F – Right, so how long have you been back F2C3?

F2C3 – I went back Tuesday....

F – Right, so what about you F7C?

F7C – I went back on Wednesday.

F – Oh I see, so its you that got the really short straw isn't it because you've been back a lot longer already.

F2C2 – Right, well my school, like, we have loads of days off, like a couple of weeks ago we had like a bacteria in the water or like when we was back in Year 7, I had like a week and a ½ off for that. In a week's time I have a half a day, give it another week I have got a day off so.....

F – These part-timers!

Me - I want to go to your school (laughs). That is hard actually thinking about what is special in your family...

F – It is..... I am sure there are some very special things.....

Me - There might be special things you do, it might be something you bought, special things that people say or do or it might be the best times when your family is having the greater time or it might when things are really difficult and what your family do when things are really difficult. I am not helping am I?

F – No (laughs). So what did you do in your holidays then F3C? I know you have been back to school a week and a bit and it probably seems a long away, away but what did you do in your holidays?

F3C – Well, the first week I got my hair blow-dried but it has all gone curly cos the last week we had swimming and cos you can't get it wet but it was very expensive...

F – Was it?

F3C – Yeah, about £44 I think and there were no chemicals in it or anything and on the

Me – Why did you want straight hair?

F3C – Well we went there cos my hair was very tight at like that moment. My mum just said can you do just something to try and sort it out a bit so we just did that really... they come from Thursday blah blah and we'll just wash it and blow dry it and then after that we went on the London Eye for the second time and I was like hugging all these coats over my head so I wouldn't get wet cos it was raining. We had to buy an umbrella there and umm, on the last week we went to Devon. That was the second last week. We stayed with some friends and that was quite nice and my dad went on the machine in Exmouth.

F – So you were able to get away even with the machine as it were?

F3C – Yeah!

Me – That must make it a bit more complicated doesn't it, going on holiday?

F2C3 – A few years ago we went to Center Parcs when our dad was on the machine and we had to like get someone to bring it over....

Me – Right!

F – But you still managed to go which is good?

Me – What like a delivery truck to go all the way down to Center Parks and deliver your dad's machine?

F2C3 – Yeah....

F2C2 – I think we got one over there or something like that, like a nearer hospital or something like that I think but we didn't take our one at home, we, I dunno, I think our hospital supplied it or something like that.

F – Another one miraculously appeared in your chalet at Centre Parks?

F2C2 – First of all we didn't have one but then my dad had to like phone up a couple of hours later....

F – Right, phew, that must have been a bit worrying...

F2C3 – We got to do everything was gonna do except our dad wasn't around to go swimming.

F – Right. Why was that?

F2C3 – Umm, I'm not sure, just that I think he had loads of scars and stuff and he couldn't get wet otherwise he would just make it worse so occasionally we came out and just kept him company.

F – So did it get too lonely?

F2C3 – Yeah, but he had a couple of books.

F – So he was happy was he? Peritoneal dialysis, they often don't recommend it.

F2C2 – But you can like get a bag or something.

F – Yeah, they have got special holes in to put your tube in and sometimes its like....did your dad used to take lots of showers rather than baths when he had his tubes.

F2C3 – Yeah.

F2C2 – I think my dad always had showers.

F – Cos for some people that's quite a big change. What about you like, did you go away?

F7C – Centre Parks again but umm, there was nothing wrong with our mum in the water.

F – Se she could swim with you?

F7C – But err, most places she don't need her tablets but I don't know why she doesn't need her tablets when she goes away but she either takes them when I'm asleep she does Pause.

F – I thought you said you weren't very good at drawing? That looks amazing!

Me – Like a view isn't it? (All laugh) Maybe that's him when he had a bit more hair!

F3C – Yeah, he was chubby as well.... cos I think he was ill before my mum and dad's wedding.

Me – Right! I am very pleased that you all had a holiday this year.

F2C2 – Well we didn't go to Centre Parks this year, we went to America so....

Me – Ooh, you lucky thing!

F3C – My cousin went to America and my friend.

F2C3 – We just escaped the first major hurricane. (*Oh right!*) We had a little one.

F – A little one? How big is a little one? Was it very frightening?

F2C3 – Umm, no, it wasn't in our part, it was like just above us. (*Right.*) We saw it forming and then we say that... you know them vans that try and stir it up so that they can And then the next day it was like the actual thing cos that one just blew away and then the next day there was a tiny one for, I'm not sure how long, cos were just going around theme parks. We didn't even think about it.

Me – Right!

F – So it didn't affect your holiday?

F2C3 – No, and then we went back home I think the next day it said that there was a huge hurricane.

F2C2 – We had, like, 24 hour delays.

F – Oh dear, what in the airport?

F2C2 – Yeah, but we got put into a hotel about seven.... about six in the morning but luckily because all like young children and like medical needs had to go first so umm we got there, like, the first people in there so like we virtually got the best room and umm, like a lot of people got there about 10. If you was at the back of the aeroplane they done it by seat numbers so was quite lucky there.

F – So sometimes its useful to have a dad with a medical problem is it (joking)!

F2C2 – Yeah!

F2C3 – But we didn't think we was gonna have that long a delay, in fact, we didn't think we was gonna have a delay at all so umm my dad packed all his tablets in the suitcase and then when we had the delay, he didn't have them so he had to go right to the hospital.

F – Oh my goodness!

F2C2 – Of course they don't have like the NHS, you have to pay for them. (*Right*) . And that was like, something in England that is really hard to get hold of. I have no idea what the tablets are called but

umm luckily he got it and made the flight as well. He had to leave about 12 and the flight was about 2 or about 3 but you had to be in there... no its 4, but you have to be in there 3 hours... 2 hours early so just made it!

Me – Right, its an exciting life isn't it when you have got all those things..... pause.

F – And you say your friend went to America as well F3C?

F3C – Yeah, my friend and my cousin. She knew the... she had just come back with the hurricane thing, it was on the news and everything and there were

Me – Its so scary...

F3C – Yeah, she had just come back in Thailand at the time

F – I bet you were glad that she was back weren't you?

F3C – Yeah, and my friend, yeah! She's one of my funny close friends.

F – Laughs... your funny close friends, okay!

F3C – My close friend but she's really funny! (*Right!*) No one wanted her to go but me cos she's really funny!

Me – Well the good thing I have learnt from listening to you already is that even though things can a bit tricky like tablets being locked away in suitcases on planes and sometimes even forgetting dialysis machines and even taking tablets down to Center Parcs and having people to sort of sort them out there, all of you have still been able to sort of go away and have a holiday and have a really nice time with your family.

F – So do you think that is one of the important things that I tell the mummies and daddies that, you know, you can still do things with your children.

F2C3 - Yeah.

F2C2 – Preferably get a dog!

F – Get a dog? Okay, why have they got to get a dog?

F2C2 – A beagle!

F – A beagle! Right!

F3C – I did have a dog, I have a hamster.

F – You have a hamster?

F3C – My dad takes him laughs. We I have got to like him a bit, I've had to.

F2C3 – Well we used to have a dog ages ago but it was like err, like err border collie and it bit F2C2 when he was a little baby (*Oh right*) so we got rid of it and then we had umm goldfish and we gave them away cos too big and then we had guinea pigs and they died.

F – Right!

F7C – So you had a lot of pets in the past?

F – Have you got pets then at the moment then F7C?

F7C – I have only got one at the moment, a dog!

F – You’ve got a dog? What sort of dog have you got?

F7C – I have got a cross breed and he’s tan.

F – What’s he called?

F7C – Bobby!

F – Do you take him for lots of walks?

F7C – Yes, umm, I called him Bobby because I went to this dog place when I was about 2 and there was this dog called Bobby, I really liked him but unfortunately he didn’t like kids and I was really upset and then we went to Battersea Dogs Home and got a dog and we called him Bobby because he was okay with children. *(Good!)* He was a bit soppy! *(That sounds like a good sort of dog!)* We went to the vets once and he had to have an operation because he was a bit too hyper. He had his nuts chopped off! *(Oh dear)* *(laughs)*. And he had problem with his glands sometimes. He rubs his bum on the floor so we had to take him to the vets and umm, he puts his hand up his bum and squeezed acid out and he yelped.

F – Oh dear, that sounds nasty. I think hamsters are easier (laughs).

F7C – And I was like....that must have hurt.

F –I’m sure it must have.

Me – Do you reckon you know more about like medical stuff because of what happens to your dad or to your mum, do you think you sort of know a bit more about you know what happens to bodies and stuff?

F7C – Sort of!

F3C – No!

Me – No, you probably have learnt more through your dog haven’t you? LAUGHS I wondered if it makes you more worried about what might happen to somebody’s body or because whether, or, because your mums and dads are okay that it makes you feel a lot of thing can happen with the body and still be alright again?

F3C – Well one thing I did um is because well what I did like about our families.... my mum and dad do like me to know umm about.... they wouldn’t lie and say like no, if someone’s body was like a bit wrong or something and I asked they would say this is how they were born and stuff or they wouldn’t just say like that ... they would say what it was and how you get it, its just nice to know what is actually going on.

F – Do you feel happy cos they actually explain what is going on to you

F3C – Yeah.....

F -so that’s important as well isn’t it, okay?

Me – they wouldn’t just say oh no, not to worry about that.....

F3C – Yeah!

F – Do you think it is difficult sometimes, for mums and dads to tell you things in a way that you will understand, cos “Bobby’s” are quite complicated aren’t they? They are amazing things... pause

F7C – A little bit!

F3C – It probably is hard to tell you what is going in a way that you understand like, umm, like umm, you couldn't say it like you would say it to an adult cos you are quite little and you wouldn't understand really. You have to say it like a children way, you know, how children think.

Me – I guess one part of it is actually saying it in ways that people can understand but also I guess lots of mums and dads don't want to say anything that is going to upset their children or make them worried. Do you think sometimes your mums and dads have really had to think about how they can say what they need to say to you in a way that doesn't make you worry about them?

F3C – Yeah.

F7C - My dad tried once but I just burst into tears.

Me – Some things are just very difficult aren't they no matter how nicely people put things. Do you reckon you worry more about your mums or dads then other people of your age might or do you think you're very relaxed?

F7C – A bit more!

F – A little bit more do you F7C?

F7C – Yeah.

F – Why do you think you worry a bit more?

F7C – I dunno really.... PAUSE

Me - I bet all of you have got some friends at school whose mums and dads have never been into hospital, never had to do anything to look after themselves....

F - ... never taken any tablets....

Me - or do anything like that and would probably find it very hard to understand what it is like to be in a house where your mum and dad go to hospital quite a bit.

F7C – I know one, and I think you know him too, F1C

F – Yes, we have met F1C

F7C – He's in my class.

Me – That's interesting. Do you and F1C ever talk about stuff?

F7C – No! Because, we really like doing walks or games with another person. We are not really like best friends or nothing, we are like middle friends.(Okay!) We don't really talk about it really....

Me – I think that is quite unusual to find someone in your class who has, you know, someone in their family who has been in hospital, that's quite unusual.

F7C – Yeah, and my mum had the same thing wrong with F1C's mum and they had the same, at the same time they had their transplants.

Me – Gosh!

F7C – I think F1Pt.... I think F1C's mum had it as well or like a machine.... PAUSE

F – That's really incredible. See in a few minutes you can talk us through and make some little notes about what you pause.

Me – It really is very interesting talking to you because it is just quite helpful to know what we can help other parents say to their children, you know, do we tell them to tell them everything about what is going on or do we tell them just to tell them some of the stuff or wait for you to ask questions first.....

F3C – Well I would sort of say to tell them the truth.

F – Cos telling the truth is very important!

F3C – Because then if your child found out without you telling them they would be really upset so it is sort of like better to tell them like, truthfully when it actually happens.

Me – Okay. That's very good advice! I think it might also be very helpful to make sure that teachers at school know. Do you ever talk to your teachers?

F7C – I talked to Mrs . She tried to calm me down but with her cow. The other teachers didn't really know, not really any of them.

Me – Okay!

F7C – And the one in my class now, I don't think she'll know either! LAUGHS. Unless she has to have another operation.

Me - Right!

F3C – Well I don't talk to my teachers about it. All my teachers I have had already know about it and umm my head teacher does, umm, like cos my school's really small, it's actually a really nice school. Like, everyone asks about your family and just to see how they are and, like, my head teacher, every time I see him he asks how's your dad, how's your mum, how are you and all of that? He always asks how my family are.

F – Good! Do you think it's important that as much as possible that it is your mum and dad that talk through things with you?

F2C2 – Err, yeah!

F – Is there anything that you think might help them that perhaps we could do?

F3C – Don't know really.

F – I mean do any of you like reading books or do you prefer watching TV or playing computer games or something?

F3C – Playing computer games!

F – Playing computer games!

F7C – All of them really!

F – All of them? You like doing all of those things?

F2C2 – I'm not really into computer games. I prefer like playing guitars and listening to music.

F – We will have to do some sort of musical presentation.

F2C2 – I'm more that type of guy (laughs).

Me – I think the reason we're saying that is we wondered whether it might be helpful to write a story for girls and boys about mum's and dad's having dialysis or having a kidney transplant and whether that would be another way of people finding out about sort of what happens and why it happens. Also, the sort of things that mum's and dad's could use with their children just to sort of start to diffuse the topic cos I

mean you know quite a few people could sit there and you're having your tea or whatever and your mum or dad suddenly said "by the way I just need to talk to you about, you know, dialysis" and you think "what's that, why do I need to know about it?"

F – I suppose it's a bit different for you F3C cos you can only remember the machine being there can't you?

F3C – Yeah!

Me – Have you ever imagined what it might be like at home if your dad didn't need dialysis?

F3C – Well, we could go more places, like, when my mum goes abroad every year but my dad can't come obviously cos of his dialysis so he has to stay behind but if we could go and see him it would be quite fun cos we could all go out together not like me and my mum going somewhere and me and my dad somewhere... us not getting to go somewhere cos my dad

F – Right, so you have still been abroad but its just been with your mum?

F3C – Yeah.... well my dad has... he has been on an aeroplane, like we've been to Ireland but we only stayed for about 2 days because my best friend, they live across the road, they come from Ireland and we have known each other since we were babies and stuff and her aunty and uncle were getting married we went to....they said that we could come over so we went to Ireland.

F – So you did manage to get somewhere as a family but only for such a short time between dialysis sessions.

F3C – Yeah.

F – These pictures are just amazing. They are very, very detailed.

Me – You have worked so hard on those pictures. It has been lovely watching you do that!

F – Lots more colours here if you want any.....

F2C2 – I don't think I will colour in my picture because I just can't.

F – No, that's brilliant....

F2C2 - I think I did quite good drawings and then when it gets on to the colouring and painting I just can't.....

Scribbling Sound In Background

Me – Do you do quite a lot of sports then F2C3?

Pause

F2C3 - Yeah. Go on, tell us about your picture F2C2?

F2C2 – Umm, well, first size is like my guitar and like cos my big brother plays guitar as well and like I....

F-Do you all play guitar at your house?

F2C2 – Umm, my little brothers might like play like a bit of guitar and like you see it and then

F2C3 -..... and then hopefully I am going to play with drums.

F – Oh right, so you are going to have a whole band in your house?

F2C3 – Yeah!

Me – I could be a backing singer!

F2C2 – Right there's my first section with all my guitars, umm, my second section is like a Lift Company, like my dad's work and my next section is like a CD collection and vinyl.

Me – Its huge by that picture. Huge collection.

F – How much time do you spend listening to music?

F2C2 – Well, when I'm home from school, about 80% of day. Well I just put it on and then do other stuff in my room.

F – But does the whole house have to listen to it or do you have headphones?

F2C2 – No, the whole house but like my mum has her music downstairs and my big brother has his music and my little brother has his music and I have my music.

F – Does the house vibrate with it?

F2C2 – My next section which is nearly finished but is all dedicated to Jack Black, the biggest legend in the wild. Its my dad's and mine favourite actor in the house and he has got his own band.

F – Right!

F2C3 – He's in things like Ice Age and School of Rock.

Me - I love that film....

F2C2 – And he's got like years and years of films planned out like Shark Tale and..... lots of stuff.

Me – Oh him?

F2C2 – ... and I'm just about to draw Curt Cobain, the biggest legend in music, from Nirvana, as you can see there. *(Yes!)* Unfortunately 10 years ago he committed suicide. *(Right)* Because people knew his name when he didn't want them to. *(Right)* And the Massive.....

F - lot to do with you and your music but also quite a bit to do with your dad isn't it?

F2C2 – Yeah!

F – Okay, have you finished yours?

F7C – Yes, I've nearly finished my hospital but.....

F – okay, you've got a picture of the hospital have you? Why have you got a picture of the hospital?

F3C – I'm mainly colouring in my important picture. Laughs.

F – So you have got a picture of the hospital. Is it this hospital?

F7C – Yes.

F – So why have you got a picture of the hospital then?

F7C – Cos I was born in here. *(Oh right.)* And my mum had her operation PAUSE

F – So it is quite an important hospital if you were born here isn't it? And if you're mum had her transplant here.... okay.

F7C –kidney tablets....

F – kidney tablets, right.....very important cos your mum needs to take them.

F7C – Yeah.

Pause

F – What else have you got there?

F7C – Books and....(Books?) And my very, very important Game Boy Advance.

F – Game Boy Advanced?

Me – That's a new one isn't it?

F2C3 – Yeah, I've got my one in my mum's handbag.

F – You hope she hasn't sort of pawned it to Borough Market (Laughs).

F2C3 – Hope not!

F7C – And My dad at his house has "Pierce 2"??

F – Oh wow!

F3C – I'm gonna get Pierce 1.

F – What sort of books do you like?

F7C – I like a rude type of story called Captain Underpants.

F3C – Yeah, when we did the books week Mr was wearing tights and his underpants

F7C - and he had a little red cape!

F – (Laughs.) Are you ready to explain yours C2C3 or not yet?

F2C3 – Umm yeah, there is music cos our whole family likes music and holidays.

F – Any particular sort of holidays?

F2C3 – No!

F – Any holiday?

F2C3 – And sports.

F – Is that for your or

F2C3 – Yeah and, like, everyone in our family likes sports.

F - cricket bat!

F2C3 – Baseball bat!

F – Oh it's a baseball bat is it? Oh right, okay!

F2C3 – and there's a cricket bat and then baseball and football net, cricket stumps, tennis racquet and tennis ball and American foot ball.

F – Oh that's American football, not rugby?

F2C3 – and a rugby post.

F – My goodness that a lot of sport.

Me – Do you play sports?

F2C3 – Yeah I'm signing up for..... last year I couldn't get into the football team, I signed up for that and I signed up for rugby and my last section is entertainment like TV..... PAUSE

F – So that's just the whole family night entertainment as well?

F2C3 – Yeah!

whispering in background

F – Yeah well we have been here an hour nearly. Yeah, I know!

F3C – Well the first one is just our faces because we are all happy in our family and second one is umm like a rollercoaster cos we do like rides. We go to Lego Land every year and sometimes maybe even twice and um we just go on all the rides. The third one is well all like sports, like, we were watching the Olympics and one thing that we didn't like was that the second week of the Olympics we were on holiday and the people we stayed with didn't have a TV. *(Oh dear!)* We were listening to the radio but their dad had the TV laughs And then we all like music really. We got all our different types of music. Like, me and my dad maybe sometimes we like reggae and my mum likes all this old stuff like Genesis and Meatloaf and everything.

F – Now that's what you're talking about, I understand now (Laughs).

F3C – Meatloaf is alright and now she likes Keane.

F – Keane?

F3C – Keane, they're new people! Laughs.

F – Never heard of them.

F2C3 – I like them!

F3C – They're alright!

F7C – I haven't heard them!

F – No, I haven't either!

F2C3 - I like small bands. Yeah, I like David Bowie and Bob Marley.

F – Now they are names I recognise you see, David Bowie and Bob Marley.

F2C3 – and T Rex and I don't mind....

F2C2 – Queen?

F2C3 – Oh right, I don't mind them and I don't mind Rod Stewart.

F7C - My mum loves Queen.

F – Your mum loves Queen, did she go and see the play, the musical?

F7C – When we were moving, she looked for a Queen CD, it wasn't at daddy's house and like

F – Was she upset because she couldn't find it?

F7C – Yeah!

F – F3C was saying that they are all happy in their family and that they all like sport and they all like music and they all love rides and they go to various different places where they can do lots of different roller coaster rides.

F3C – Hopefully we will go to Thorpe Park.

F7C – I've been there.

F – You've been to Thorpe Park?

F2C3 – Our brother's going to university.....

F – Is he?.....

F2C3 - and he's going near, where is it, .

Me – Oh right!

F – Has he got in to do physio?

F2C3 – Err, yeah, yeah!

F2C2 – That's' what he wanted to do.....

F7C – If you are going to go on a tidal wave, bring your umbrella or your welly boots. (*laughs*) Told you, not just a tidal wave but a like when it goes down so fast like you get soaked.

F2C2 – When we went to America there was this ride called a journey through Atlantis and if it's a really big one you don't get that wet and then you do a really small one about a metre and it all.....

Focus group 3

Information

F2C2 – My dad told me.

F2C2 – No, umm I think he talked to us separately like different times.....

F2C3 – Yeah cos like when he was in hospital we went up on different days...

F2C2 – Umm, like how dialysis works and stuff like that.....

F2C2 - about 6 months I think. The waiting list was about 2 years... the average is about 2 years I think!

F3C – Well I don't actually remember when I actually got told about, I think I was really little I think. My mum just explained it to me and I was just... and every night I used to watch him on the machine and everything....

F3C – Well he just umm... well he's got those lumps on his arms.....(Yeah) and he puts some needles in them and attaches the tubes and then attach it to the machine. He sort of then sets the machine up on different things.

F2C2 – He had like a tube from his stomach, to drain the blood or something.....

F2C3 - then we had to drain it out in the bath.

F7C – my dad picked me up from school and he told me the bad news and um a bit sad and umm That your mum might not be home because she is going to go to the hospital cos her kidney has gone a bit bad and.... can't really remember everything.

F7C – Cos it came from my grandma's... Yeah.

F2C3 – Yeah like, when my dad was on, like, dialysis I asked him what it done and stuff like that!

F3C – No, not yet! My mum tried to teach me but I think I did ask him, I sometimes asked him cos when he puts the needle in, the blood comes out and I had to ask him does it really hurt.

F7C – She takes tablets

F3C – Well one thing I did um is because well what I did like about our families.... my mum and dad do like me to know umm about.... they wouldn't lie and say like no, if someone's body was like a bit wrong or something and I asked they would say this is how they were born and stuff or they wouldn't just say like that ... they would say what it was and how you get it, its just nice to know what is actually going on.

F3C – It probably is hard to tell you what is going in a way that you understand like, umm, like umm, you couldn't say it like you would say it to an adult cos you are quite little and you wouldn't understand really. You have to say it like a children way, you know, how children think.

F7C - My dad tried once but I just burst into tears.

F3C – Well I would sort of say to tell them the truth.

F3C – Because then if your child found out without you telling them they would be really upset so it is sort of like better to tell them like, truthfully when it actually happens.

Family life

F2C2 - I couldn't go because I was on a school trip for, like, a week.

F2C2 - No umm, because the night my dad got the phone call I was just about to leave for the school trip, umm, it was about, it was about 8, 9 and I was going to go.... and so I had to go around to a friends so I slept over there the night.

F2C3 – No cos umm my dad took it out cos he only needed it at night. (*Right!*) and then we had to have our baths and showers in the day but.....

F2C2 - like my mum sterilised it to get rid of all the... I don't know what it is but.....

Friends and school

F3C – Well sometimes I've got close friends when they come to my house like, umm, they know about it already as we have told them but sometimes... sometimes we don't know what their mums want us to tell them about it so we have just have to sort of not let them in that room.

F2C2 – No I think.... Ma - no, it was all kept in and covered in our bathroom and in our mum and dad's bedroom and when like our friends come around we have to shut the doors. But like a lot of our friends were in the area and like every one of my friends cos I got like quite a lot of friends and they all came around, a lot of them came round and like my dad got a phone call for the transplant then... they all knew.

F2C2 – Well it is important, like I haven't ever come across it yet but I might do later on but like if you ever need to talk to him or something at least you know you have got in, lets say, you are at school and you can't actually talk to your mum or dad because they are at work at the moment, like you have actually some people you can talk to.

F3C – Like when you're at school and your mum and dad are at work you can talk to.... I have only told a couple of my friends, I haven't told all of them.

FC3 – Yeah, most of my teachers and my Head Teacher.

F2C3 – My Head Teacher knows and when my dad had it the teacher I had then knew about it. (*Right!*) I'm not sure about the Teacher I have got now. (*Right!*)- The teacher I had last year, I don't think she knew.

F3C – Well I don't talk to my teachers about it. All my teachers I have had already know about it and umm my head teacher does, umm, like cos my school's really small, it's actually a really nice school. Like, everyone asks about your family and just to see how they are and, like, my head teacher, every time I see him he asks how's your dad, how's your mum, how are you and all of that? He always asks how my family are.

Holidays

F3C on the last week we went to Devon. That was the second last week. We stayed with some friends and that was quite nice and my dad went on the machine in Exmouth.

F2C3 – A few years ago we went to Center Parcs when our dad was on the machine and we had to like get someone to bring it over....

F2C2 – I think we got one over there or something like that, like a nearer hospital or something like that I think but we didn't take our one at home, we, I dunno, I think our hospital supplied it or something like that.

F2C2 – First of all we didn't have one but then my dad had to like phone up a couple of hours later....

F2C3 – We got to do everything was gonna do except our dad wasn't around to go swimming.

F2C3 – Umm, I'm not sure, just that I think he had loads of scars and stuff and he couldn't get wet otherwise he would just make it worse so occasionally we came out and just kept him company.

F2C2 – But you can like get a bag or something.

F2C2 – I think my dad always had showers.

F7C – Centre Parks again but umm, there was nothing wrong with our mum in the water.

F7C – But err, most places she don't need her tablets but I don't know why she doesn't need her tablets when she goes away but she either takes them when I'm asleep she does Pause.

F2C2 – Well we didn't go to Centre Parks this year, we went to America so....

F2C2 – We had, like, 24 hour delays.

F2C2 – Yeah, but we got put into a hotel about seven.... about six in the morning but luckily because all like young children and like medical needs had to go first so umm we got there, like, the first people in there so like we virtually got the best room and umm, like a lot of people got there about 10. If you was at the back of the aeroplane they done it by seat numbers so was quite lucky there.

F2C3 – But we didn't think we was gonna have that long a delay, in fact, we didn't think we was gonna have a delay at all so umm my dad packed all his tablets in the suitcase and then when we had the delay, he didn't have them so he had to go right to the hospital.

F2C2 – Of course they don't have like the NHS, you have to pay for them. (*Right*) . And that was like, something in England that is really hard to get hold of. I have no idea what the tablets are called but umm luckily he got it and made the flight as well. He had to leave about 12 and the flight was about 2 or about 3 but you had to be in there... no its 4, but you have to be in there 3 hours... 2 hours early so just made it!

F3C – Well, we could go more places, like, when my mum goes abroad every year but my dad can't come obviously cos of his dialysis so he has to stay behind but if we could go and see him it would be quite fun cos we could all go out together not like me and my mum going somewhere and me and my dad somewhere... us not getting to go somewhere cos my dad

F3C – Yeah.... well my dad has... he has been on an aeroplane, like we've been to Ireland but we only stayed for about 2 days because my best friend, they live across the road, they come from Ireland and we have known each other since we were babies and stuff and her aunty and uncle were getting married we went to....they said that we could come over so we went to Ireland.

Pictures

F2C2 – Umm, well, first size is like my guitar and like cos my big brother plays guitar as well and like I...Umm, my little brothers might like play like a bit of guitar and like you see it and then Yeah! Right there's my first section with all my guitars, umm, my second section is like a Lift Company, like my dad's work and my next section is like a CD collection and vinyl. Well, when I'm home from school, about 80% of day (listening to music). Well I just put it on and then do other stuff in my room the whole house but like my mum has her music downstairs and my big brother has his music and my little brother has his music and I have my music. My next section which is nearly finished but is all dedicated to Jack Black, the biggest legend in the wild. It's my dad's and mine favourite actor in the house and he has got his own band. He's in things like Ice Age and School of Rock, And he's got like years and years of films planned out like Shark Tale and..... lots of stuff. and I'm just about to draw Curt Cobain, the biggest legend in music, from Nirvana, as you can see there. (*Yes!*) Unfortunately 10 years ago he committed suicide. (*Right*) Because people knew his name when he didn't want them to. (*Right*) And the Massive.....

F7C – Yes, I've nearly finished my hospital but – I'm mainly colouring in my important picture. Laughs. – Cos I was born in here. (*Oh right.*) And my mum had her operation PAUSE....kidney tablets.... Books and.....(*Books?*) And my very, very important Game Boy Advance. I like a rude type of story called Captain Underpants. and he had a little red cape!

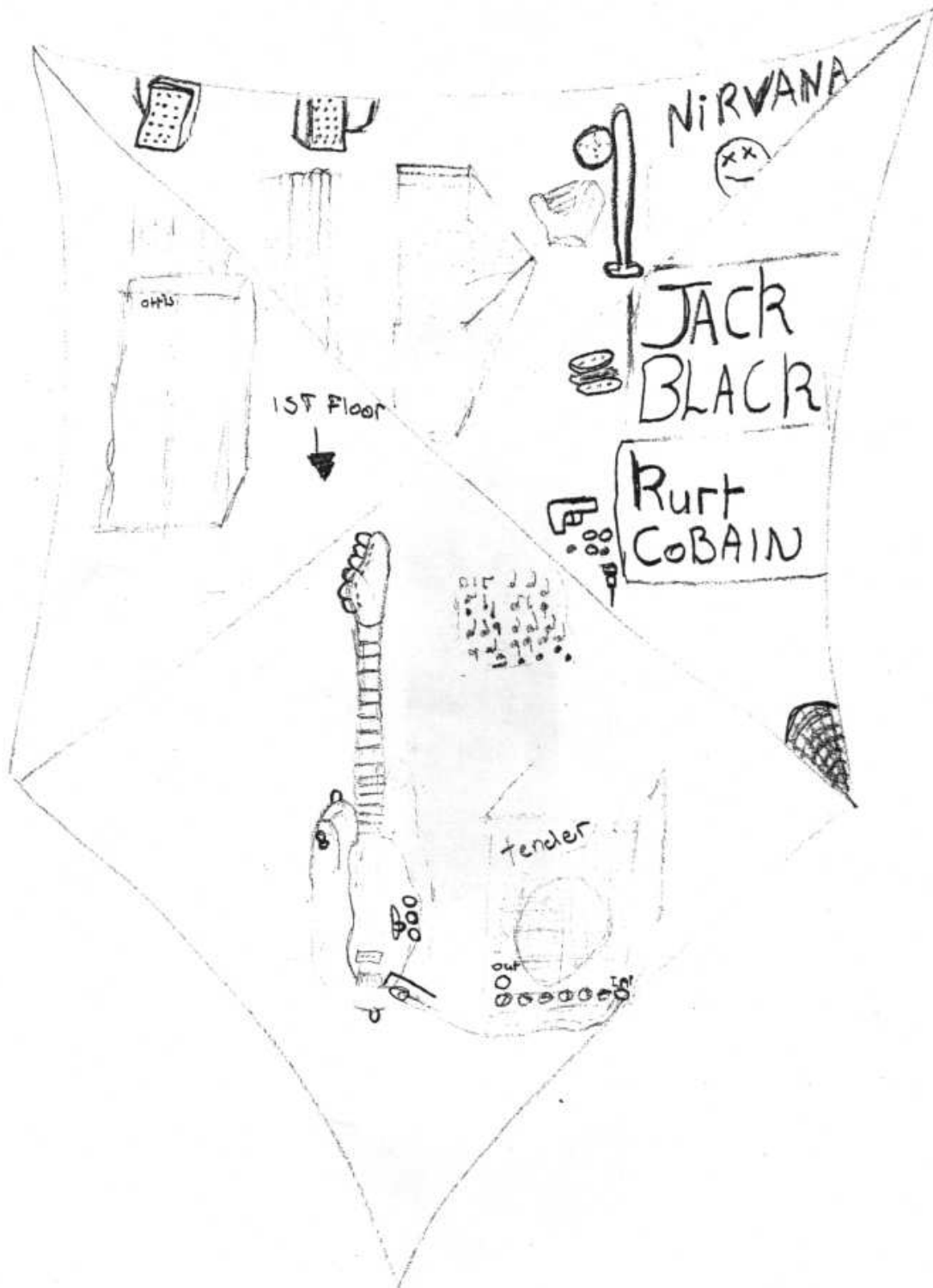
F2C3 – Umm yeah, there is music cos our whole family likes music and holidays. And sports. Yeah and, like, everyone in our family likes sports. Baseball bat! and there's a cricket bat and then baseball and football net, cricket stumps, tennis racquet and tennis ball and American foot ball.– and a rugby

post.– Yeah I’m signing up for..... last year I couldn’t get into the football team, I signed up for that and I signed up for rugby and my last section is entertainment like TV..... PAUSE

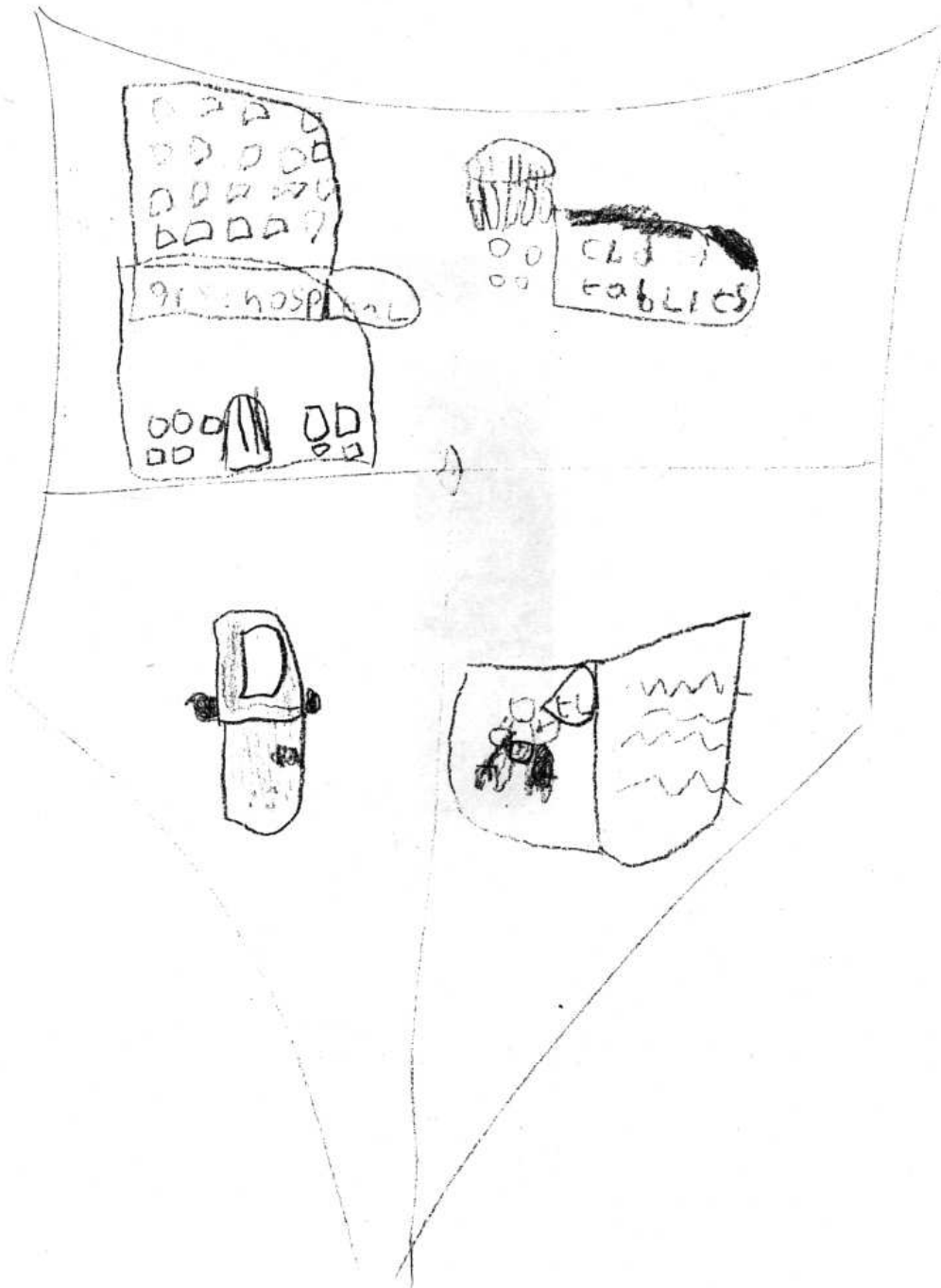
F3C – Well the first one is just our faces because we are all happy in our family and second one is umm like a rollercoaster cos we do like rides. We go to Lego Land every year and sometimes maybe even twice and um we just go on all the rides. The third one is well all like sports, like, we were watching the Olympics and one thing that we didn’t like was that the second week of the Olympics we were on holiday and the people we stayed with didn’t have a TV. (*Oh dear!*) We were listening to the radio but their dad had the TV laughs And then we all like music really. We got all our different types of music. Like, me and my dad maybe sometimes we like reggae and my mum likes all this old stuff like Genesis and Meatloaf and everything.

Appendix 17

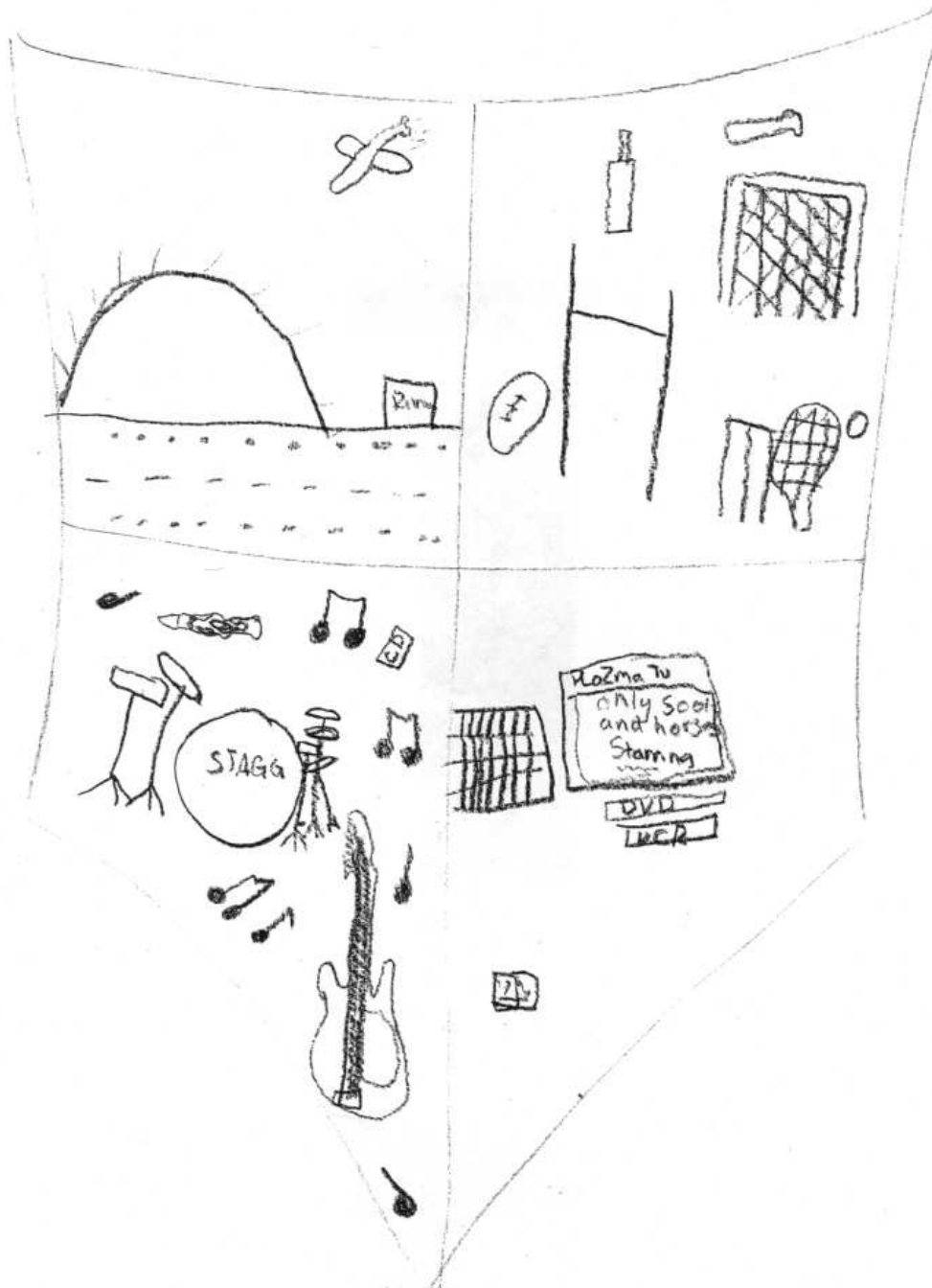
Children's pictures



F7C

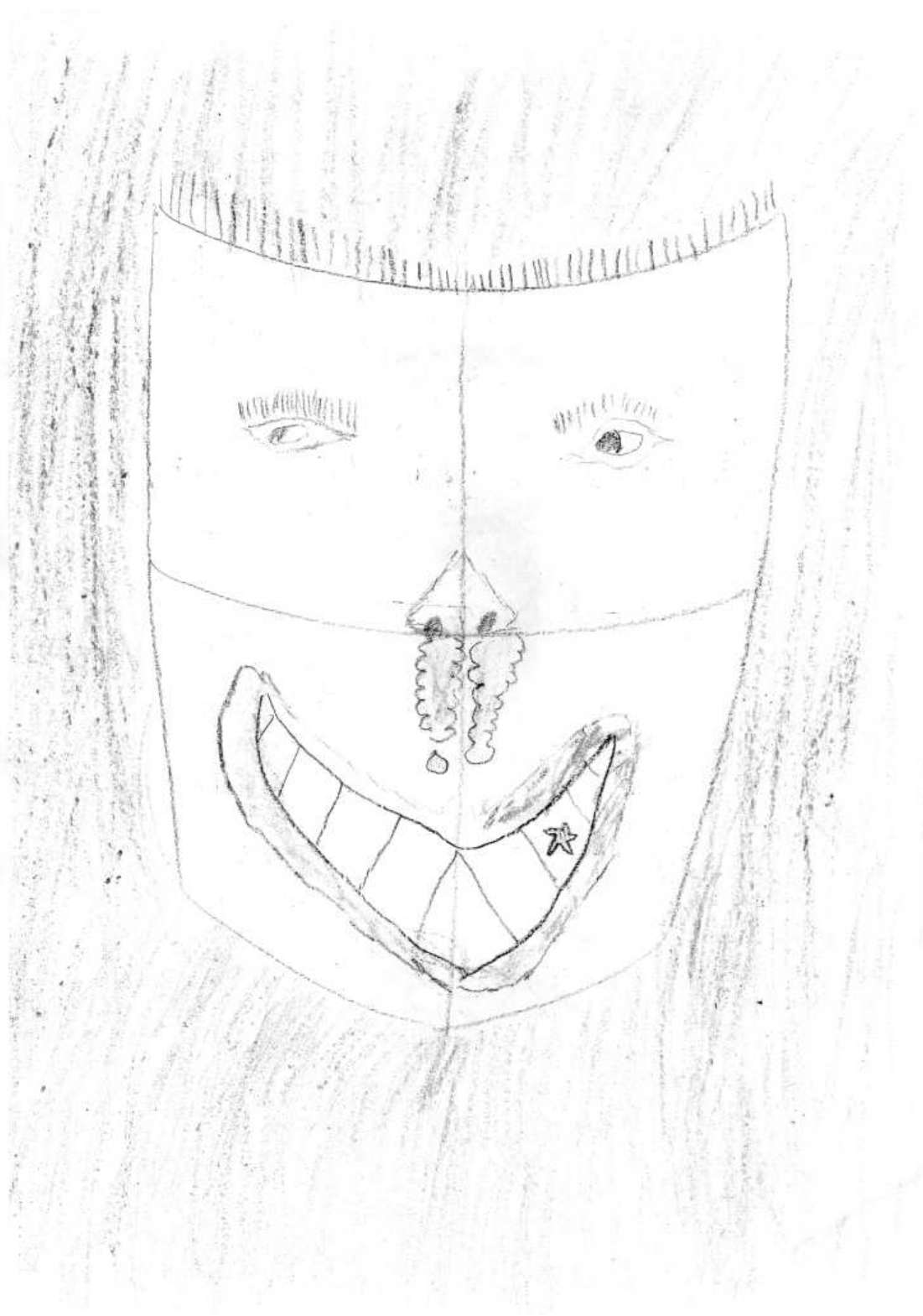


F2C3





F1C



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