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Learning to Manage Chronic Renal Disease:  
The Experiences of Children and Families

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A thesis submitted in partial fulfilment  
of the requirements of the  
University of Northumbria at Newcastle  
for the degree of  
Doctor of Philosophy

Research undertaken in the  
School of Health, Community  
and Education Studies

April 2006

## ***Abstract***

Advances in health care have led to an increasing emphasis on family involvement in the day-to-day care of children with chronic renal disease, but if families do not become competent in this it can negatively influence the child's management. Research into the psychosocial implications of childhood chronic disease has been prolific in recent years, although relatively few studies have investigated the way that families learn about chronic disease management. However, a body of work is emerging in the human sciences around the premise that social engagement in communities of practice is a fundamental process by which people learn. Building on these lines of research this study, therefore, aimed to explore the way that children with chronic renal disease and their families learned to manage the condition, and to determine the impact of relationships between families and professionals on the learning process. Using grounded theory within a symbolic interactionist approach, data were collected and analysed in two phases (retrospective and prospective). Phase one aimed to uncover the issues that eight children and/or their parents identified as important in learning about the condition since diagnosis in the preceding four years. In phase two, a longitudinal approach (building on phase one analysis) involving six families and key professionals, allowed detailed exploration, over eighteen months, of learning events that arose following referral to a Children's Kidney Unit.

A focus on learning by families as social participation in care was identified in the study. A novel, substantive theory, the social theory of learning in childhood chronic renal disease is proposed comprising three categories: the processes of assessing; interacting and synthesising. Assessing is the process by which families and professionals learn through assessing the disease course as well as each others' ability and social positioning. Interacting is the process whereby families and professionals learn through sharing knowledge, earning and maintaining trust and engaging jointly in decision making. Synthesising is the process whereby families' and professionals' learn through a new, shared understanding based on knowledge of each others' communities of practice, cultures and patterns of learning. The theory conceptualises family learning as: a two way process of interaction in developing an ongoing practice between family members and professionals; the influence of interpersonal as well as intrapersonal learning; and not only acquisition of skills but also the formation of identities in the context where the skills are learned. Three patterns of learning also emerged from the data (parallel, integrated and synthesised). These help to explain some of the

*Abstract*

differences and similarities between families' learning as they move through the chronic disease journey. This study develops and modifies Wenger's (1998) social theory of learning and Gibson's concept of participatory competence (1995) and contributes an innovative perspective to the growing body of knowledge around childhood chronic disease. Testing and further development of the theory and its use in child health is indicated.



## *Acknowledgements*

There are many people to whom I owe a debt of gratitude in completing this study. I thank my academic and clinical supervisors whose guidance and professionalism was a major impetus for me: Professor Charlotte Clarke, (my Principal Supervisor who motivated and inspired me at every stage); Professor Steve Campbell; Dr Heather Lambert and Professor Ann Jacoby, all for giving me time in their busy schedules and generously sharing their extensive knowledge and expertise. I thank them for patient and highly skilled mentorship, encouragement and wisdom, for kind and constructive comments on my drafts and for helping to ensure I saw the project to completion. I thank the children, families and staff who participated in the study. They gave their time and freely shared with me their experiences of learning and teaching in relation to chronic childhood renal disease. I do hope that the outputs from this research will contribute to an increased understanding of their worlds of childhood chronic disease.

I thank many colleagues for: encouragement; supporting my time to help me complete the project; thought provoking discussions around the research topic; friendship and humour; technical and administrative support; lending me personal copies of relevant and sometimes rare, books and documents, suggesting new material and new perspectives; willingly reading and commenting on drafts. In particular, these include; Dr Joan Aarvold; Dr Colin Chandler; Mrs Joyce Charlton; Mrs, Glenda Cooke; Dr Malcolm Coulthard; Professor Sir Alan Craft; Lady Ann Craft; Mrs Jean Crosier; Mr Stephen Farrier; Mrs Tracey Forrester; Mrs Judith Hunter; Ms Monique L'Hussier; Dr Craig Mackerness; Mr John Miller; Dr John Newton; Dr Joanna Reynolds; Mrs Margaret Rowe; Mr John Scott; Professor Linda Shields; Dr Maureen Sookhoo; Mrs Valerie Stuart; Mrs Sue Vernon; Dr Jane Wilcockson; Ms Sandra Windeatt; Mrs Pat Wright; the administration and secretarial staff in CHESs, Northumbria University and in the Children's Kidney Unit, Newcastle upon Tyne Hospitals NHS Trust; members of the Children's Nursing Teaching Team at Northumbria University and of the Northumbria Library and Learning Services.

I thank many family and friends for their interest, wise words and support, in particular Larry and Jenny Jackson, Ann and Geoff Lee, Alan and Kathleen Swallow, Iris and Rob Winter; Sandra and David Armstrong and Dorothy Morris. Most importantly though, I thank my husband Mike and children Andrew and Anna for their loving support and unflinching belief in my ability to complete this study.

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### *List of terms used in the thesis*

**Dimercapto succinic acid scan:** an isotope kidney scan involving an injection into a vein in the arm of a small quantity of liquid tracer preparation. This goes round in the bloodstream, and is taken out by the kidneys. When the gamma camera is placed over the abdomen it detects the radiation coming from the radioisotope in the kidneys. Consequently, an image is produced of the kidneys, showing what they look like, and also reflecting how well they are working. It is necessary to wait for 2 or 3 hours after the injection before obtaining the images. Source: <http://www.cafamily.org.uk/>.

**Central line (for dialysis):** a soft plastic tube (twice the length and half the width of a pen) placed through the skin into one of the large veins in the neck or the groin at the top of the thigh. Once inserted and made secure it can be connected to the tubes on the haemodialysis machine to allow blood to be pumped from the body to the machine and back for dialysis.

Source: <http://www.kidney.org.uk/Medical-Info/glossary/glossary.html#> 16<sup>th</sup> Oct. 2005.

**Continuing professional development:** the means by which members of professional associations maintain, improve and broaden their knowledge and skills and develop the personal qualities required in their professional lives (Eraut 1994).

**Erythropoietin:** a glycoprotein, acts on bone marrow to increase production of red blood cells. People with failing kidneys can be kept alive by dialysis. However, dialysis only cleanses the blood of wastes. Without a source of erythropoietin, these patients suffer from anaemia. Nowadays, thanks to recombinant DNA technology, recombinant human erythropoietin is available to treat these patients.

Source: <http://users.rcn.com/jkimball.ma.ultranet/BiologyPages/K/KidneyHormones.html#epo> 24<sup>th</sup> May 2005.

**End stage renal failure:** the term for advanced chronic kidney failure. People who develop end stage renal failure will die within a few weeks unless treated by dialysis or transplantation. These treatments control end stage renal failure but cannot cure it.. Source: <http://www.kidney.org.uk/Medical-Info/glossary/glossary.html#> 16<sup>th</sup> Oct. 2005.

**Family centred care:** the professional support of the child and family through a process of involvement, participation and partnership underpinned by empowerment and negotiation.

**The familial ureteric reflux study:** was conducted with the overall aim of identifying antenatally, from the mothers' family medical history, an 'at risk' group of babies who were screened as new-borns to exclude or diagnose vesico-ureteric reflux. Twenty four percent of those screened were diagnosed with vesico-ureteric reflux and are currently being managed by careful monitoring for urinary tract infection to minimise or prevent development of kidney damage. (Scott, Swallow, Coulthard, Lambert and Lee, 1997).

**Henoch Schonlein Purpura:** a non-genetic disorder caused by an inflammation of blood vessels (vasculitis) it is usually preceded by an infection, often a viral respiratory tract infection, resulting in: vasculitis: painful, occasionally swollen joints; red/purple skin rash that fails to blanch with pressure (purpura); abdominal pain and kidney inflammation. Abdominal pain may be caused by inflammation and swelling of the wall of the intestines or, more rarely, by a twisting inversion of the lining of the bowel termed acute intussusception. Kidney involvement causes blood (haematuria) and protein (proteinuria) in the urine. Whilst kidney involvement is common in up to 60 per cent of

sufferers, serious kidney damage is very uncommon. Haematuria may persist for months if regular urine testing is performed. Recurrences may occur in subsequent infections. However, the prognosis for full recovery is excellent. Source: <http://www.cafamily.org.uk/>.

**Initial professional education:** attempts to provide the knowledge required for a lifetime in the profession, there is little, if any, link to ongoing learning. (Eraut, 1994).

**Legitimate peripheral participation:** is not itself an educational form, a pedagogical strategy or a teaching technique, but an analytical viewpoint on learning and a way of understanding learning. It is proposed, as a descriptor of engagement in social practice that entails learning as an integral constituent. Legitimate peripheral participation is a complex notion implicated in social structures involving relations of power. As a place in which one moves towards more-intensive participation, peripherality is an empowering position. As a place in which one is kept from participating more fully – often legitimately, from the broader perspective of society at large – it is a disempowering position (Wenger, 1998).

**Nasogastric tube:** a plastic tube inserted through the nose, down the throat and into the stomach to allow diet, fluids and medications to be administered to a baby or child.

**Nephrotic Syndrome:** is a description of symptoms which commonly includes oedema (swelling of the tissues) which can be observed in the face and legs, and proteinuria (protein in the urine). Increased thirst is often reported. The condition commonly appears in early childhood. Although the appearance of swelling can be alarming, the amount of swelling and proteinuria has no bearing on the outcome and most children grow out the condition by early teens with no long-term kidney damage. Treatment with corticosteroids or cyclophosphamide has been shown to alleviate the condition, although relapses can be expected. Because the swelling is salt and water, salty foods should be avoided. More than 90% of children will reach adulthood with normal renal function. <http://www.kidney.org.uk/Medical-Info/glossary/glossary.html#>, 7 January 2006

**Plasma exchange:** a procedure that removes plasma from the blood and replaces it with new plasma fluid. Blood is removed from the patient (a small amount at a time) and separated so that the plasma can be discarded. The red and white blood cells and the platelets are returned to the patient, along with the replacement fluid. An anti-coagulant is added to the blood to stop it clotting. Throughout the procedure, the blood is pumped around the child's system as usual by his or her heart. Only a small amount is out of the body at any one time. Plasma exchange is always done in hospital and a nurse who is trained in the procedure will stay with the child throughout. Source: <http://www.ich.ucl.ac.uk/factsheets/families/F030073/#exchange>.

**Stoma:** (the Greek word for "mouth" or "opening") is surgically created from the bowel (intestine) through the skin onto the abdomen to help in the removal of body wastes such as faeces or urine. Source: [http://www.nuh.com.sg/healthinfo/stoma/1\\_stoma.asp](http://www.nuh.com.sg/healthinfo/stoma/1_stoma.asp).

**Urinary tract infection:** occurs in 5% of children, in particular those below the age of seven years (Scott *et al.*, 1997), may be asymptomatic and, therefore, difficult to diagnose. Although the peak age incidence for the first attack of urinary tract infection is in the pre-school years diagnosis may be hindered or delayed because of practical problems of urinary collection in young children (Vernon, 1995).

**Vesicoureteric reflux:** the retrograde flow of urine from the bladder into one or both ureters. It is a pathological process and congenital in origin, although it can occasionally occur following surgery, trauma or infection. It is asymptomatic and unless complicated

*List of terms used in the thesis*

by urinary tract infection is of no clinical significance. A diagnosis in pre-school children is usually made only when they are investigated because of a diagnosis of urinary tract infection. A combination of vesico-ureteric reflux and urinary tract infection can lead to scarring of the kidney tissue (reflux nephropathy) which can ultimately lead to end stage renal failure (Scott and Stansfield, 1968; Scott, 1987).

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# **Chapter 1: Introduction**

## ***Background***

It is estimated that between 6% and 30% of children and young people are affected by chronic conditions with families increasingly becoming primary carers (Mattson, 1972; Rutter, Quine and Chesam, 1993). The incidence of chronic renal conditions amongst children is approximately 2.0 per 1000 live births (Cooper, 1999) and they can manifest at any age (some conditions are identified during routine antenatal screening). Living with chronic disease has implications for the quality of life of children and families (Hayes, 1997; Judson, 2004). They often need to develop knowledge and expertise in a wide range of skills and complex health care issues while coming to terms with the uncertainty of a condition with an unpredictable course (Cohen, 1993; Hayes, 1997). Although careful compliance with care regimes is seen as the key to promoting the quality of lives of children with chronic disease (Thompson and Gustafson, 1996), and can improve general health and nutrition, it can make life arduous for children and families. Indeed for some families it may be almost impossible to maintain such strict regimes (Coulthard and Crosier, 2002). Families are taught much of the skill and knowledge they need to manage the disease and its implications by professionals, who themselves have usually spent years being trained to provide health care. Families, however, have to learn quickly about the condition (Jerrett, 1994; Gibson, 1995) usually without the benefit of 'insider knowledge' of issues such as professional roles and hierarchies, funding and rationing of services, and the prevailing professional expectations of the role families will play in chronic disease management.

Increasing requirements for families to deliver and coordinate complex care at home and in hospital places them into new and often challenging situations (MacDonald, 1995; Kohlen, Beier and Danzer, 2000; Lowes and Lyne, 2000b). Setting out on a chronic disease course often means entering an unfamiliar, unpredictable and perhaps frightening world whilst having to navigate the way through previously uncharted territory. Children, parents, siblings, grandparents and friends bring to the experience a myriad of skills, personal knowledge, values and beliefs about health, disease and healthcare (Cooper, 1999; Callery, Milnes, Verduyn and Couriel, 2003). Some have previous experience of using the health service and some have no such experience. Some have expertise from working in the health service either as a professionally or non-

professionally qualified person and others know someone, perhaps a relative or close friend, who works in health care.

Unlike those who choose to work in health care, children and families do not choose to become part of the health service. There is, therefore, no application or selection process for becoming a patient or carer and no selection criteria against which children and families can be formally assessed (and if necessary rejected), to determine whether or not they have the ability to learn the required skills and manage the condition. There are no 'minimum educational entry requirements' and no 'curriculum' to establish what they will need to know and they are not subjected to written examinations or assessment of their 'progress and achievement' in the way that professionals are. No formal shift patterns, minimum or maximum working week or job descriptions exist and there are no unions or professional organisations to advocate and legislate on their behalf.

Many of those living with chronic disease are increasingly seen to aspire to achieving normalisation (Eiser, 1993; Robinson, 1993; MacDonald, 1995; Bradford, 1997) and are supported by a growing number of specialist nurses who provide a valuable bridge between home and health care settings (While, Cornish and Citrone, 1996; Glasper and Ireland, 1997; Feeg and Hunter, 2002; Scullion, 2004). However, colleagues in these evolving posts have expressed concerns about the growing volume of associated work, meaning that they have to spread their time thinly to support all families in their caseload (Darbyshire, 1990; Cowan, Warner, Lowes, Riberio and Gregory, 1997; Lowes and Lyne, 2000b; Griffiths, Foster, Barnes, Eldridge, Tate, Begum, Wiggins, Dawson, Livingstone, Chambers, Coats, Harris and Feder, 2004). As a result, children and families often need the competence to assess clinical situations and make decisions without immediate recourse to professional guidance.

Professionals, on the other hand, encounter a different set of circumstances at the outset of every child's chronic condition depending on their own role, status and level of expertise. At any one time, they are likely to be caring for many different patients at varying stages of the disease course and with varying degrees of dependence. Because of the way care is organised and services are configured, professionals may communicate with patients and colleagues in many different settings. Initial professional education and training, supplemented by ongoing continuing professional development (Eraut, 1994) reflection and work-based learning (Chalmers, Swallow and Miller, 2004) within an evidence based culture, helps to maintain a practice-related knowledge base involving technical and practical 'know-how' (Eraut, 1994). Working patterns for

professionals are organised by the employer into a shift-like approach to cover 24-hour care responsibilities. Staff work in teams, often multiple teams, each involving colleagues from different disciplines. Employment rights and equal opportunity regulations underpin working life. Professional input into the care delivery process is supported and legislated for by professional bodies (such as the Nursing and Midwifery Council and the General Medical Council) and government departments (such as the Department of Health, the Department for Education and Skills and the Department for Work and Pensions). Recognition of these many factors has been instrumental in the development of this study. An additional factor was my own motivation for wishing to explore the research topic in such detail and this is briefly discussed in the next section.

### ***The researcher's approach to the study***

As a registered general nurse and registered sick children's nurse, my clinical career has focused on the care of children in hospitals and I have cared for those affected by a wide range of chronic disorders at different stages of the disease course. Throughout my career, I have been proactive in cultivating a philosophy of family-centred care and believe that children and families should be supported to participate fully in decision-making and care if that is their wish. A wealth of published evidence has consistently advocated the real benefits to all concerned of this inclusive approach (Darbyshire, 1995; Hutchfield, 1999; Thomsen, 1999; Becker, 2002; Coleman, 2002b; Smith, Coleman and Bradshaw, 2002a; Franck and Callery, 2004). Working with families while leading and developing hospital based children's nursing services had made me curious about the way they acquired the competence to integrate the condition into their daily life. This interest led to a discussion paper in a paediatric nursing journal regarding the value of hospital out patient facilities for children (Swallow, 1990) and a subsequent publication with a mother of a child with asthma, one of the most common childhood chronic conditions, regarding our shared initiative to establish a hospital based parent support group (Swallow and Thompson, 1992).

A change in career direction to a Senior Nurse/Research Associate post introduced me to the world of health care research. This was in the area of chronic childhood renal disease (Scott *et al.*, 1997) and was a shift that coincided with my undertaking a part-time Diploma and then a Degree in Nursing. These experiences highlighted for me the immense potential that existed for experienced nurses to collaborate with colleagues on investigating aspects of health care and subsequently contribute to the knowledge base in chronic illness. This led to my undertaking an NHS Research Training Fellowship and

my MMedSci. research, a qualitative study exploring the views of mothers coping with chronic childhood renal disease (Swallow, 1997b). The literature review informing that study acknowledged a wealth of evidence on coping in chronic disease. It also highlighted a lack of empirical evidence about the way that families learn in health care despite widespread recognition that they are often regarded as experts in the care process. There was, however, an extensive literature based on professional learning in health care. An unexpected finding from that study was that some mothers reported difficulty in learning about their child's condition and further research was recommended to map prospectively the evolution of relationships between mothers and staff across the disease course (Swallow and Jacoby, 2001b).

It was this apparent gap in the knowledge base, combined with my move into a university based teaching development post in the area of continuing professional development and resulting insight into theories of learning, which stimulated my desire to investigate this topic further. These insights had, I believed, informed my own approach to teaching nurses and other health professionals in a positive way. Nevertheless, they also raised new questions for me about child health practice, in particular nursing practice. Could the way children and families learn about chronic disease be different from the way in which professionals learn? What would be the best way to evaluate families' learning? My reasons for undertaking this study then were twofold: to contribute to the knowledge base at a time when boundaries between families and professionals were becoming increasingly blurred, and to enhance my own understanding in clinical practice. Therefore, after discussing this widely with colleagues in higher education and clinical practice, I concluded that more appraisal of the process of learning by families participating in health care would allow the experiences of individuals to be explored and produce research findings to inform professional practice. This led to the development of the research described in this thesis. The study's aims are presented below:

### ***Aims of the research***

- To investigate the way that children and their families learn to manage chronic renal disease following referral to a Children's Kidney Unit.
- To explore the impact of the relationship between families and practitioners upon the way children and families learn.

Having discussed the background to the study and introduced the aims of the research, the following section summarises the structure of this thesis.

## **Structure of the thesis**

The thesis comprises eight chapters: introduction; literature review; philosophical, theoretical and ethical approaches to the study; research design; three chapters of findings and a final chapter containing discussion and final conclusions. For conciseness throughout the thesis, the term 'children' is used when referring to 'children and young people'. When referring to chronic disease or illness, both terms which are frequently used interchangeably in published literature, the term 'chronic disease' is used for consistency.

In chapters 3, 4, 5, 6 and 7, participants' verbatim quotations are widely used to illustrate and support aspects of the discussion. In order to protect anonymity and confidentiality, accounts by family members are identified using the child pseudonyms outlined in Figure 6 and reference to the relevant study phase. Where professionals' accounts are included and because of the small number of staff involved as research participants, these are identified by the professionals' role only (for example nurse, dietician, doctor). My own involvement in dialogue with participants during research interviews, is indicated by the term 'Int': (an abbreviation for interviewer). Other conventions used in presenting the data include:

- Clarification by me of an aspect of a verbatim account is included in square brackets [ ]. Emphasis by an interview participant on a particular word or phrase is denoted by bold text. An example of these is presented below using an excerpt from an interview account by Nina's mother in phase two:

I can't fault Dr [local paediatrician] although he had never checked them [Nina's kidneys] again, I can't fault him because he has been **fantastic** [Mother's own emphasis], I mean, and we could see how shocked he was when he came with the results of the scans. He was **totally shocked**.

- A gap in the data presented, denoting a section of an interview that was deemed irrelevant to the context and, therefore, excluded in the reporting is indicated by the use of a short space in the text ...with three full-stops.

## **Outline of the remaining chapters**

In chapter 2, the literature review sets the scene for the research and focuses around the two main themes of this thesis, social participation by families and professionals in caring

for the child, and learning by families in the health care context. An examination of the evolution of child health principles, practices and attitudes leads into an exploration of the current context of care for children and young people with chronic health problems. Models of care for chronic disease are compared and contrasted and prevalence, aetiology and management of chronic disorders, including chronic renal problems, are discussed from the global and local perspectives. The psychosocial consequences of chronic disease are explored with literature about the uncertainty associated with coping, reconstitution of the self, life-biography and relationship developments being discussed. The literature on patient and professional learning, competence development and the impact of social engagement in communities of practice is investigated and the main themes extrapolated as background for the research.

Chapter 3 places the research into its philosophical, theoretical and ethical contexts. In discussing the philosophical and theoretical approaches to the study, a rationale is provided for adopting a qualitative approach using symbolic interactionism within an interpretive framework to help address the issues of social processes, identities and shared experiences of participants. It highlights the main ethical considerations relating to the conduct of research involving children and families and emphasises the fact that children, as a relatively powerless group in society, nonetheless have the same rights to confidentiality and anonymity as adults. The need to demonstrate integrity and rigour of this research was a key endeavour of the thesis and so chapter 4 provides readers with an overview of the research design and process. The issues of theoretical sampling and theoretical sensitivity and co-construction of knowledge are considered and the processes used for collecting and analysing data from interviews involving children and adults, reflective accounts and casenote documentation are described. Finally, the steps taken in generating the social theory of learning in childhood chronic renal disease are outlined.

The findings of this study are presented in chapters 5, 6 and 7 using examples from participants' accounts and records. In addition, Cases identified in phase two are used to illustrate the emergent categories and concepts. Within these chapters, the three categories (assessing, interacting and synthesising) that underpin the social theory of learning in childhood chronic renal disease are explored and discussed. Assessing 'mutual ability', 'social positioning' and the child's 'disease trajectory' were interrelated concepts within the process of assessing that were explored in chapter 5. Participants' accounts help to illustrate: the diversity of disease courses regardless of the level of intervention required; the significance of mutual assessments of competence; and the

relevance of social positions which individuals adopt and ascribe to others in the management of childhood chronic disease. Chapter 6, meanwhile, explores the central category, the process of interacting. Participants' accounts help to highlight the important but sometimes challenging issues of sharing 'personal and professional knowledge', trying to foster 'mutual trust' and the significance of these concepts in respect of shared 'decision making'. Chapter 7 demonstrates the way in which the process of synthesising occurred and emphasises the importance of children and families being recognised by professionals as co-learners.

In the final chapter, the main debates from the preceding chapters are drawn together. The concept of learning as social participation in childhood chronic renal disease is reconsidered and the implications of the study for theory, practice and research are explored. Consideration is given to the use of symbolic interactionism in developing the current theory. The provenance of the social theory of learning proposed by Wenger in 1998 is explored and the product of this current study, the social theory of learning in childhood chronic renal disease, is compared against this and then used to appraise existing related literature. This critical analysis of the social theory of learning in childhood chronic renal disease includes detailed discussion of the three emergent and interrelated categories of assessing, interacting and synthesising identified by this study. The two main themes of the thesis, social participation by families and professionals in caring for the child, and learning by families in the health care context underpin the discussion. Further development of the theory and its usefulness in caring for children with chronic renal problems is indicated by this study.

## **Conclusion**

This initial chapter provides some background information and the rationale for carrying out the study. The next chapter presents a review of selected literature pertaining to the research.

## **Chapter 2: Literature Review**

This chapter grounds the research in an exploration and discussion of the literature relating to the clinical context; the psychosocial context and the learning and teaching contexts of childhood chronic disease. The literature to be reviewed was located following manual library and computer searches involving CINAHL, Web of Knowledge, MedLine and PsycLit. and included only English language material from 1947 until 2005. Search terms used included: children; young people; parents; families; chronic disease; chronic illness; renal; coping; learning and competence.

### ***The clinical context of childhood chronic disease***

This section provides background information about the evolution of current contexts of care for chronic childhood conditions. This leads into an overview and discussion of the prevalence and aetiology of generic, childhood chronic disease and in particular chronic childhood renal problems. Finally, conclusions are drawn from the review about the significance of these issues to child and family learning about chronic renal problems.

### **The evolution of child health care**

The backdrop for today's child health service is a complexity of practices, policies, concepts and beliefs. Historical events and society's prevailing attitudes have determined whether or not children are highly valued and the concept of 'childhood' as we know it today is surprisingly new. Throughout history there are many examples of children's health and welfare being accorded low priority, as well as isolated examples to the contrary. A rare example of early institutional health care for children and their mothers was established in London in 1769 by Dr George Armstrong because he believed that taking a sick child away from its mother would break its heart immediately (Miles, 1986). Later, in 1851, and against much opposition in a society where children's needs were always subordinated to those of adults, Dr Charles West founded the Hospital for Sick Children in Great Ormond Street, London. The early 1900s saw the emergence of a political philosophy that viewed children as a national resource, which led to significant changes in the level of influence governments were prepared to exert upon families. Women of all classes were encouraged to see their duty in bearing and raising healthy children (Foley, 2001), while those from working classes were held responsible for the social problem of weak and sickly children (Lewis, 1984) and the



education of mothers as a solution to the problem of children's ill health was promoted (Hendrick, 1990).

Nevertheless, concerns persisted about the levels of poverty, sickness and malnutrition amongst the poorer classes and their effects on the health of children (Miller, 1997). In 1923, Sir James Spence, the first Professor of Child Health in the UK, opened the Babies Hospital and Mothercraft Centre for 'malnourished' children in Newcastle upon Tyne, where inevitably care proceeded beyond 'feeding difficulties'. The novel feature of this situation was that mother and baby were admitted to the same room where care could continue and separation be avoided. Here children were assessed and treated for a wide range of disorders. Technical care was administered by trained nurses while 'daily care' continued to be provided by the mothers (Spence, 1947; Ridley, 1956). The prevailing UK paediatric policy required that, whenever possible, sick children be treated in their own homes. Hospital systems, meanwhile, were based on asepsis and rigid routines to prevent cross-infection and usually excluded family members (Spence, 1946; 1947; 1950).

Apart from the Babies Hospital example, it appears that up to the 1950s hospitalised children and their families in developed countries continued to be separated during prolonged hospital stays. This practice reflected the widely held, behaviourist ideologies that discouraged emotional interaction with children and promoted regimented care and restricted parental visiting (Darbyshire, 1993; Alsop-Shields, 2002). The 1950s saw 'separation from mothers' beginning to emerge as a recognised cause of deprivation in young children (Bowlby, 1953; Robertson, 1953; 1955; 1958). Platt (1959) endorsed this work and once again the psychological needs of hospitalised children were recognised with the recommendation that parents be able to visit at reasonable times. This was closely followed by the creation, by parents, of the National Association for the Welfare of Children in Hospital.

Although implementation of Platt's recommendations was exceedingly slow and sporadic (Palmer, 1993; Bridgeman, 1999), it and the impact of the National Association for the Welfare of Children in Hospital, gradually became remarkably influential in the social construction of the concept of family-centred care. Nevertheless, there was often resistance from health care staff who were not convinced that parental presence was a positive move (Darbyshire, 1989; Robbins, 1991; Darbyshire, 1995). However, services started to respond slowly, triggered by subsequent policies advocating the involvement of families in children's care in both home and hospital environments. Court (1976), in

reinforcing the differences between children and adults, described children's services as a 'Cinderella Service' and recommended that nurses and parents work in partnership. Meanwhile the Children Act (DoH, 1989) emphasised the responsibility parents hold for their children and urged health professionals to adopt a family-centred approach to care. This was further reinforced by the Audit Commission (1993; 2003) and the DoH (1996).

More recently, the children's policy agenda has become increasingly focused and complex with the implementation of the National Service Framework for Children (DoH/DfES, 2004), the Poverty Review (HMSO, 2004a) and the Children's Bill (HMSO, 2004b), all aiming to improve lives and health for children, young people and pregnant women and reduce widening inequalities by setting standards for health and local authority services. Much adult ill health has its roots in childhood and children are vital for our national economic survival (DoH/DfES 2004). Systems failures exposed by Kennedy on behalf of the Department of Health (DoH, 2001b) and Lord Laming on behalf of the Department for Education and Skills (DfES, 2003) included the following:

- care always subordinated to adults,
- lack of concern for vulnerable individuals,
- ignoring rights that require protection,
- quality of care less than it should be,
- fragmentation and lack of responsibility,
- lack of effective planning,
- failure to listen to patients and carers,
- lack of effective leadership.

Addressing these is a key feature of the current policy agenda and has led for the first time to a coherent strategy for children's health in England as well as more effective responsibility for integrating service delivery at local level. Implicit in this strategy is the belief that:

*Children and young people are a nation's most precious resource and their health is vital for the future success of society (Aynsley-Green, 2000:230).*

The concept of family-centred care is the professional support of the child and family through a process of involvement, participation and partnership underpinned by empowerment and negotiation (Smith, Coleman and Bradshaw, 2002b). As part of the evolving concept of family-centred care, parents have since the 1960s demonstrated an

ability to influence child health care through the activity of the National Association for the Welfare of Children in Hospital. This included monitoring and reporting on how the Platt report's psychological recommendations are being implemented (Darbyshire, 1993). Since 1991, The National Association for the Welfare of Children in Hospital has been called Action for Sick Children in recognition of the increasing emphasis on community care for sick children. Action for Sick Children also involves parents and plays an influential consultative role to key policy makers and government in the development of healthcare policies for children. Family-centred care has subsequently gone through constant refinement of meanings (Richman and Skidmore, 2000) and child health care in the UK has moved from care by the family at home to care by professionals in hospital to care at home or in hospital by family and health professionals in partnership (Evans, 1994; Casey, 1995; Coyne, 1995; 1996; Alsop-Shields, 2002). The next section will focus discussion on the issue of partnership in child health care.

### **Partnerships in child health care**

Implicit in this debate about the clinical context of chronic disease is the need to recognise the concept of partnership as increasingly pivotal in the health, education and social care of children. In an attempt to clarify the complex relationships that exist between parents of children with special needs and professionals, Cunningham and Davis (1985) identified three models (the expert model, the transplant model and the consumer model). In the expert model, professionals take control of the relationship and make all decisions leading to a situation where often parents are reluctant to question the professional. Rather than reinforcing feelings of competence and independence, this model is more likely to foster dependence in the parents. The transplant model sees professionals recognising that part of their own expertise can be transplanted into the care of the parents where it might grow. This model does, however, require the professional to use additional skills of facilitation, but is likely to improve relationships and parental compliance while reducing dissatisfaction. By contrast, the consumer model sees the professional acting in a consultative and instructional capacity, with the parent being very involved in decision-making. One implication of this model is that professional power is not entirely determined by professional status but by their effectiveness in establishing the negotiating processes and helping to find solutions.

In exploring the issue of partnership nursing and its influence on involvement of family carers in the management of hospitalised children, Casey (1995) surveyed 243 children, 85 percent of whom were receiving some care from a family member. Major influences

on the amount and type of family involvement included: type and acuity of disease, length of stay and the language spoken by the family. Non-significant influences included the number of dependent siblings, ethnicity and social class of the family. The characteristics of interaction, such as communication and nursing style, were found to be more significant than social structural factors. Therefore, a typology of nursing approaches was proposed, involving an intersection of two axes: a 'communicating' to 'non-communicating' continuum and a 'person-centred' to 'nurse-centred' continuum. Casey suggests this framework could apply beyond the paediatric context, especially as current policies mean that relatives caring for sick, elderly and disabled people of all ages in the community work in partnership with nurses and other community staff. There is some resonance, therefore, between the notion of partnership in child health and in other areas of health care where family carers prevail.

For instance, Twigg and Atkin (1994) were amongst the earliest researchers to recognise that family carers are the bedrock of community care and yet our understanding of how they do and do not fit into the care system is limited. Similarly, when discussing partnerships in relation to dementia care, Clarke (1995), generated a theory of normalisation which proposes that family carers define and redefine what is perceived to be normal for their life; that of the person with dementia and their relationship. Family carers are described as being orientated to the past relationship with the person and to that which is normal in the relationship and the individual with dementia. Conversely, professional carers are presented as being orientated towards the future, the disease and that which is problematic. In a similar way, in child health care parents are viewed as informal carers who may grieve for the loss of the child they knew before the diagnosis and the future they had anticipated for them. Canam (1993), points out that the period following a diagnosis of childhood chronic disease is an anxious and distressing time for the whole family.

Partnership with children is of course an essential part of chronic disease care, especially if children are to learn to become competent in managing a condition that is likely to stay with them for an indefinite period of time. Developing partnerships with children requires excellent communication skills on the part of professionals who, as Cooper (1999) points out, need to see children as partners in their own right. This is particularly challenging, however, as children are constantly changing and developing and may have limited skills to enable them to express their wants or needs. Consequently, children may depend on their family and professional carers to interpret their needs rather than adults putting their own interpretation on the child's needs. In

addition to family centred approaches, therefore, strategies need to be developed that are child centred and which view the child and the parents as equal partners in the decision making process (Cooper 1999). Therefore, the issue of partnership is clearly relevant to families learning, especially in view of the prevalence and aetiology of childhood chronic disease. Both these factors will now be discussed in the next section.

### **Prevalence and aetiology of childhood chronic disease**

Children under 16 years of age comprise 20% of the population of England and Wales (OPS, 2004). Globally, childhood chronic disease has become an increasing concern (Marks and McQueen, 2001; Judson, 2004) and as the global, infant and child mortality rate is declining there is a concomitant increase in childhood chronic disease. It is predicted that in the next 50 years there will be a growing transition from acute to chronic diseases (Oduntan, 1995; Marks and McQueen, 2001). Advances in health care are leading to improved life-expectancy for children with chronic disease and a growing number are now surviving into adulthood (Newacheck and Taylor, 1992; MacDonald and Callery, 2004; Wang and Barnard, 2004). Meanwhile Craft (2004), when considering the community support required by children and young people with complex and enduring health care needs, reminds us that:

*Health services have for many years concentrated on curative medicine or the promotion of health, meaning that those who experienced a long-term disability have had to take a back seat... (Craft 2004:193)*

It is predicted that by the year 2015, 623 million children worldwide under 5 years of age and 1.2 billion aged between 5 and 14 years will have a significant chronic disease (Buckens and Boerma, 2001). Estimates of prevalence of chronic disease are variable, ranging from 6% (Rutter *et al.*, 1993) to 30% (Mattson, 1972). The reasons for this discrepancy are complex but include the following:

- a number of differing definitions exist for 'chronic disease' (Strauss, Corbin, Fagerhaugh, Glaser, Suczek and Weiner, 1984; Thorne, 1993; Bradford, 1997; Vila, Nollet-Clemencon, de Blic, Mouren-Simeoni and Scheinmann, 2000), this will vary between developed and developing countries and the exact definition used will significantly influence the number of children identified (Judson, 2004),
- tracking the figures in populations has up to now not been a priority (Wallander, 1996; WHO, 2002; Wilson, Bladin and Saling, 2004),

- diagnosis is not a straightforward process. It can take many years and is influenced by the recognition and reporting of symptoms on the part of families and a willingness on the part of professionals to listen to and take families' concerns seriously (Eiser, 1993; Eiser, Kopel, Cool and Grimer, 1999; Swallow and Jacoby, 2001a),

The following figure presents an estimate of chronic childhood disorders, extracted from a variety of sources worldwide. This is followed by a brief discussion about the way in which chronic disease has been defined:

Figure 1: Estimated incidences of common chronic disorders of childhood worldwide (Cooper 1999:4)

| Chronic disease  | Estimated incidence per 1000 live births |
|--|--|
| Arthritis  | 0.1                                      |
| Asthma   | 13.1                                     |
| Chronic renal disease  | 2.0                                      |
| Cystic fibrosis  | 0.5                                      |
| Cancer   | 14.0                                     |
| Diabetes mellitus  | 1.9                                      |
| Epilepsy   | 1.7 (under 10 years) 3.3 (over 10 years) |
| Eczema and allergies   | 32.9                                     |
| Congenital heart disease   | 8.0                                      |
| Inflammatory bowel disorder, Ulcerative colitis, Crohn's disease | 6.0                                      |
| Haemophilia  | 0.13 (Male)                              |
| Leukaemia  | 0.032                                    |
| Sickle cell disease  | 0.4                                      |

### Definition of childhood chronic disease

It is difficult to define accurately what constitutes a chronic disease, indeed Bradford (1997:5) suggests that one of the most difficult tasks in writing about chronic disease is:

*...to be clear what is meant by the term. A number of definitions exist with Eiser's being the most relevant to current practice and, therefore, the one adopted in this study:*

*...conditions that affect children for extended periods of time, often for life. These 'diseases' can be managed to the extent that a degree of pain control or reduction in attacks, bleeding episodes or seizures can generally be achieved. However, they can not be cured. (Eiser, 1990:3)*

This definition is indicative of the longevity of chronicity and so reflects current trends by not referring to long periods of hospitalisation. Eiser does allude to the possibility of

controlling symptoms although does not acknowledge that with good preventative management the impact of some conditions can be relatively minor and that children can often, despite the condition, achieve a degree of 'normalisation' (Robinson, 1993). There is also broad agreement that the range of conditions considered to be 'chronic' is being extended and there is increasing overlap between the terms 'chronic disease', 'chronic illness', 'disability' and 'handicap' with regard to children (Gravelle, 1997; Shakespeare and Watson, 1998; Sloper, 1999; DoH, 2001a; Watson, Townsley and Abbott, 2002). There is still some dissonance in the research literature about whether or not chronic disease and disability should be classified as a single group or as separate groups (Boyle, Decoufle and Yeargin-Allsopp, 1994). This may be due partly to the difficulty of separating out the problems of children with a chronic disease and those with a congenital or acquired disability (Cooper 1999). A child with a disability is not necessarily ill but a child with a chronic disease may (or may not) have a disability. Disabled people themselves as part of the international disabled people's movement have developed this social approach, the social model of disability. Disabled people and disabled commentators are constantly subjecting it to review and re-evaluation. Its key feature is that it distinguishes between 'impairment' and 'disability'. Impairment is taken to be the actual or perceived absence or functional limitation of a limb or sense. Disability is defined as the negative societal response to people with (perceived) impairments. Disability, therefore, is conceived of as a form of social oppression, linked with, but certainly not necessarily following from impairment. The social model of disability, therefore argues that no-one has a disability but that they are disabled by societal reactions towards them (Shakespeare and Watson, 1998; Cocks, 2000; Watson *et al.*, 2002).

### **Acute versus chronic disease**

Despite a predicted, growing transition from acute to chronic disease (Oduntan, 1995; Marks and McQueen, 2001), acute childhood diseases currently make up a high proportion of consultations with general practitioners and practice nurses (McCormick, Fleming and Charlton, 1995). The Health Commission reports that the most common reason for attendance is upper respiratory tract infections that make up 27.6% of consultations for those aged 1-15 years (DoH, 1997b). The majority of acute childhood disease is of short duration and takes place in the home (Neill, 2000). It is widely recognised that unlike acute disease in childhood, chronic conditions often have a vague onset (Thompson and Gustafson, 1996). Because of the vagueness of early symptoms (Ray and Ritchie, 1993) or the problem of medical scepticism (Burton, 1975; Swallow

and Thompson, 1991; Cohen, 1997) arriving at a diagnosis may take a long time. There is a possibility that mothers' attitudes towards professionals will be coloured by dissatisfaction when consulting about an acute disease, which may lead to them under-reporting symptoms of what could be the early stages of a chronic disease (Scott *et al.*, 1997).

In my own earlier research, time of diagnosis of a child's chronic renal problem was found to influence mothers' ongoing ability to cope with its consequences; earlier diagnosis leading to better coping (Swallow and Jacoby, 2001a). In addition, mothers' evolving relationships with professionals across their child's chronic disease course were found to be influenced by the quality of the relationships they had developed with professionals during the pre-diagnostic phase (Swallow and Jacoby, 2001b). Reynolds, Garralda, Jameson *et al* (1988), Macdonald (1995) and Scott *et al* (1997) found that families reported significant difficulty in coping and learning to live with chronic renal conditions and that the quality of relationships with professionals was central to the learning process. Failure of families to become competent in managing the condition may negatively influence the child's clinical outcome. For instance a child requiring dialysis may need to return frequently to hospital for haemodialysis if the family is not considered competent to manage peritoneal dialysis at home (MacDonald, 1995). The lack of agreement on what actually constitutes chronic disease is mirrored in reported attitudes towards systems of classification of chronic diseases. This is explored further in the next section.

### **Classification of childhood chronic disease**

Categorical approaches to classification have led to conditions being grouped according to aetiology, disease characteristics or disease severity. One example of the *aetiological approach* is Mattson's classification (1972). This was modified by Fielding (1985:34) who suggested that there are five main causes of chronic disease and suggested that the psychological effects of chronic disease should, therefore, be studied in relation to these categories. Fielding identified these causes as being:

- Due to chromosomal aberrations.
- A result of abnormal hereditary traits.
- Due to intrauterine factors.
- A result of perinatal traumatic and infectious events.
- Due to postnatal and childhood infection, neoplasm and other factors.



The advantage of this approach is that it closely aligns to the Medical Model of care, reflecting the way health care services are administered, funded and managed. As Bradford (1997) points out, classifying chronic diseases according to condition specific factors, for instance all children with cystic fibrosis, diabetes or renal problems may be a pragmatic approach. Dedicated staff will become experts in managing condition(s) and supporting families (Clarke-Steffan, 1993; 1997). This approach has also determined the direction of much epidemiological, medical and health service research and has proved beneficial in enabling advances in diagnosis and treatment of specific disorders. However, it is still uncertain whether particular disease groups are associated with specific psychological outcomes as suggested by Fielding (1985). For instance Rutter, Tizard and Whitmore (1970) identified an increased risk of emotional and behavioural problems in children with neurological disorders. On the other hand, Pless and Perrin (1985) concluded that there was insufficient evidence to establish a link between specific diseases and particular psychosocial problems. Therefore, it appears that grouping chronic conditions according to aetiology may be a limited approach.

According to the *disease characteristics* approach, psychological outcomes are mediated by specific disease outcomes (Pless and Perrin 1985). Diseases can be categorised according to whether they have an impact upon the child's level of mobility; whether the disease is static or dynamic; the child's age at diagnosis; whether the child's sensory or cognitive function is affected by the disease and finally whether the condition is visible. The main proponents of this approach are Pless and Perrin (1985) who claim that these dimensions might be significant in assessing the variable impact of chronic diseases on children. However, their hypothesis has not yet been subjected to extensive empirical study. Whether a disease course is static or dynamic may have significant implications for psychological adjustment. Similarly, children who have grown up with a chronic condition may have very different patterns of adjustment compared to those who develop conditions during adolescence (Eiser, 1986).

In the third approach, *disease severity*, there are two conflicting bodies of evidence. One hypothesis is that the more severe conditions lead to worse psychological outcomes, however, the evidence suggests overall that disease severity is not in itself a reliable predictor of psychological distress in children. MacLean, Perrin, Gortmaker *et al* (1992) demonstrated a relationship between clinical severity of asthma and children's psychological adjustment while Perrin, Maclean and Perrin (1989) found that children with moderate asthma were better adjusted than those with mild or severe asthma. Meanwhile Wallander, Feldman and Varni (1989), who investigated children with

cerebral palsy and spina bifida, failed to establish any association between the conditions and children's emotional adjustment.

Stein and Jessop (1982) and Varni and Wallander (1988) claim that there is already sufficient convincing evidence to justify a cessation of attempts to search for idiosyncratic reactions to specific disorders, and that children's adjustment problems did not vary according to their diagnosis. The non-categorical approach to classification increasingly replaces the categorical, however, and Bradford (1997) argues that research should stop trying to find idiosyncratic consequences to conditions and concentrate upon the challenges that apply across a range of conditions. There are other factors suggesting that this non-categorical approach has more advantages than disadvantages. For example, whatever the reason for admission to hospital a child of school age will lose time from school so a non-categorical approach will explore the common experiences of children across the disease spectrum. As pointed out by Eiser (1993) and reiterated by Cooper (1999), this approach will serve to benefit children with rare conditions who would not normally be involved in research. Consequently, this approach can lead to promotion of positive policies.

There is now an emerging school of thought promoting a modified approach to classification. Initially promoted by Pless and Perrin (1985), it can identify the disease specific characteristics and the general adaptation processes of children while using examples of how they might differ according to individual conditions. It is anticipated that this two-pronged approach will help practitioners and researchers to develop a broader strategy to improve child health services (Cooper, 1999). From the preceding discussion, it is clear that there are some cross-cutting issues relating to the way in which services are structured for managing childhood chronic disorders. Therefore, an agenda that is aligned to the modified approach is likely to create far reaching benefits. In the next section, I will outline some of the relevant issues concerning chronic childhood renal problems.

### **Chronic childhood renal care**

The incidence of chronic renal problems amongst children is approximately 2.0 per 1000 live births (Cooper 1999) and they can manifest at any age (some conditions are identified during routine antenatal screening). According to the British Association for Paediatric Nephrology (BAPN, 1995) services must be:

- Provided by specialists who can maintain and develop their expertise, which necessitates a minimum caseload and hence population base.
- Convenient for patients and their families.

However, there may a conflict between the two preceding points and the organisation of services needs to take into account the comparative rarity and complexity of the conditions, the high cost of service provision and the fact that population density will vary in different geographical areas. Service provision requires links with other specialities including: paediatric intensive care; cardiology; oncology; endocrinology; haematology; surgery (for the management of surgical disorders that threaten renal function) and peritoneal and vascular access surgery; Fetal Medicine Services (including obstetrician, radiologist, ultrasonographer, urologist, neo-natologist and geneticist for management of fetal uropathy) and adult renal services for transfer of adolescents requiring ongoing care and renal transplantation service. There are currently 14 designated Children’s Kidney Units in the United Kingdom and Eire (BAPN, 2002). The range of conditions managed in these units are outlined in the following figure:

Figure 2 :Type of service and related renal problems in UK Children’s Kidney Units : (BAPN, 1995:6)

| Type of Service   | Renal problem  |
|---|--|
| <i>Specific</i><br>(Available in Regional Children’s Kidney Units only) | <ul style="list-style-type: none"> <li>• End Stage Renal Failure.</li> <li>• Acute Renal Failure.</li> <li>• Renal Biopsy.</li> </ul>  |
| <i>General</i><br>(Also available in District General Hospitals)        | <ul style="list-style-type: none"> <li>• Pre-end stage renal failure.</li> <li>• Pre-biopsy assessment of glomerulonephritis, haematuria and proteinuria, urinary tract infections and associated conditions.</li> <li>• Neuropathic bladder and other conditions requiring urodynamic investigation.</li> <li>• Prenatal diagnosis.</li> <li>• Hypertension.</li> <li>• Renal Tubular Disorders.</li> <li>• Metabolic Renal Stone Disease.</li> </ul> |

Managing chronic renal disease can involve children and families in a wide range of home based care regimes including: dietary modifications; obtaining and testing (or arranging for testing) urine samples; administration of oral medications; overnight gastrostomy feeding; subcutaneous injections of erythropoietin or growth hormone and

peritoneal dialysis; as well as care and maintenance of a central venous lines. Although careful compliance with care regimes is seen as the key to promoting the quality of lives of children with chronic disease (Thompson and Gustafson, 1996), and can improve general health and nutrition, it can make life arduous for children and families. Indeed for some families it may be almost impossible to maintain such strict regimes (Coulthard and Crosier, 2002). The BAPN highlights the fact that the burdens of renal disease on the child and family can be extensive and that these may have implications for the long term success of treatment and, therefore:

*...it is essential that adequate psychological support is provided to mitigate the difficulties associated with effective treatment and ensure the best quality of life [for children and families]. (BAPN, 1995:4)*

Like other chronic childhood diseases chronic renal diseases appear to present a number of challenges to the child, family and professionals concerned in the clinical setting.

## **Summary**

Despite a long-standing recognition of the need to provide seamless care for children and families in health care, there is evidence in the literature that this is still not happening widely. The position of children on the national political agenda has persistently been subordinated to the position of adults. The number of children affected globally by chronic conditions is expected to continue rising, yet this situation is complicated by the lack of agreement about definition and classification of chronic disease. This section has helped to set the scene for the research by outlining the changing world of child health care and the clinical context of childhood chronic disease. The next section will consider the psycho-social consequences of chronic disease and the effect these may have on families' learning about the conditions.

## ***The psycho-social context of childhood chronic disease***

It is widely recognised that when a child or young person is affected by a chronic disease, the impact of the condition and its consequences can have far-reaching psychological and sociological effects on them, their families, their friends and temporary carers. In this section, selected literature on communication, models of coping and adaptation and the problem of uncertainty as well as that relating to reconstitution of self, life biography and social positioning will be considered and subsequently examined in relation to the development of family learning in childhood chronic renal disease.

## Communication

There appears to be a need to identify the strengths of families to meet challenges of chronic disease in order to develop interventions that enhance child and family adaptation. (Manfredi, Czaja, Buis and Derk, 1993). In discussing adaptation to childhood chronic disease, Thompson and Gustafson (1996) emphasise the amazing resiliency of children with chronic disease and their parents in the face of adversity and Gibson (1995) has discussed the development of the process of empowerment in mothers. Kieffer had previously explored the developmental perspective of citizen empowerment in preventive social and community interventions (Kieffer, 1981). This was in response to an acknowledged gap in the existing body of literature in the area of citizen participation in community organisations and the area of empowerment, a concept with roots in the 'social action' ideology of the 1960s and the 'self-help' perspective of the 1970s. That research which existed, related empowerment to concepts such as coping, mutual support, personal efficacy, competence and self-esteem (Davies and Zerchykov, 1978; Gittel, Hoffacker, Rollins and Foster, 1979). In particular, Kieffer identified a striking absence of research evidence pertaining to issues of individual empowerment. Concurrently, Rappaport (1981) explored the ideology of emphasis on 'rights and abilities' rather than 'deficits and needs'. In particular, she described empowerment as a process of learning and development in the face of adversity rather than an unchanging status.

This was in harmony with Kieffer's approach and so helped to extend the dialogue on the developmental perspective of empowerment. This was subsequently investigated by Kieffer (1984) who used a phenomenological approach to explore empowerment as a developmental process in adults who were emerging citizen leaders in grassroots organisations. The transition from a state of powerlessness to participatory competence was characterised as a dynamic of long-term development from socio-political 'infancy' to socio-political 'adulthood'. Kieffer identified four distinct and progressive phases of involvement (era of entry, era of advancement, era of incorporation, era of commitment) as these individuals constructed the skills and insights that constitute a fully matured attainment of participatory competence. These are outlined in more detail in Appendix 11. Two pervasive themes underlie the movement through all four phases. First, in the struggle towards empowerment, conflict and growth are inextricably intertwined with a continuing, internal constructive dialogue. Second, experience and reflection are at the core of empowering learning. Therefore, involvement generates insight that in turn promotes more knowing participation. Ultimately, Kieffer viewed empowerment as an

abiding set of commitments and capabilities or participatory competence. Participants did not view themselves as 'having more power' but as 'feeling more powerful'. They had not necessarily gained social influence or political control but felt able to engage effectively in the dynamics of socio-political exchange.

More recently, Gibson (1995) redefined Kieffer's definition of participatory competence in relation to the process of empowerment in mothers of children with a chronic disorder. This appears to be the first example of this concept being used in child health care. Following a theoretical analysis, Gibson (1995) conceptualised empowerment as a *social* process of recognising, promoting and enhancing people's abilities to meet their own needs, solve their own problems and mobilise the necessary resources to feel in control of their lives. Subsequently, a fieldwork study was undertaken to describe the process of empowerment pertaining to mothers of children with a chronic neurological disorder. Four components of the process were identified: discovering reality, critical reflection, taking charge and holding on. Gibson presents the process in a sequential manner although in reality it is iterative and interactive rather than linear in development. The mothers who did attain participatory competence had developed sound knowledge of their child and the condition. In addition, they were competent in caring for and had developed confidence in communicating to professionals, what was best for their child. Those who were most empowered attained participatory competence. Nevertheless, empowerment resulted in some negative consequences. For instance, at times professionals were unwilling to share power and rejected the mothers' suggestions. Conversely, when professionals recognised mothers' competence they sometimes placed too much responsibility on them to make decisions and assume total care of the child. Furthermore, those deemed to be empowered reported that they did not always receive the support they required from professionals.

Factors influencing the process of empowerment were both intrapersonal and interpersonal. However, the unique and pervasive finding of Gibson's study was that the process of empowerment was largely intrapersonal and included factors such as values, beliefs, determination and experience. Some mothers benefited from support, for instance from family, friends or professionals. However, unlike Kieffer's findings in which a sense of community was critical to personal empowerment, most of the mothers in Gibson's study did not benefit from such support and did not have a facilitator or external enabler to mentor them along their path to empowerment. Indeed only one mother identified anyone who was influential along the way. The components of Gibson's

process of empowerment are interdependent and overlapping; these are detailed in Appendix 12.

Gibson concluded, therefore, that research efforts to understand the process of empowerment in mothers who have such support will shed further light on the phenomenon of empowerment in mothers of chronically ill children. Therefore, Gibson recommended future research efforts to understand the process of empowerment in mothers who have support through nursing interventions directed at facilitating social support. This, she claimed, would provide an understanding of what, when and how support is efficacious during the empowerment process. A parent support group initiated by myself and a mother following a survey of parents of children with asthma (Swallow and Thompson, 1992) is one example of the way in which interpersonal communication can empower families.

Attempts to understand the significance of relationships between those with chronic disease and professionals highlighted several factors that may influence satisfactory relationship developments. These include the sources of stress for families and attitudes and values of professionals, in particular nurses and doctors. Consequently, research is increasingly directed at exploring the evolution of these relationships. Cohen (1995) identified three phases before early concerns for their child were eventually appraised as serious by professionals and a diagnosis was made: Lay Explanatory; Legitimizing and Medical Diagnostic. In the first of these phases parents sought lay explanations for unexplained symptoms presented by their child. Cohen also found that learning to communicate effectively with professionals about their child's early signs and symptoms was a significant source of stress for parents. The transition from the Lay Explanatory phase, when signs and symptoms forced their way into parents' conscious awareness, to the Legitimizing stage happened only when they conceded their parental limits. In order to maintain parental credibility while ensuring they engage the doctor's interest in their child, parents adopted a strategy for presenting the problem. Thus, transition to the Medical Diagnostic phase began with an appointment to see the doctor, and only ended with diagnostic certainty. The process of developing relationships across the disease course as one involving naïve trust; disenchantment and guarded alliance was conceptualised by Thorne and Robinson (1988) and later related to negotiation in health care (Thorne, 1993). Guarded alliance leads to a state in which a measure of trust could be constructed by families on the basis of new insights about the limitations of the health care system and the realities of living with chronic disease.

Communication is also deemed to be of great significance by policy makers. The Department of Health (1991) and (1997a), for instance, argue that every citizen has the right to a clear explanation of any proposed treatment, that includes the risks and alternatives, before they agree to that treatment. However, communication is a two-way process and according to Arthur (1995) it is important to discover what patients want to know before providing information. There is also evidence from the Audit Commission (1993) that lack of appropriate information is a major source of complaint from patients and parents (Alderson, 1990a). Identifiable underlying causes for information provision being criticised by patients include differing views of staff and patients (Tates and Meeuwesen, 2001); inefficiencies in the available information systems; lack of expertise and standards in information provision and lack of resource management (Boyd, 1987; Caughey, 1989). Crawford (1992) and Hagenhoff, Feutz, Conn, Sagehorn and Moranville-Hunziker (1994) emphasise the importance of ensuring that the content of patient and parent education material is up to date, accurate and contains what they need and want to know. This reinforces the ideal of information seeking behaviour described by Lazarus and Folkman (1984). More recently the Department of Health in the National Service Framework (NSF) for Renal Services recommends that:

*All children, young people and adults with chronic kidney disease are to have access to information that enables them with their carers to make informed decisions and encourages partnership in decision making with an agreed care plan that supports them in managing their condition to achieve that best possible quality of life (DoH, 2004:6)*

Recent research by Beresford and Sloper (2003) found that factors affecting the effectiveness of communication between adolescents with chronic disease and professionals included: duration and frequency of contact; gender; perceived attitudes towards adolescents; the communication skills of the adolescent and health professional and the type of information needed. Adolescents were reluctant to initiate sensitive issues or ask questions that might reveal poor adherence to treatment. A perceived lack of interest in the wider impacts of a chronic condition on daily life was also a barrier to adolescents discussing difficulties at school and socio-emotional problems. The research, therefore, highlights a population with potentially high levels of information need who are facing considerable barriers to addressing these needs. The authors concluded that steps taken to improve adolescent-health professional communication need to address a range of practical, attitudinal and behavioural factors. In the light of this discussion it is encouraging to note that the NSF for Renal Services also



recommends that a robust transition policy should be in place for the transfer of young people into an adult setting (DoH, 2004).

Maintaining balance in family life has been recognised as a continual source of stress for parents, with professionals both hindering and supporting them in their caring role (Barlow, Harrison and Shaw, 1998; Atkin and Ahmad, 2000). During periods of hospitalisation, although nurses and doctors made care of the child a priority, they also co-created satisfying relationships with parents (Callery, 1997a). These alliances are believed to be instrumental in the development of competence in families and may have implications for the way in which families cope with and adapt to chronic disease (Thorne and Robinson, 1989). These issues are discussed in more detail below.

### **Coping and adaptation**

Concurrent with advances in health care, there have also been advances in the behavioural and social sciences that are contributing to our understanding of the way in which families may adapt to chronic disease. Thompson and Gustafson (1996) point out that the concept of family is not static but continues to evolve, thus leading to many alternative family structures and styles. In addition, the burden of care for families coping with childhood chronic disease stretches over a long period of time and according to Williams, Lorenzo, Borja *et al* (1993) and Callery (1997c) produces strain on the family's physical, financial and emotional resources. Families who demonstrated open communication and a sharing of responsibilities had a positive influence on children's ability to cope with the effects of chronic disease (Clawson, 1996) while the management styles of parents have been recognised as contributing factors in children's adaptation to these effects (Knafl, Breitmayer, Gallo and Zoeller, 1996; Thompson and Gustafson, 1996). Experience of stigma associated with a condition can result in the child and family feeling isolated (Grey, 1993; Jacoby, 2002) and the ability to cope with chronic disease is shaped by the values of the society in which it occurs (Turner-Henson, Holaday and Ogletree, 1994).

The nursing model for chronic illness management, a conceptual model built around the idea that chronic conditions have a variable course that changes over time has a long history that Corbin and Strauss identify as going back 40 years (Corbin and Strauss, 1991). It was introduced by Strauss and Glaser (1975) while using grounded theory to study the care of chronically ill patients. Their insight was that health professionals, patients and families use many different strategies to manage the shape of disease. Therefore, the model, that is inductively derived, can facilitate understanding of the

problems associated with chronic disease. Each chronic condition has a potential course although this is often uncertain, as its details cannot be fully determined ahead of time but depends on the action taken to shape that course and the turn of events that occur. As the framework evolved, further development and refinement was based on long narrative histories recounted by chronically ill patients and their carers. This led to identification of eight different phases through which chronic diseases may pass and that could inform the practice of health care professionals (pre-trajectory, trajectory onset, crisis, acute, stable, unstable, downward and dying). Corbin and Strauss (1991) and Corbin (1998) also defined the 'vision' of the disease course. The meaning of symptoms, biography and time are built in, with affected people wondering what will happen and what the condition means for the future. Each individual who encounters the condition and its management (doctor, nurse, patient, relative) has his or her own vision and ideas about how it should be shaped. This is based on knowledge, experience, hearsay and belief (Thorne and Robinson, 1988). Finally Corbin and Strauss refer to the plan that is designed to shape the disease course and control and manage symptoms. This can include alternative forms of treatment as well as medical and nursing management. This model has value in childhood chronic renal disease research and was used to inform the theoretical framework of my earlier research in this area (Swallow, 1997b; 1997a).

A conceptual model of chronic and life-threatening disease and its impact on families was proposed by Rolland (1987; 1988) as a means of facilitating the creation of categories for a wide array of chronic conditions. This typology conceptualises broad distinctions of onset, course and outcome as well as the degree of resulting incapacity. Rolland describes the stages of the disease course as crisis (pre-diagnosis and diagnosis with symptoms), chronic (long-haul that may be stable or degenerative) and terminal (pre-terminal, death and mourning). This model is designed primarily to facilitate examination of relationships between family dynamics and chronic disease rather than for clinical purposes, nevertheless, it has value in the area of childhood chronic disease management and research.

The 'stage-based' models of coping (Kubler-Ross, 1969; Horowitz and Kaltreider, 1980) have tended to lead to expectations from professionals that there are 'right' or 'wrong' ways of responding to a crisis and that any deviation from these indicates psychopathology. Authors who investigated the reactions of individuals to a wide range of trauma concluded that many continued to experience distress over a long period of time and that this distress was exacerbated by unexpected events, transitions or

memories (Bury, 1982; Clarke-Steffan, 1993; Eiser and Morse, 2001; Sloper and Lightfoot, 2003). Eiser (2001), when considering the psychosocial impact of childhood chronic disease on parents, welcomes the current emphasis on coping and views it as an improvement over the traditional approaches that focused on the maladjustment of families.

One of the most comprehensive measurements of parental coping strategies, the Coping Health Inventory for Parents (CHIP), was developed by McCubbin, McCubbin, Patterson *et al* (1983) and identified three positive coping strategies from parents' responses: the first, maintaining family integration; the second, maintaining social support; the third, understanding the condition. However, a second study (Nevin, McCubbin and Birkebak, 1983), which investigated parental coping with stress in chronic disease, uncovered a difference between the strategies used by mothers and fathers. Meanwhile, researchers are developing and refining inductively derived concepts e.g. chronic sorrow, critical times and normalisation that capture important aspects of disease experience (Robinson, 1993; Knaf, Ayres, Gallo, Zoeller and Breitmayer, 1995). A full understanding of the disease experience, therefore, needs knowledge of both the processes by which families manage the experience and outcomes associated with it.

The social-ecological systems-theory perspective of human development (Bronfenbrenner, 1979; 2005) and the transactional model of development (Sameroff and Chandler, 1975) have been very influential in informing this understanding. Sameroff and Chandler highlight the effect that children have on their environment through their characteristics and behaviours and the bi-directional influence between children and parents over time. On the other hand, Bronfenbrenner's theory proposes a series of concentric circles that represent settings (e.g. family, school, society and cultures) with bi-directional influences on the child who is at the centre. The main tenets of this are:

- Reciprocity (not only does the environment affect the child but the child affects the environment).
- Interconnections and relations between settings, that influence the child's development.
- Transitions (successive shifts in role and setting across a life span have developmental significance).

A confluence of these two approaches is claimed by Thompson and Gustafson (1996:146) to provide a structure for conceptualizing the:

*...nested hierarchy of family and societal contexts within which to consider adaptation to chronic disease.*

There are mutually influencing effects among the proximal environments of parents and family as well as the more distal, cultural environments in which the child is located. At any one time the outcome is a function of the complex interplay among components of these approaches over time. In particular, Conrad (1990) identified some broad themes around which sociological research into chronic disease experience has focused. These are the problem of uncertainty, reconstitution of self and life biography. These lines of research are significant in the context of this study because they focus on different dimensions of family functioning within proximal and cultural environments, and are outlined below.

### **The problem of uncertainty**

Uncertainty, a cognitive state created when an event cannot be adequately defined or categorised due to lack of information, is a major factor influencing expectations about chronic disease, treatment and prognosis (Hilton, 1992; Horner, 1997). It invades all stages of the condition: the recognition and interpretation of symptoms; learning of the diagnosis and managing the consequences of the condition. Radley (1994) observes that uncertainty in chronic disease is not limited to one period of time or one situation but is endemic to the situation. A number of studies have shown that people often try to ignore or normalise their initial symptoms: (Bury, 1982; Gallo, Breitmayer, Knafl and Zoeller, 1993; Cohen, 1997; Gallo and Knafl, 1998), then as symptoms persist, try to find explanations for them (Canam, 1993). Robinson (1988) described this as 'diligent detective work' that involved reading, discussing symptoms with friends and relatives and interpreting overheard conversations between medical staff. Because of the vagueness of early symptoms (Ray and Ritchie, 1993) or the problem of medical scepticism (Burton, 1975; Cohen, 1997) arriving at a diagnosis may take a long time. For example, compared to controls, children diagnosed with a first urinary tract infection had more visits at which symptoms of infection were recorded and more antibiotics prescribed prior to the visit at which the first urinary tract infection was diagnosed. The purpose of these excess visits may have included undiagnosed urinary tract infections. Both those with and without renal scarring had a similar degree of excess visits; and

additional aetiological factors must have played a role in scar formation (van der Voort, Edwards, Roberts, Newcombe and Jones, 2002).

When the ambiguity of diagnostic uncertainty is replaced by a diagnosis this may be welcomed rather than rejected even when it is unfavourable (Bury, 1982; 1991). However, Cohen, (1995) describes the 'biographical disruption' encountered by patients when the diagnosis brings to an end one set of uncertainties but at the same time creates another; this requires the patient to confront questions about the nature of his or her life from now on (Williams, 2000). In the same way, when a child is diagnosed with a chronic disease, the family's taken-for-granted world is affected. The most influential studies to have investigated *parental* uncertainty are those by Mishel (1983) and more recently Cohen (1995). Mishel saw uncertainty as 'a major perceptual variable' that impeded parents in their psychological management of the ill child. Cohen (1995), in developing Mishel's work, suggests that the current interest in uncertainty is an evolutionary process in response to biomedical and technological advances in the treatment of disease, that have created a 'medically fragile population'.

### **Reconstitution of self and life biography**

There is an increasing literature (Williams., 1984; Williams *et al.*, 1993; Williams, 2000; Williams, Williams, Graff, Hanson, Stanton, Hafeman, Liebergen, Leuenberg, Setter, Ridder, Curry, Barnard and Sanders., 2002) suggesting that the sense of meaning and order that individuals normally experience as a result of being constantly engaged in the interpretation of daily life events is disrupted by chronic disease. This is only restored by reconstruction of 'biographical narratives' leading to normalisation. Robinson (1993) conceptualised data from 62 accounts by people living with chronic disease in their family and found that although normalisation was not a primary focus, it emerged as a significant theme in relation to living with and managing chronic conditions. Charmaz (1983) comments that chronically ill people can experience 'a crumbling away of former self images without simultaneous development of equally valued new ones', which she claims is a fundamental form of suffering for them.

Paralleling this work with adults, several authors have described the externally imposed restrictions facing mothers of children with a range of chronic diseases (Grey and Thurber, 1991; Whyte, 1992; MacDonald, 1995). Whyte (1992) points out that the burden of care posed by childhood chronic disease is additional to the stresses of ordinary family life, with the result that quite minor events can sometimes cause distress

of crisis proportions. Mothers may also experience self imposed restrictions, a desire to overprotect the child (Eiser, 1993) or inaccurate perceptions of the severity of the child's condition. Several authors have identified the problem of social isolation in mothers caring for a child with a chronic condition (Florian and Krulik, 1991; Katz, Baker and Osborn, 1991; Carter, Urey and Eid, 1992; Desguin, Holt and McCarthy, 1994), the greatest isolation being reported by those who had limited professional and social support to help them to cope at home (Burton, 1975; Copeland, 1993; Copeland and Clements, 1993).

Childhood diabetes has also been regarded as a source of stress and Lowes and Lyne (1999) concluded that a diagnosis of childhood diabetes may represent a significant stressor event for parents. However the level of stress and the way individuals cope is dependent on several factors including:

- Their view of the world.
- Individual family systems and resources.
- Their perception of the severity of diabetes.
- The age and characteristics of the affected child.
- The extent of social and professional support.

A growing body of research is now emerging that relates to the impact on family units of a family member's chronic disease (Knafl and Gilliss, 2002). The complexity of studying families has in the past deterred researchers from considering families as the unit of care and it is a particular challenge to combine childhood chronicity with family study (Hayes, 1997). As increasing responsibility for care moves to the family it is profoundly important to think about providing care for the family as a whole. This has implications for the relationships between families and professionals that are influenced to some extent by the way in which individuals position and are positioned by each other. The next section will, therefore, briefly review the emerging body of literature relating to social positioning.

### **Social positioning**

Positioning theory originated in the work of Harre and Van Langenhove (1976) and Holloway (1984) and can be seen as a dynamic alternative to the more static concept of role to help understand human interaction. It is underpinned by theories from social constructionist psychology such as that proposed by Vygotsky (1987) who emphasised

the power of discourse to influence thinking and consciousness. Meanwhile Harre and Van-Langenhove (1999) describe how two main principles relate social constructionism with positioning. Firstly, what individuals do is intentional and secondly what individuals are to themselves and others is a result of interpersonal interactions developed throughout life. A 'position' therefore is a metaphorical concept in which an individual positions themselves within the three entities (people, institutions and societies) where discursive practices are conducted (Phillips, Fawns and Hayes, 2002) and:

*People tend to be treated as complex, casually interacting 'things'; institutions as groupings of people and societies as higher order aggregates of people groups. (Harre and Van-Langenhove, 1976:393).*

The concept of position manifests as a set of rights, duties and obligations for a speaker where each episode in daily life can be viewed as a development of a storyline (van-Langenhove and Bertolink, 1999). Davies and Harre (1990) compare the concept to someone listening to or reading a story involving a narrative that incorporates a braided development of several story lines. Readers may, for instance, position themselves or be positioned as outside the story but looking in. This positioning may be created by the way they perceive the author to be positioning them (as the reader) or it may be created by the reader's perception of the characters.

Paralleling this analogy to episodes of human interaction, such as those that occur between family members and health care professionals, permits speculation that these encounters involve a braided development of story lines around various dimensions such as treatment episodes, ethical dilemmas and disease courses. Cultural stereotypes such as doctor/patient, child/parent or expert/novice may be called on as a resource. However, different people may understand these cultural resources differently. Positions are generally relational so that when one person is positioned as powerful (for example a nurse specialist teaching a child about the technical care of peritoneal dialysis equipment) then others may be positioned to feel powerless (for instance the child and parents). Although individuals may choose whether or not they wish to respond to being 'positioned', in institutional settings choices may not exist for those subjected to positioning (for instance children and/or parents) by those who hold positions of authority (for instance professionals and/or parents). In addition, the fact that interactions are viewed from the vantage point of differing positions, however complementary they may be, militates against any easy assumption of shared understanding. Nevertheless Davies and Harre (1999) remind us that individuals live their lives in terms of the kind of person they take themselves to be which is a product of interpersonal interaction and

that positions can and do change. Thus, it is fluid positionings and not fixed roles that are used by people to cope with the situations they are in at any time. Language also has an important relationship with social positioning. Davies and Harre (1990) claim it is the foundation upon which social structures and agencies are developed and understood locally as the 'social force'. Individuals construct internal or external stories that have symbolic meanings about institutions or events and the discursive act of positioning needs a reconstruction of the speaker's biography in relation to the individual being positioned.

## **Summary**

This section of the review suggests that the impact of childhood chronic disease on children, parents and families is to do with the potential or real losses of identity and way of life and their attempt to preserve them as much as possible. Professionals often relate the difficulties encountered by families to role uncertainty, inadequate information provision and lack of recognition of their personal knowledge base. Often chronic disease has negative impacts on some or all family members. Families may lack the time, energy or financial resources to sustain social activities and relationships and a sense of isolation may intensify as the disease course progresses. The way individuals cope depends on several factors including their view of the world; individual family systems and resources; perceptions of the severity of the condition; age and characteristics of the affected child and the extent of social and professional support. Finally, people are likely to differ in their capacity to position themselves and others and will differ regarding their willingness to position or be positioned. In the next section, the teaching and learning context will be explored in relation to childhood chronic disease.

## ***The teaching and learning context of childhood chronic disease***

The consequence of increasing numbers of affected families, changing societal attitudes towards health care and a growing shift of responsibility for day-to-day care from professionals to families, emphasises the importance of seeking to understand the processes involved in learning across the disease course. In this section, findings from the small number of studies identified as having considered competence development by families in childhood chronic disease are discussed. Selected types of knowledge and theories relating to child and adult learning are explored and considered in relation to their possible use to explain family learning. Concepts of communities of practice and situated learning are discussed in the context of health professionals and families and



finally, preliminary conclusions pertaining to the context of teaching and learning are drawn.

### **Ways of learning in health care**

Some knowledge has been accrued about the way mothers make decisions regarding their children by Gross and Howard (2001) who surveyed a sample of 114 mothers and conducted interviews with seven of the mothers to determine their views about social support, interaction with professionals and self determinism as well as investigating their competence in problem solving regarding their child's conditions. Most mothers' decisions were based upon the perceived degree of seriousness, degree of fear of the child's condition, attitude of the health care provider, previous experience with the situation and the level of social support available to them. Recommendations included teaching mothers assessment skills to identify serious versus non-serious situations.

The extent to which parents are able to help their children respond to the demands of asthma were found to be critical components to understanding the effects of the disease on parental competency (Maltby, Kristjanson and Coleman, 2003). Perceptions of mothers of 15 children with a child with asthma were elicited through face-to-face interviews and data analysis revealed three main themes: naming asthma, taking on the reality and getting on with it. There do appear to be some parallels between the findings of this study and those from Gibson's earlier study (1995) regarding the issue of dealing with reality and taking control and the concept of 'guarded alliance' identified by Thorne and Robinson (1988) and alluded to earlier in this chapter. In addition, my own earlier research found that mothers reported the negative impact of professional scepticism in the pre-diagnostic phase upon their subsequent learning about their child's chronic disease management (Swallow and Jacoby, 2001b).

A limited literature exists that considers children's competency to make decisions about their own health care although it is widely recognised that children's rights ought to be given high priority (UN, 1959; 1989). A comprehensive tool, the Measure of Competence to Render Informed Treatment Decisions (MOC), was constructed in 1980 (Weithorn, 1980) and subsequently tested in different contexts with children. The instrument was found to have several shortcomings however (Breitmayer, Gallo, Knafli and Zoeller, 1992; Deatricks, Dickey, Wright, Beidler, Cameron, Shimizu and Mason, 2003). For instance, correlations tended to be higher within each artificial dilemma rather than within the scales, reflecting a situational (e.g. having diabetes) context for

decision-making. Therefore, the MOC needs further refinement before being used more widely.

Situated learning is located in the process of co-participation and contributes to the growing body of research in human sciences that explores the situated character of human understanding and social interaction. Implicit in this approach are the works of Vygotsky (1987) and more recently Lave and Wenger (1991) and Wenger (1998). According to Wenger (1998), communities of practice are everywhere and we all belong to several at any given time: at home; at work, at school; in our hobbies, and the communities of practice to which we belong change over the course of our lives. They are an integral part of our daily lives, they are so informal and so pervasive that they rarely come into explicit focus, but for the same reason they are also quite familiar. Wenger points out that communities of practice manifest within families and in the workplace. Families, for instance, develop their own practices, routines, rituals, conventions, symbols, stories and histories:

*They do what it takes to keep going. Even when families fall apart, members create ways of dealing with each other. Surviving together is an important enterprise... (Wenger, 1998:6)*

In the same way, workers organise their lives with their immediate colleagues and customers to get their jobs done:

*No matter what their official job description may be, they create a practice to do what needs to be done. Although workers may be contractually employed by a large institution, in day-to-day practice they work with – and in a sense, for – a much smaller set of people and communities. (Wenger, 1998:6)*

A community of practice is an intrinsic condition for the existence of knowledge and the social structure of the practice. Its power relationships and its conditions for legitimacy define possibilities for learning (Lave and Wenger 1991).

Vygotsky (1987) was one of the earliest writers to argue that learning is a social activity and he made the distinction between intramental (inside one's own head or intrapersonal) and intermental (interpersonal) learning stages. In their early work in this area Lave and Wenger (1991) developed this line of thinking further and promoted the concept of 'communities of practice' that focuses theory on what people do together and on the cultural resources they produce in the process.

Wenger (1998) puts increasing emphasis on the concept of practice and focuses a great deal of attention on identity, the experience of meaningfulness and the concept of community. He argues that meaning is located in a process called 'the negotiation of meaning' that involves the interaction of two constituent processes known as participation and reification. He defines participation as 'to have or take a part or share with others (in some activity or enterprise for instance) while reification, is defined as 'to treat an abstraction as substantially existing, or as a concrete material object' (Wenger 1998:57). In this way Wenger uses the concept of reification in a broader sense than its dictionary definition. He uses the term to cover a wide range of processes that include making, designing, naming, encoding, and any means by which we can create a point of focus around which the negotiation of meaning becomes organised. Therefore, he proposed that a social theory of learning must integrate the components necessary to characterise social participation as a process of learning and knowing. Within this context a community of practice includes the discourse by which members create meaningful statements about the world as well as the ways in which they express their forms of membership and their identities as members.

It is clear from the literature as well as from anecdotal accounts that children and families (experts in personal knowledge) are increasingly becoming part of the world of professionals (experts in professional knowledge). It is now widely understood that experts do not operate by following rules derived from higher-order knowledge but by using complex situational understanding, a mature and practised dexterity emerging from breadth and depth of experience (Dreyfus and Dreyfus, 1985; Cope, Cuthbertson and Stoddart, 2000). Most expertise is directed to dealing with contextually bound demands of the situation that cannot be accounted for by context-independent technical-rational models. There is growing consideration of the tacit nature of this understanding and the difficulty of making expert behaviour explicit (Polanyi, 1967; Atkinson and Claxton, 2000; Eraut, 2000). The key to development of skills of this type is practice in authentic settings or cognitive apprenticeship. The central place of this type of exposure has pointed out that becoming proficient is as much to do with joining a culture of practitioners as it is of becoming technically skilled.

Research has highlighted that a critical part of socialisation into practice is to join a community of context (Lave and Wenger, 1991). Novices are given tasks to complete that are peripheral but authentic to an activity and so considered to be critical aspects of eventual success (legitimate peripheral participation) and part of the communal enterprise. In this context, experts are able to guide novices through the complexities of

practice. The concept of scaffolding defined by Vygotsky has significance here also. Learning within a community of practice can be described as a form of cognitive apprenticeship (Spouse, 2003) in which novices are supported by strategies such as modelling, coaching, scaffolding, fading, articulation, reflection and exploration. Wenger describes the types of learning trajectories that can occur in communities of practice; these are outlined below in Figure 3:

Figure 3: Types of learning trajectories in communities of practice (Wenger 1998:154)

| Type of Trajectory           | Definition of Learning Trajectory   |
|------------------------------|---|
| <i>Peripheral trajectory</i> | By choice or necessity, some trajectories never lead to full participation. Yet they may well provide a kind of access to the community and its practice that becomes significant enough to contribute to one's own identity.   |
| <i>Inbound trajectory</i>    | Newcomers are joining the community with the prospect of becoming full participants in its practice. Their identities are invested in their future participation, even though their present participation may be peripheral.  |
| <i>Insider trajectory</i>    | The formation of an identity does not end with full membership. The evolution of the practice continues, new events, new demands, new inventions and new generations all create occasions for renegotiating one's identity.   |
| <i>Boundary trajectory</i>   | Some trajectories find their value in spanning boundaries and linking communities of practice. Sustaining an identity across boundaries is one of the most delicate challenges of this kind of brokering work.  |
| <i>Outbound trajectory</i>   | Some trajectories lead out of a community, as when children grow up. What matters then is how a form of participation enables what comes next. It seems perhaps more natural to think of identity formation in terms of all the learning involved in entering a community of practice. Yet being on the way out of such a community also involves developing new relationships, finding a different position with respect to a community, and seeing the world and oneself in new ways. |

## Types of knowledge

Whilst boundaries and definitions of learning have been extended through research, concepts of 'knowledge' have also been refined (Mathews and Candy, 1999). Knowledge has been classified according to whether it is personal or social (Kolb, 1984; Valsiner and Leung, 1994). Kolb describes personal knowledge as a combination of direct appreciation of experience and socially acquired comprehensions used to explain experience, while social knowledge is a culturally transmitted network of words, symbols and images based on comprehension. Valsiner and Leung adopt a similar stance and state that knowledge construction is simultaneously personal and social as it entails interdependence of the person and the socially organised world.

Many areas of professional knowledge and judgement have not yet been codified (Eraut, 1994) and it is widely recognised that experts often find it difficult to define and explain the nature of their expertise (Barnett, 1994). The professions are a group of occupations with ill defined boundaries (Eraut, 1997). The most powerful professions of law and

medicine are commonly perceived as the 'ideal type' while those with significantly less power such as teaching and nursing have been described as semi-professions (Etzioni, 1969) and according to Rueschemeyer (1983:41):

*Individually and in association, collectively, the professions 'strike a bargain with society' in which they exchange competence and integrity against the trust of a client and community, relative freedom from lay supervision and interference, protection against unqualified competition as well as substantial re-numeration and higher social status.*

The traditional basis of teaching in higher education is *propositional knowledge*, an example being when concepts and ideas from disciplines are drawn upon directly during deliberations about practical situations and actions (Eraut 1994). There are also many experiences from which people learn without there being any intended educational purpose and without any codified professional knowledge being articulated to them. In these situations it is believed that individuals acquire a level of 'social knowledge' through informal and incidental learning in the workplace (McGivney, 1999). There is an increasing debate around the issues of informal and non-formal learning; the emphasis appears to be on the value of the processes and experiences involved as well as the context within which the learning occurs:

*Informal learning should no longer be regarded as an inferior form of learning whose main purpose is to act as the precursor of formal learning; it needs to be seen as fundamental, necessary and valuable in its own right. (Coffield, 2000:18).*

Eraut (2000) promotes three typologies of non-formal learning:

- Implicit learning: the acquisition of knowledge independently of conscious attempts to learn and without explicit knowledge about what was learned.
- Reactive learning: explicit learning that takes place spontaneously and in response to current situations but without time set aside for it.
- Deliberative learning: planned learning with time set aside for the explicit learning process.

*Process knowledge*, on the other hand, can be defined as knowing how to conduct the various processes that contribute to professional action; this includes knowing how to access propositional knowledge. Eraut (2000) also defines skilled behaviour as a type of knowledge and sees it as a complex sequence of actions that has become so routinised through practice and experience that it is performed almost automatically. Much of a

teacher's actions, for instance, are described by Eraut as skilled behaviour, largely acquired through practice with feedback. Gradual routinisation of the teacher's work is accompanied by a reduction in self-consciousness and a focusing of perceptual awareness so that knowledge of how to teach may become *tacit knowledge* that is difficult to articulate to others (Polanyi, 1967).

In an attempt to theorise the knowledge that nurses use in the conduct of their work, Liaschenko and Fisher (1999) drew upon their respective empirical research data and proposed a classification of knowledge that they called case knowledge; patient knowledge and person knowledge with a common link being social knowledge. It seems then that there are many different facets to knowledge: some is declarative (knowing what) and some is procedural (knowing how), some is explicit and publicly shared and some is tacit or implicit. The knowledge we need to adapt to an environment (such as the unspoken rules of a hospital) is not explicitly taught or necessarily verbalised but has been described as a veil through which we see, interact with and interpret the world (Mathews and Candy, 1999).

## **Theories of learning**

The act of learning can be viewed from a number of different theoretical perspectives, some of which emphasise the role of interaction in the process and some that are largely based on the assumption that learning is an individual process; that it has a beginning and an end, is best separated from other activities and is the result of teaching. For instance, neurophysiological theories focus on the biological mechanisms of learning whilst activity theories, such as that proposed by Vygotsky (1987) focus on the structure of activities as historically constituted entities. Socialisation theories focus on the acquisition of membership by newcomers within a functionalist framework where acquiring membership is defined as internalising the norms of a social group (Parsons and Shils, 1962). Organisational theories, however, are concerned with the way organisations and individuals within organisations can learn (Argyris and Schon, 1978). Nevertheless, learning has traditionally been the province of psychological theories. These include: Skinner's behaviour modification theories (Skinner, 1974); cognitive theories that focus on internal cognitive structures and view learning as transformations in these structures (Hutchins, 1995); and constructivist theories such as Piaget's (1954) that focus on the processes by which learners build their own mental structures when interacting with an environment. Social learning theories on the other hand focus on the

study of cognitive processes by which observation can become a source of learning (Bandura, 1997).

Most recently a social theory of learning has been proposed by Wenger (1998). This perspective places learning in the context of our experience of participation in the world and proposes that learning is as much part of our human nature as eating or sleeping, that it is both life-sustaining and inevitable and that, given a chance we are quite good at it. In particular, Wenger suggests that learning is a fundamentally social phenomenon that reflects our own deeply social nature as human beings capable of knowing. This theory does not replace other theories of learning but it does have its own set of assumptions and does yield a conceptual framework from which to derive principles and recommendations for understanding and enabling learning.

The four premises that underpin this theory are:

1. We are social beings. Far from being trivially true, this fact is a central aspect of learning.
2. Knowledge is a matter of competence with respect to valued enterprises (such as discovering scientific facts, growing up as a boy or girl).
3. Knowing is a matter of participating in the pursuit of such enterprises, that is, of active engagement in the world.
4. Meaning, our ability to experience the world and our engagement with it as meaningful, is ultimately what learning is to produce. (Adapted from Wenger 1998:4).

The primary focus of this theory then is on learning as social participation.

### **Children and young people**

A number of key theorists, Dewey, Montessori, Piaget, Vygotsky and Erikson, have significantly influenced attitudes to child development and learning. These will be briefly explored here to help in understanding the factors that might influence the development of children's competence in chronic disease. The central idea of these theorists was that education should be child centred, be active and interactive and should involve the social world of the child. Dewey (1938) claimed that children learn best when they interact with other people and so believed that education is a process of living and not simply preparation for future learning. Dewey was a strong advocate of the importance of family values and argued that these should be reflected in and deepened by what happens at

school. Montessori's theories (1916) have influenced the way all early childhood educational experiences are shaped today and provided the foundations for the work of Piaget (1954) and Vygotsky (1987). In 1907, when Montessori opened her first school, her ideas about the value of child sized furnishings and of children working independently were considered radical. She believed that children should be able to do everything they are capable of and believed it was the teacher's responsibility to increase each child's competence.

In contrast, Erikson's work (1950) showed how children develop the foundation for emotional and social development through learning. His theory covers the entire human life-span and claims that there is a task that must be accomplished at each stage of development, with success at one stage affecting the next one. Erikson coined the term 'identity crisis', based on the idea that as people pass through each stage they form personality strengths or weaknesses. Piaget, however, thought that children learn through interaction with the environment and that they construct their own knowledge by giving meaning to the people and things in their world (Piaget, 1954). He was Montessori's student and built on her idea that meaningful work was important to children's cognitive development. Like Dewey, he thought that children learn only when their curiosity is not fully satisfied. According to Piaget, children's cognitive development passes through four stages (0-18 months - the Sensorimotor; 18 months-6 years - Preoperational; 6-12 years - Concrete Operational; 12 years and older - Formal Operational). It is largely the influence of Montessori and Piaget that encourages uninterrupted periods of play during early childhood in child care today.

Finally, Vygotsky (1987) has changed the way educators think about children's interactions with others as his work demonstrated that social and cognitive development work together and build on each other. Like Piaget he believed that play stimulates learning in children. His most important contribution to child and adult development has been to describe the concept of the *zone of proximal development*. He defined this as the distance between the most difficult task a child can do alone and the most difficult task a child can do with help. He described the support a teacher or peer offers a child as *scaffolding*, arguing that in the same way that a house painter uses a scaffold to reach parts of the house that would otherwise be out of reach, adults or peers can help a child 'reach' a new concept or skill by giving supporting information (Vygotsky, 1987). These ideas are more flexible than Piaget's because they encompass the skills that children have not yet come to on their own but which they can acquire from the example of others (Maier, 1969; Wood, 1998; Mooney, 2000).



## Adults

Experience in itself is not necessarily transformative and, as had been discussed previously, Vygotsky (1987) emphasised the need for a teacher to structure activity and support learning from one stage to the next. Most theories of adult learning, therefore, have their origins in the work of Piaget and Vygotsky (Cottrell, 2001) and those that are most pertinent to this study are those that focus on the use of experience and intuition. Experiential learning is the cornerstone of the humanistic education theory and Ramsden (1992) and Kolb (1984) regard the teacher as a facilitator of the student's learning who will learn alongside the students.

The experiential learning concept has three aspects:

- Involvement in a situation.
- Reflection on the situation to effect learning.
- The transformation of knowledge into a usable tool on which to build future learning.

According to Eraut (1994), knowledge that does not get used in practice is rapidly consigned to long term memory so that although knowledge may be included in a curriculum because it is deemed relevant, it does not become part of professional knowledge unless and until it has been used for a professional purpose. Therefore, a piece of biological knowledge does not become professional knowledge for a nurse until it has been used as part of a nursing process (i.e. propositional knowledge). This is reflected in the training of other professional groups as well so that knowledge that is not seen as professionally relevant is given a low status by students. Therefore, he recommends that:

- A significant part of the initial qualification must be performance-based.
- Blocks of knowledge should be kept as short as possible with maximum opportunity being available for students to use knowledge in practice related processes.

Smith (1991) also recognises that all human beings learn by and through experience and that experiential learning can capitalise on the natural desire to learn. The provision of relevant situations in which the student can practise and analyse, build for the future, develop positive attitudes and appropriate intervention strategies in a non-threatening

setting can, according to several authors, only bring positive results (Burnard, 1985; Miles, 1987; Smith, 1991; Dewar and Walker, 1999). The approach adults take towards their learning is determined to some extent by their understanding of what learning itself consists of and they can develop an increasingly sophisticated conception of learning (Gibbs, 1992). Therefore, 'learning to learn' and 'learning about learning' (i.e. metacognition) can be as important as the actual knowledge and skills that are learned. This in turn helps to foster deeper approaches to learning that according to (Ramsden, 1992:81) are encouraged by:

*Stimulating and considerate teaching, especially teaching which demonstrates the lecturer's personal commitment to the subject matter and stresses its meaning and relevance to the students.*

These cognitivist models have, however, more recently been superseded by an organic model of work based learning. This suggests that life at work is typically experienced as an integration of feeling, thinking and doing where purposeful actions fill the day and workers interact with each other, deliberate over experiences and become increasingly aware of what is learned in the doing of the work, while the work is being undertaken. Typically, this awareness raising can take place incidentally for example during coffee breaks, but also in a more formal way during disagreement or when seeking a colleague's opinion about an issue. When a worker is aware that they are learning from the experiences then an organic learning phenomenon exists. The test of the experience having been learned from will be the contribution it makes to individual and perhaps organisational learning. Beckett recommends that to effectively provoke workplace learning it is necessary for workers to exist in a culture that explicitly cultivates deliberate awareness of the learning as it occurs. Three simple prompts to provoke this work based learning response are proposed by Beckett (1999) and these are:

- What am I doing?
- Why am I doing it?
- What comes next?

These models have resonance with the world of adults such as parents and grandparents as they and the child with chronic disease interact with professionals in the world of health care.

## **Summary**

There are gaps in the literature about the way in which children and families learn yet it may be that there are some parallels to be drawn between the way professionals and families learn. Theories of learning have been explored in relation to children's and families' experiences and it emerges that concepts of cognitive apprenticeship, situated learning and communities of practice have potential in seeking to explain the way in which families learn in health care.

## **Conclusion**

Despite a long-standing recognition of the need to provide seamless care for children and families, there is evidence in the literature that this has, until now, not been achieved successfully. The position of children on the national political agenda has persistently been subordinated to the position of adults. The number of children affected globally by chronic conditions is expected to continue rising; yet this situation is complicated by the lack of agreement about definitions and classification of chronic disease. There are many gaps in the knowledge base about the psychosocial context of childhood chronic disease. The impact on children, parents and families is to do with the potential or real losses of identity and way of life and their attempt to preserve them as much as possible.

Professionals often relate the difficulties encountered by families to role uncertainty, inadequate information provision and lack of recognition of their personal knowledge base. Often chronic disease has negative impacts on some or all family members. Families may lack the time, energy or financial resources to sustain social activities and relationships and this sense of isolation may intensify over time. The way individuals cope depends on several factors including their view of the world; individual family systems and resources; perceptions of the severity of the condition; age and characteristics of the affected child and the extent of social and professional support. Finally, people are likely to differ in their capacity to position themselves and others and will differ regarding their willingness to position or be positioned. In exploring the teaching and learning context it emerges that there are gaps in the literature about the way in which children and families learn, yet it may be that there are some parallels to be drawn between the way professionals and families learn. Theories of learning have been explored in relation to children's and families' experiences and it emerges that concepts of cognitive apprenticeship, situated learning and communities of practice have potential in seeking to explain the way that families learn in health care.

## **Chapter 3: Philosophical, Theoretical and Ethical, Approaches to the Study**

In this chapter, the aims of the study are re-introduced. This leads into discussion about the particular philosophical perspectives, the rationale behind the chosen theoretical framework and the main ethical perspectives of the study.

### **The research aims**

This study was undertaken to highlight the issues and problems experienced by children and families as they learn to manage chronic renal disease. The findings will contribute to an understanding of learning by children and families and help to inform future health care practice. Therefore, the aims of the study are to:

- investigate the way that children and their families learn to manage chronic renal disease following referral to a Children's Kidney Unit.
- explore the impact of the relationship between families and practitioners upon the way children and families learn.

### **Philosophical approach to the study**

Any research study is undertaken from a particular perspective or paradigm that determines almost everything about the research (Harper and Hartman, 1997). In considering the most pertinent approach to this study, I began by drawing upon my own recent research experience and training in a Medical Faculty in positivist and naturalistic approaches. I believed this had given me a broad understanding of some of the key debates in health care research. However, I was aware that I also needed to explore in more depth the precise position of nursing research in today's changing health service. In order to appreciate the differences between the various perspectives, an exploration of the underlying ontological, epistemological and methodological assumptions was undertaken. The various claims from these assumptions are what differentiate perspectives or paradigms (Robson, 2002). *Ontology* is the branch of philosophy that deals with the nature of being and ontological questions address the nature of reality such as peoples' experiences and understanding (Abercrombie, Hill and Turner, 1984). There are no definitive answers to ontological questions but, as they are those that

address the nature of reality, they are also important when we are considering what we can know about reality.

*Epistemology*, on the other hand, is the branch of philosophy concerned with the origins, nature, methods and limits of human knowing (Blaikie, 1993; Milliken and Schreiber, 2001) or theory of knowledge, and can only arise once we have answered the ontological question about the nature of reality. Therefore, if social reality consists of the experiences and understanding of people then knowledge of reality will be knowledge of these experiences and understanding (Cormack, 2000). However, some qualitative researchers question whether it is always possible to acquire absolute knowledge of social reality as it may be coloured by the interpretation of the researcher (Porter, 1993). *Methodology*, meanwhile, concerns questions about the way in which knowledge can be obtained about what exists. This allows the reader to judge the authenticity of the research findings (Hammersley and Atkinson, 1995).

There is also an emerging school of thought suggesting that both qualitative and quantitative methods ought to be seen as part of the social researcher's 'toolkit' (Seale, 1999). This pragmatic approach is entirely consistent with my own perspective that prefers to view the differing paradigms as complementary strategies which are selected for use according to the nature of the research question. In applied fields, such as nursing or educational research, a strong autobiographical element often drives the research interest (Marshall and Rossman, 1999) and a challenge for the qualitative researcher is to ensure that this personal interest will not bias the study. With this discussion in mind, therefore, in the present study I adopted an *ontological* position similar to that proposed by Hammersley and Atkinson (1995) that is 'subtle realism'. Thus I accept that the social world does exist independently of individual subjective understanding and that it is accessible in this study via my own interpretation of the participants' accounts. Whilst I can, like Hammersley and Atkinson (1995), accept that different vantage points will yield different types of understanding, I do not feel that diverse perspectives rule out the existence of multiple realities.

The idea that multiple realities exist and create meaning for the individuals studied is a fundamental belief of qualitative researchers. Instead of searching for one reality or truth, qualitative researchers believe that individuals actively participate in social actions and through these interactions come to know and understand phenomena in different ways. Therefore, there can be many truths (Streubert and Carpenter, 1999). Consequently, my aim in this study was to apprehend as fully as possible the nature of

the multi-faceted reality from the children's, parents' and professionals' accounts in this study.

My *epistemological* stance, on the other hand, is based on the belief that the participants in this study are the experts who have experience of the phenomenon under investigation (learning in childhood chronic disease). I saw my job as researcher being to investigate the socially constructed meanings that form the participants' realities and the behaviours flowing from those meanings (Glaser and Strauss, 1967; Milliken and Schreiber, 2001). Therefore, I wish to know how they understand and act within their worlds. This leads me to the *methodology* behind my study.

In considering the most appropriate methodology to meet the aims of the study I explored differing options before selecting grounded theory. Phenomenology is increasingly popular in qualitative nursing studies (Crotty, 1996) because of its relationship with the concept of life-world that represents reality or the lived experience of the participant (Koch, 1999). An essential part of this approach is the idea that respondents' knowledge of their worlds constitutes several layers of experience that build up through time and that through a process of bracketing, researchers can get back to the real 'lived experience'. Nevertheless, the possibility of being able to bracket my presuppositions, experiences and beliefs about health care and childhood chronic disease seemed unlikely for me. By suggesting that an objective reality could be accessible to me through bracketing, this approach seemed to me to echo a positivist approach that I had previously discarded as inappropriate for this study. For these reasons, I decided not to adopt a phenomenological approach.

I did also consider the use of observational narratives that would have provided the opportunity to present data qualitatively in narrative format that would be gathered at key points in the learning and teaching process. Observational narratives have previously been used in illustration of life in institutional settings (Clark and Bowling, 1989). Both structured and unstructured data were interpreted by them in relation to a theory of institutions, which emphasised the dehumanising and demeaning nature of institutional routines. However, I decided that this approach would not enable me to achieve the aims of the study as my presence when children and families were involved in practising skills and learning about the condition and the service may have inhibited their behaviour. Grounded theory within a symbolic interactionist approach, on the other hand appeared to be an appropriate way of meeting the aims. The rationale for this decision is discussed in detail in the next section.

## Symbolic interactionism and grounded theory

Symbolic interactionism is a branch of interpretivism with an emphasis on eliciting and understanding the way meaning is derived in social situations (Schwandt, 1994; Stern, 1994). The main ideas of symbolic interactionism were provided by George H Mead (1863-1931) and at the heart of his approach was the assumption that there is a difference between animal reaction and human conduct (Bond and Bond, 1986). According to Mead, conduct requires the possession of mind and the concept of 'self' that are distinctive to humans. Therefore, humans undergo experiences and are aware of doing so. Symbolic interactionism, moreover, illuminates the relationship and processes between individuals and society as mediated by symbolic communication. Interaction is symbolic because these processes use symbols, words, interpretations and languages (Denzin, 1989). The use of symbols to denote objects is an essential human characteristic that allows communication to take place and shared meanings to be derived from this. It is the capacity for self-consciousness that makes humans different from animals. Central to this belief is the ability of humans to take the same attitude towards themselves as others take towards them. According to Mead different individuals will attach different meanings to the same object and an individual will experience the different meanings he himself holds for others reflected back to him. To handle this complexity the individual constructs a picture of himself according to the predominant views of himself as shown by others. This is carried out largely through the medium of language that is described as the significant symbol (Bond and Bond, 1986).

It is through these exchanges that individuals learn the ways of acting that others expect and so the 'self-consciousness' necessary to engage in social life. The meanings of objects are also derived from social interaction with these meanings being handled in and modified through an interpretation process used by people in dealing with encounters. The hallmark of symbolic interactionism is the explanation of such processes, leading to an understanding of how and why things are as they are by finding out about people's life circumstances (Blumer, 1969; Milliken and Schreiber, 2001). Blumer furthered the debate in this area by contending that circumstances do not exist in themselves as stimuli to which individuals react but depend on the purposes and plans the individual has *in mind*. Blumer, therefore, advocated an approach to enquiry that is distinctly sociological in that it involved detailed enquiry into instances of social life as they occur in natural settings. Symbolic interactionists have made a distinctive contribution to knowledge, in particular into the concept of career. The career concept of

progression with differentiated stages can be applied to professionals or patients and career can be said to be a chronological ordering of steps that are fairly predictable.

In qualitative research, in particular in grounded theory, there is emphasis on theory being derived from data and recognition that theory is a complex term that has more than one specific meaning. It is viewed as a grouping of related concepts and propositions with explanatory power (Holloway, 1997). Social theorists tend to distinguish between types of theory, for example 'grand theory', 'middle range theory' 'substantive theory' and 'formal theory'. It is substantive and formal theory that are developed through the use of grounded theory methodology (Strauss and Corbin, 1998). Substantive theory is specific and refers to a substantive area of study whilst formal theory is developed at a conceptual and more general level (Strauss, 1987a). The place of theory in qualitative research is quite unlike that in quantitative research as is the relationship between theory and data different. Qualitative researchers, particularly those using grounded theory, engage in theory building. Marshall and Rossman (1999) use a funnel metaphor to illustrate the complex process of conceptualising a study. This metaphorical approach has been used and adapted for the present study.

Within this approach there are three levels of conceptualisation. In the first level, the wide end of the (conceptual) funnel contains the general theories the study used. Therefore, symbolic interactionism provided an interpretive framework (Blumer, 1969) and grounded theory (Glaser and Strauss, 1967; Strauss and Corbin, 1990) led ultimately to the theoretical output of the study. Meanwhile the narrow end of the funnel depicts the specific focus for the study and so the Nursing Model for Chronic Illness Management (Corbin and Strauss, 1991) and the theory of social positioning (Harre and Van-Langenhove, 1976) are introduced, while symbolic interactionism and grounded theory remain and flow through the entire funnel.

In the second level, the wide end represents the phenomenon of participation in family centred care. Midway down the funnel, the focus narrows to the issue of children and families learning to participate in chronic disease management. Finally, the narrow end of the conceptual funnel focuses even more closely on the research aim of investigating the process of learning by children and their families following diagnosis of a chronic renal problem. In the third level, the wide end of the funnel represents phase one of this study (retrospective) and the narrow but more focused end represents phase two (prospective). This approach, known as theoretical pluralism, involves the use of more than one lens or theory in shaping a study and analysing a data set (Duffy, 1987). In



positivist studies, investigators identify two theories 'a priori' and articulate rival hypotheses. During the study, the rival hypotheses (or theories) are tested and the output may mean accepting one theory over the other or merging the theories to form a new one (Streubert and Carpenter, 1999). By contrast, in qualitative studies more than one theoretical explanation can inform the study and emerge from the data and researchers test the use and power of these by iterating between data generation and analysis until a conclusion is reached.

The epistemological conjectures of grounded theory are rooted in symbolic interactionism which explores the process of interaction between people's social roles and behaviours. The underlying assumption of grounded theory is that people make sense of and order their social world even though, to the outsider, their world may appear irrational (McCann and Clark, 2003). Therefore, grounded theory provides a useful set of strategies for researching the experience of chronic disease (Charmaz, 1990) and so was deemed the appropriate methodology for exploring the way children and families learn to manage childhood chronic disease.

Grounded theory was developed by Glaser and Strauss (1967) in response to the prevailing view of positivist approaches as the only model of social science research and refined by Strauss *et al* (1984) and later refined again (Strauss and Corbin, 1998). It is an approach that can specifically address issues of identities, social processes and shared experiences. Blumer when discussing the philosophy behind grounded theory comments:

*...human beings act towards things on the basis of the meaning that the things have for them. The meaning of such things is derived from or arises out of social interaction that one has with one's fellows and these meanings are handled in and modified through an interpersonal process used by the person in dealing with the things he encounters. (Blumer, 1969:3)*

Therefore, those sharing common experiences, for instance parents who have a child with a chronic renal problem, experience common perceptions, thoughts and behaviours that are the essence of grounded theory. Those using this research approach premise their work on the assumption that each group experiences a common social, psychological problem that is not always articulated (Hutchinson, 1993). It is the researcher's main aim to identify and uncover this problem, so in this present study I began with an expectation, based on my experience, anecdotal accounts from colleagues and a preliminary review of the literature that families learning to manage

chronic disease may share similar experiences that are not always clearly understood by themselves or others.

In developing grounded theory, Glaser and Strauss were attempting to bring the researcher closer to the issues that people experience and develop a rigorous qualitative methodology with its own integrity, distinct from quantitative methods:

*If the epistemology of grounded theory is steeped in symbolic interactionism and the methodology is the link between epistemology and the conduct of research, then it follows that grounded theory flows from symbolic interactionism.*  
(Milliken and Schreiber 2001:181).

Both the classical and Strauss and Corbin approaches to grounded theory have been influenced to some extent by positivism and post-positivism (Charmaz, 1990; Benoliel, 1996). Published literature is used differently in the grounded theory methodology than in most other research approaches. In their earlier published discussion, Glaser and Strauss (1967) admonished researchers to omit the usual literature review in favour of direct investigation of the phenomenon of concern and to formulate their own interpretations, based on participants' accounts of what was going on. This represented a significant shift away from the domination of positivist ideals in social and nursing research and so rejected the idea of research driven by 'a priori' theory. This approach does, nevertheless, present some problems of rigour and definition for the social researcher (Marshall and Rossman, 1999).

In the first instance, funding bodies and peer reviewers would find it difficult to condone a project investigating human subjects that involved plunging into field research without first delving into relevant literature to provide a rationale for the study (Schreiber, 2001). There are also methodological reasons for conducting a literature review. Strauss and Corbin (1998) suggest that reading related literature is a good way to expand one's ideas about the topic under study and to help promote theoretical sensitivity. They acknowledge that few researchers approach a topic without past experience and that it is not possible to unlearn what is known. By not conducting a literature review there is a risk of superimposing preconceived ideas onto the data. By carrying out a literature review, the researcher can fully explicate existing conceptualisations and sensitizing concepts of the study phenomenon and subject them to the challenge of ongoing comparison with data (Schreiber, 2001).

In this way, the researcher uses *constant comparison* with data to scrutinise the literature for its fit with emerging concepts and theories, so increasing the rigour of findings (Strauss and Corbin, 1998). In the present study, I conducted a detailed initial review of key literature to learn what the salient problems were. At this stage I considered the literature on knowledge development, child development, chronic disease and child health philosophies. However I was aware of the need to try not to become so steeped in the literature that I became constrained or stifled by it (Woods, 2003). This stage did, however, provide a 'stepping off point' (Strauss and Corbin, 1998) for initial data collection and provided insights to inform *theoretical sampling*. An iterative process of theoretical sampling and constant comparison is a key feature of grounded theory (Chenitz and Swanson, 1986) with the researcher 'cycling' back and forth between data collection, analysis and literature until theoretical saturation is achieved (Schreiber, 2001). This, therefore, is consistent with the interplay between induction and deduction described by Strauss and Corbin (1998).

Glaser and Strauss (1967) and later Strauss (1987a) remind us of the 'concept-indicator' model that is central to grounded theory. This model suggests that there are many empirical indicators (or symptoms) of a concept or category, and that these can be searched for in the data or literature as data collection proceeds. Thus, a concept can then be inferred from them. By checking these indicators constantly the researcher can enhance the likelihood that they will ascertain whether categories or concepts are still relevant and if so whether any of their features have changed. It was against this background that I tried to recognise the possible effect of my own involvement in the data collection and analysis and the possibility of distorting the meaning in participants' accounts. In both phases, I attempted to validate my interpretations through the time consuming process of constantly comparing one piece of data with another and by providing evidence of an audit trail (Guba and Lincoln, 1989). Tools such as Microsoft Excel and Framework Technique were used to assist with retrieval of data if needed (Bryman and Burgess, 1994; Swallow, Newton and Marshall, 2003). This process is discussed further in chapter 4 in relation to research design.

In addition, at the beginning of second and subsequent interviews in phase two, the results of the analysis of participants' preceding interviews were shared with them and their comments were incorporated into the process. This sharing of early results was done verbally and involved a summing up of main emergent categories. Only one respondent asked for further clarification about one of the categories that emerged from one of her interviews (Lucy's mother, phase two). The explanation was accepted as an

accurate representation of her comments. The remaining respondents agreed with my interpretation of their accounts and on a few occasions, this initial discussion provided a trigger for further exploration of the issues raised. For instance in her third interview, Nina in phase two (a 15 year old with a condition requiring a moderate level of intervention) demonstrated that she had been conducting an internal analysis, since her previous interview, of her comments about her preferred styles of communication by professionals:

Nina:            Since then [interview conducted six months previously], I've been thinking about that and have found some really good information on the internet about kidney function. It would have been really good if I had seen that at the beginning.

Through conceptual coding, the researcher transforms raw data into theory but it is widely recognised that grounded theorists may encounter difficulty in raising the level of theoretical abstraction from description to theory in the emerging theory (Becker, 1993; Stern, 1994; Milliken and Schreiber, 2001). The goal of good grounded theory is the construction of a tight theory with concepts linked together in explanatory relationships that, in accounting for the variation in the data, explains how participants resolve their basic social problem (Schreiber, 2001).

The use of grounded theory in nursing research is becoming increasingly evident. One example of a published study using grounded theory in childhood chronic disease is by Horner (1997), who investigated the experience of mothers as they cared for their young children during disease episodes, prior to a diagnosis of asthma in their children. A study was conducted with 12 families, involving three rounds of interviews. In these interviews, the mothers revealed that the pre-diagnostic phase of the disease was an overwhelming time for them. 'Groping in the dark' is the core variable that reflects (a) the harrowing experiences of sleepless nights while mothers watched their children struggle to breathe, (b) the wearing toll incurred while helping their children through seemingly unending disease, and (c) their increasingly intensified search for answers to resolve their children's health crisis. Similarly, in Swallow and Jacoby (2001b), we used a grounded theory approach to explore the effect of time of diagnosis on mothers' coping in chronic childhood renal disease. It emerged that pre-symptomatic diagnosis of their child's condition enhanced the quality of mothers' relationships with health professionals across the disease course compared to those whose child was diagnosed after a protracted and uncertain pre-diagnostic period. A further example of the use of

grounded theory approach in child health explored children's, parents' and health professionals' experience of childhood chronic disease (Sartain, Clarke and Heyman, 2000). Seven families and their professional carers participated in semi-structured interviews. The children's interviews were augmented with a 'drawing' technique. A grounded theory approach facilitated data collection and analysis.

The *emphasis* in grounded theory is on the importance of deriving theories and explanations of social structures and processes *inductively* by grounding explanations for observed phenomenon or events firmly in the data that have been collected. This leads to uncovering the insider perspective (Conrad, 1987). Two main factors influenced the decision in the present study to use Strauss and Corbin's version of grounded theory instead of Glaser and Strauss's classical version. Firstly, Strauss and Corbin placed emphasis on the importance of identifying structural as well as contextual, symbolic and interactional influences. This highlighted for me the need to take account of both macro and micro influences on the phenomenon under investigation. I believed that this approach was wholly justified as personal experience and published evidence had indicated that the strategies used by children and families in acquiring competence were mediated by various macro and micro influences. These included political, social, economic and psychological factors and micro influences such as socialisation into the 'community of practice', time of diagnosis or previous healthcare experience.

The second factor was the paradigm perspective proposed by Strauss and Corbin (1998). This structured organisational model for data collection, analysis and category development helped to bring more coherence and clarity to the process than the less structured approach advocated earlier by Glaser and Strauss. For instance, in phase two of this study, I had originally intended to use Krippendorff's less structured approach to content analysis to analyse clinical case-note documentation, parents' and children's reflective accounts and my own field notes (Krippendorff, 1980). Content analysis is discussed in more detail in chapter 4 with regard to research design. At this point it is sufficient to acknowledge that content analysis came to prominence in the social sciences at the start of the 20<sup>th</sup> century in a series of quantitative analyses of newspapers, primarily in the United States (Robson, 2002). Nevertheless, when designing this study, I learned through detailed reading about grounded theory that it was possible to collect grounded theory data from documents (Stern, 1980). Streubert and Carpenter (1999:107) point out that:

*Researchers may collect grounded theory data from interview, observation or documents or from a combination of these sources.*

Documentary data are thus regarded as 'social facts' with the same status as other forms of data. In the present study, I was interested in how these social facts were produced, shared and used in socially organized ways. Hutchinson (1992) describes how she used grounded theory in a study exploring the transformation of professional identity amongst nurses. Data were obtained using interviews, participant observation and document analysis. She goes on to describe how she then examined and analysed the data gathered through a system of constant comparison until the investigation generated a number of hypotheses. She then consulted the literature for previously developed theories that related to the emerging hypotheses of the study in progress. The developed theory, consisting of related factors or variables, was then suitable for testing (Strauss and Corbin, 1990; Hutchinson, 1993).

In the present study, the sample in phase two represented children who had recently been referred to the Children's Kidney Unit because of a chronic renal problem. The research design sought to map the process of learning for children and/or their families during the first eighteen months following referral. Analysis of casenote documentation recorded by professionals often uncovered examples of the categories that make up the social theory of learning in childhood chronic renal disease that emerged from this study. For instance, the following excerpt from nursing notes illustrates how a nurse assessed Carol's mother who was in the process of practising (using a practice machine) the technique of connecting Carol to her peritoneal dialysis machine:

Nurse [I] observed Mum doing a practice machine. Excellent, handling of bags. Some prompts required with connections. Observed her making Carol's machine-did very well. Needed some observation of connections - safe but a little uncontrolled - to hold them more firmly at the bag side and observe hand position

This is an example of the category 'assessing' that is discussed in detail in chapter five. Carol's mother, meanwhile, referred to this process of learning to 'do PD' on several occasions in interviews and valued the fact that the nurses gave her knowledge of what to do and how to do it incrementally. In addition, she saw repeated practice as an important aspect of her learning. By emphasising a developmental approach to learning, the nurses conferred several advantages on Carol's mother. For instance, by reinforcing the view that competence in performance is achievable through repeated practice on the

'practice machine', they were able to assess her skill and knowledge development and use this to structure support sessions. Further instances of the category 'assessing' were identified in subsequent data obtained through interviews with professionals and further documentary analysis. The aim of a grounded theory analysis is the formulation of complex models that best describe the data at a conceptual level (Corbin and Strauss, 1987). With this in mind, therefore, I considered the significance of mutual 'assessment' of ability in relation to the category of 'synthesising' (another category from the social theory of learning in childhood chronic renal disease that is discussed in detail in chapter 7).

In summary, this study was conducted using a modified version of the approach outlined by Strauss and Corbin. Therefore, emphasis was placed on the importance of identifying structural as well as contextual, symbolic and interactional influences. In addition, a structured organisational model for data collection, analysis and category development such as that promoted by Strauss and Corbin (1998) allowed me to bring coherence and clarity to the process that the less structured approach outlined by Glaser and Strauss would not have supported. Finally, consideration of the issues of reflexivity and relationality (both issues which are discussed in more detail in chapter 4) during the collection and analysis of data led to the approach used being a modified version of that outlined by Strauss and Corbin.

### ***Ethical considerations***

Approval to gain access to participants was obtained from the Head of Research and Development at Newcastle upon Tyne Hospitals NHS Trust and from the Newcastle and North Tyneside Local Research Ethics Committee (Appendices 1 & 2). In addition, clinical access was negotiated through the Children's Kidney Team and the Head of Nursing at Newcastle Hospitals NHS Trust. The study was conducted in accordance with Northumbria University's ethical requirements for research and evaluation studies. Children and adults have the same rights to confidentiality and anonymity (UN, 1989; RCN, 2004), so in this thesis pseudonyms are used when referring to all participants. Because of the need to maintain anonymity and respect confidentiality, detailed information about participants' characteristics are not outlined.

There is increasing discussion in literature and policy regarding the importance of involving children in the decision about whether or not to take part in research (Morrow and Richards, 1996; Alderson, 1997; Coyne, 1998; Allmark, 2002). These discussions

are explored below and have informed the conduct of this study. I have also been mindful of relevant new guidelines that have arisen since commencing the study in 1999 (DoH, 2001c). This is particularly important because children, as a powerless group in society, are not in a position to challenge the way in which research findings about them are presented (Morrow and Richards, 1996). Historically, it was often assumed that adults could extrapolate memories from their childhood to inform service delivery and development so children were not involved in research that informed these (Coyne, 1998). However, a child-centred approach is now exemplified in research (MRC, 1991; RCPCH, 2000; RCN, 2004) although it is only relatively recently that codes of research ethics have been developed that focus specifically on children (Allmark, 2002). To a large extent, therefore, the development of such regulations has been the same as those for adults.

The main precursor to modern ethical review processes is the legacy of appalling things done in the past to people, including children, in the name of research. Kennedy and Grubb (2000) and later Allmark (2002) and Shields and Twycross (2003) remind us of the Nuremberg trials that took place after World War 2. These revealed horrifying research that was conducted on wartime captives in an environment where no regulations, apart from those relating to conventional treatments, existed regarding the testing on humans of new ideas and treatments. As a result the Nuremberg Code was developed in 1946 (BMJ, 1996) to regulate research and included a requirement that voluntary consent of research participants be obtained. Paradoxically this meant that research could not be conducted with those considered 'incompetent' to consent. This included those with a learning disability, the unconscious and children. This meant that these groups could not, therefore, benefit from interventions that had been scientifically evaluated with a similar population. In 1964 the Helsinki declaration (WMA, 2000) modified the Nuremberg code to permit research on 'incompetents' according to strict controls. One control was that healthcare research proposals should be submitted to independent research committees for approval. The declaration, however, was not a legal requirement and so was not always implemented. Indeed some healthcare researchers argued at the time that they could be relied upon to act ethically without the need for 'state interference' (Weindling, 1996).

Nevertheless, research published in the 1960s (Beecher, 1966) revealed a wealth of unethical clinical research that had been published in reputable journals, some involving



children. As a result of these cumulative events:

*Reputable journals now insist that the research they publish has been subject to ethical review; ethical committees exist throughout the western world and researchers are subject to control by many ethical codes. (Allmark, 2002:9)*

In reviewing proposals, research ethics committees are now required to consider the three main criteria of scientific validity, welfare of participants and respect for the dignity and rights of participants (DoH, 2001c; Allmark, 2002). These criteria have informed the design and conduct of this study and are discussed in more detail in the section on data collection in chapter 4.

Assessments of the age at which children become adults have varied over the years. Currently the UK Children Act (DoH, 1989) indicates that a child is any person under the age of 18 years and Kennedy and Grubb (2000) define three stages of childhood according to UK Case Law:

- Children of 'tender years' who lack capacity to consent to healthcare treatment.
- Gillick Competent children who are under 16 years and have developed sufficient maturity to consent to some or most healthcare procedures.
- Those aged 16 and 17 years who according to the Family Law Reform Act (DoH, 1987) are assumed to be as competent as adults unless there are grounds to suggest otherwise.

These definitions have implications for this study in which the age of children recruited ranged from three months to 15 years on entry to the study. There is also an important distinction to consider between the concepts of consent and assent in research with children. Consent is permission given by one with legal authority such as a parent or guardian while assent is voluntary permission given by one with no legal status (Lamprill, 2002), in this instance a child. Competence to make a decision is critical in determining the age of assent (UN, 1989) and yet competence needs to be assessed carefully, as does the context in which that competence is being assessed. The Law Lords decreed that children who are competent to make informed and wise decisions can give valid consent on their own behalf (Gillick, 1986). However this ruling related to treatment rather than research participation and Lamprill (2002:2) points out that:

*It would be a foolhardy investigator who consented a child into a trial against*

*parental wishes.*

Clearly the study reported here was not a clinical trial but I was, nevertheless, mindful of the advice by the British Medical Association (2001) that competence needs to be assessed carefully; that information from those who know and love the child is of great importance when assessing competence to consent to research (although this may of course be subjective); and that consent is a process not a single event and so should be constantly reassessed as children develop. In this study, there was no potential for physical harm but any possibility of psychological exploitation was minimised by following carefully the guidelines for conducting research with children (MRC, 1991; RCPCH, 2000; RCN, 2003). As far as possible, the principles of beneficence, non-maleficence, respect for autonomy and justice were observed (Beauchamp and Childress, 1994; Brykczynska, 1994; Alderson, 2005) and children's rights were respected at all times in line with the United Nation Convention on the Rights of the Child (UN, 1989). For instance, every effort was made to: avoid invasiveness and intrusions into family life by arranging interviews at a time and place convenient to the child and family; to interview the child without the parents present if that was their wish and to try to ensure that any benefits arising from the study are greater than any potential disadvantages to the child and family. In addition, I was aware of the possibility that conducting research interviews of a potentially sensitive nature soon after the family were referred to the Children's Kidney Unit may cause distress to family members and, therefore, was guided by the Senior Renal nurse about the most appropriate time to approach families. This concern about approaching families at sensitive times was also a consideration by Alderson (2005) when conducting research with parents in intensive care baby units. She acknowledges the need to keep away from parents who look extra anxious, even though this can make projects longer and harder to complete than in a less intensive situation. I was also aware that my concern about approaching families too soon after referral to the Children's Kidney Unit in order not to cause additional stress may have negatively influenced the quality of response I obtained from family members. Because of the time lapse between interviews in phase two, I reaffirmed consent (verbally) with adult participants before each interview as well as those children able to give assent.

## **Conclusion**

Some key philosophical debates around research have been explored and conclusions drawn regarding the most appropriate approach for this study. Grounded theory within a symbolic interactionist approach is presented as the chosen philosophical perspective as the understanding of meaning by participants is central to the research. The emphasis in grounded theory is on the importance of deriving theories and explanations of social structures and processes inductively by grounding explanations for observed phenomena in the data. The decision to use Strauss and Corbin's version of grounded theory is justified and finally a funnel metaphor is used to illustrate the complex process of conceptualising and organising the study. In considering the ethical aspects of the study, the importance of a child centred approach to research has been discussed in this chapter. The case has been made for assessing children's competence to assent to taking part in studies concerning their views of and experiences in health care and I have emphasised the fact that children and adults have the same rights to confidentiality and anonymity. In keeping with current guidelines on research governance the study has been designed to ensure that it meets the key criteria of scientific validity, welfare of participants and respect for their dignity and rights.

## Chapter 4: Research Design

This chapter focuses on research design. Issues pertaining to sample selection, participant recruitment, data collection and analysis and theory development are discussed in relation to the study. Throughout the discussion consideration is given to the various steps taken to ensure, as far as possible, that the research was rigorous in conduct through the systematic and transparent collection, analysis and interpretation of data (Spencer, Ritchie, Lewis and Dillon, 2003).

### *The study design*

The study involved two phases. Phase one was retrospective and aimed to uncover the skills and knowledge children and/or parents identified as having been important in learning about the chronic renal disease since referral to the Children's Kidney Unit up to four years previously. This phase marked the beginning of a longer process of data collection and helped to lay the foundations for phase two. Morse (2001) urges grounded theorists to consider carefully the significance of *process* in grounded theory. Process, she maintains, implies a beginning and an end, an antecedent and a consequence or some level of causality. Data should be temporal, similar to stories with a beginning, middle and end. Initially, Morse suggests that participants who have experienced the phenomena under investigation should be invited to tell their stories so that an overview of the process can be obtained. This can inform the sampling frame for purposively selecting other participants and can begin the process of theoretical sampling. In this way comprehension will be achieved earlier and faster than if the researcher worked prospectively and can lead the researcher to an understanding of the context (Morse, 1997). Thus 'one off' interviews in which respondents were asked to recall significant learning experiences since diagnosis were selected to begin the process and comprised phase one of this study.

Phase two was prospective and longitudinal. Its development was informed by the analysis from phase one. This approach allowed detailed exploration of issues as they arose during the first eighteen months after referral to the Children's Kidney Unit and enabled a process of mapping of learning patterns to emerge. Four sources of data collection were used:

- Repeated interviews with children and/or family members.
- Interviews with key professionals at the beginning and end of phase two data

collection.

- Multidisciplinary casenotes and researcher's field notes.
- Reflective diaries completed by children or family members.

The case for conducting a longitudinal phase was based on the sociological and philosophical viewpoint that reality is experienced in concepts that are constantly changing (Seed, 1995; Murphy-Black, 2000). In longitudinal studies the researcher is continually endeavouring to capture a 'moving picture' that challenges thinking and ingenuity (Seed, 1995). The purpose of longitudinal research is to examine change over time (Cormack, 2000). For instance, Beresford (1996) conducted an in-depth longitudinal study of 20 families caring for a severely disabled child and observed changes occurring in their family management styles. Glaser and Strauss (1967) maintain that the researcher should return to the field continually in order to test the relevance of ideas and to stimulate further developments. A longitudinal study permits this approach. A disadvantage, however, of this approach is that in continually trying to describe a moving picture and decide what has changed since an earlier interview, it is possible the researcher may fail to capture the complexity of particular issues in aiming for theoretical saturation. A key aspect of study design is the research setting, therefore, this is discussed in the next section.

### **The research setting**

Participating families were recruited from the Children's Kidney Unit, Newcastle upon Tyne Hospitals NHS Trust. Participating staff were also recruited from the workforce in the Children's Kidney Unit. The unit, one of 14 such units in the United Kingdom and Eire (BAPN, 2002), provides a Regional Service with specialised care for children with kidney, bladder and connective tissue disease. Referrals to the unit come from throughout the Northern Region of England and include some families from North Yorkshire and the Borders Region. The population served is approximately 3.5 million. The staff comprises: four Consultant Paediatric Nephrologists, one Specialist Registrar, one Paediatric Dietician, one Social Worker (unavailable for the duration of this study), two Senior Nurses, three Renal Nurse Specialists, one Senior Paediatric Haemodialysis Nurse, two Haemodialysis Nurses, one Health Care Assistant, one Senior Nurse (urinary tract infection direct access) and six Medical Secretaries. Staff from the unit liaise closely with staff in other parts of the Trust. Children requiring inpatient care are usually cared for on one of the acute paediatric medical wards or the Paediatric Intensive Care

Unit. Outpatient care is delivered on the Paediatric Haemodialysis Ward, the Children's Day Care and Acute Assessment Ward and the Children's Outpatient Department. In addition, Consultant and Nurse led outpatient clinics are held in District General Hospitals in the region and nursing staff regularly visit families in their homes to provide teaching and support as well as offering telephone advice to families as needed.

Research interviews with children and families were conducted either in the family home, the Children's Ward or the Children's Outpatient Department according to the respondents' stated preferences. I believed this was important in order to minimise inconvenience for the participants and to allow them to have some control over the situation, thus reducing the power differential between them and myself. This awareness of the power and trust relationship between myself and the participants and its possible effect on data collection is an example of relationality that is discussed later in this chapter in relation to the co-construction of meaning. However, the measures I have described to optimise the research environment also presented me with some interesting challenges when setting up the interviews. Faux, Walsh and Deatrick (1988) remind us that gaining access to children for the purpose of research often requires dealing with multiple gatekeepers. In addition to the steps outlined above to identify a sample in the current study, access was often negotiated with ward or department based personnel in order to conduct interviews in the hospital setting.

For instance, in phase one, three interviews (one with an unaccompanied child, one with his parents and one jointly with a girl and her parents) were conducted in a consulting room of the Children's Outpatient Department. This was convenient for the families who asked if I could arrange the interview to coincide with their attendance at the department for treatment or follow up. Nurses in the department arranged access to a room and ensured we were not interrupted. Other interviews with families took place in the home either during the day or in the early evening. When the children were too young to be involved, the interview took place while they were having a daytime sleep or after they had gone to bed in the evening. Interviews with older children who wished to be interviewed alone took place in the living room while the parents went into another room. Interviews with professionals took place in a quiet office or consulting room although during one 90 minute interview, that had to take place in a shared office in the busy and crowded department, we were moved three times in order to allow the respondent's colleagues to access the desk space we were using.

There were also other occasions when I had to be quite adaptable in my approach to the data collection process. For instance, the first interview with David (phase two), a five year old, was conducted at his bedside on the children's ward (while his mother went for a cup of coffee in the parent's room) because he was attached to the plasma exchange machine. This was in the middle of a busy, noisy ward and the nurse caring for David needed to intervene occasionally to deal with his treatment and the equipment. This required a flexible approach, as I needed to ensure the tape recorder was switched off during these interruptions but David and I were able to play a game of Connect during these pauses. In line with a recommendation regarding data collection with young children recently reported by a colleague and myself (Swallow and MacFadyen, 2004), I had at the outset encouraged David to operate the on/off switch on the tape recorder. He enjoyed this role and dealt with it very efficiently! I had previously interviewed his mother in the parents' sitting room on the same ward, the nurse in charge having offered a 'Please Do Not Disturb' notice that she placed on the door. As she predicted, this allowed us to talk for 45 minutes without interruptions. Another key feature of research design is the selection of a sample, this is discussed in the following section.

## **Sampling**

### **Phase one**

The total number of children listed as current patients on the Children's Kidney Unit database at the start of the present study was 974. At the start of phase one, nine children (current patients) with a chronic renal problem diagnosed during the preceding four years were selected from this database, using a theoretical sampling matrix (Figure 4). One additional child (Jane aged 10years) whose condition required moderate intervention, and her mother had agreed to take part in a joint, pilot interview in the Children's Outpatient Department before the study commenced. This allowed me to test the topic guide and led to my making slight refinements to the questions and the way in which I later asked the questions.

Figure 4: Theoretical sampling matrix (phase one)

| Level of intervention   | Low     |           |            | Moderate  |           |           | High      |          |           |
|-------------------------|---------|-----------|------------|-----------|-----------|-----------|-----------|----------|-----------|
|                         | 0-5     | 6-10      | 11-16      | 0-5       | 6-10      | 11-16     | 0-5       | 6-10     | 11-16     |
| Age (years) at referral | 0-5     | 6-10      | 11-16      | 0-5       | 6-10      | 11-16     | 0-5       | 6-10     | 11-16     |
| Years since referral    | 4       | 2         | 3          | 4         | 4         | 2         | 4         | 4        | 2         |
| Patients recruited      | √       | √         | √          | √         | √         | X         | √         | √        | √         |
| Study number            | 8       | 1         | 5          | 6         | 7         | 9         | 4         | 3        | 2         |
| Pseudonym (Gender)      | Ann (F) | Susan (F) | Leslie (M) | Billy (M) | Nancy (F) | Kelly (F) | Keith (M) | Jane (F) | Milly (M) |

Subsequently, eight mothers, two fathers and three children consented (Appendix 4) to participate (the parents of the ninth child declined to participate because of time constraints). Theoretical sampling is a specific type of non-probability sampling in which the objective of developing theory or explanation guides the process of sampling and data collection. According to Strauss and Corbin (1998), it is important when exploring new or uncharted areas because it enables the researcher to choose those avenues of sampling that can bring about the greatest theoretical return. The aim is to maximise opportunities to compare events, incidents, people or accounts in order to determine how a category varies in terms of its properties and dimensions.

Glaser and Strauss, in their earlier discussions on grounded theory (1967), advised researchers to select participants; collect, code and analyse data and produce a preliminary theoretical explanation before deciding what further data to collect. Once these data are analysed, refinements are made to the theory that in turn will guide further sampling and data collection. Therefore, the relation between sampling and explanation is theoretically led. Mays and Pope (1996) also stress that it is very important to engage in a search for counter-evidence in order to look for an example in the data which contradicts the emerging explanation. This can assist the researcher to make informed decisions about how to broaden or deepen the analysis (Mason, 1994; Schreiber, 2001). In order to provide information that can generate, illuminate and explain the issues around the research question the cases must be relevant to the question. The cases should form a coherent pattern from which reliable and robust explanations can be created. This reduces the possibility of bias arising from selecting a sample on the basis of simply convenience.



Theoretical sampling is cumulative and iterative with each event sampled building from and adding to previous data collection and analysis (Schreiber, 2001). Furthermore, sampling becomes more specific with time as the researcher is directed by evolving theory. Hence in this study, I initially generated as many categories as possible in phase one during the open coding stage and axial coding stages (Figure 11). Once I had achieved the axial codes (living in a maelstrom, using intuition and playing the game), further sampling was aimed at developing, densifying and saturating the categories. Thus the initial sampling strategy was enhanced by introduction of the emergent categories from phase one into the topic guide for phase two (Figure 13). In keeping with Strauss and Corbin's recommendations (1998), I tried to maintain a degree of consistency (so that comparisons were made systematically on each category, ensuring each was fully developed) and flexibility (to take advantage of or make adaptations because of unexpected occurrences).

A limitation with this sampling strategy is that it allows no way of knowing precisely the degree to which the sample corresponds to the population from which it is drawn. However, as the aim of the study was to explore patterns of learning since referral rather than individual characteristics of the participants, the sample obtained was appropriate in relation to children and families learning to manage chronic renal problems. The aim of theoretical sampling is to maximise opportunities to compare events, incidents or happenings (Strauss and Corbin, 1998). The main criteria used in this sampling frame are outlined and discussed in more detail below.

### **Levels of intervention:**

The three different levels of intervention used to inform the sampling frame are related to three different groups of chronic renal conditions that may affect children at any age. These are outlined in Appendix 3. The levels of intervention are artificial clinical classifications that were identified to assist with sample selection in this study after considerable discussion with my clinical supervisor. As can be seen there are gradations of degree of intervention required, with 'low intervention' requiring minimal input from the renal team and family and 'high intervention' requiring maximum input from both. The clinical classification of severity of a condition can influence families' ability to cope with and understand a chronic condition. For instance, in the management of end stage renal failure in adults, there is evidence that higher levels of perceived disease interventions were associated with reduced life satisfaction and self esteem and subsequently with depression (Welch and Austin, 1999; 2001).

### **Age at diagnosis:**

The decision to include 'age at diagnosis' in the sampling matrix was based on a combination of clinical experience and empirical evidence from the psychological and sociological perspectives. The age at which children are diagnosed is likely to affect the way in which they adapt to the condition and it is also possible that it will affect the way in which they respond to being a research participant. Clinical experience and research evidence (for instance Sartain *et al.*, 2000) has shown that children's ability to learn about and cope with a chronic condition is determined to some extent by their age and stage of physical and emotional development and that this changes across the disease course as they grow and develop. As children develop, they become more competent at reasoning and language. Coping and development have in the past been studied separately but it appears that in childhood, coping and development are interconnected, with age-related factors playing a major part in shaping adaptational processes to stress (LaGreca, Siegal and Wallander, 1992). The study of coping with childhood chronic disease is, however:

*...a unique and challenging task because children seem to have quite divergent views from adults about the cause, aetiology, treatment of disease and their own strategies to deal with the disease. (Schmidt, Peterson and Bullinger, 2003:65)*

It is adult coping with chronic disease that has been the subject of most empirical work and, compared with this, it is even more important to take developmental considerations into account when assessing coping in children. Schmidt, Peterson and Bullinger (2003) reported on a Medline search (1975-2001) for empirical studies on coping in childhood chronic disease. A total of 391 articles were identified: 118 assessed parents' views while 71 assessed children's views (only a few of these used age appropriate coping inventories). This is probably illustrative of the fact that a developmental approach complicates coping research (McCubbin *et al.*, 1983). There appears to be no consensus about whether coping in children is more or less diverse than in adults. Kavsek and Seiffge-Krenke (1996) claimed that coping strategies differentiate into several dimensions in adolescence. By contrast, others have shown that childhood coping consists of various single behavioural strategies and that qualitative changes occur when a child gets older, leading to coping strategies that can be used in a more flexible manner (Compass, Worsham and Ey, 1992; Spirito, Stark and Gill, 1995; Thompson and Gustafson, 1996). Finally, Hoffman, Levy-Shiff, Sihlberg (1992) suggested that during the transition from concrete to formal operations (as described by Piaget, 1954 in chapter 2 of this thesis), adolescents develop the ability to use subtle

cognitive forms of appraisal and so may be more flexible and differentiated in the coping strategies they use.

### **Time since referral**

The time since referral was viewed as the third significant issue in the ability of families to learn to manage chronic disease. In trying to assist patients and their families to cope with chronic disease after referral, Burke, Harrison, Kauffmann *et al* (2001) recognised that the concept of 'intentional action' is a key concept. As most action in health care is carried out with a purpose, initiated and controlled by the individual, this concept is seen as important for those who aim to influence the action or behaviour of patients following referral or diagnosis. Therefore, a nurse who teaches a new patient about the importance of hydration is hoping the patient will respond in an appropriate way, thus the relationship involves not only action by the nurse but subsequent action by the patient. The process through which patients learn to manage chronic disease appears to be influenced by the way in which the professional relays the information to the patient at the outset (Burke, 1999; Burke *et al.*, 2001). The concept of intentional action, therefore, assists with understanding how intentions (for example, teaching a skill to a patient) become actions.

Alderson (1990b) and Bartlett (1984) recognised the positive benefits of teaching patients relevant information soon in the disease course, as did Carter, Urey and Eid (1992) and more recently, my own research (Swallow and Jacoby 2001b). Referrals can create organizational, clinical, and emotional problems for all involved. Franz, Lawrence, Somov *et al* (1999) investigated the relationship between time since referral, length of stay and selected variables, such as diagnosis, referral source and severity of condition at referral. There were differences in the emotional problems reported by families according to length of time since referral, diagnosis and referral source. Therefore, time since referral was considered significant in sampling for the present study.

### **Phase two**

Initial sampling in phase two involved a combination of theoretical and purposive sampling (Bowling, 2002) using the sampling matrix below (Figure 5). In order to bring about the greatest theoretical return, the sampling matrix used was the same as that used for phase one except that 'time since diagnosis' was necessarily excluded. Between January and November 2003, six children who had not previously been registered with the Children's Kidney Unit were identified as soon as possible after first

referral to the Children’s Kidney Unit for a chronic renal problem. All six families were invited to take part in the study and all agreed to participate.

Figure 5: Theoretical sampling matrix (phase two)

| <b>Level of intervention at referral</b>                 | <b>Low</b> |  | <b>Moderate</b> |      | <b>High</b> |       |      |
|--|------------|--|-----------------|------|-------------|-------|------|
| <b>Age (years) at referral to Children’s Kidney Unit</b> | 3          |  | 6               | 15   | 14          | 5     | 3/12 |
| <b>Pseudonym</b>   | Eric       |  | Kevin           | Nina | Carol       | David | Lucy |
| <b>Gender</b>  | M          |  | M               | F    | F           | M     | F    |
| <b>Patient study number</b>                              | C1         |  | C2              | C3   | C4          | C5    | C6   |
| <b>Patients recruited</b>                                | √          |  | √               | √    | √           | √     | √    |

In positivist research approaches, the overriding consideration in sampling is representativeness of the sample. In reality it is difficult to be certain that a sample is completely representative of the population to which one wants to generalise results but procedures such as randomised controlled trials and statistical tests help to control for this (Bowling, 2002). When building theory inductively, however, the concern is with:

*...representativeness of concepts and how concepts vary dimensionally. We look for instances in which a concept might be present or absent and ask why?...Because we are looking for events and incidents that are indicative of phenomena and are not counting individuals or sites per se, each observation, interview or document may refer to multiple examples of these events.*  
(Strauss and Corbin 1998:214)

Thus in phase two, sampling also extended to documentary data (casenote documentation, reflective accounts, researcher’s field notes) relating to the children sampled in order to provide a wider perspective on the phenomenon of the study. In the process of theory building, this enabled me to look for indicators representative of theoretically relevant concepts, and then compare these for their properties and dimensions, always looking for dimensional range or variation. Another component of theoretical sampling, the use of ‘negative cases’ (that is those that apparently refute the emerging conceptualisations) is, according to Schreiber (2001), often overlooked. Examination of such cases challenges the researcher to develop a fuller understanding at a higher level of abstraction and forces the researcher to develop concepts and explanations that account for the fullest range of data. The longitudinal nature of this phase permitted further exploration of any such examples and these are discussed in more detail later in the thesis.

## **Participant recruitment phases one and two**

Once the sample population had been identified, the recruitment procedure was initiated. This followed earlier discussion with my Clinical Supervisor in the Children's Kidney Unit, during which I was shown how to access the patient database to facilitate sample selection using the sampling matrix for phase one. Identifying a sample for phase two proved to be more challenging because of the intention to contact children and/or families as soon as possible after referral to the Children's Kidney Unit for a chronic renal problem. After detailed discussion with members of the clinical and administrative team in the Children's Kidney Unit, a series of steps were put in place to increase the possibility that I would be contacted as soon as possible after a child was referred. If a child met the criteria outlined in the sampling matrix one of two approaches were adopted:

1. I contacted the child and/or parents by letter inviting them to take part in the study.
2. If the child was an inpatient, the renal nurse or doctor would approach them and/or the parents on my behalf to introduce them to the study and ask if they were willing to talk with me in connection with the study. In this case I gave the letter/information leaflet personally.

Once a sample was selected, General Practitioners and, where appropriate, Paediatricians in District General Hospitals were notified of the intention to invite patients in their care to participate in the study. None expressed concerns about this. Selected children and/or their parents received a letter and information leaflet (Appendices 6,7,8 and 9) about the study (either by post or from me when I spoke to them on the ward) with contact details (for obtaining further information) for the Consultant Paediatrician/Clinical Supervisor to the project and myself. Signed consent was sought from all participants after receiving both written and verbal explanations (parental consent was obtained for their child's participation). Children who were considered competent to understand the research and consent process were also invited to sign a consent form. In phase one, four children chose to complete the form and in phase two, three children chose to complete it. In phase two, I reaffirmed consent with participants before second and subsequent interviews took place.

I did not wish to cause additional stress to children and/or parents who may be already anxious because of the nature of the disease and its treatment. Therefore, I was guided

by the Senior Renal Nurse about the most appropriate time to approach them with an invitation to take part in the research. This worked well as it meant that children and/or families were able to give reasonably undivided attention to the interview when I did contact them. However, it also meant that some of the Cases did not start immediately after first contact with the unit if the child was considered too ill and/or the family too distressed and preoccupied. With full parental agreement, children considered competent to assent were involved in the consent process in this study. They were informed that if they wished to withdraw at any time, even if there was continuing parental consent, this would not affect their normal care in anyway. In particular, every effort was made to ensure that consent or assent were informed and freely given by encouraging families to take time to consider or to discuss the project with relatives or staff. In addition they were assured that declining to enrol or later withdrawing would not jeopardise subsequent care or relationships with professionals.

Figure 6: Key to respondents on entry to the study, phase one and two

| <b>Pseudonym of child</b> | <b>Age of child (years)</b> | <b>Level of intervention</b> | <b>Family context</b>  |
|---------------------------|-----------------------------|------------------------------|--|
| <b>Phase one</b>          |                             |                              |  |
| <b>Ann</b>                | 2                           | Low                          | Youngest of three children, parents had little previous experience of health care.   |
| <b>Susan</b>              | 7                           | Low                          | Oldest of three children, parents had little previous health care experience.  |
| <b>Leslie</b>             | 12                          | Low                          | Only child of parents who are both health professionals. Has little previous health care experience himself.   |
| <b>Billy</b>              | 5                           | Moderate                     | Youngest son of Professional parents (not English) have little previous experience of the English Health Service, significant experience of alternative medicine in another country. |
| <b>Nancy</b>              | 8                           | Moderate                     | Oldest of three children, one of whom also has a chronic disease (not renal)-family very confident with management of the condition.   |
| <b>Keith</b>              | 4                           | High                         | Second of three children in a single parent family (Father not in contact with the family). Mother has little family support.  |
| <b>Jane</b>               | 9                           | High                         | Oldest child of three, no previous health care experience.   |
| <b>Milly</b>              | 14                          | High                         | Oldest of two, Father works away, mother very supported by grandparents.   |
| <b>Phase two</b>          |                             |                              |  |
| <b>Carol</b>              | 14                          | High                         | Only child, parents separated, father works away but maintains close contact with Carol and her mother. Family little previous health care experience.                               |
| <b>Lucy</b>               | 3 months                    | High (shifted to Moderate)   | Only child to single mother who is very supported by her parents. Mother wishes to become a nurse.   |
| <b>Eric</b>               | 3                           | Low (shifted to Moderate)    | Second child, parents teachers, lives one hundred miles from the Unit.   |
| <b>Nina</b>               | 15                          | Moderate                     | Third child to parents who also have grown up children from previous marriages. Mother and several other family members have chronic ill health. Nina wants to train as a nurse.     |
| <b>David</b>              | 5                           | High (shifted to Low)        | Second son, parents little previous health care experience.  |
| <b>Kevin</b>              | 6                           | Moderate (shifted to High)   | Second child, lives with mother, younger sister and older step-sister and stepfather, Mother very apprehensive about hospitals since her father was in hospital several years ago.   |

**Data Collection:**

Below is a summary of the timing of interviews and data collected during the study:

Figure 7: Timing of family and professional interviews phase two

|              | Timing of family interviews<br>(from referral to Children’s Kidney Unit) |                       |                       |           | Timing of professional<br>interviews (from referral to<br>Children’s Kidney Unit) |                  |
|--------------|--|-----------------------|-----------------------|-----------|---|------------------|
|              | 1 <sup>st</sup>  | 2nd                   | 3rd                   | 4th       | 1st   | 2nd              |
| <b>Carol</b> | 3 weeks  | 8 months              | 16 months             |           | Nurse: 4 weeks<br>Dietician: 4 weeks  | Nurse: 18 months |
| <b>Lucy</b>  | 6 weeks  | 6 months              | 10 months             | 17 months | Nurse: 6 weeks<br>Dietician: 6 weeks  | Nurse: 18 months |
| <b>Eric</b>  | 1 week   | 10 months             | 14 months (telephone) |           | Nurse: 4 weeks  | Not available    |
| <b>Nina</b>  | 3 weeks  | 5 months              | 11 months             | 18 months | Nurse: 4 weeks<br>Dietician: 4 weeks  | Nurse: 18 months |
| <b>David</b> | 3 weeks  | 12 months (telephone) | 18 months (telephone) |           | Nurse: 4 days   | Nurse: 12 months |
| <b>Kevin</b> | 5 weeks  | 5 months              | 9 months              | 17 months | Nurse: 6 weeks<br>Dietician: 6 weeks  | Nurse: 18 months |

Figure 8: Summary of data collected in phase one and two

| Phase one  | Phase two  |
|--|--|
| Total Interviews x 10<br>Total participants = 16<br>These involved:<br><ul style="list-style-type: none"> <li>• Mothers x 6</li> <li>• Parents jointly x 2 (one with grandmother as well)</li> <li>• Children x 3 (2 were unaccompanied)</li> <li>• Sibling x 2</li> </ul> | Total Interviews x 37<br>These involved:<br><ul style="list-style-type: none"> <li>• Parents jointly x 5</li> <li>• Mothers alone x 10</li> <li>• Mother and child x 3</li> <li>• Mother x 1 (with grandmother)</li> <li>• Professionals x 15</li> <li>• Children x 3 unaccompanied</li> </ul> |
|  | Reflective diaries x 4 = Total 8 pages A4  |
|  | Casenote documentation = 6 x 3 pages A4 (1 proforma completed after each family interview) – Total 18 PAGES A4   |



There were three sources of documentary data, multi-disciplinary casenotes, research field notes and reflective accounts by parents or children. In the figure below these are compared with interviews as sources of evidence in Cases:

Figure 9: Strengths and weaknesses of documentation, interviews and reflective accounts as sources of evidence

| Sources of evidence                                  | Strengths   | Weaknesses   |
|--|---|--|
| <b>Documentation</b><br>(Case notes and field notes) | <ul style="list-style-type: none"> <li>• Stable: can be reviewed repeatedly.</li> <li>• Unobtrusive.</li> <li>• Exact: contain exact names and details of events and accounts.</li> <li>• Broad coverage: long span of time, many events and settings.</li> </ul> | <ul style="list-style-type: none"> <li>• Retrievability can be low.</li> <li>• Biased selectivity possible if collection is incomplete.</li> <li>• Reporting bias can reflect (unknown) bias of authors.</li> <li>• Access may be deliberately blocked.</li> </ul>   |
| <b>Interviews</b>                                    | <ul style="list-style-type: none"> <li>• Targeted: focuses directly on topic.</li> <li>• Insightful: provides perceived causal inferences.</li> <li>• Allow for further probing and questioning.</li> <li>• Can lead to clarification of queries.</li> </ul>      | <ul style="list-style-type: none"> <li>• Possible bias due to poorly constructed questions.</li> <li>• Possible response bias.</li> <li>• Inaccuracies may result from poor recall.</li> <li>• interviewee may respond with what they think interviewer wants to hear.</li> </ul>  |
| <b>Reflective accounts</b>                           | <ul style="list-style-type: none"> <li>• Allows for internally examining and exploring an issue of concern.</li> <li>• Permits honest exploration of learning experiences.</li> <li>• Can be therapeutic to the reflector.</li> </ul>                             | <ul style="list-style-type: none"> <li>• Can lead to a sense of discomfort and feelings of 'exposure' for participant.</li> <li>• Can be an unwanted reminder of the enduring nature of the chronic disease.</li> <li>• May lead to feelings of distress which can be counter-productive in the learning process.</li> </ul> |

## Documentary evidence

Documents serve to corroborate and augment evidence from other sources. Thus, in phase two, documentary evidence was obtained from multi-disciplinary casenotes, reflective accounts by children or parents of self-selected, significant learning experiences relating to the chronic condition and detailed field notes written by myself soon after interviews were conducted. In particular, I recorded these after collecting, categorising and anonymising casenote data and when reflecting on the emerging categories and concepts. Data collection was facilitated by a proforma. Initially I had tried to make hand written notes of my interpretation of correspondence and handwritten entries in relation to the codes that had emerged from phase one analysis. Then I tried

to insert my interpretation into the word-processed interview transcript for the appropriate case at relevant places using a different font. However, I quickly realised the limitation of this approach, as I had no way of tracing my comments back to their original source for verification or later clarification.

Subsequently, I designed the pro-forma to assist retrieval of pertinent information from casenotes. It was developed as a word document comprising a series of boxes to assist with data collection. A continuation sheet enabled me to make additional notes as required. A separate pro-forma was completed for each case as soon as possible after each interview with the family. In this way I was able to ask 'naïve' questions of respondents about events that had occurred since we last spoke and subsequently seek any clarification or corroboration (or not) from the casenotes. Information in casenotes helped me to verify correct spellings and names that had been mentioned in interviews, in particular with regard to names of conditions, medications or investigations that were sometimes difficult for children or family members to articulate or myself and/or the typist to understand. An example of this is the way in which Nina's mother (phase two), during the first interview, said that several family members had recently had SSA scans but she did not know why. This was a term I had not heard before, but when I read the casenotes I discovered that some family members had undergone dimercapto succinic acid scans (routinely referred to as DMSA scans) to determine whether or not they had any kidney damage and if so, to assess the extent of the damage. Therefore, in the next interview when she and her husband mentioned the scans again I understood what they were referring to and pursued the discussion with them in a more informed way.

Documents can also provide other details to corroborate information from interviews or reflective accounts. Yin (1994) reminds us, however, not to be over reliant on documents in research. It is important when reviewing a document to remember that it was written for a specific purpose and audience other than those of the study being carried out. The researcher is a vicarious observer and the documentation reflects communication among other parties attempting to achieve some other objectives. Yin also points out that if the documentary evidence is contradictory rather than confirmatory, the researcher has specific reason to inquire further into the topic.

I was able to confirm my perception of respondents' accounts in phase two through reading reflective accounts of their experiences recorded in a diary format. Robson

(2002:258) warns against indiscriminate use of diaries in research, pointing out that they can be:

*Tantalisingly attractive because they appear on the surface to provide the means of generating very substantial amounts of data.*

Large volumes of free-text data may, however, prove to be very unwieldy and Robson, therefore, advises researchers to aim for a balance between volume and relevance. Because the diary involves self-completion, Robson urges researchers to make sure that respondents know exactly what they are expected to do, why and when. Nevertheless, research diaries can serve as a proxy for observation in situations where it would be difficult for direct observation to take place. The rationale behind the use of diaries in this study was to allow for children and families to express their views about meaningful experiences as they learned about aspects of the condition. I was aware that while unstructured diaries leave the interpretation of the task very much with the respondent (Robson 2002), using a more structured approach, for instance, a specific set of questions about respondents' activities at given times, could produce data that were prone to bias (Bourgue and Crompton, 1982). Therefore, I adopted an approach that was similar to that described by Robson (2002) as a 'reflective journal'. Thus, participants were asked to provide an account of their learning experiences in a particular setting or situation and a reflection on that experience.

When I introduced the diary at the beginning of phase two data collection, four respondents agreed to make entries into the diary between the first and second interviews. The other two respondents declined without giving a specific reason for their choice. I had stressed in my introduction to the diary approach that they were not required to provide a reason if they chose not to use a diary (in keeping with my philosophy of non-coercive research practice).

The information about the diaries stated:

*“ Please make notes, using your own words to explain your views and/or feelings about:*

- *A situation or situations that occurred in which you learned something new about your (if the respondent was a child)/your child's kidney problem.*
- *Any good aspects of the situation.*

- *Any difficult aspects of the situation.*
- *Anything you would do differently if the same situation occurred again.*
- *Anything you would do the same if the same situation occurred again .”*

This approach was based on the work of authors such as Beckett (1999) and Boud and Solomon (2001) who investigated the way in which adults learn at work. In addition, it was informed by earlier research I had been involved with in relation to work based learning by nurses (Swallow, Miller and Chalmers, 2001; Swallow, Chalmers and Miller, 2004). An aggregate of these studies suggests that to effectively provoke ‘workplace’ learning (in the context of this study the term ‘workplace’ is used to denote the setting in which the participant believes that learning has occurred that is in some way related to the renal problem) it is necessary for learners to exist in a culture that explicitly cultivates deliberate awareness of the learning as it occurs.

The respondents were asked to record their entries, as many times as they wanted between the first and second interviews. As outlined in figure 7, the length of time between first and second interviews varied between cases, this was influenced by the clinical condition of the child and the family member’s willingness and availability for interview. Because of the uncertainty about the nature of the children’s disease course, I maintained telephone contact with the parents between interviews in order to arrange mutually convenient times for interviews. Diary data were obtained in four of the six Cases (two children and two mothers), with entries varying in length from multiple short notes to detailed and lengthy accounts. All four respondents accepted my offer of a folder containing sheets of paper with brief guidance to guide their responses. However, in the event three respondents used a word processor instead to record their reflections. All four respondents had made several entries in their diary, three respondents made several lengthy entries covering between 2 and 4 pages. All except one mother had used the suggested headings to help frame their responses; this mother had written a very detailed but unstructured reflection of two incidents involving her communicating with health professionals about her child’s condition

## **Interviews**

All interviews were based on a Topic Guide. In phase one, interview topics were initially based on a combination of evidence from my own experience, anecdotal accounts from

colleagues and a preliminary review of the literature. As analysis proceeded, subsequent interview topics were supplemented by issues arising from earlier interviews and Open and Axial Coding of these. The topics used are listed in Figures 11 (phase one) and 13 (phase two). Interviews are a data collection method used extensively by qualitative researchers and can be described as a 'conversation with a purpose'. Typically the researcher explores a few general topics to help uncover the participant's perspective, but otherwise respects how the participants structure the response (Legard, Keegan and Ward, 2003). According to Marshall and Rossman (1995:80) the participant's perspective on the phenomenon of interest should:

*...unfold as the participant views it, not as the researcher views it...The most important aspect of the interviewer's approach concerns conveying an attitude of acceptance that the participant's information is valuable and useful.*

Like all data collection methods, interviews have particular strengths and weaknesses. As they involve personal interaction, co-operation is essential but the participant may be uncomfortable sharing all that the interviewer hopes to explore, or may have good reason not to be truthful (Douglas, 1976). The interviewer may not have the necessary skills in listening, question framing, interaction and gentle probing for elaboration (Marshall and Rossman, 1999). They may not ask the appropriate questions to elicit long narratives from participants, either because of lack of training in the technique or because of shared assumptions between the researcher and participant (Bryman, 1988). In addition, interview data are time consuming to analyse (Patton, 1990). Nevertheless, interviews are a valuable way to gather large amounts of data quickly. Immediate follow-up and clarification are possible enabling the researcher to understand the meaning people hold for their everyday activities. Other advantages are that they are interactive, responsive to the language and concepts used by the respondent and permit deeper investigation of relevant topics uncovered during their course (Marshall and Rossman, 1999). Different qualitative traditions have led to a diversity of perspectives on the use of interviews in research. For example, some authors have considered the extent to which knowledge is constructed in the interview or is a pre-existing phenomenon and suggest that this may depend on the extent to which the interviewer adopts an active or passive role (Legard *et al.*, 2003).

Kvale (1996) proposed two alternative metaphors (the miner and the traveller) regarding the way knowledge arises from interviews. The first falls within the modern social science research approach and sees knowledge as 'given'. He claims the knowledge is

waiting in the respondent's interior to be uncovered, uncontaminated by the miner. The interviewer, he suggests, digs nuggets of data from the subject's experience. In contrast, the traveller metaphor falls within the constructivist research model and suggests that knowledge is not given but is created and negotiated. Thus the interviewer is regarded as the traveller who journeys with the respondent. The meanings of the respondents' stories are developed as the traveller interprets them. Through conversation, the interviewer leads the respondent to new insights. There is a transformative element to the journey and the researcher is an active player in development of data and co-construction of meaning and knowledge with the participants:

*The traveller...asks questions that lead the subjects to tell their own stories of their lived world and converses with them in the original Latin meaning of 'conversation' as 'wandering together with'. (Kvale, 1996:4)*

In the current study, the approach to the phase one interviews was similar to that described by the miners metaphor, while those in phase two were more consistent with the approach of the traveller metaphor. Thus in phase two, in particular, I saw myself as an active player in the development of data and of meaning, rather than simply a 'pipeline' through which knowledge was transmitted (Holstein and Gubrium, 1997).

Legard *et al* (2003) claim that the success of an interview depends to a large extent on the personal and professional qualities of the interviewer. As an experienced children's nurse with recent experience of conducting research interviews with parents as a practitioner researcher (for example Scott *et al.*, 1997; Swallow, 2001), I was nevertheless aware that my role in this study was rather different. I was no longer employed as a practitioner researcher in the Children's Kidney Unit (although I still work occasionally at weekends as a bank nurse on a general, acute paediatric ward) so could admit to being 'out of touch' with the current practice in children's renal nursing. This then freed me from the anxiety about how I would deal with clinical questions from anxious parents, a situation that had arisen several times during my earlier involvement in research in this field (Scott *et al.*, 1997). Nevertheless, I thought it was important to be honest with parents and professionals about my background interest in the study. It may be that my previous clinical experience led to us making some shared assumptions about interview topics that an interviewer with a different professional background may have explored in more depth.

Because of the need to ensure the trustworthiness and credibility of the research (Robson, 2002) it was important for me to acknowledge and reflect upon my motivation for conducting the study and to provide a transparent audit trail of the process. There is an emerging discussion in the literature about the need to enhance the rigour of grounded theory studies by incorporating reflexivity (Hall and Callery, 2001). Hall and Callery point out that reflexivity can supplement theoretical sensitivity because assumptions that are taken for granted by participants and the researcher can influence data collection. In the same way, qualitative findings can be more credible if the researcher declares their personal interest in the research (Silverman, 1998). Therefore, reports that provide a reflective account of the research process entailed in a particular study enable readers to judge the quality of the data for themselves (Hall and Callery, 2001). Thus by examining and reporting on how my own understandings and experiences have impinged upon the nature of this research (reflexivity), I aim to make my influence transparent to the scrutiny of the reader.

It has been tradition for researchers to deny personal interests in their research rather than be criticised for introducing bias and subjectivity into the study (Schatz and Walker, 1995). However, qualitative researchers increasingly recognise the importance of acknowledging that the research is carried out with subjectivity and, therefore, may be biased (Streubert and Carpenter, 1999). There is now a growing trend amongst nurses for investigating topics closely related to their areas of expertise. For example, Lowes, a paediatric diabetes nurse specialist investigated parental coping in childhood diabetes amongst families with whom she worked (Lowes and Lyne, 2000a). Similarly, Long (1997), explored the issue of parental needs whilst a sister on the surgical unit. Earlier in this thesis, I stated my own rationale for conducting this study and for using the chosen approach. Because of the processes involved in identifying respondents and inviting them to participate it is possible that my position as a nurse who has previously worked with the renal team may have influenced the way in which participants responded. Due to this possibility, I endeavoured to conduct the interviews in an impartial way and stressed at the end of each interview that none of the reported findings would be attributed to any individual. Nevertheless, because of the small sample size it was especially important in the reporting that I removed details that could lead to easy identification of individuals. Because of this, I have not reported specific diagnoses relating to the sample, where these were very rare. This helps reduce the likelihood that children would be easily identified if staff read the thesis.

It was possible to anonymise data from most professionals by labelling it simply as 'doctor' or 'nurse'. Where there was a possibility of data being attributed to an individual, for instance the only dietician involved with the team at the time of data collection, we discussed this when I reaffirmed consent after the interview and she was happy for all data from her interview to be attributed to her. In the same way, I reaffirmed consent with all participants after all interviews (and sometimes during interviews if respondents appeared uncertain about anything). There were no requests to withhold data. In keeping with the guidance from the Local Research Ethics Committee and the Research and Development Department of the NHS Trust, I also reassured participants that all tapes and transcripts would be stored securely and destroyed five years after completion of the study.

Legard *et al* (2003) list the main qualities that go to make up a successful depth interviewer. These are: the ability to listen; a clear logical mind; a good memory; an enquiring mind; the ability to establish a good rapport with participants, demonstrate interest and respect as well as respond flexibly to the participant. In addition, Robson (2002) reminds us that the researcher's role is to ease the participant down from the everyday social level to a deeper level at which they can together focus on a specific topic. Towards the end, the researcher needs to signal a return back to the everyday level, a process that needs to be fully completed before the researcher leaves. This whole process involves six stages: arrival; introducing the research; beginning the interview; during the interview; ending the interview and after the interview (Legard, *et al* 2003).

A combination of open ended and semi-structured questions were used and all interviews were tape-recorded using a small portable tape recorder with a long-range microphone. This ensured that the recording was of good quality and that dialogue could later be transcribed verbatim by a professional typist. Using a tape recorder meant I did not need to make notes during the interview that would have been distracting to the respondents and myself. This also meant that my hands were free to drink a cup of coffee with the parents or play a game or draw with a child. However, I did make detailed field notes as soon as possible after the interview, usually in the car before driving away from the research setting. This enabled me to record my overall impressions of the interviews while they were still clear in my mind. I also noted any issues I felt I had not explored in sufficient depth on that occasion or which had been raised by the respondent after the tape recorder had been switched off. In a situation where the respondent raised pertinent issues after the tape-recorder was switched off, I



asked them whether they would object to my including that information in the analysis while maintaining anonymity and confidentiality in the usual way. None of the respondents raised objections to this. The following section focuses discussion on issues relating to adult interviews.

### **Adult interviews (parents and staff)**

Interviews with parents and staff lasted between 30 minutes and two hours, the average length of time being one hour and 20 minutes. Wherever possible, I followed the process and approach outlined earlier by Legard *et al* (2003). During interviews, I tried to ask questions that would help to achieve breadth and depth in the responses. The first interview with a respondent always involved me in using 'ground mapping questions' (Legard *et al* 2003) that are designed to encourage spontaneity and allow the respondent to raise the issues that are most relevant to them. For example, in phase one, I visited Nancy and her mother at their home. The following excerpt from that interview helps to illustrate how different types of content mapping and content mining questions (ground mapping, amplificatory probes, explanatory probes, clarificatory probes) were used in the interviews in both phases. After initial introductions in which Nancy showed me what Santa had recently brought for her, I asked her mother what were the main things she remembered about the time she had received the diagnosis for Nancy three years ago when she was a baby. The situation referred to below, occurred in the District General Hospital before the family were transferred to the Children's Kidney Unit:

Mother: Well, it was the fact that they [the doctors] didn't agree with each other about what was wrong with her at first. One said it was just a febrile convulsion, I mean JUST - I thought it was horrific, thought she was dead... the other thought she had a bad UTI [urinary tract infection] that had caused the fever and made her have a fit. Until then, I really thought doctors always agreed with each other, it didn't do much for my confidence in them!

Int: So what do you think is the main thing you expect from health care professionals now that gives you confidence in them? [this was a dimension mapping question]

Mother: That they are honest about the difficulty of sometimes knowing exactly what is the matter! [exasperated sigh from Mum]

Int: Are there any other things that you think professionals could do to help you feel more confident in them? [perspective widening question that resulted in only a shrug from the mother and a pause until I continued]. Some people have said that involving parents in the discussion helps if there is uncertainty. [amplification probe]

Mother Oh yes, I know what they mean cos later they [both doctors] did come past the bed at the same time and one, the one who had said it was 'only a fit' said to me 'oh it was a UTI that caused the temperature that caused the fit...'

Int: What effect did that have on you then? [exploratory probe]

Mother: They both went up in my opinion, I should have been involved before - but maybe they were just having a bad day earlier [laughs]

Int: Could you explain what you mean by 'they went up in your opinion'? [clarificatory probe]

Interviews with staff also involved the use of ground mapping questions, amplificatory probes, explanatory probes and clarificatory probes. The following example helps to demonstrate this:

Int: So, can you tell me something about your role here in the Children's Kidney Unit? [ground mapping question]

Nurse: ...we teach parents from the Northern region to do traditionally nursing roles, giving subcutaneous injections and gastric feeds, gastrostomy feeds...and we usually train two parents, you know research has shown that two parents or two carers doing a machine is of a higher standard than one constantly doing it.

Int: Why do you think that is? [amplificatory probe]

Nurse: Just the pure stress of it, you know!.

Int: Oh I see, you might think that I am asking you questions that I should know, but for the interview I'd like to be sure I understand what your point of view is...[explanatory probe]

Nurse: ...oh no, that's fine. It [peritoneal dialysis] takes about half an hour, you know, it is half an hour either during the day or during the evening – parents can do a machine, set up a machine ready for the children to go on at night, ...can set it up during the day and leave it, so that is ideal for when children are at school, you know half an hour, sometimes it is easier to find [time] during the day than it is at bedtime, but obviously if one person is doing it every single day, they eventually cut corners, it is going to become a chore – you know, Coronation Street is coming on so 'I'll watch that' [at the same as time as dialysing] – whereas if they are taking turns, and maybe they are only doing it three or four times a week, somebody else is doing it the other times so they can have nights out and you know, social things, even just to watch something on television, you can sit down and know you can relax knowing you can watch this without knowing you have got the machine to do. So, as I say, some people do it during the day and some do it at bedtime. And, initially it is all done in hospital and then we support the parents when the children are discharged, because doing it in hospital is very different to doing it at their home and in their child's bedroom.... and we give subcutaneous injections, we give EPO [erythropoietin] injections, maybe once or twice a week.

- Int Right, could you explain a bit more about the EPO? [exploratory probe]
- Nurse: EPO is a hormone that the kidneys make. When children are in renal failure, they don't make their hormones, so we give artificial subcutaneous .... We do have cartridges which fit into a pen type of devices, it is much better than drawing up syringes and they are very small needles and a lot of the older children don't (some of the older children do it themselves but a lot of them don't) complain about any pain because it is such a fine needle, and obviously that is a really difficult thing to do to your child, you know I have done that particular injection many times, hundreds of children, and I have taught parents to do it but I have never done it to my own, so I am teaching parents to do something that I have never done, injecting my own child which is a bizarre concept at times.
- Int: How do you tackle that with parents? Do you ever talk to them about your own feelings about it? [amplification probe]
- Nurse: Yes, because I think you can talk to them about it till the cows come home, about how it [erythropoietin] is necessary, but unless you try to understand how it is for them...?

In addition there were specific issues concerning the conduct of research interviews with children and young people. These are explored and discussed below.

### **Children and young person interviews**

Some authors claim there are limitations to interviewing children, believing them to be more difficult to interview than adults: less attentive; slower to respond and that they have more difficulty than adults in understanding questions (Hetherington and Parke, 1986). According to Coyne (1998), obtaining access to conduct research with children may in fact be less difficult than establishing a rapport with them before the interview because of the perceived inequality of the adult-child relationship. Children's anxieties need to be taken care of before their communicative abilities can be maximised in an interview and Coyne (1998:416) urges that:

*To be effective in research with children, researchers must be prepared to step into another world, far away from the world they inhabited when they were children. It is important that we do not attempt to impose our perspectives on children's views. Rather children must be allowed to convey their perspective as best they can and researchers should be receptive to their views. It needs to acknowledge that children are the most important source of evidence on how their lives are lived and experienced. Research needs to be conducted with children rather than on children.*

In an exploratory study of families' and professionals' experiences of childhood chronic disease, Sartain *et al* (2000) debated the perceived passivity of the voice of children in health care and research and illustrated data collection methods that seek to give children and other disadvantaged groups a voice. The interviews of children who

participated in their study were augmented with a 'drawing technique' and the participating children were described as competent interpreters of their world. Many children enjoy drawing and this is increasingly used as an 'ice breaker' when undertaking research, as well as a valid means of obtaining data (Backett and Alexander, 1991; Inman, 1991; Sartain *et al.*, 2000; Swallow and MacFadyen, 2004). In the present study, I carried drawing paper, crayons and pens with me in my interview tool kit and used them where appropriate to build up a rapport with the participating child or provide a distraction for a bored sibling during the interview. Therefore, although I did not obtain data through drawing, it aided the smooth running of the interviews.

Interviews with children lasted between 10 minutes and one hour (the average being 45 minutes) and were tape-recorded. The typical sit-down interview is more difficult to conduct with children who may find sitting and answering an adult's questions a dull activity. Grave and Walsh (1998) suggest that the first step in interviewing children is to negotiate the process; what it is all about and how one does it. They advise researchers to be very creative in finding ways to interview children and to expect to get information indirectly. One of the first challenges for the researcher can be to negotiate privacy to conduct the interview (Coyne, 1998). As discussed earlier, this was more of a challenge when conducting interviews in the ward setting than in the home setting.

When interviewing children, I found it sometimes helped to consider the different aspects of their learning about their disease by using hypothetical questions. For instance, when talking to David (phase two), the little boy referred to earlier in this chapter I asked:

Int: Suppose I was a little boy admitted to the ward for the first time and being put on dialysis and I was frightened by the dialysis machine, what would you say to me so I would not feel scared ?

David: Well, I would tell you its all right cos its washing your blood, that's the red stuff in those tubes, and the noise is just like the noise your mam's washing machine makes.

Int: But what if I asked why my blood needs to be washed when my brother's doesn't?

David: Easy peasy, you've got special blood that won't work without washing and the tests on your blood tell them what's wrong...

The next section considers some of the factors associated with joint interviews between parents or children and parents.

### **Joint parent/family interviews**

The decision to offer to interview parents or entire families jointly was determined in part by the lack of consensus in the literature about the most effective approach. Much of the reported accounts from parents in childhood chronic disease is actually about mothers (Hayes 1997). Sometimes the title of research reports is explicit about this but not always. There are a small number of reported studies about differences between mothers and fathers and some suggest that we should be cautious about making generalisations from one role to another (Eiser and Havermans, 1992; Copeland and Clements, 1993; Hayes, 1997). Eiser (1993) implies that the paucity of accounts from fathers may be because mothers tend to be the primary carers so are more likely to be available to participate in research, or they may in fact be more interested in research. Jerrett (1994) reported a study that explored 'parents' accounts of coming to know their child's chronic disease although the number of interviews conducted with fathers was much less than those with mothers. Jerrett maintains that both parents in two-parent families share a common world with their child and that their joint participation is necessary to understand the reality of that world.

Meanwhile Whyte (1992), in reporting a longitudinal (5 year) study with parents of four children with cystic fibrosis, demonstrated that interviewing parents separately can allow the emergence of rich and significant data. However, the fact that she was also a nurse specialist in caring for the children is likely to have had some bearing on their reactions to being interviewed by her. Therefore, in this study I decided to interview both parents if they were willing and to offer individual interviews if they wished. In phase one, only two fathers were available to be invited and both consented and chose to be interviewed jointly with the mothers. In phase two, two fathers were available and also chose to be interviewed jointly. Building upon this discussion about data collection the following section explores the process of data analysis and development of the substantive theory.

### **Analysis**

Throughout the thesis I have attempted to expose some of the main approaches I adopted at different stages of the study to enhance the rigour of the research. In grounded theory, two of the major procedures that are integral to the analytic process are making comparisons and asking questions. I spent a great deal of time carrying out these procedures, sometimes in an implicit way when, for instance, I was doing something unrelated to the project but was reminded of it through a conversation or something I read. This sometimes helped me to gain new insight into an aspect of

analysis that I had been struggling with. However, there were some particular analytic tools and interactional phenomenon that helped in a more explicit way. These include Theoretical Sensitivity, Co-construction of meaning with respondents, Memos and Integrative Diagrams, Open, Axial and Selective Coding and Framework Technique. These are described and discussed in more detail below in relation to this study.

### **Theoretical sensitivity**

Theoretical sensitivity is one way to guard against potential biases that could threaten the rigour of a study. It is the ability of the researcher to think inductively and move from the particular (the data) to the abstract or general (Schreiber, 2001). This approach can help curb potential bias from the researcher's background experience and diminish the risk of compromising the study through premature closure in favour of the researcher's preconceived ideas. Schreiber reminds us that the personal background of the researcher is the filter of salience through which data are sieved and that development and refinement of the skill of theoretical sensitivity requires vigilance and practice. Even though the researcher tries to approach the study with as few pre-determined ideas as possible, they cannot *un-learn what is already known* (Glaser, 1978:3). The researcher has already identified what they think the issue is and commenced the study accordingly. However, the first goal is to understand the shared basic social situation from participants' perspectives so that the grounded theory reflects what participants do to address it:

*To cultivate theoretical sensitivity the researcher must recognise and constantly challenge personal theories and biases against the data...this allows for emergence of theory that is truly grounded in data. (Schreiber, 2001:61)*

For instance, at the time I began this study I supported the view that if the disease course of a child with a chronic renal problem changed from one requiring high intervention (according to one of the criteria in this study) to one requiring low or moderate intervention, then this would reduce parental anxiety and uncertainty. However, through being alert to the possibility of deviant cases as the research proceeded, I encountered one family whose accounts contradicted this and appeared to refute the emerging conceptualisations about integrated and synthesised learning. In this situation, theoretical sensitivity helped me to consider a variety of possible explanations for what was happening in the data I was collecting in Kevin's Case (phase two). The parents of Kevin, a 5 year old boy who had been diagnosed with a serious condition with a long and demanding disease projection initially requiring high levels of

intervention, told me in the second interview that his outlook had improved and was now changed to one that would require less intervention. They reported that while they were pleased that the uncertainty was reduced and his life was no longer considered to be in danger, they were angry that the serious prediction had not after all manifested. They were upset about their perceived lack of information on how the situation could have changed so dramatically. They wondered if they had misunderstood the information or if the original information had been incorrect.

I was puzzled by their extreme reaction and sensed that his mother, in particular, was disappointed about something in relation to this. She also said she found it difficult to express her concerns and often forgot to ask the questions in her mind during conversations with professionals. Whilst maintaining an impartial approach myself and in accordance with the inductive approach used in this study, I pointed out that some parents in this and other studies (Bradford, 1991) had also reported that they often failed to ask all the questions they wanted. Some had subsequently found it helpful in future encounters to write down their questions before talking to professionals. Whilst maintaining anonymity I cited the example of Nina's mother (phase two in the current study), who made the following comment in the first interview when discussing information gathering:

Nina's mother: Writing down my questions helped a lot, otherwise I forget everything and then come home and think 'Why didn't I ask that?'. Then it has to wait until another time.

I asked Kevin's mother if she had ever considered using this approach herself and at that stage she said she had not, but was beginning to think she might do that.

In later exploring other possible theoretical explanations for what was happening, I considered the observation made by Whyte (1992) that was referred to in the earlier literature review (Chapter 2). Whyte suggests that as the burden of care posed by childhood chronic disease is additional to the stresses of ordinary family life, it may be possible that quite minor events can sometimes cause distress of crisis proportions. I therefore, considered the possibility that despite a more hopeful prognosis, Kevin's mother found the stress imposed by his condition up to the point when his clinical outlook changed, negatively influenced the way in which she reacted to the change.

I further explored the issue raised by Canam (1993), who points out that the period following a diagnosis of childhood chronic disease is an anxious and distressing time for

the whole family. Family members may experience a variety of responses similar to those normally associated with bereavement. The process of adjustment and adaptation is often similar to bereavement (Cox, 1994) producing grief reactions followed by the stages of shock and disbelief, denial, anger, adaptation and adjustment (Bradford, 1997). Some people, however, may never achieve a state of adjustment and may suffer from chronic sorrow where grief may be perpetual, with periods of remission and intensification of grief symptoms (Murgatroyd and Woolfe, 1993; Bradford, 1997). Typically these symptoms may intensify at times of transition (Fraley, 1990; Jerrett, 1994). I considered the possibility then that Kevin's mother may have been suffering from chronic sorrow and the changing circumstance had intensified symptoms of grief such as anger.

I also considered the theory of social positioning after discussing this issue anonymously with one of my supervisors and a colleague who was familiar with my research. As discussed earlier in this thesis, positioning theory is a tool in which individuals metaphorically locate themselves within discursive action in everyday conversations to do with personal positioning, institutional practices and societal rhetoric (Harre and Van-Langenhove, 1976; Phillips *et al.*, 2002). When I returned to the transcript of the first interview with Kevin and his parents, I was reminded that they had told me in graphic detail about how they had, immediately following his referral to the Children's Kidney Unit, tried to acquire the skills to manage its consequences. Their description was of a family who spent a lot of time on the ward. They saw themselves becoming part of the team caring for him and seemed to be describing a position of 'situated learning' (Lave and Wenger, 1991). They appeared to believe they had become members of a 'community of practice' (Wenger, 1998).

This 'position' changed, however, when his condition was seen to improve and the need for interaction between them and the professionals began to reduce. It appeared that the prevailing philosophy of family centred care and partnership working had begun to integrate the family into the health care setting at the critical time when Kevin was seriously ill. However, communication around the time when the level of intervention required by Kevin was reduced had left them feeling 'rejected' by the 'other team members' as the following quotation from his stepfather illustrates:

Kevin's Stepfather: They [doctors and nurses] don't seem to bother with us as much now, if only they had said 'Well, maybe we got it wrong thinking it was going to continue being so bad' - they used to tell us everything that was going on but now it's as if we hadn't played such a big part in his care.



These insights generated through theoretical sensitivity led to my exploring in subsequent interviews in this and other Cases the phenomena of chronic sorrow, social positioning and the possibility that times of transition can create stress that negatively influence the way in which families respond even to positive changes in circumstances. This experience also reminded me of the benefits of discussing with my supervisors and other colleagues (while maintaining confidentiality and anonymity) the categories and emerging theories. Indeed Schreiber (2001) points out how this can assist the researcher to keep perspective and not get lost in the endlessly ruminative process of analysis.

While considering the issue of theoretical sensitivity, in particular concerning the interactional element of the research relationship between myself and participants, I became increasingly aware of the significance of the emerging body of literature surrounding the co-construction (or social construction) of knowledge and meaning in qualitative research. The emerging literature around this phenomenon is explored below. Subsequently I highlight some examples of the way in which co-construction of meaning between myself and participants occurred in the present study.

### **Co-construction of meaning in qualitative research**

In considering the issue of rigour in grounded theory studies, Hall and Callery (2001) were amongst the earliest authors to claim that a lack of attention to the social construction of knowledge and research relationships neglects important aspects of data collection and analysis that could significantly effect the emergent theory. Therefore, they argue for the inclusion of reflexivity and relationality into grounded theory in order to attend to the effects of researcher-participant interactions on the social construction of data and of power and trust relationships. Reflexivity addresses the influence of relationships between researcher and participants on the research process while relationality deals with the effects of power and trusting relationships between the researcher and participants (Hall and Callery 2001). More recently, recognition of the phenomenon of co-construction of meaning was found to enhance a grounded theory study of stress in mental health nurses (Majomi, Brown and Crawford, 2003). Similarly, Meiers and Tomlinson (2003) explored the interactional phenomenon of family-nurse co-construction of meaning in a paediatric intensive care unit. In their study, Meiers and Tomlinson reported that the family-nurse interaction, the relational connection and the

evolution of meanings that families and nurses constructed were major vehicles in the co-construction experience.

Earlier in this chapter, I discussed the way in which I have incorporated reflexivity and relationality into the present study in order to maximise the rigour of the research. In this section, I present a further example that helps to illustrate how the interactions between respondents and me affected the nature of data collected. By making the effects of these interactions more transparent, I believe I can demonstrate the way in which knowledge and meaning have been socially constructed and subjectivity has been minimised in this study. I hope that this will help the reader to judge the standard of rigour applied to the research and subsequently the soundness and trustworthiness of the theory proposed by the study.

In the first interview in phase one I asked Susan's mother as the interview was coming to a close if she thought we had missed any points of importance and she surprised me with her reply:

Int: So do you think there is anything we haven't talked enough about that is important to the way you learn about Susan's kidney problem?

Mother: Well yes, you know, we've talked a lot about her medicines and tests and that but really you know I think the most tricky bit to learn is who's who-you said here [pointing to the topic guide I had shown her] you want to talk about Social Knowledge and that, we've touched on it but really you haven't picked up on all the things I mentioned...like knowing how to work out who you can trust and believe in, **really**, to me that's more tricky than the medicines and that, other Mams say the same, you know when we talk in the waiting room and that. You see they [staff] are really very good at making sure we know about medicines and tests and that, I suppose that's a priority for them, making sure about that, but no-one really sees it as their job to tell you what the different staff are supposed to do, and how you [meaning parents generally] suss that out, I don't really know...but unless someone makes it their job to do that, we won't know!.

Int: So maybe I've done the same thing, assumed the technical stuff was the most difficult bit to learn and concentrated more on that with you.

Mother: Yes, well I can see why, you did say you are a nurse by background so I suppose you would see it like them as well.

Int: Yes that's right, although as a mother myself I can appreciate what you are saying now you have pointed it out. Well I am glad you pointed that out, have you time to talk for a bit longer now about that in more detail?

Mother: Yeah no problem, we're ok for another ten minutes or so.

Int: Oh thanks, then I'll make sure I pick up on that aspect of learning more

carefully in the next interviews I do with other families, that's a really important point we've uncovered, that the social knowledge is so difficult to learn, it's like invisible knowledge isn't it?

Mother: That's it exactly, it's all so obvious to nurses and doctors, but it's not at all obvious to us, unless someone tells us, its just trial and error really!

Int: So is this [social knowledge] more trial and error than learning the drugs and so on, That's what you seem to be saying, have I got that right

Mother: Yeah, trial and error and learning from other parents for that side of things.

After this interview I reflected carefully and realised that together we had co-constructed some meaning about the issue of learning. In the same way that coping with chronic illness has been demonstrated to involve some trial and error and support from other parents (Loves and Lyne, 1999; Swallow and Jacoby, 2001a), so too does learning appear to rely on these phenomenon. Therefore, I realised that in the first interview I had allowed my professional experience to override the cues the mother was giving me and almost missed a valuable opportunity to co-construct some of the meaning in the interview. In subsequent interviews I, therefore, made a conscious effort to pay attention to all cues coming from respondents, even if I did not initially recognise their significance. Having considered the potential for co-construction of knowledge in research interviews, the next section focuses discussion on the use of memos and diagrams in grounded theory research.

## **Memos and diagrams**

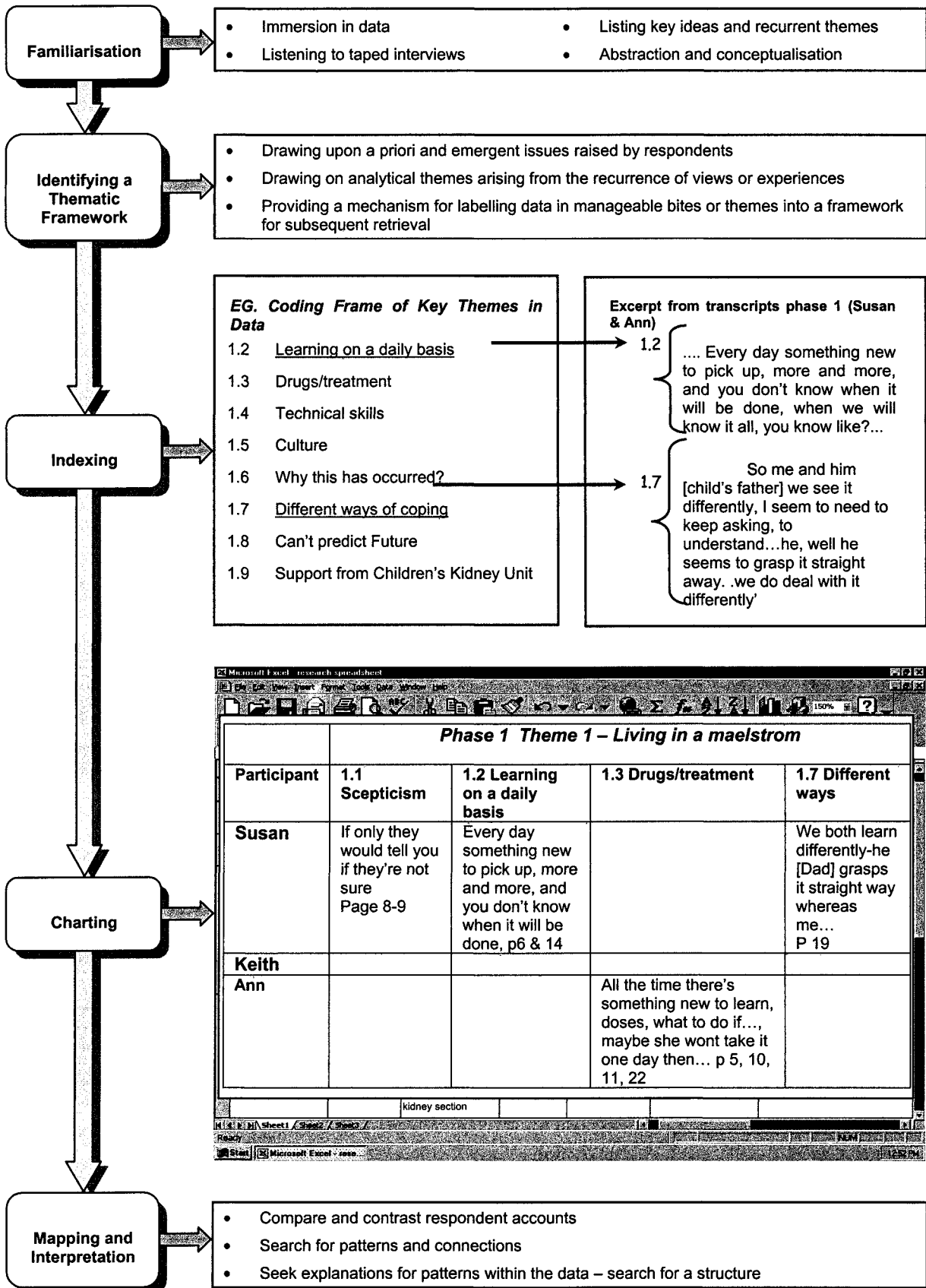
Theoretical comparisons are tools (a list of properties) for looking at something objectively rather than naming or classifying without a thorough examination (Strauss and Corbin, 1998). They move the researcher more quickly away from describing the specifics of a case to thinking more abstractly. Strauss and Corbin (1998) introduce the idea of 'analytic tools' as devices and techniques that can assist researchers with making comparisons, asking questions and that can facilitate the coding process. Their purpose is to increase sensitivity, help the user to recognise bias and overcome 'analytic blocks'. Written verbal memos (Figure 12 below) and diagramming (Figures 14 and 15, chapter 5) were invaluable tools throughout this study to help augment data with analytical ideas, as a primary record of data analysis and as the study proceeded, to help me reflect on and understand the relationship between and among emerging categories (Strauss and Corbin, 1998; Schreiber, 2001). Strauss and Corbin point out that as memos and diagrams evolve during the research (Strauss and Corbin, 1998), they grow in

complexity, density, clarity and accuracy. They help the analyst to: *gain analytical distance from materials...to move from working with data to conceptualising* (Strauss and Corbin 1998:218).

A journal of field notes was also kept in which I described the context of each interview and the disposition of each participant. This was useful for my own reference and helped in the process of constant comparison of data during analysis, as I was able to contextualise each piece of data. In both phases, the analysis of transcripts involved me in reading each transcript in its entirety while also listening to the tape recording of the interview for checking transcription accuracy and filling in any gaps I could from my recall of the interview. Using a large piece of paper for each transcript, I identified and recorded meaningful statements from the interviews. In both phases I analysed each transcript sequentially between interviews and used the retrieved statements to inform discussion in subsequent interviews. In this way, an iterative process of data collection and analysis was completed. Phase one involved Open Coding and Axial Coding stages and led to the generation of three categories (Playing the Game, The Maelstrom Effect and Learning by Intuition-see Figure 11) which then informed the development of the Topic Guide for phase two and subsequent data collection from interviews with staff and family members as well as casenote data and reflective notes. Phase two involved Open Coding, Axial Coding and Selective Coding and led to the generation of the social theory of learning in childhood chronic renal disease (comprising three categories, Assessing, Interacting and Synthesising).

During the axial and selective coding stages of this study, data were managed and displayed using 'Framework Technique' and Microsoft Excel. This method is systematic, thorough and grounded in the data but also flexible and enables easy retrieval of data to show others. It also allows both between and within case analysis and involves a process of familiarisation with data; identification of recurrent themes; indexing; charting; abstraction and interpretation (Ritchie and Spencer, 1994). An example of the way this was used in this study is below in figure 10.

Figure 10: Example of using Microsoft Excel and Framework, based on Swallow, Newton and Marshall (2003)



In both phases I found that coding was a fluid and dynamic process. The process was assisted by breaking the analytic process down. Thus, the process of Open Coding helped me to open up the text in the transcripts and my field notes and to help uncover the thoughts, and meanings that were contained there. For instance, in the early interviews when discussing the topic of diagnosis, issues arose which allowed me to break the data down into discrete parts that I compared for similarities and differences. For example, 'different ways of coping' and 'scepticism' and 'support from Children's Kidney Unit staff' became labelled concepts. Then I realised that these concepts shared some common characteristics and so they were placed into the same 'in vivo' code 'Living in a maelstrom'. This then went on to inform the process of data collecting in phase two.

Figure 11: Interview topics, Open and Axial Coding (Phase one)

| Interview topics  | Open coding   | Axial coding  |
|---|---|---|
| <ul style="list-style-type: none"> <li>• Details of diagnosis-</li> <li>• when, how long it took to arrive at diagnosis, who gave information and how</li> <li>• What needed to learn following diagnosis</li> <li>• Technical knowledge e.g. meaning of the condition, treatment and management,</li> <li>• Systems knowledge e.g. who's who in the team, how the service operates, what is expected of families, where to go for information/support</li> <li>• Social Knowledge e.g. how to approach different interactions with professionals, what you do if you feel you are not being listened to</li> <li>• How you approached learning/who assisted you/what they did or said to help this</li> <li>• What you would do differently if you were to embark on this again</li> <li>• What advice you would give others in a similar situation</li> </ul> | <ul style="list-style-type: none"> <li>• can't predict the future</li> <li>• culture</li> <li>• different ways of coping</li> <li>• discretion accessing alternative approaches</li> <li>• 'knowing how' knowledge e.g dialysis</li> <li>• drugs</li> <li>• friends</li> <li>• internet opens up wider scope of knowledge</li> <li>• joining parent support groups</li> <li>• learn different from other parent</li> <li>• learning on a daily basis</li> <li>• meta cognition</li> <li>• rational calculation of various responses</li> <li>• scepticism</li> <li>• scepticism from professionals</li> <li>• searching internet</li> <li>• selectively attending to situations</li> <li>• sense of salience</li> <li>• share experiences with other parents</li> <li>• siblings</li> <li>• similarity recognition</li> <li>• support from renal team</li> <li>• technical skills</li> <li>• trial and error learning</li> <li>• using the internet to verify</li> <li>• valuing common sense</li> <li>• why this has occurred</li> </ul> | <p>1- Living in a maelstrom:</p> <ul style="list-style-type: none"> <li>1.1 Scepticism</li> <li>1.2 Learning on a daily basis</li> <li>1.3 Drugs/treatment</li> <li>1.4 Technical skills &amp; Searching internet</li> <li>1.5 Culture</li> <li>1.6 Why this has occurred</li> <li>1.7 Different ways of coping</li> <li>1.8 Can't predict the future</li> <li>1.9 Support from Children's Kidney Unit</li> </ul> <p>2 – Using intuition</p> <ul style="list-style-type: none"> <li>2.1 Uncertainty</li> <li>2.2 Metacognition</li> <li>2.3 Scepticism</li> <li>2.4 Internet</li> <li>2.5 Trial and error</li> <li>2.6 Learning from other parents/children</li> <li>2.7 Share experiences</li> <li>2.8 Valuing private knowledge</li> <li>2.9 Similarity recognition</li> </ul> <p>3 - Playing the game</p> <ul style="list-style-type: none"> <li>3.1 Support groups</li> <li>3.2 Discretion, assessing alternatives</li> <li>3.3 Knowing how knowledge</li> <li>3.4 Rational calculation of responses</li> <li>3.5 Sense of salience</li> <li>3.6 Selectively attending to situations</li> </ul> |

An example of the way I used 'storylines' and memos, tools described by Strauss and Corbin (1990) is described below:

Figure 12: Example of a storyline and a memo from phase one analysis

### Writing the storyline-research notes

Phase one- a striking feature of these interviews is that although all families describe a process of learning very few explicit references are made to the activities they describe as 'learning'-they are seen as a natural continuation of the parenting process –especially where children are younger. However, older children –for instance Milly and Leslie – volunteered information about experiences that were similar to what happens at school-eg-*So the doctors showed us how the body works using a diagram and linked it with my kidney damage*-(they recognise cause and effect relationships) I-need to look at developmental stages of children-?? Concrete Operational phase-but I wonder why parents don't make these explicit links-?? Fear/unknown....maelstrom-?? maelstrom effect diminishes ability to understand/comprehend.

### Excerpt from coded transcript

*You can just ring them [renal team] at anytime...even at the weekend...[1.2 learning on a daily basis] they work in your favour, they're great [1.5 culture] Well being in contact with America [via the internet] it makes you realise just how good our Health Service is [2.4 internet] because over there they've got to fight for every medication that the children need...imagine on top of everything else worrying about the costs of everything but here, well for the growth hormone, you know she needed it and she just got it and it's so expensive [3.4 rational calculation of various responses] .*

*Well, it was a shock actually, getting a name for it after worrying about her for so long, I didn't know what it [mod intervention condition] entailed [1.8 uncertainty/cant predict future]...she [specialist nurse] was ringing all the time ...I was thinking 'what's this nurse ringing me for?'...you know...I didn't realise it was going to be sort of, such a long term thing [1.8 uncertainty]...but it sunk in pretty quickly once I got hold of the information- went out and bought a PC and learned to use the Internet for more information [2.4 using the internet to verify]...the more information I got, the better I felt about it [2.2 metacognition]. After about a year, we learnt to follow our hunches more...after al,I we know our own child better than they [professionals] do [2.8 valuing private knowledge]...we still value very much what they say but are more confident in our own judgement [3.6 selectively attending to situations]*

Figure 13: Interview Topics, Open Coding, Axial Coding and Selective Coding (Phase two)

| Interview topics   | Open coding  | Axial coding   | Selective Coding  |
|--|--|--|---|
| <ul style="list-style-type: none"> <li>• <i>The Maelstrom effect</i></li> <li>• Scepticism</li> <li>• learning on a daily basis</li> <li>• drugs</li> <li>• technical skills</li> <li>• culture</li> <li>• why this has occurred</li> <li>• different ways of coping</li> <li>• can't predict the future</li> <li>• support from renal team</li> <li>• searching internet</li> <li>• meta cognition</li> <li>• uncertainty</li> <li>• <i>The Role of Intuition</i></li> <li>• scepticism from professionals</li> <li>• internet opens up wider scope of knowledge</li> <li>• trial and error learning</li> <li>• learn different from other parent</li> <li>• share experiences with other parents</li> <li>• valuing private knowledge</li> <li>• similarity recognition</li> <li>• <i>Playing the game</i></li> <li>• using the internet to verify</li> <li>• joining parent support groups</li> <li>• discretion accessing alternative approaches</li> <li>• 'knowing how' knowledge e.g dialysis</li> <li>• rational calculation of various responses</li> <li>• sense of salience</li> <li>• selectively attending to situations</li> </ul> | <ul style="list-style-type: none"> <li>• social participation</li> <li>• non-participation</li> <li>• identities</li> <li>• social engagement</li> <li>• expert knowledge               <ul style="list-style-type: none"> <li>– professional</li> <li>– family</li> </ul> </li> <li>• drug/treatment knowledge</li> <li>• practical skills</li> <li>• friends</li> <li>• internet verification</li> <li>• reification</li> <li>• negotiation</li> <li>• becoming autonomous</li> <li>• community of practice</li> <li>• peripheral participation</li> <li>• boundary</li> <li>• competence</li> <li>• alignment</li> <li>• enterprise</li> <li>• share experiences with other parents</li> <li>• siblings/relationships</li> <li>• support from renal team</li> <li>• technical skills</li> <li>• reflection</li> <li>• using the internet to verify</li> <li>• confidence growth</li> <li>• trajectories</li> <li>• mutual enterprise</li> </ul> | <p>Mutually assessing</p> <ul style="list-style-type: none"> <li>• non-participation</li> <li>• identities</li> <li>• internet verification</li> <li>• drug/treatment knowledge</li> <li>• peripheral participation</li> <li>• competence support from renal team</li> </ul> <p>Interacting</p> <ul style="list-style-type: none"> <li>• social engagement</li> <li>• social participation</li> <li>• practical skills</li> <li>• negotiation</li> <li>• boundary</li> <li>• enterprise</li> <li>• share experiences with other parents</li> <li>• siblings/relationships</li> <li>• trajectories</li> </ul> <p>Synthesising worlds</p> <ul style="list-style-type: none"> <li>• friendships</li> <li>• expert knowledge               <ul style="list-style-type: none"> <li>◦ professional</li> <li>◦ personal</li> </ul> </li> <li>• reification</li> <li>• becoming autonomous</li> <li>• community of practice</li> <li>• alignment</li> <li>• confidence growth</li> </ul> | <p><b>Processes of:</b></p> <p>Assessing:</p> <ul style="list-style-type: none"> <li>• Ability               <ul style="list-style-type: none"> <li>◦ Scepticism</li> <li>◦ Relationships</li> <li>◦ Scaffolding</li> </ul> </li> <li>• Social positioning               <ul style="list-style-type: none"> <li>◦ Families' perspectives</li> <li>◦ Professionals' perspectives</li> </ul> </li> <li>• The disease course               <ul style="list-style-type: none"> <li>◦ Projection</li> <li>◦ Scheme</li> </ul> </li> </ul> <p><b>Central category-interacting in:</b></p> <ul style="list-style-type: none"> <li>• <b>Knowledge transfer</b> <ul style="list-style-type: none"> <li>◦ Vicarious knowledge</li> <li>◦ Unarticulated knowledge</li> </ul> </li> <li>• <b>Engaging effectively</b> <ul style="list-style-type: none"> <li>◦ Engaging trust</li> <li>◦ Earning trust</li> <li>◦ Maintaining trust</li> </ul> </li> <li>• <b>Decision making</b> <ul style="list-style-type: none"> <li>◦ Intuition</li> <li>◦ Autonomy</li> <li>◦ Negotiation</li> </ul> </li> </ul> <p>Synthesising:</p> <ul style="list-style-type: none"> <li>• Cultures               <ul style="list-style-type: none"> <li>◦ Retaining</li> <li>◦ Redefining</li> </ul> </li> <li>• Communities of practice               <ul style="list-style-type: none"> <li>◦ Identities</li> <li>◦ Brokering</li> <li>◦ Legitimate peripheral participation</li> </ul> </li> <li>• Patterns of learning               <ul style="list-style-type: none"> <li>◦ Parallel</li> <li>◦ Integrated</li> <li>◦ Synthesised</li> </ul> </li> </ul> |



In grounded theory the researcher attempts to account for patterns of behaviour that are relevant for those involved by generating a theory around a core emergent category. The core category encapsulates the substance of a pattern of behaviour seen in the data and summarises what is happening (Schreiber, 2001). Determining the core category is something that Glaser (1978) claims happens as if by magic while Strauss and Corbin (1998) argue that considerable manipulation of data is necessary before a core category emerges. In this study an iterative process of data collection, theoretical sampling and analysis helped me to raise the level of abstraction from a conceptual framework, or loose association of ideas to a substantive theory in which the relationships between and among the concepts were revealed. This led to generation of the core category (interacting) and two categories (assessing and synthesising). Interacting was defined as the core category because it was the one that according to Schreiber's definition:

*...occurs again and again and seems to link other categories together*  
(Schreiber 2001:74)

In addition it meets with the criteria presented by Strauss and Corbin (1998) for choosing a core category which are that:

- It must be central so that all other categories can be related to it.
- It must appear frequently in the data or have indicators pointing to it in all or most cases.
- There is no forcing of data, the explanation that evolves by relating the categories is logical and consistent.
- The name must be sufficiently abstract so that it can be used in other research areas.
- As the concept is refined analytically through integration with other concepts, the theory grows in depth and explanatory power.
- The category explains variation.

A particular type of category is the Basic Social Process that was defined initially by Glaser (1978). While all grounded theories have core categories, not all have Basic Social Processes (Schreiber 2001). What distinguishes a Basic Social Process is that it is processural in nature and, therefore, by convention it is labelled with a gerund (an 'ing' word such as redefining). The theory that was derived from this study, the social theory of learning in childhood chronic renal disease is, according to the definition presented by Morse (2001) a substantive, mid-range theory because it is focused on a behavioural

concept. In early discussions of grounded theory Glaser and Strauss (1967) described an inquiry into a topic of interest as a process with a resulting theory consisting of phases and stages and built around a Basic Social Process. The three categories identified within this theory are all classified as gerunds and as such are indicative of the process that informed and was informed by the analysis. The significance of process in grounded theory has also been exemplified in chapter 3. In addition, it is important to bear in mind in this discussion that theory without process is missing a vital part of its story, namely:

*...how the action/interaction evolves...[it is] the difference between a snapshot and a moving picture (Strauss and Corbin 1998: 179)*

In this study, the three categories emerging from the theory were all Basic Social Processes that illustrate the processual nature of the theory and allowed me to look more closely at participants' behaviour, unpack its meaning for them and place my own interpretation on it. The theory is not linear in its development but iterative, with multiple processes occurring simultaneously. The categories within the theory are interdependent and overlapping, although for clarity they are presented sequentially in the following three chapters as distinct processes. In building the theory and reporting my interpretation of participants' accounts, I tried to refine the theory for internal consistency and for gaps in logic. According to the iterative principles of grounded theory, I returned frequently to the data to fill in poorly developed categories, trim excess ones, validate the categories and achieve saturation. The aim was to achieve categories that were sufficiently developed in terms of properties and dimensions in order to demonstrate their range of variability as concepts (Schreiber and Stern, 2001).

## **Conclusion**

In considering and describing the research design of the study, this chapter has focussed on issues pertaining to sample selection, participant recruitment, data collection and analysis and theory development. The need to demonstrate integrity and rigour of this research was a key endeavour. Throughout the discussion, consideration has been given to the various steps taken to ensure, as far as possible, that the study was rigorous in conduct through the systematic and transparent collection, analysis and interpretation of data. The issues of theoretical sampling and theoretical sensitivity and the co-construction of meaning are considered and the processes used for collecting and analysing data from interviews involving children and adults, reflective accounts and

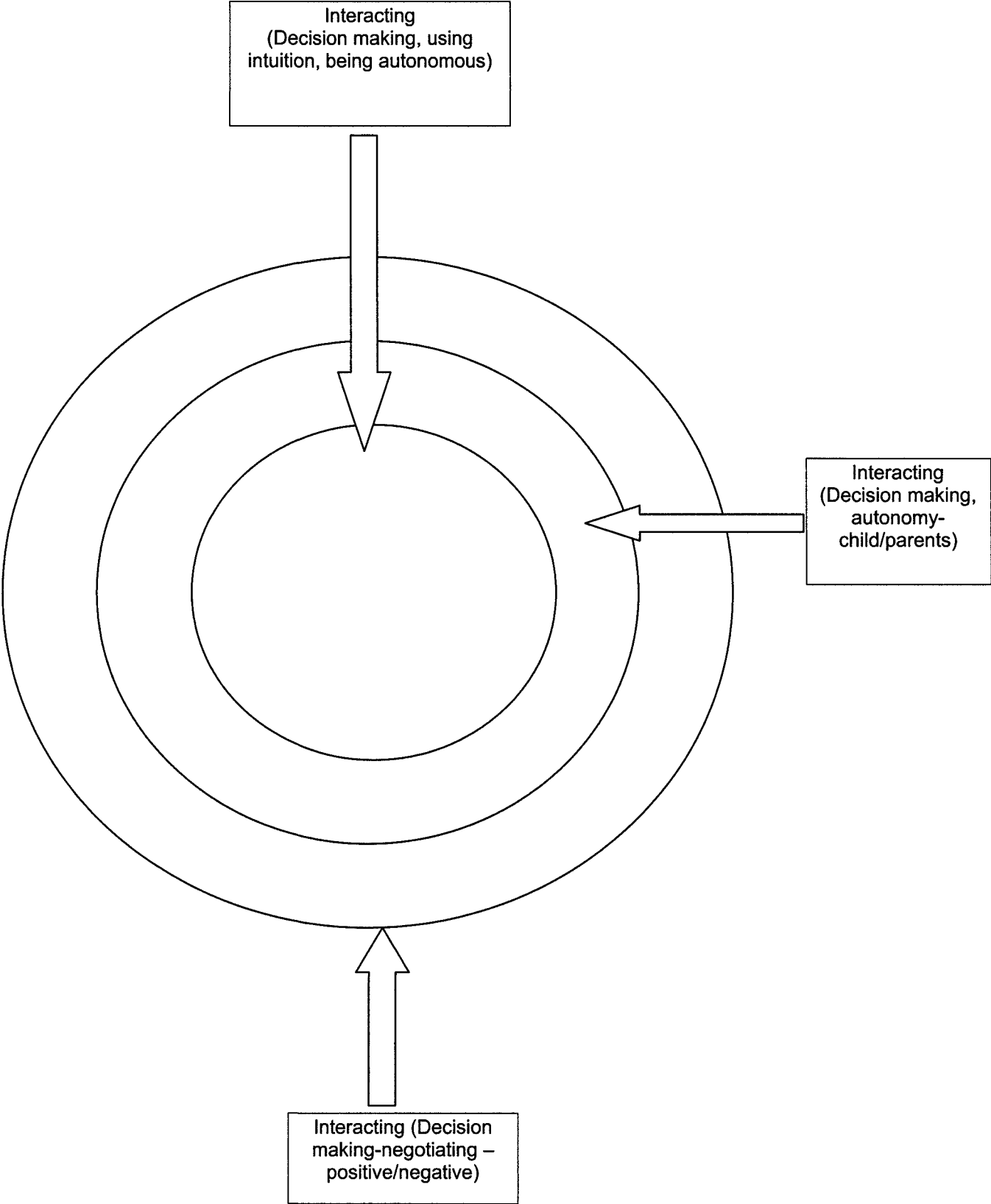
casenote documentation is described. Finally, the steps taken in generating the research output, the social theory of learning in childhood chronic renal disease are outlined. Excerpts from data collected in both phase one and two have been used to help illustrate some of the processes used in data analysis.

## **Chapter 5 – Assessing the Worlds of Chronic Disease**

This, the first of three chapters discussing the findings of the study, firstly introduces examples of diagrams used in the analytical process and discusses their relevance to the subsequent discussion of findings. The first aim of this research was to investigate the way in which children and their families learned to manage a chronic renal problem following referral to the Children's Kidney Unit. In exploring the way families learn as they move through the disease course it was also necessary to take into account the professional perspective on family learning. The importance of partnerships in family centred care is widely reported and as this study progressed into deeper levels of analysis it became increasingly obvious that family's learning was not a one-way process.

Specific use of a conditional/consequential matrix (Figure 14 below) as an analytic aid to help me keep in mind several analytic points was incorporated into theory development. The matrix concept was proposed by Strauss and Corbin (1998) as a way of emphasising the fact that both micro and macro conditions are important to the analysis.

Figure 14: Example of Conditional/Consequential Matrix (Phase two)



The use of memos and diagrams has in this study has previously been described in chapter 4. Figure 14 and also figure 15 (below) provide an example of how a simple diagram illustrating micro and macro conditions in the axial coding stage, evolved into an integrative diagram showing the relationship between Parallel, Integrated and Synthesised Learning. Subsequently this evolved into a more complex diagram of the three categories: assessing, interacting and synthesising in the selective coding stage. Therefore, in Figure 16 (below) the product of this study, the social theory of learning in childhood chronic renal disease is presented in diagrammatic form

Figure 15: Integrative diagram showing relationship between Parallel, Integrated and Synthesised Learning.

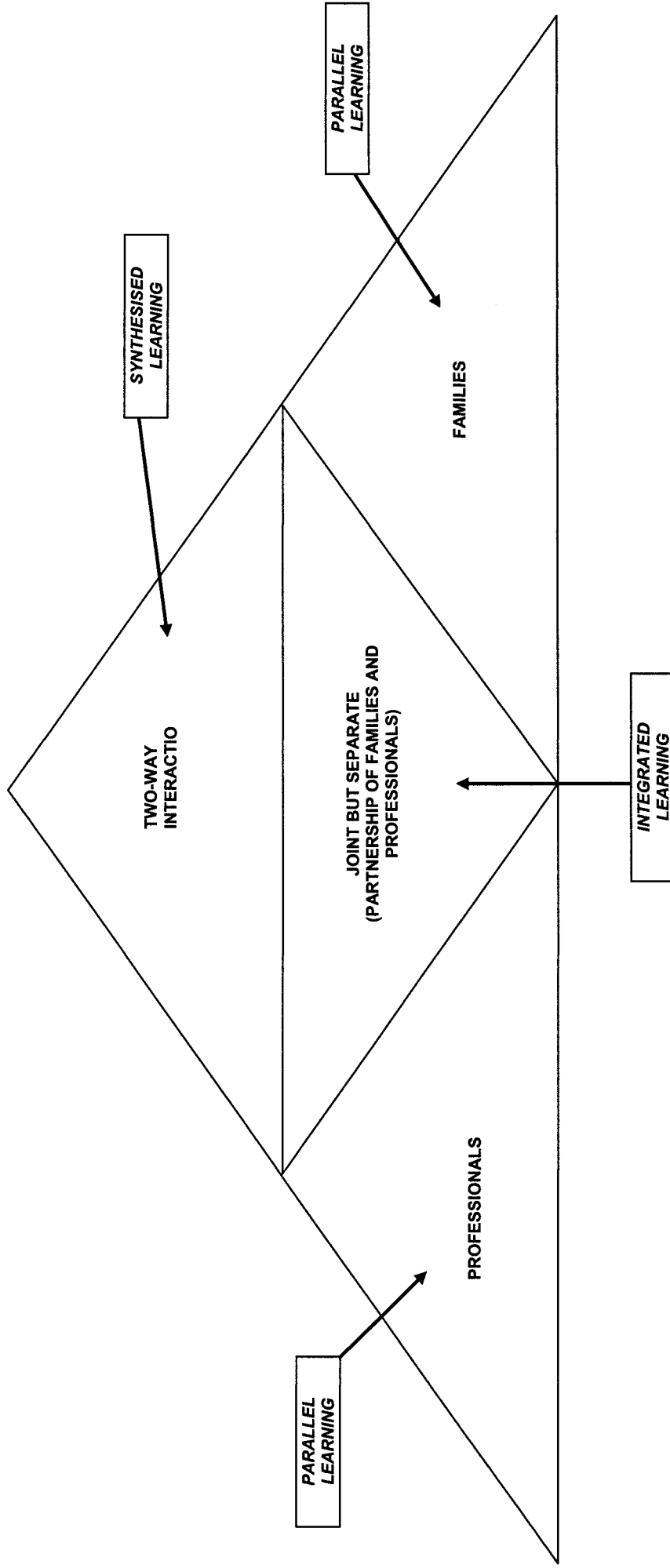
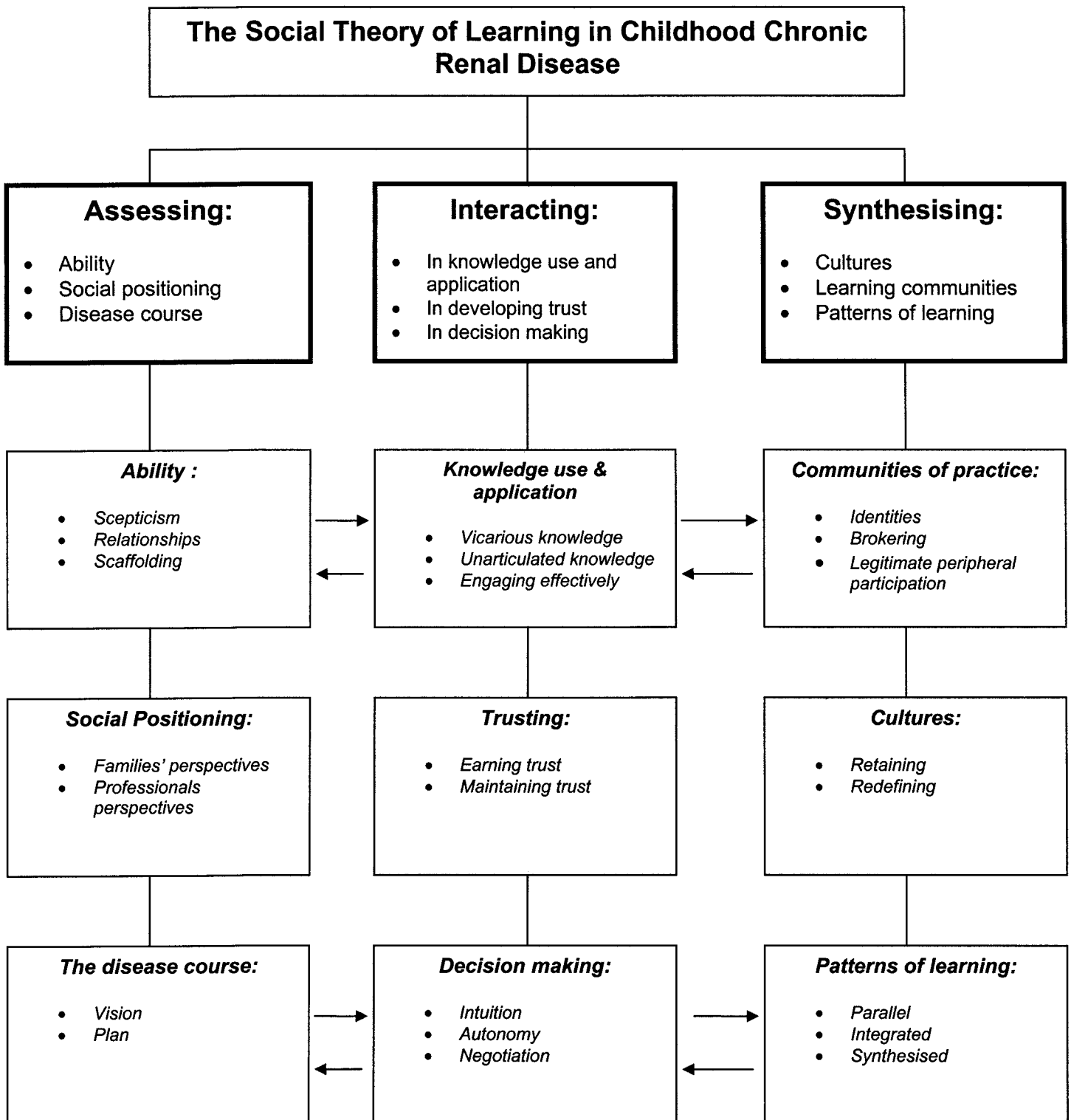


Figure 16: Diagram representing the social theory of learning in childhood chronic renal disease





Establishing the credibility of qualitative research increases the likelihood that findings will be applied to practice (Guba and Lincoln, 1989) and the ultimate test of trustworthiness is whether we believe the findings strongly enough to act on them. By using these methods and incorporating an audit trail in this thesis the research process has been made more transparent, thus enhancing its trustworthiness. There were times in the analysis when diagrams were more useful than memos for sorting out the relationships between categories. They helped me to gain some distance from the data. I was sometimes so immersed in it that I could not easily visualise the concepts that were emerging.

In this and the next two chapters, discussion focuses on the three categories comprising the social theory of learning in childhood chronic renal disease. Participants' verbatim quotations or written accounts are used to illustrate and support aspects of the discussion. As stated in chapter 1, in order to protect anonymity and confidentiality, accounts by family members are identified using the child pseudonyms outlined in Figure 6 and reference to the relevant study phase. Figure 6 also provides a brief introduction to the children and their individual family contexts. To protect anonymity and confidentiality, where professionals' accounts are included and because of the small number of staff on the team these are identified by the professionals' role only (for example nurse, dietician, doctor). My own involvement in dialogue with participants during research interviews, is indicated by the term 'Int:'. (an abbreviation for interviewer). Other conventions used in presenting the data include:

- Clarification by me of an aspect of a verbatim account is included in square brackets [ ]. Emphasis by an interview participant on a particular word or phrase is denoted by bold text. An example of these is presented below using an excerpt from an interview account by Nina's mother in phase two:

I can't fault Dr [local paediatrician] although he had never checked them [Nina's kidneys] again, I can't fault him because he has been **fantastic** [Mother's own emphasis], I mean, and we could see how shocked he was when he came with the results of the scans. He was **totally shocked**.

- A gap in the data presented, denoting a section of an interview that was deemed irrelevant to the context and, therefore, excluded in the reporting is indicated by the use of a short space in the text and three full-stops, as the following example denotes:

Nurse: So, she [Claire] was really interested in watching the TV when I was setting up the peritoneal dialysis machine, she liked to watch all the usual programmes, you know like...and all the usual Soaps and such like, and we used to chat when she wasn't concentrating on a programme...I needed to know she would give me her full attention you know when I was explaining something important.

In these three chapters the research findings are presented and discussed in relation to the three categories, Assessing, Interacting and Synthesising. The remainder of this chapter, therefore, focuses on the way in which the process of assessing contributed to family learning. Initial awareness of a child's chronic renal problem can occur in a variety of ways either before or after symptom presentation. Because of this, some families report a history of unexplained symptoms and associated uncertainty before a diagnosis is made. In others, however, the problem manifests as an acute presentation or is detected during routine antenatal scanning so there may have been little pre-diagnostic anticipatory time. Although there is no particular sequence to these events, the relationships created at these critical points in the disease course are very significant and may set the tone for the way in which families and professionals make assessments about each other and the subsequent disease course.

Assessing was, therefore, a major category to emerge from the analysis and this chapter will explore and discuss the interrelated concepts of 'ability', 'positioning' and 'disease course', within the category of 'assessing'. These are addressed from the perspective of families and professionals. The accounts will illustrate the diversity of perspectives regardless of the level of intervention required, the significance of mutual assessments of competence and the relevance of social positions that individuals adopt and ascribe to others in the management of childhood chronic disease. Later in the chapter, two of the Cases from phase two will be introduced and used to elucidate the experiences of families and professionals in relation to the category 'assessing'. Finally, the conclusion will draw together the main points to have emerged during the discussion.

### ***Assessing ability***

For some families, the insidious nature of symptom onset meant they encountered a variety of professionals before knowing what the problem was. For the same reason, information about a diagnosis was often provisional and events were circumscribed by uncertainty and confusion. When recalling the time around referral to the Children's Kidney Unit, accounts from family respondents in phase one were as vivid as those in phase two, despite the long time-lapse between referral and the research interviews for

phase one participants. This suggests that events around this time were highly significant and deeply meaningful for those participants, many of whom said they continue to contemplate and critically reflect upon these events regularly. One of the most significant issues recalled by families was encountering scepticism by professionals, in particular during the pre-referral period. This is discussed below.

## **Scepticism**

Billy's mother (phase one) readily recalled the time four years previously when, as a fifteen month old, he had been 'off colour' for a few days and eventually developed swollen feet and puffy eyes. Suspecting he had a problem with his kidneys, she took him to the General Practitioner four times in four weeks asking if his urine could be tested, but was told that he was fine and probably had hay fever. Eventually, after considerable persistence on her part the General Practitioner agreed to test his urine and said it was 'absolutely clear'. When his symptoms persisted, the General Practitioner prescribed steroid medication for hay fever but with no effect. A week later, feeling very frustrated, Billy's mother consulted a different General Practitioner who immediately referred Billy to the Children's Kidney Unit where he was diagnosed with Nephrotic Syndrome. As a result of the delay in receiving a diagnosis and even though she subsequently received reassurances that this was unlikely to have aggravated Billy's condition, his mother said she believed the first General Practitioner was incompetent. Four years later, at the time of the research interview, she still held the same view:

Mother: ...because the symptoms were quite clear you know, puffy eyes, puffy legs and a simple test of urine, [she] could have tested that, and she didn't do it...and when I insisted she told me everything was fine, very simple symptoms ...you should pick it up...very angry with my GP! [General Practitioner].

Subsequent encounters with health professionals were more positive, however:

Mother: .. doctors in the hospital gave us a lot of help, lent us a book about the problem and the nurse, you know, once we got any trouble we just phone her.

For other families, acute onset or recognition of the problem meant that they were launched unexpectedly into an unfamiliar world that was characterised by urgency and bewilderment. Several children were initially assessed at a local hospital before being referred to the Children's Kidney Unit for ongoing care. Children and parents made explicit reference to the way in which their perception of professionals at the local hospital made a difference, in either a positive or negative way, to their own ability to

learn about the condition. If the condition had for some time gone undetected by staff in the local hospital, an existing good relationship with these staff led to expressions of continuing support and loyalty from families. For example, Nina's mother (phase two) described her shock and distress to learn from the paediatrician at the local hospital, who had been seeing Nina regularly for a less serious problem, about the existence of a chronic renal condition requiring moderate intervention. However, her mother was at pains to qualify this:

Mother: What I'd like to know is, well not really, like, although they [Nina's kidneys] were clear ten years ago, it was just something Dr [Paediatric Nephrologist] had said, if we had been under them and they had had tests done, seeing that it was in the family, they would have kept a check on it over the years to see if it came. I can't fault Dr [local paediatrician] although he had never checked them [Nina's kidneys] again, I can't fault him because he has been **fantastic** [Mother's own emphasis], I mean, and we could see how shocked he was when he came with the results of the scans. He was **totally shocked**.

This was a clear indication of how important established and ongoing relationships with professionals are in chronic disease management. Some examples of the way in which families assessed professionals according to the relationships that existed with them are outlined in the next section.

## Relationships

Nina and her parents (phase two) explained in the first interview that they were happy for her ongoing care to be shared between the local paediatrician and the nephrologists, whilst recognising that ultimately decision-making about management was the responsibility of the nephrologists:

Mother: ...we see [nephrologist] a week on Wednesday, are at the [local hospital] this Wednesday and they are going to check her blood pressure, the following week depending on how it is, we are back at the kidney unit because [local paediatrician] phones [nephrologists] with whatever her blood pressure is.

Other families who had less well-established relationships with local health care providers did not view this 'shared care' approach so favourably. Where the first encounters with the local health care system were characterised by scepticism, subsequently the child and family were reluctant to maintain ongoing contact with those professionals involved. Several families remarked that they had been naive in their early relationships with local professionals, especially when adopting a passive stance to the situation early in the disease course was found to be unproductive. There is some

resonance between these remarks and Thorne's reported concept of naïve trust in chronic disease (Thorne, 1993).

Carol (phase two) and her mother recalled how, despite repeated visits to the General Practitioner because Carol was vomiting and complaining of tiredness and abdominal pain, they had been treated dismissively. Having very little previous experience with the health service, Carol's mother went through an initial period of disenchantment before she eventually learned to become proactive. She believed that her parenting competence was being challenged by the General Practitioner, indeed this was typical of the reaction from other parents experiencing scepticism from professionals early in the disease course:

Mother So we came back [from the General Practitioner] and I didn't know what to do, when you know there is something wrong and nobody is saying there is something wrong, so I took her to Casualty at [local] Hospital, I thought it was no good going back to the General Practitioner because I had been there and they said there was nothing

After spending over twelve hours in casualty during which time several investigations were conducted, including Carol being asked to undertake a pregnancy test:

Carol ... so I said 'Well yes, I will do one but it's a bit over the top, isn't it?'

the situation was quite suddenly treated as urgent by professionals, even though Carol's condition had not noticeably deteriorated whilst in casualty:

Mother The pregnancy test came back alright... consultant came, thought she had something wrong with her kidneys and we would have to go [to the Children's Kidney Unit], from early morning, this was now 6 pm ... put in an ambulance with a blue light and a nurse came, Carol had this mask over her face and we met Dr [nephrologists] who said she was a really sick girl, it could be life threatening, she would need an emergency operation to have her dialysis line put in, and I reeled a bit, you know - I am educated enough to know what dialysis is, but I was just totally shocked!

What then began for Carol and her parents were a maelstrom of events and a long period of turmoil. The high level of intervention required by Carol's condition meant all her care would be given by the regional paediatric team. The lack of credibility ascribed to local health care professionals by Carol and her mother was a recurrent theme during phase two and was typical of the attitude of other families whose assessment of the competence of local health care staff was determined by the way in which early

encounters were conducted. Where the level of intervention for children was moderate or high this usually meant the family needed to learn a new and often challenging set of skills related to the interventions. Nurses providing metaphorical 'scaffolding' to facilitate the learning process often supported this process of learning these skills.

## **Scaffolding**

An example of this was portrayed by an account from Lucy's mother (phase two):

Mother: The nurses show us things in stages, one step at a time so that we learn it [how to pass a nasogastric tube] more easily.

Below is an excerpt from a memo written soon after this interview and which I added to a when I received the transcript of this interview. I subsequently made further comments after reading the nursing and medical notes and cross referenced this finding with that from an interview with Kevin's parents (phase two) in refining the category of assessing and its sub-category of scaffolding.:

**Memo derived from an interview with Lucy's mother (phase two) in relation to the development of the sub-category "scaffolding".**

Fieldnote recorded in my notebook when I arrived home after this 1<sup>st</sup> interview with Lucy's mother. In reality these memos were jotted down in note form and were handwritten and sometimes involved me drawing lines and arrows to indicate a cross reference from one topic (or interview) to another. For the purpose of clarifying the process used in the research and to help explain the development of categories and sub-categories in this thesis, the notes are tidied up and typed

*Her mother talked like some of the nurses in the AWBL A&E [accredited work based learning in accident and emergency] evaluation in which nurses talked about the way in which they had learnt certain skills from more experienced professionals by being shown in stages (Swallow, Miller and Chalmers, 2001) or steps and stairs as I recall one saying. In this quote:*

Mother: The nurses show us things in stages, one step at a time so that we learn it [how to pass a nasogastric tube] more easily.

*Lucy's mother seems to be describing a process where she is being given a helping hand in learning to pass a nasogastric tube on her baby, I remember when I was a new staff nurse many years ago and learned from a more experienced staff nurse to do this on a young baby and how scared I had been, so for a new mother who is concerned about learning to be a mother while also needing to learn this and other clinical and technical skills before she can take her baby home could be even more scary. Through the process of metacognition though she seems able to recognise this as part of her learning. It is this recognition of her own learning through a supportive framework devised by the nurses that reminds me of the work that Spouse did in 2003 when she explored the way in which student nurses learned from their mentors through a process of scaffolding. This process has not previously been described in relation to families learning, yet it seems that it goes some way to explaining the way in which Lucy's mother learns. There does seem to be a great deal of similarity between some aspects of this mother's learning and learning by nurses.*

**The following was recorded by me after reading Lucy's nursing and medical notes from the period before this interview (but accessed after the interview)**

I see that the nurses have described how they set up " a series of skills to teach her [Lucy's Mam] so that she gets information in bits and pieces that build on each other, taking a step at a time". This process is also alluded to by a doctor in writing to Lucy's general practitioner when summarising a period in hospital during a written discharge summary. This letter is also sent to Lucy's mother for information. This level of documentation appears to reify the information in the way described by Wenger (1998) [ and discussed further later in this chapter in relation to Kevin, phase two]

Meanwhile, Lucy's mother described how she worked alongside the experienced nurses as they dressed Lucy's central line site and they gave her increasing responsibility until eventually she could carry out the technique without support. This type of scaffolded learning is also indicative of legitimate peripheral participation described by Lave and Wenger (1991). This mother's positive observation that the nurses 'showed us things in steps' was typical of the way in which families described the experience of learning to perform a technical skill that was critical to the child's management. Several families described the way that nurses would 'think aloud' about what they were doing while showing them how to learn a skill such as nasogastric tube insertion 'in stages'.

This type of 'voice over commentary' was described by Vygotsky (1987) as a supportive mechanism in teaching new skills to learners. This staged approach to learning new skills was not only critical to the development of the necessary skills by family members but also served as a means for professionals to assess the ability of children and families. Professionals' accounts suggested that learning by family members is a process that takes place collaboratively, not solely in an individual mind, although learning does have to be owned by the individual. Thus, learning was not seen as a one person act but a form of social co-participation and was mediated by the differences of perspectives among the co-participants. This is illustrated by the following quote from a dietician:

...so the first aim with Carol was to get calories into her when she was in an anorexic state and for as long as reasonably possible and so that was difficult but the family were very co-operative. The second phase was just going on to education in that all information was written down so it was practical and that, but obviously the patients are in crisis so you can't expect them to remember everything and I think that epitomises the problem of Carol's family [phase two] coming to terms with everything, because all of the information was given to them at a time when they were in a crisis and, therefore, how much they retain of that information is determined by the way it is given and I think that Mum still has a problem differentiating between lost weight and fluid balance and that is not her fault, I think that is just the timing...

The issue of social co-participation was also illustrated by one of the nurses who described how the renal team are responsible for teaching parents to adopt what would traditionally have been regarded as nursing roles. This could mean home administration of subcutaneous injections, gastrostomy feeds or nasogastric tube feeds to their child and may also include the need to learn how to set up and run peritoneal dialysis on their child. All these skills need to be acquired before the child is discharged. She explained that this involves teaching parents about self-care of equipment. This includes teaching



them how to set up and run peritoneal dialysis before the children are discharged, teaching them how to manage it and maintain a high standard of care at home:

Nurse: We do frequent visits to make sure that they aren't beginning to cut corners and just trying to keep the standards high at home, which obviously is much better for the children. So we try – well, initially when the children are diagnosed and they need to go onto peritoneal dialysis we do all of the training in hospital on the Ward and it takes as long as it takes

An individualised learning plan is developed for each family who needs to learn how to set up peritoneal dialysis. This is in recognition of the fact that people learn at different paces and that families have many other commitments as well as having to deal with the clinical aspects of their child's condition:

Nurse: It would be lovely to say it [teaching peritoneal dialysis] can be done in two weeks, but it is very difficult, because obviously they have got a sick child in hospital at the time, and we usually train two parents, you know research has shown that two parents or two carers doing a machine [peritoneal dialysis] is of a higher standard than one constantly doing it.

Nurses explained how they have built up a repertoire of anecdotes of things that have happened to other families to reinforce learning points. These are often written down for families to keep. For instance, all families are given basic written and verbal information about the risks of peritonitis for children on peritoneal dialysis:

Nurse: ...talk about kids getting peritonitis, causes, signs and symptoms, how to prevent contamination and all these anecdotes about kids come back and back and back, so they all know about the same kids who have the same problems they have got.

Central to this approach is the need to provide reassurance by creating the sense of 'support without presence' or the possibility that collaboration from the professionals is 'invisibly present' while the families are coping with the technical aspects of care at home. Vygotsky (1987) refers to the idea of 'virtual support' or 'invisible support' when describing the way in which a schoolchild solves a problem at home on the basis of a model that he has been shown in class

For nurses, however, assessing the ability of children and parents to manage independently such skills as dressing a central line site or setting up and managing peritoneal dialysis equipment at home, is similar to the assessment qualified nurses

make on student nurses prior to judging them competent to work independently within a ward setting (Spouse, 2003). A critical part of this assessment is the need to know that the learner has clear boundaries of responsibility and knows where they can gain help. Through repetitive practice, learners can begin to see patterns in their experiences and to develop their own 'portable knowledge base'.

## **Summary**

Thus, the need to assess ability was a two-way process and it manifested in both negative ways, such as through parents encountering scepticism by professionals and positive ways including scaffolded learning. Central to the process was the quality of interaction between families and professionals.

## ***Assessing social positioning***

This study revealed several examples of the concept of social positioning during interactions between family members and professionals, with recurring examples across the data sets being identified by the constant comparative approach. As discussed in chapter 2, positioning is a metaphorical concept in which an individual 'positions' themselves and others and where discursive practices are conducted either privately or publicly in order to support a desired position. Generally, positions are relational. For instance, when one person is positioned as powerful, others may be positioned to feel powerless. Conversely, when an individual positions themselves as confident another individual may not feel confident (Harre and Van-Langenhove, 1976). While discussion in the previous section alluded to some of the ways in which families assessed and were assessed by professionals with regard to ability and the significance of relationships in that process, the next section focuses analysis on the ways in which families and professionals mutually assessed social relationships.

## **Families' perspectives**

Issues of identity and interpersonal interactions in relation to feelings of empowerment arose on a number of occasions in families' accounts, in particular those of several mothers, two of the fathers and the children who were old enough to participate in the study. In this respect there was clear divergence between the findings from this study and those reported by Gibson (1995) who found that the process of empowerment amongst mothers of chronically ill children was largely intrapersonal (Appendix 12). In Gibson's study, the intrapersonal factors cited by mothers included their personal values,

beliefs, determination and experience. The only interpersonal factor was social support and only one mother from the 14 who participated identified a facilitator or external enabler to mentor them along the path to empowerment. Although mothers acknowledged the support of health care professionals and other mothers, these individuals were not positioned as enablers in participants' competence development.

In contrast, children and most parents in the study reported here alluded to the position they attributed to members of the professional team, as people who look out for them and show them how to deal with everything relating to the condition. Uppermost in children's accounts were references to the way professionals (nurses, doctors, dieticians) communicated with them at an appropriate level, although this was sometimes a matter for negotiation. The children all positioned themselves (or were positioned by others) as participants in their own management whilst acknowledging their dependence on the professionals. An example is portrayed by the following quote from Carol (phase two) who has a condition requiring high levels of intervention:

Carol: When you are outside [at home and not requiring any health care support] you don't think much about hospitals, then when you go in you realise what goes on... and how much they do for you, you think 'Oh yes, nurses are great and they look after you'...but really they talk to you as a friend as well...you are not like embarrassed to tell them anything...that helps you to feel ok about what you have to do to yourself, peritoneal dialysis and that.

The way children positioned themselves in relation to professionals was influenced to some extent by the roles their parents adopted in communicating with professionals. Over the course of the disease course, the parents of the older children (Nina and Carol) adjusted their communication style from one involving a controlling and directive approach to one of partnership in which the parents' and young persons' positions became more equal. Early in the disease course Nina's father, in particular, talked of wanting to be a communication buffer to shield Nina from learning the full impact of her condition too quickly. During the first research interview, the family discussed this issue and Nina indicated that she was happy for her parents to act as facilitators of communication with professionals as well as information buffers. By the second interview, however, Nina discussed this again with her family and later reiterated in an unaccompanied interview that she no longer felt the need to have her parents shielding her from the full facts about her condition. By this stage, she saw herself having access to information through her own interactions with professionals and being able to cope independently with this information.

Older children's accounts also indicated that they often critically reflected upon their interactions with professionals, were aware of the hierarchy that existed in health care and were also aware of their own social positioning in relation to professionals. Most related this to the way in which professionals initiated communication during the first encounter. Where professionals introduced themselves using their own first name, children perceived that as an invitation to use first names in subsequent conversations. The informality created by the tone of the introduction meant that while children respected the professionals they also felt more relaxed in their company and were, therefore, more able to learn about their condition. However, in direct contrast to this, if a professional introduced themselves using their title without their first name, this seemed to create a barrier between them and the child that had a negative effect on the child's ability to learn about their condition. This more formal approach meant that while the child acknowledged that professionals all hold a higher status in the organisation, the children were reminded of their own subordinate position that had a negative impact on future communication. Nina (phase two) expressed this vividly during one of her interviews:

Nina: I prefer it when they are a bit friendly really and they try to have a laugh with you.

She also observed that professionals who do not encourage use of first names position themselves as dominant at the beginning of the communication, whereas those who initiate the use of first names in communication '*...seem to be on the same level, sort of thing...*' and this relationship prevails thereafter. This is an example of 'interactive positioning' as described by Davies and Harre (1990) in which what one person says positions another.

In describing her views about the link between learning and social positioning, Nina contemplated whether in fact the professionals using a more informal approach towards families were actually adopting an intentional strategy:

Nina: I think they know if they pretend they are on the same level that you will warm to them and will understand them and be willing to listen to them

Int: Do you think it is pretending?

Nina: I don't know really because they know that they are higher up - they are doctors and we are just kids!

This quote suggests that Nina believed herself to have been positioned as subservient by the doctor but, because of the manner in which this was communicated to her, through deliberate self-positioning (Harre and Van-Langenhove, 1976) she subsequently positioned herself to be confident. In contrast, Lucy's mother (phase two) found that the ward round was a time when she encountered forced self-positioning in that she positioned herself as 'passive' because of the way in which the ward round was conducted in front of her:

Mother: ...doctors should turn round and say [to parents at the bedside] that this medicine is going to increase because she is growing so we are upping the dose to work with her body, and that is it. Yes, so you are like in the background but you are now just watching a play, if you know what I mean? **And the play is going by and you are just sat watching it**, which is fair enough, they are doing what they should be doing but it is the renal nurses and the nurses that actually sit and explain things to you all day and all night, so in the end I thought I would join in here and I started to ask questions about Lucy.

The preceding quotation also serves to illustrate the way in which the dramaturgical model of human life is sometimes demonstrated in health care practice. According to this view, during daily encounters people are actors on a stage with the audience consisting of the people who observe what others are doing. The [acting] parts are the roles people play or the positions they adopt or are attributed. Meanwhile the dialogue consists of ritualised conversational exchanges. Goffman (2003) claims that in order to have effective interpersonal encounters, individuals must 'put on a performance' (hence the use of the term dramaturgical). Analysis embedded in this perspective regards the theatre as a metaphor for understanding interactional encounters. This approach to interpreting conversational encounters helps to make more comprehensible the accounts of parents such as Lucy's mother or Nina (phase two). Both, eventually used the theatre as a metaphor when describing how they made the transition from an accepting role as a recipient of care to a synthesised role in which they decided to join in with the professionals after observing an exchange of symbolic and ritualistic politeness (Tanner and Timmons, 2000).

### **Professionals' perspectives**

Professionals articulated, in different ways, the fact that all families interacting with the team present a unique combination of circumstances to which management must be adjusted and refined. Where possible, holistic care is delivered in the context of the child's total life circumstances. In addition, it is clear from staff's accounts and their written documentation that children's health care needs are continuously changing as

their condition improves or deteriorates and as they grow and develop. The following account from a dietician is an example of the individualised approach staff would often adopt when teaching a family. Although the dietician's comments were framed in a general way they were related to discussion about Carol in phase two:

Dietician: ...but my job is to figure a way that makes it [dietary management] better for them, giving them security and respect, you know.

Int: So do you see them as part of the team?

Dietician: Yes, very much so. Yes, whether it is the right way, I don't know, but it is the one that gets you to know them quite well and you get to know them as people, I don't know how much they get from it...then you can share things, I mean I don't always go in and talk about the condition or ask the questions, I tell her a story about what has happened at the weekend and you know, the social chit chat

Int: Yes. So when you are first starting to get to know families like Carol's, how do you judge them in their ability to understand what you are saying and to put what you are talking about into practice?

Dietician: I think the best thing is to do an assessment of what the norm is within the family's life and you spend time listening to the family and you notice what level of reading has been done, what level of schoolwork has been done, you notice magazines that have been lying around, so you take in a number of factors to decide the social aspect if you like - you know, like does mum cook, for example? How easy is it for her to boil a potato, or would she be able to peel a potato, or do they buy frozen vegetables? Do they cook vegetables at home or is it only convenience foods? What cooking skills are there in the family? And from all of that, you do make assumptions about people's lifestyles...and give them examples and from their questions you can gauge how much they have understood.

It emerged from earlier accounts in this section that family members differ in their capacity to position themselves and others. This is also evident in the accounts of professionals. A member of the nursing staff observed when describing the way Carol's mother adapted to providing peritoneal dialysis for her daughter that:

Nurse: [Carol's] Mum was very good, she is a very organised person, so she got to grips with the organisation of actually learning to do the PD [peritoneal dialysis] really quite quickly

However, the nurse expressed concern about Carol's Mum's ability to understand the principles behind peritoneal dialysis. In common with other parents, she could easily use the terminology and so could appear very knowledgeable, being able to use the words

but apparently unable to convince staff that she has the underpinning knowledge to support a good understanding of the techniques:

Nurse: So the staff on the wards tend to be a little bit intimidated by parents who come onto the ward because the parents can say these words and look like they actually understand, but really the larger understanding that nurses have of disease and the treatment and what to do if such and such happens...it takes a lot longer and it is really an experience thing! It can be quite intimidating to a lot of junior nurses

This apparent lack of 'propositional knowledge' as described by Eraut (1994), particularly in the early days of the disease course was displayed by many families dealing with chronic disease. Professionals' accounts suggest that tension can often exist between parents and professionals (who are concerned about the parents' apparent lack of deep learning about the condition and are primarily concerned about the child's clinical safety). This finding corresponds with those of Callery (1997b), who suggested that conflicts arise from the different nature of maternal knowledge that develops in the 'private' domain of intimate contact and professional knowledge that is based in the 'public' domain of the world of work. The nurse who made the preceding comment referred to her own extensive experience of caring for children with a range of chronic conditions and acknowledged that:

Nurse: ...I do find that parents pick up the jargon really quickly when they have children with chronic diseases and also they know the children really well, but the deeper insight into why we are doing things is sometimes lost in them.

Staff are concerned not to undermine parents but see that their position as professionals imposes responsibilities on them to make sure that the child is clinically safe. Thus, effective dyadic or triadic communication does not just mean keeping families happy but may have profound effects on health care delivery. This can lead to conflict with parents who may disagree with the professionals although this may (or may not) be on the basis of limited understanding. When asked how she would resolve this dilemma, a nurse explained that she would discuss her concerns with the remainder of the team:

Nurse: ...they [multi disciplinary team] are all very supportive at meetings. If any of us have problems with any of the families we discuss it with the dietician, the consultants and nurses - discuss the evidence, the consultant would back that up and eventually ... the family will take that on board and will think about it.

This comment about the professionals being 'correct' may be interpreted as an example of the 'expert model of partnership' previously described in chapter 2 (Cunningham and

Davis, 1985) in which professionals view themselves as having total expertise and therefore, sole control over the child's health. Alternatively, it may be interpreted as the professionals acting in the way they believe to be in the best interests of the child that is of course the overriding concern in the management of chronic disease.

People also appeared to differ in their intention or willingness to position and be positioned. For example, there was evidence from professional accounts that newly appointed staff and students would often resist being positioned as 'expert' because they are intimidated by some of the procedures such as peritoneal dialysis. More experienced staff will have told them that if they do not connect children to the peritoneal dialysis using the correct aseptic technique then the child may develop peritonitis. The following quote from one of the nurses helps to illustrate this point:

Nurse: That might slow up their [new staff's] process of learning because they are worried and want to watch and they want reassurance that they are doing the right thing. Whereas the parents, although they also know that because we have told them, I don't think they really have the experience to know what peritonitis is and so maybe they don't worry about it as much so they [appear to] learn quicker, if that makes sense...?

Expressions of concern about the possible superficial level of parental learning were typical in other staff's accounts. For instance, there were examples of considerate teaching that demonstrated the professional's personal commitment to the subject matter, stressed its meaning and relevance to the family and was designed to foster deeper approaches to learning such as those described by Ramsden in chapter 2 (1992). During these conversations, some staff drew upon their own experience of parenting to try to understand the position of parents. Having a great deal of knowledge about the particular problems associated with renal disease was seen as both an advantage and a disadvantage. The overwhelming concern related to the vulnerability likely to be experienced as was explained by a quote from a nurse:

Nurse: ...they have so much to learn and I think if I put myself into their situation, as a nurse, to have to do all that to my own child I think I would really struggle, would be terrified, having the knowledge I have. (Nurse)

A major challenge for professionals was determining the most appropriate position to attribute to parents and children at each encounter. The positions adopted by and attributed to parents both facilitated and inhibited communication. Generally, however, young people developed the ability, quite early in the disease course, to express their preference regarding the amount of responsibility for communication that was delegated



to their parents. This conflicts with reported findings from recent research in the area of childhood chronic disease (Young, Dixon-Woods, Windridge and Heney, 2004) in which professionals were urged to consider delegating less of the responsibility for communication to parents.

## **Summary**

The accounts of children, parents and professionals in this section suggest that the concept of social positioning is more significant than has previously been acknowledged in the literature regarding childhood chronic disease. This concept helps focus attention on dynamic aspects of encounters in contrast to the way in which 'role' serves to highlight static aspects. Despite the prevailing philosophy of family centred care in child health, family members generally had little knowledge of the role they were expected to adopt on entry to the disease course. Positioning theory can be considered as a tool to explore the dynamics of social episodes in which families and professionals assess and learn about each other across the disease course.

## ***Assessing the disease course***

The previous two sections in this chapter have considered the ways in which families and professionals have assessed their own and each other's ability to share in the condition's management, the differing social positions each adopts and attributes to others within that process and the possible significance of these positions. Building on this discussion, the current section explores the way in which professionals and families assess the different aspects of the disease course. The combined accounts indicated that multiple convergent and divergent trajectories existed across the course of the conditions. In phase two, the study design enabled a 'mapping' of lay and professional accounts over a period lasting up to eighteen months using a combination of verbal and written data sources. Two concepts in the chronic illness framework, previously described in chapter 2 (Strauss *et al.*, 1984), of particular relevance to this study are *vision* and *plan*.

Families, and to a lesser extent professionals, contemplated the different changes in status that the condition may undergo during its course and so articulated a vision for the disease course. This vision of the disease course was the way in which participants considered the future meaning of the disease, biographical disruption and the temporal nature of the condition. Secondly, respondents' accounts described a *disease scheme* in

which a plan was designed to shape the overall course of the condition, control immediate symptoms and where possible mitigate against further symptoms.

### **Disease vision**

Children, family members and professionals described differing visions of the disease course. David's mother (phase two) took part in a research interview in the third week of his disease course while he was attached to the plasma exchange machine during his plasma exchange treatment. According to Piaget's stages of cognitive development, David was chronologically at the Preoperational stage (*egocentric*—thinking of everything only as it related to himself, inclined to *over-generalise* based on limited experience and able only to *focus on one variable at a time* (Piaget, 1954). His mother had previously told me:

Mother: Well, in the beginning they said that they would definitely do it [plasma exchange] for a fortnight – the news this morning is that after three weeks of plasma exchange, he has improved so they are going to continue next week – there has been an improvement...I am really pleased. (David's mother)

She also told me that the nurse had explained this to David and she [his mother] was sure that he understood that he would probably need to have the treatment only for another week. The following excerpt from David's nursing notes at that time verify what his mother had said about the nurses' efforts to inform David about all aspects of his treatment:

Figure 17: Excerpt from David's nursing care plan in the third week of the disease course (Phase two)

| Problem  | Expected outcome  | Actions   |
|--|---|---|
| David's anxiety due to having plasmapheresis ( <i>exchange</i> ) | For David to have a good understanding of his treatment and how it feels to be on a machine, reducing anxiety | 1- Discuss with David and family his Rx ( <i>Treatment</i> ).<br>2- Allow to observe another child on a machine or to look at some photos<br>3- Consider David's age and development and use play therapy to help reduce anxiety<br>4- Ensure David is occupied during exchange to reduce boredom |

However, when I asked David later that morning (in an unaccompanied interview), how long he would carry on with the treatment he said *...for always - we do it every day*. This is consistent with Piaget's concept of *over-generalisation* in relation to the preoperational stage. It appears that although the nurses and David's mother had considered a number of ways to reduce his anxiety regarding the treatment (with apparent good effect as he appeared totally unconcerned about it), they had not considered the possibility that because of his developmental stage he did not, nevertheless, understand the temporal nature of the treatment. He appeared to assume that the situation he was in at that time was likely to be unchanging.

Conversely, Nina (phase two) provided a detailed account of the different changes in status her condition might go through according to how her blood pressure and weight might fluctuate. During the interviews, she demonstrated an ability to think abstractly and consider the benefits and risks of hypothetical situations. For instance, she explained how she had read and been informed by a professional about the increased risk of having a stroke if the blood pressure went above a certain level. She had told her friends of this risk because:

Nina I know a little bit of first aid but my friends didn't, but if I collapsed and stuff I would like to think they would know what to do, so I told them a bit of what they should do...

This account is consistent with a child in the formal operational stage that occurs in late childhood and is characterised by thinking that reflects an understanding of basic principles of cause and effect. Thus, Nina demonstrated deductive and inductive thinking and the ability to engage in hypothetical, abstract and propositional thinking.

The first year after diagnosis seemed to be highly significant as a period of steep learning and quite early in that year people talked of playing the game with the health care system, professionals and parents of other children with a chronic condition. All parents and two children in phase one recalled being given a *mountain of information to digest* but said they quite quickly learned how to decipher information they were unclear about by sharing it with as many people as possible, including professionals, teachers, friends and, in particular, other parents. Nevertheless, two of the families in phase two appeared to be floundering in their efforts to coordinate the different aspects of the condition. The mothers in these families, in particular, searched for a professional who could be a primary source of support. Where such a professional was 'discovered', this relationship was coveted and changes in such relationships were regarded as stressful and unsettled the family vision of the disease course. Parents often mentioned individuals, such as a nurse, who they regarded as a guide providing support and knowledge about the vision of the disease course. For instance, Kevin's mother talked in the first interview of a nurse who:

Mother: ....tapped me on the shoulder when we were on the ward and said I'm here any time you want to talk to me.

This nurse helped the family to anticipate the different stages of the disease, but by the second interview Kevin's mother displayed a sense of frustration, powerlessness and hopelessness similar to that described by Gibson (1999) in saying that she had not seen this nurse again and that she didn't feel confident enough to ring her or speak to a different nurse but felt *abandoned in the health service*. At the same stage in the disease course, however, all other parents described a situation where they were empowered and felt comfortable about ringing a 'named nurse' or contacting a doctor's secretary for advice whenever they were experiencing uncertainty about treatment regimes, investigation results or worrying symptoms in the child.

## **Disease plan**

While family members envisioned the disease plan through an emotional and practical lens, professionals tended to rely on practical and biochemical markers that were measurable and referred to such terms as outcomes and options. As well as the uncertainty articulated by families there was also evidence in this study of professionals' uncertainty about a set of symptoms and their communications with parents and General Practitioners about the challenges that can arise when searching for a definitive diagnosis. Through triangulating data in the Cases, it was possible to compare different

accounts of the same encounters. In childhood chronic disease there is no such thing as a standard treatment regime for a standard patient (Thompson and Gustafson, 1996) and this fact often contributes to uncertainty (Mishel, 1983). Uncertainty, a cognitive state created when an event cannot be adequately defined or categorised (Cohen, 1993) was seen to be a major factor influencing expectations about the treatment plan in this study.

In the same way that in the pre-diagnostic period patients often take part in diligent detective work to try to find explanations for persistent symptoms (Robinson, 1988; Swallow and Jacoby, 2001a), professionals in this study provided evidence of similarly diligent detective work to explain extremely rare presentations of symptoms. There were detailed accounts in all the casenotes but particularly those of Lucy, Carol and Kevin of the steps being taken to assess the condition, develop the most appropriate treatment regime and keep parents up to date with information. This could involve making contact with other children's kidney specialists to determine whether they had experience of managing patients with such a rare combination of symptoms.

For instance, during the first interview with Kevin's parents five weeks after his referral to the Children's Kidney Unit, his mother gave an emotional and confused account of her understanding of his condition and what it meant:

Mother: ...we didn't know what it was, so we were worrying and thinking 'What the hell is it, you know'...oh, I am an emotional mess sometimes...I mean if he [K] is taking it so well then I have to pull myself together and do it as well...but oh, the information! I have just got doctors and nurses coming up to me and saying 'Hi, I'm such and such' - I can't remember everybody's names - I mean it has been so much of a shock.

Whereas doctors were recognised as the people who ultimately designed the plan to shape the overall disease, it was often nurses who translated this information to parents, including Kevin's mother, and who provided the ongoing link through which this information could be channelled. In this way nurses in this and other Cases were seen to fulfil the role of 'broker' that involves processes of translation, coordination and alignment between perspectives (Wenger, 1998). The following quote from Kevin's mother (phase two) helps to illustrate this:

Mother: I can't think of his name [doctor] but I mean he has been very nice but until I spoke to [nurse] – when she came over [when family were in hospital soon after referral to the Children's Kidney Unit] and we had a bit of a chat, she phoned me [at home] on Monday to find out how he was and on Tuesday he was sick, so she phoned and got in touch with [doctor] and he said we should bring him in [to hospital] to make sure it was nothing else

There were several times during the disease course when anxiety among parents was most likely to appear. The most prominent times were during transitions, such as the beginning or end of treatment. At such times, nurses routinely offered parents contact telephone numbers so they would have access to professional advice at any time they needed it as Kevin's mother also explained:

Mother: ...she gave me all the numbers I needed during 9 till 5 and after that to contact the ward. She has given me all the renal nurse numbers so if they weren't there and they needed to be bleeped, I have their numbers - they[nurses] talk more at your level, whereas the doctors talk in jargon - they [doctors] know what they are talking about but to explain it to you and if you **could** [mother's own emphasis] take it in, but it just doesn't work that way.

Once parents had been given contact numbers to use in this way, almost all would continue to use them whenever they thought it was necessary. This was corroborated by accounts from nurses and parents, for instance a nurse explained:

Nurse: A lot of the parents will ring us up, even if they haven't seen us for a year, but to ask advice if they are not sure about their child's condition.

As stated earlier, however, Kevin's mother (phase two) did not feel able to use telephone contact in this way. Another major issue for Kevin's mother was the need to act as an ambassador for the family with concerned friends and acquaintances, as she described in the second interview:

Mother: It has been a lot to take in, and until he started to get this treatment people were asking how he was and what exactly was wrong and I just had to keep saying I didn't know, and even his teachers at school were asking if he would be allowed to come to school and I was saying I think so and they said Well, you must know! and I was like NO, I am sorry, I don't know, nobody has said to me 'Oh, he has this and he is going to have these kind of symptoms' and even now if he has got sniffles or anything like that I am asking him if he is okay.

His stepfather, in contrast, was able to articulate quite clearly what his interpretation was of the information they had received and this seemed to correspond with the information in the casenotes and in the summary letter to the General Practitioner (that the parents received a copy of):

Stepfather: ...the doctor says it is like if you have a transplant, your body can like reject the transplanted bit and that is what his body is doing – he just hasn't had a transplant.

It may be that his stepfather's less emotional reaction is because he and Kevin are not biologically related although he is much more involved in Kevin's life on a daily basis than his natural father is. The absence of a social worker on the team during the period of the Cases may also have been a factor influencing the way in which Kevin's parents coped with the consequences of his condition. When asked if this is likely to affect families' abilities to adapt to chronic conditions, a nurse reported that:

Nurse: ...it will have made a massive, massive difference not to have had someone different [a social worker] there to pick up all the different pieces [of the plan].

The following excerpt from a Doctor's letter to Kevin's General Practitioner (copied to the parents) and that Kevin's mother showed me at the first interview is typical of the written information that parents routinely receive (if they wish) about their child's condition:

*We are awaiting further studies [clinical tests] as well as a literature review to better understand this extremely rare presentation which is not within the experience of colleagues in this department. Literature review so far has proved minimally helpful. The indication so far is that the condition progresses to CRF [chronic renal failure]. In any event, the degree of chronic interstitial damage would indicate that will be the case. I spent some time with Kevin's mother, biological father and stepfather explaining the chronic nature of Kevin's pathology and long term poor outlook with regard to declining renal function, dialysis and transplantation...*

She reported that she and her husband had read and re read such letters and even shown it to friends and relatives as a way of trying to explain exactly what the child's condition involved. This was an example of reification as previously described by Wenger (1998) in chapter 2. In this instance, therefore, the letter created a point of focus around which the negotiation of meaning became organised.

## Summary

Combined accounts created a rich description of the multiple and divergent trajectories that existed across the course of children's conditions. Generally, families' projected views of the disease course were more emotionally defined than the functional approach demonstrated by professionals. Family members' accounts of the uncertainty associated with the disease course plan were consistent with those described in the literature, for

instance by Mishel (1983). However, professional accounts of uncertainty over the disease course offer a valuable insight into the difficulties they can encounter in identifying a label for an unusual set of symptoms. This corresponds with Thorne's (1993) observation that patients are reassured by professionals who are comfortable admitting to the limits of medical science. The next section involves two Case accounts that help to illustrate different aspects of the category 'assessing'.

## **Cases**

### **David- 5 years old (High to low intervention)**

David lives with his mother, father and 10-year-old brother. He was transferred to the Children's Kidney Unit from the children's ward of his local District General Hospital because of a diagnosis of Henoch Schonlein Purpura that initially required high levels of intervention. He had a short history of pain and swelling of both hands and feet, a rash on his back and recurrent vomiting for which he had recently been an inpatient at the District General Hospital before a definitive diagnosis was made. On arrival at the Children's Kidney Unit, his parents were told that Henoch Schonlein Purpura was an allergic reaction to a viral infection that had involved his kidneys and would require him to have a kidney biopsy under general anaesthetic. The results of the biopsy indicated that David would need to begin a series of plasma exchange treatments that involved him having a central venous line inserted, under general anaesthetic, to facilitate plasma exchange. Initially he was treated as an inpatient but as he began to respond well to this he was discharged and returned daily for the treatment to be administered. In total, his plasma exchange lasted four weeks and he was discharged on oral antibiotics as prophylaxis with regular outpatient follow up arranged. David and his mother took part independently in interviews during the third week of the disease course. His mother subsequently took part in two further short telephone interviews.

#### *Assessing ability*

David's mother described her difficulty in getting an initial assessment for David when his symptoms first presented acutely. She contacted NHS Direct who advised her to contact the General Practitioner where the receptionist:

Mother: ...actually said it could just be a viral infection that was causing it but I just wasn't prepared to sit and wait-decided I couldn't wait for the General Practitioner and took him to [District General Hospital].



After being seen in the Accident and Emergency department at the District General Hospital he was admitted to the children's ward for investigation and observation. She was, however, very dissatisfied with the explanations she received from the District General Hospital:

Mother: We did a lot of research ourselves at home on the computer and found out quite a bit about what it was because we didn't have a clue what it was basically

She explained that she used 'Just Ask Jeeves' because:

Mother: ...the doctor down there didn't really know and everytime we asked him a question, he kept saying he would have to go and check on that so he wasn't really forthcoming with his answers...we actually found out more than they were telling us you know [from the internet], then we went to [Children's Kidney Unit] and the doctor explained that it's very, very rare.

Simultaneous with the transfer to the Children's Kidney Unit was a much more positive assessment of staff's ability that David's mother attributed to the fact that staff understood the condition and were able to provide structured information in an appropriate way:

Mother: I mean I talk to the Renal nurses.

Int: Do you find the language that they use is easy to understand? Does it need any translation at the beginning?

Mother: No, because they showed us a file as well on what the plasma exchange was all about and that was quite easy to understand as well.

Like other parents in this study, David's mother valued the opportunity to communicate information about David's condition and his treatment with friends and grandparents. In the same way that Kevin's mother in phase two adopted a role of learning ambassador with friends and family members, David's mother also took on this role once she has assessed the staff caring for her son as competent:

Mother: I mean, my mam has been up and seen him, my dad's been up and seen him, but I find it very hard to explain to other people exactly what we are going through.

Int: Which other people?

Mother: Just like my friends and what have you, because they are all dead interested and dead worried and that.

### *Assessing social positioning*

It was also common in the Cases for parents to explain how one of them took on the role of 'spokesperson' when communicating with professionals. This seemed to reflect the way in which professionals positioned parents and consequently this influenced the way in which family members chose to interact with them. David's mother explained that:

Mother: It was a lot to take in. A lot of the times I was asking my husband to speak to the doctor so that he could translate back to me...yes it's like everything, he deals with all the insurance policies and the mortgage and that, and he gets me to sign it and then tells me what it's all about.

When asked if she felt confident to tell professionals about the information she had obtained from the internet, she explained that her husband had told a doctor at the Children's Kidney Unit and that:

Mother: She was lovely, she said if we were reading and finding things out we shouldn't be afraid to mention it and that they were there if we wanted to discuss something with them.

Nevertheless, despite the open and interactive style of communication that the family encountered, the parents still felt unprepared for the full impact of the disease on the whole family.

### *Assessing disease course*

David's mother explained that she and her husband had not realised at the beginning how serious David's condition was and described how his brother had also been affected by the disease course:

Mother: I feel it has been a big upheaval to David's lifestyle and to all of our lifestyles, you know, because for the first week and a bit when he was in and out of hospital, when he had his line in on the Friday, we had to have our Nathan [David's brother] go and sleep at my mam's and my sister's – so he had to be out a lot, or if we were coming up to the hospital for 8 o'clock in the morning, Nathan had to be looked after by other people as well.

The impact of David's condition had far-reaching effects on his parents' working lives that they were unable to predict during the acute phase of his disease and so were only able to assess according to the daily fluctuations in his condition. His mother explained during the initial interview:

Mother: It's hard because I feel like, well, you see I work as well and I haven't been able to go back to work and now it's like next week [before the exchange is expected to finish] – well, that's another lot of time off, and it's not knowing when I am going to go back as well. Yes, they do understand but of course it's like everywhere, they are all short staffed and I have been off for four weeks and I don't know when I will be going back. But I need to go back. I don't get paid if I don't work.

David was due to return to school from hospital after his plasma exchange, for the first time since he became ill, on the afternoon of the first research interview. This was viewed as another upheaval in the family's life, but in particular her own:

Mother: I'll probably feel horrible when he goes to school because he has been with me for six weeks, so that'll be a bit of an upheaval, him going to school.

Nevertheless, in a subsequent interview, by which time David's condition was stable and requiring only occasional outpatient follow up, his mother reported that family life was back to its usual pattern and that David had not displayed any signs of anxiety or stress following the short disease course.

### **Kevin – 6 years old (Moderate to high intervention)**

Kevin was 6 years old when admitted to the Children's Kidney Unit with a condition requiring high intervention. He lives with his mother, stepfather, 4 year old sister and 11 year old step-sister. He was admitted from a local District General Hospital in February 2003 with a four month history of wetting and drinking a lot. He was found to have abnormalities in his blood tests and his urine indicating that he had a heavy loss of various chemicals and protein in his urine. A subsequent kidney biopsy showed severe abnormalities and because of this he commenced a six-month course of immunosuppressant therapy that was given intravenously, on an outpatient basis, once a

month for six months and combined with oral steroid treatment. He tolerated the treatment extremely well and did not suffer from any of the distressing side effects, such as hair loss, that are extremely common. Because of his good response to treatment, it was agreed with his parents that a further kidney biopsy would not be performed unless or until his clinical condition warranted it. Kevin's mother and stepfather were involved in discussions with the nephrologists and they, as well as the General Practitioner, also received detailed written summaries of these discussions. By the end of the data collection period, however, Kevin's condition had moved through a stable phase and into a more acute, downward phase where his kidney function had deteriorated to the extent where he was being considered and assessed for dialysis/transplantation.

### *Assessing ability*

Throughout the study, Kevin's mother's and stepfather's accounts fluctuated between uncertainty, confusion and renewed clarity. At each interview, there were comments about the difficulties they encountered in communicating with staff and the influence this had on the way they assessed the ability of staff. Throughout the disease course, Kevin and his parents and sisters had come into contact with a wide range of health care settings and services that meant that they encountered many different professionals in different organisations. Rather than enabling them to become experts in communicating with professionals, as was the situation for families in the other Cases, this seemed to make a significant difference to them in a negative direction. They placed emphasis on the fact that they believed the ward to be 'short staffed' as the following discussion between them explains:

Mother: There is not enough people there. On [ward] when we were in, there was about five tiny babies, and all the nurses seemed to be up there looking after these tiny babies but forgetting about all the other kids on the ward.

Stepfather: I mean, I must admit, it wasn't just their fault, they had the babies there...

Mother: I mean, I don't leave him in hospital [meaning she or her husband always stay with him], but then you have got these babies who are only weeks old and their mams don't stay in with them, so obviously you don't have to stay in, but they [nurses] make you feel that you have to, because I don't want him sitting by himself all day. I mean, you have like your nursery nurse or whatever on the ward, but it is just that ward, there is machinery beeping for a good 20 or 25 minutes and nobody will come.

*Assessing social positioning*

Both parents appeared to believe they were powerless to influence the way that they perceived themselves to be positioned by professionals. For example, being asked questions about Kevin's current medication was viewed as a test of their own ability by the professionals as well as causing them to question the professionals' ability and so such questions were viewed with suspicion, as the following quote from his mother explains:

Mother But that is the stupid thing, every month we go, and obviously he [stepfather] can't take time off work all the time, so I go and they ask things like 'What medication is he on now?', and I feel like saying that I am his mam not his nurse, why don't they read his notes? It is all clearly written in his notes, but we see a different doctor every time we go.

Apparently, this lack of clarity about the role of parents in the child's care was never formally discussed with Kevin's parents, so they waited for professionals to explain what was expected of them. It was as though they had commenced a new job but had not been told what the job entailed or what their role would involve. This is similar to the situation identified by Spouse (2003) when investigating the way student nurses adapted (or not) to different clinical placements. Spouse recognised that for people who are learning new skills, the task becomes almost insurmountable unless they receive some sort of social support or sponsorship. Although Kevin's mother had, in an earlier interview, acknowledged that a nurse had offered her support, including an invitation to make telephone contact if necessary, she did not feel sufficiently integrated into the health care community to do this. Because of this, both parents believed themselves to be isolated, as the following quote from his stepfather describes:

Mother: We won't rely on anybody else except ourselves [in the health care setting].

When, during the final research interview, they were asked why they thought they felt this way about relationships with health care professionals, Kevin's mother said:

Mother: I was in hospital all the time with my dad when he was poorly and I just don't like hospitals. It's just the fact that you get ignored and it seems to be the same in every hospital.

The difficulty in being able to communicate effectively with staff meant they were unable to determine what their identity was in this 'community of practice' and this in turn

impinged on their ability to negotiate a place that would enable them to fully participate in Kevin's care. They believed themselves to be 'outsiders':

Mother: Things with some of the nurses still haven't improved, we are still just faces with no names, nobody asked if we wanted lunch, the only time you see a nurse is when his drip beeps.

Stepfather: They were understaffed before when we were in there, but the newborn babies were just left, but their parents weren't there. The nurses have them to look after and they are trying to run around doing other people's obs [observations], do you know what I mean?

### *Assessing disease course*

Initially Kevin was reported by his mother to cope extremely well with everything and she recorded in her research diary "*Kevin doesn't seem to have noticed any difference yet (thank God)*". Uncertainty was, however, a major perceptual variable with both his mother and stepfather as they tried to understand the complexities of his condition and the various aspects of his treatment. Practical issues were uppermost in his mothers' accounts as she described his various trips to hospital. The following excerpt from her diary is typical of the difficulties she also often identified and articulated during interviews:

Mother: He has been in for the second dose of treatment. We were told to be there for 9 o'clock, we were and were still waiting at 10:40, as if the day isn't long enough. The doctor came and took blood, only to return five minutes later to say 'Sorry we didn't need it, took it the other day' - makes me wonder what kind of job they are doing.

## **Conclusion**

Assessment was ongoing and the main areas of assessment relating to ability, social positioning and disease course were pervasive aspects of the accounts of professionals and family members. Professionals' positions afforded them authority to be overt in their assessments, family members, however, were usually more discrete in the way they performed assessments. Although the process of assessing continued throughout the disease course, as family members became more autonomous, the way they assessed personnel and situations became more sophisticated. The two Cases have helped to illustrate the ways in which two families whose children required moderate to high and high to low levels of intervention articulated the process of assessment.

## **Chapter 6 – Interacting in Chronic Disease Management**

Participants' accounts highlighted the important but sometimes challenging issues of sharing personal and professional knowledge, trying to foster mutual trust and the significance of these concepts in respect of shared decision-making. In this chapter, the interrelated concepts of 'lay and professional knowledge and expertise', 'trust' and 'decision making' within the category of 'interacting' will be addressed from the perspective of families and professionals. There is a growing need in child health for families and professionals to become co-participants in the child's care. This will help to ensure they gain sufficient mutual understanding, thus maximising the benefit to the child (Wallander, 1996; Callery, 1997b; Knafl and Gilliss, 2002). Later in the chapter, two further Cases from phase two will be presented and discussed in relation to the category 'interacting'. These help to illustrate the significance of interaction in the social theory of learning in childhood chronic renal disease. Finally, conclusions will be drawn about the main emergent issues.

### ***Sharing knowledge and expertise***

#### **Vicarious lay expertise**

Ultimately, families viewed the professionals as the experts in the management of chronic renal problems and themselves as experts in knowing themselves and their child. The following quote from Leslie's father (phase one) is typical of the comments from families in phase one and phase two:

Father: The doctors and nurses know all about his kidney problems and medicines and that, they are the knowledgeable ones in that respect.

Similarly, professionals regarded themselves as experts regarding the management of conditions while conceding that over time families acquired a type of 'vicarious expertise'. This exemplifies the importance of a partnership approach to the child's management. For families to cope with the consequences of the condition at home there was usually a minimum level of knowledge and technical skill required. This is likely to vary according to the nature of the condition and the level of intervention required. As discussed in the previous chapter in relation to 'assessing ability' this process takes '*as long as it takes*' and is indicative of the individualised approach to teaching and learning that is adopted by the renal team. Nurses demonstrated through their accounts that although they take responsibility for identifying the teaching objectives and establishing

priorities, parents are encouraged to participate in this goal setting process. In contrast, traditional views of health care relationships are based on the premise that the professional is the expert, the health care system is the legitimate gatekeeper and that the ideal patient is compliant and self reliant (Thorne, Nyhlin and Paterson, 2000).

The following quote from a nurse refers to Carol, a 15-year-old girl whose chronic condition requires high levels of intervention at home. This helps to illustrate the level of negotiated teaching and learning that may be needed before such a family can begin to develop vicarious expertise:

Nurse: ...so her mam needs to know everything there is possibly to know about PD [peritoneal dialysis] to look after her at home...and she would be allocated one person primarily to do that [teach her], ...then they would have this sit-down session where I would go through all of the problems, all of the pitfalls, so they know that they can do it by then, and then there's the problem session. That doesn't mean that you are going to have problems, but people can't go home unless they know about the potential problems and that [learning activity] lasts a very long time, and in some families it can last weeks.

Thus, an informal and individualised curriculum is created by professionals for each child that in part is built upon the earlier mutual assessments of knowledge and expertise.

### **Unarticulated knowledge**

Nevertheless, despite this mutual acknowledgement of expertise, there were some reports of dissent between parents and professionals because of their different perspectives. Early in phase two, parents in two of the Cases alluded to difficulties they encountered when their own and professionals' viewpoints about what was best for the child collided. This is consistent with earlier findings reported by Callery (1997b) who reported conflicts between the different nature of maternal and professional knowledge. In the current study, these situations were aggravated by the parent's reported difficulty in satisfactorily engaging the attention of professionals when the parent was concerned about a subtle change in their child's behaviour. These comments arose unsolicited during the first interview with both sets of parents and the issue was later raised by me in subsequent interviews with these parents. This helped to determine whether or not there was any change in the way they managed similar situations, across the disease course.

An example of this phenomenon (identified as 'unarticulated knowledge' in the open coding stage of analysis in phase one) was described by Kevin's parents (phase two) during the first interview when recalling times of stress in the management of the



condition. They described a situation very early in the disease course, just after Kevin returned from theatre having had a minor operation under general anaesthetic. The research interview appeared to act as a catalyst for an interesting 'live analysis' of the situation by Kevin's parents. On entry to this topic both parents initially appeared to forget I was there as they jointly recalled the circumstances surrounding this immediate post-operative period.

Subsequently they returned their attention to me briefly, as though to acknowledge my presence and include me in their shared account. For the next ten minutes or so, I was an observer to their interaction as well as an impartial participant in the discussion, simply using occasional prompts or questions to focus the discussion or seek clarification. The discourse focussed initially on the fact that personal knowledge of Kevin came from their familiarity with him but that they found it difficult to articulate that knowledge to professionals in a meaningful way. The professional's lack of knowledge of Kevin was perceived as a barrier to communication by his stepfather:

Stepfather: I mean, you can tell somebody what your child is like or what to expect, but until you [meaning the professionals] have spent some time with him [exasperated shrug and facial expression indicating the difficulty for an unfamiliar person to understand Kevin], you [parents] can't come across [in explaining Kevin to professionals] as well as what you would think you do.

His mother reinforced this frustration about an inability to communicate effectively on behalf of Kevin, as if to emphasise the real difficulty involved in processing information and giving that information to professionals who do not know the child. This is similar to the concept of tacit knowledge described by Polanyi (1967:4) who observed that 'we know more than we can tell'. This term has been used widely in nursing to describe the tacit understanding a nurse may hold of a patient in their care, when they know that the patient's condition has changed in subtle ways but cannot find the language (or articulate the underpinning knowledge) to express this. However, there is a subtle difference between these parents' accounts and the definition of tacit knowledge.

At this stage in the disease course, Kevin's parents were still novices in the socialised learning process and so had used their own language to explain his needs to the nurse. The nurse was a ward-based nurse who they had not met before. Nevertheless, this remained 'unarticulated knowledge' as their use of language was so different to that of nurses. The following quote from Kevin's mother (phase two) illustrates this anxiety, an

issue that is also raised in other studies of childhood chronic disease (Mishel, 1983; Cohen, 1997):

Mother: No, because when Kevin had had his biopsy done, he was lying up to me, clinging to me because he wasn't very well, and the nurse came over and said 'Well, it is better if he just lies on his back and I thought 'He wants a bloody cuddle, for God's sake!' and fair do's, he is supposed to lie on his back, but he was feeling sick and his tummy hurts and all he wants is a cuddle from his mam.

The essence of this conversation corresponds in part with Callery's observation (1997b) that subtle changes in a child's behaviour went unrecognised by professionals but were reported as significant by mothers. The difference with this mother's account was she had 'thought' about what she believed he wanted but had not tried to express her thoughts to the nurse. Unfortunately, I was unable to obtain the views of this ward-based nurse to compare her account with that of the parents.

At this point in the interview, silence ensued for a few minutes while Kevin's parents reflected on what they had just said to each other and to me. Talking reflectively in this way about the event and their responses to it appeared to enable them both to begin making sense of the situation they were describing. This is consistent with the concept of 'peer support in sense-making' described by Spouse (2003) in which student nurses found it helpful to share experiences with nursing colleagues. Through discussing their daily experiences, nurses are able to develop a collective understanding. Spouse suggests that the storyteller is able to develop new insights to the situation arising from the suggestions and sense-making activities of their friends. In the same way, Kevin's parents appeared to be gaining peer support through the telling of the story. As a result, they developed new insights into a situation that had happened earlier, but which they had not previously reflected upon together. This led to further reflective discussion between the parents:

Mother: ... Oh, that was it...I took his gown off and she [the nurse] wasn't happy about that, either, but he had this crappy gown on and was showing off his bum so I thought I would just put his pyjama top on...he was starting to pull himself round, and he didn't have any pants on and his legs were all over the place, and I thought I know he is only five but....

Stepfather Interrupts: ...even when he pulled himself round, he wanted to be up – I mean, you went in and tried to explain [to the nurse] about Kevin, Kevin doesn't sit still, he never does ...Oh he is all over the place and they were telling him to sit down or lie down – you can tell him until he is blue in the face, he is not going to - but it just doesn't sink in [with the nurse].

Mother: *And because they think they know best, but I know Kevin best!*

This was also an example of the way in which we co-constructed meaning from the research data and is entirely consistent with the constructivist approach to data analysis. For families, in particular parents, unarticulated knowledge was a factor that had a negative impact on the ability to successfully interact with professionals on behalf of their child. The next section reports and considers some of the strategies adopted by family members to promote effective skills of articulation.

### **Families learning to articulate effectively**

In a later interview, Kevin's parents' accounts indicated that a transition had taken place in their attitude towards expertise. Analysis of the data uncovered a state of guarded alliance in which a measure of trust was constructed by his parents on the basis of new insights about the health care system and the realities of living with chronic disease. This concurred with an analysis proposed by Thorne and Robinson (1988) who conceptualised the process of developing relationships across the disease course as one involving naïve trust, disenchantment and guarded alliance. Of particular significance to this study, however, was the fact that interaction was a significant aspect of this new state of trust demonstrated by Kevin's parents.

Other families in this study found this process of empowerment happened quickly and reasonably effortlessly. Kevin's parents, however, reported how they had struggled initially until eventually they learnt to jointly initiate changes in their interactions with professionals. His stepfather explained further:

Stepfather: Well it did end up...sort of [us all] getting on alright, if you know what I mean. They understood what we were thinking, and I mean it took – well not exactly a stand-up argument but a major discussion, with me losing my temper. But I mean after that, everything calmed down and everything was going okay, do you know what I mean? Conversations were alright and they seemed to get on alright with us...It seemed like we had to fetch it to a point.

Following this final research interview, Kevin's mother volunteered the information that she had a tremendous fear of hospitals and health care professionals ever since she was much younger. She associates this with memories of her father having been in hospital when she was much younger and the family having a *terrible, terrible time with everyone*. She did not want to discuss this further but said that whenever possible she does not go to the hospital with Kevin but prefers her husband to go with him. It is,

therefore, possible to speculate that this mother's previously undisclosed anxiety about hospitals had contributed to the difficulty the family encountered during interactions with professionals. Kevin's parents were also at pains to point out that their own expertise was related to 'knowing their own child' but that they did not believe themselves to be experts in the sense of 'professional expertise', in particular where treatment regimes and plans changed regularly, often in response to results from investigations:

Mother: ... because they [professionals] are all so qualified as well and I am just Kevin's mum...

Int: Do you feel like that?

Mother: Yes, I am just Kevin's mum...they are the experts.

Stepfather: They are **the** experts, yes.

Therefore, these parents did not regard their personal knowledge of Kevin as expertise although other parents believed themselves to be experts regarding their own child. For instance, the following quote from Ann's mother (phase one) talked of her daughter's ability to deal with the consequences of a moderate intervention condition:

Mother: I know Ann and knew she wouldn't be able to take that foul tasting medicine so I told them [professionals] and fortunately a student in pharmacy came up with a powder version of it - they realised I was the one who knows best how she will react. Because [doctor] says 'You know your child best, so if you think she's not right, you must tell us'

In addition, and as is consistent with the grounded theory approach to data collection and analysis, the topic of lay and professional knowledge was consciously raised by me during future interviews with the remaining families in the study. In all instances there was some degree of improvement reported in the way children and/or parents became more confident and pro-active in their intention to share their personal knowledge with professionals as they moved through the disease course. This is consistent with the concept of participatory competence described by Gibson (1995) and in particular the ability to take charge and to hold on to this sense of ownership of the situation. However, the findings of this study emphasise the importance of interpersonal (intermental) learning by families in the process of empowerment that contradicts Gibson's finding that the process of empowerment in mothers was largely intrapersonal or intramental.

## Summary

Families and professionals agreed that the professionals were experts initially about the condition whilst families were lay experts in relation to the child's personality and personal world. As the disease course proceeded though, families too became experts, vicarious experts, often needing to manage very complex aspects of care at home. Despite this, there were examples of parents experiencing difficulty in articulating their private knowledge to professionals, even later in the disease course. A form of peer support through parents reflecting on situations together was seen to facilitate new insights that served to help family members make a transition into a state of participatory competence.

## Trust

The previous section explored the fact that all family members and professionals involved in the health care partnership possess different types of knowledge and as a result hold differing interpretations of each other. This section focuses analysis on the issue of 'trust' and the two central and related themes of 'earning trust', and 'maintaining trust'. In childhood chronic disease it is important that those involved feel able to trust each other (Dibben and Lean, 2003). Recognition of differing mutual interpretations has been found to contribute to trusting relationships (Sartain *et al.*, 2000).

## Earning trust

Professionals' relationships with families can span many years but the first encounters often coincide with a need for intrusive and potentially distressing investigations or procedures such as venepuncture, gastrostomy feeding and insertion of nasogastric tubes. For professionals in this study, earning the trust of children and families would have been much easier if it were not necessary to carry out such painful and frightening procedures, this is articulated clearly by the following quote from a nurse:

Nurse: Well...there are so many upsetting things we need to do to children and that they have to get used to for their own benefit, it can be difficult for everyone, but we try to make it as stress-free as possible.

The way staff approach children and parents at such times is a very important contributory factor towards a trusting relationship as Eric's mother (phase two) explained:

Mother: ... both at [local hospital] and at [regional centre] they were all very child friendly and explained what they were doing and everything, there were no problems there, it was fine

In the same way, professionals believed it was important to be honest with children and families about possible side effects of treatment, for instance if there was a possibility that a particular medication could lead to hair loss:

Nurse: ...because they would never trust you again if their hair fell out and you had never told them.

This honesty was generally valued highly by families. Nevertheless, other factors can be equally important and can either contribute to or detract from the formation of a trusting relationship. These factors can include the way information is provided, as David's mother (phase two) explained:

Mother: So the nurses tend to translate the jargon for me so I know just what the doctors mean - the nurses are like friends really.

Nina (phase two) also discussed this:

Nina: Because with [doctor] I feel that they are on the same level as me and will talk to me as if I am an adult but also as a child – won't use big long words that I probably wouldn't understand and terms that I won't understand

In addition this can include the use of technology that has been adapted for use with young children. Eric's mother recalled how his first dimercapto succinic acid scan at a local hospital had been unsuccessful and left him very distressed and unhappy about going for subsequent investigation attempts. As a result he did not trust anyone in this hospital or the regional one when he was eventually transferred there for investigation and treatment:

Mother: ...so, they can actually get a line in if they can find a vein to put the dye in for the scan, and that is the awful part, that is the bit that it looks like it is going to hurt even if it isn't– they tried it the first time and ended up going through another place [vein]... there were more people to actually to get it put in because he actually needed to be held down by several people...and they couldn't get it in, and they actually had it done three times in the end because we have been back on three occasions

Int: Without it being successful?

Mother: Well, the first time...[after injecting the dye he had a scan of the kidneys] I wasn't allowed to hold him down so he was moving about but they said they would rather that than he got really upset – it went fine, he tried to move about but that was fine and when I got the results about a few weeks later in a letter, it said it showed that there were problems..., but it [scan] wasn't totally clear ...because he had moved about – the letter said he struggled too much, which in fact he hadn't, he had just moved about because no-one had been holding him still.

A further scan failed, however:

Mother: ...because the dye went into his arms and when they got the scan back there were three images, one of them being his arm, so that was the whole day sort of wasted really. It was at that point that they moved us over to [regional centre].

At the regional centre where the Children's Kidney Unit is situated, a different technique was used and resulted in a successful procedure:

Mother: Whereas before they sat him on your lap and he could see what was going on [to inject the dye], they actually insisted that he sat facing me while he had his arm behind him, which is a really good idea, but no-one had suggested that in [local hospital], so that was one of the things that might have made it slightly better from Eric's point of view. They said 'Have you actually had anaesthetic on his hand?' because his reaction was so bad just having the needle going in... when we had the scan done itself there was actually a chair with a harness, which again he didn't like, but it was a lot easier and they were able to hold his hand and that sort of thing, and I actually asked if they were getting a clear picture because I really didn't want it to go wrong for a third time, and they were able to confirm that they had got perfect pictures, so we knew then almost for sure that we were going to get a proper result this time

This in turn led to an increase in the level of trust experienced by this mother although her son still appeared mistrustful of professionals he subsequently encountered. In the final interview, Eric's mother recalled how he had been very reluctant to communicate with any health care staff when he was eventually admitted to a surgical ward for major surgery on his renal tract:

Mother: ...even though the nurses came in and chatted to him and tried to get to know him when they had time, he just didn't want to know. The trouble is they are so busy that usually they can only get in when they need to do something to him, something unpleasant like his dressing or blood pressure

Recognition of the fact that professional's trustworthiness comprised a combination of competence and communication skills (Thorne, 1993) was, therefore, borne out by the findings of the current study. In this study, children and parents were also aware of the

need to earn the trust of the staff caring for them. This reciprocal trusting was seen as an important part of the process by which they themselves could practice skills independently and so be judged competent by professionals to 'fly solo' with aspects of their management. Spouse (2003) exemplifies this view in relation to student nurses learning on practice placements, where a secure bond of trust was important in enabling students to undertake difficult techniques in the presence of the mentor and later be encouraged by the mentor to practice that skill independently. In addition, in the present study the level of trust parents could earn from staff would be a determining factor in the decision about when they could be discharged on self managed treatment such as peritoneal dialysis, fluid and dietary monitoring and central line care as demonstrated in the following discussion between Carol and her mother (phase two):

Carol: Like when I first went in they were strict with me, with my fluid and everything – if I went over even by a ml or something they said I had to keep within the limit, but then once...

Mother: ...I think once they get to know you, and they know what you are like and you get to know what they are like, it's [mutual trust] alright really.

In some families, the need to feel trusted by professionals was reinforced by the 'hero worship' and 'team playing' dimensions also described by Thorne (1993). In the current study, many family members demonstrated these dimensions during a phase of guarded alliance while speculating whether they themselves were recipients of the trust of professionals. In Thorne's study, these dimensions were embodied in the accounts of participants in whom naïve trust in health professionals had been shattered and so they were seeking someone in whom to place their trust. In this study, this notion of 'hero worship' was embodied in accounts such as the following excerpt from an interview with Carol and her mother (phase two):

Mother: Yes I mean [the nurses] I would say, I feel they are part of our family because they are an important part of it really, you know, because you go to them for advice and they will come back and tell you what is going to happen or they will get together and talk about it and come back and suggest I do things another way or whatever... Yes, they are like friends, as Carol says, she just treats them as her friends really.

Carol: Yes, because you know them all, don't you, when you go on the ward, it's awful when you go on and you don't know anybody.

Mother: I mean, I don't know if they think the same way about us, but yes, they are like friends, as Carol says, she just treats them as her friends really - we treat them as part of our family.



Int: So do you ever feel part of the team then?

Mother: Oh yes, that's it isn't it, I think eventually we do feel like one of them in a way.

Carol: Yeah, part of the team like, you know.

Earning trust was, therefore, recognised as an important part of interaction both by families and professionals. This is also an example of the way in which knowledge was co-constructed during a research interview in this study.

### **Maintaining trust**

Once established, trust remained fragile, however. Having developed a successful strategy for managing their child's condition at home, subsequent hospital admissions often led to parents challenging aspects of the professional power base inherent in the ward culture. This was evident in the accounts of parents in two Cases in the final interview. Significantly, four of the mothers in phase one also recalled how, as their child's disease course had progressed into a stable phase, their own self confidence about managing the condition had escalated. As a result, any new encounters with the health care system, such as their child's admission to hospital, led to the parents re-evaluating their previously held views about the expertise of staff. For instance, there were limits to the extent to which parents in particular would rely on staff to carry out aspects of care that they themselves had become expert in delivering at home.

Thus, the increasing self-confidence that some parents acquired in managing aspects of care, such as giving medications at the most appropriate times, led to a simultaneous decline in the level of trust they would invest in professionals. For instance, Ann (phase one) had been readmitted for further investigations after having been diagnosed three years previously with a condition involving her in taking medication at regular intervals. After much trial and error and discussion with doctors, Ann's mother had concluded that her daughter would receive optimum benefit from the medication if a dose was taken during the night. This then was part of the usual family routine at home and involved her mother setting the alarm clock for 3am so that she could wake and help Ann to take the medication.

During a routine admission to hospital the medication was, according to the usual hospital practice, taken away by the nurse and stored in the ward medicine trolley. The responsibility for drug administration was, therefore, taken away from Ann's mother by

the nursing staff. They informed her that the doctor would have to prescribe all Ann's medications using an inpatient prescription sheet and that the nurse in charge of Ann's care at each shift would administer the medications. During the research interview she explained how she felt about the system in which her control over administration of Ann's medication was taken from her because they were in a hospital setting:

Mother: I'd be happier just keeping the medication myself and just giving her it when I know, because I know when to give it and I don't trust anyone as much as I trust myself to do it...even the nursing staff, you know, obviously they're great. But they don't do it every night like I do, you know

Int: No. So do they let you do that? Or do you have to hand it over to them?

Mother: No, most of the time they prefer us to hand it over.

Int: What happens if, say, it doesn't turn up at three o'clock in the morning?

Mother: I go looking for it.

Int: Right. And have there ever been any problems with that?

Mother: No, no, well I know them all on the ward and get on great with the nurses, they don't change much, so we know them well.

Through experience that was built on the confidence of knowing what was best for her child, this mother had developed a strategy to promote adherence to her daughter's treatment protocol. This is consistent with the Self Regulation Model of adherence promoted by Leventhal (1993) who reviewed existing models of compliance and adherence as a basis for developing a self-regulation model that offers a lifespan perspective in which *necessities* (acts that one must do) are converted into *preferences* (acts that one wishes to do). Thus, acknowledgement by Ann's mother that she doesn't trust the nurses as much as herself in this respect is tempered by the confidence to negotiate with the nurses for a change to their planned care of her daughter while maintaining a good relationship with the nurses.

## Summary

The need to earn and maintain trust was an important aspect of the process of interaction. The emphasis in this section has been on reciprocity of trust and generally,

honesty was pivotal in this process. Paradoxically, the intrusiveness of clinical interventions appeared to increase trusting relationships rather than decrease them. Trust was, therefore, seen to be the cornerstone of relationships between children, parents and professionals.

### ***Decision-making***

In the current study, it was clear that staff played a critical role in mediating family participation in decision-making. Mutual acknowledgement of expertise and the existence of trusting relationships were found to have a positive influence on families' participation in decision-making. The better-informed family members believed themselves to be, the more likely it was that they felt empowered to take part in decision making. The degree to which a family believed themselves to be 'uninformed' did not necessarily correspond, however, with professionals' verbal accounts and written reports of information giving. If children and/or their parents trusted and felt trusted by professionals, then decision-making was regarded as a collective enterprise. However, if a trusting relationship with professionals was not reported by the family (as was the situation in Kevin's Case) then decision-making was sometimes challenging for those concerned. Accounts fell into three categories regarding the issue of decision-making: intuition, autonomy and negotiation.

In order to feel confident enough to participate meaningfully in decision-making, children and families, therefore, demonstrated a need for a good working knowledge of the condition, its consequences and the prevailing concept of family centred care. It has for a long time been recognised that the negotiation of the level of mothers and more recently both parents' involvement, is a core component of partnership approaches to care (Spence, 1947; Smith, 1995). To minimise parental feelings of helplessness and inadequacy if the initial phase of a child's disease course requires intensive care in hospital, Rolland (1994) urges clinicians to include parents in the care giving process. Additionally, UNICEF (1989) state that any child has a right to express an opinion and to have that opinion taken into account in any matter or procedure affecting them. This is increasingly epitomised in the way care decisions are made in childhood chronic disease (Lowe, 1996). In the same way that staff in this current study played a key role in mediating participants' involvement in decision making, so too were parent/child/staff relationships significant in the way participants learned to use their intuition about health care situations.

## Intuition

In phase two. Lucy's mother first learned of Lucy's renal problem when she was pregnant. The obstetrician at her local hospital had raised early concerns in the 16<sup>th</sup> week of pregnancy; so she was referred to the regional centre for a more detailed scan. The results of the scan led to her being introduced to a paediatric nephrologist who told her that it was 99% likely her baby had an extremely rare kidney problem:

Mother: apparently from the kidneys it can spread up the spine, they told me that when she was born she would lose a huge amount of protein through holes in her kidney so she would have to have protein put back into her to keep it topped up – they call it albumen, so she would be on quite a few medicines, be in hospital for her first year and then when she was about four or five she would have her kidney taken out and she would have to have a transplant.

So me and my mam were sat there, and basically my jaw was just about touching the floor, so he asked me to make a decision whether I wanted to go through with this or whether I wanted to terminate the pregnancy. He didn't put any pressure on me but he told me they were my options – so I went away to decide and I am from a really close family, my mam lives four doors away from me, so I thought 'She is not mentally handicapped, she is not physically handicapped, she has got all her limbs', I felt her kicking and she felt part of me then, so I decided I would get through with this.

Intuition was also an issue that influenced decisions made by professionals. For instance, a nurse explained her 'hunch' that one of the children at home was not being given his twice weekly injections of erythropoietin by his mother as had previously been arranged (a hormone that helps to prevent children with chronic renal failure from becoming anaemic). Historically, a lot of renal children would have regular blood transfusions to treat the associated anaemia but since the advent of erythropoietin, renal patients don't usually need blood transfusions any more. This, therefore, reduces the associated risks:

Nurse So one little injection, twice a week sounds wonderful [as an alternative to blood transfusions] and it is wonderful, but at the end of the day, if you have got to give it to your own four year old child

The nurse described how she was alerted to the possibility that he may not be receiving his erythropoietin because of the results of blood tests and because she knows the little boy often struggles with the injection. During a visit to the family at home, she administered the injection herself:

Nurse: Only last night I was the baddie and I had to give it, because Mum is having a few problems, because he knows what it is and he struggles, it takes seconds to do but it took about ten or fifteen minutes...he had been at home for two or three months and only now we are looking at blood results and, we don't think he is getting it as often, and I think it is purely because it is a bit of a battle, only once a week, so he is probably only getting it about every ten days because she keeps putting it off, you know 'Oh, I'll do it tomorrow', which you can understand.

Int: Is that something that the Mum has said to you, or is it just something you are just judging from the results?

Nurse: Well I am sort of judging from the results and the fact that I said 'Oh go and get the pen and I'll have a look' and there was an empty cartridge in the pen and it was such a struggle so I don't blame her, you know – you can understand her thinking 'Oh, he's settled now, I'll do it tomorrow' and she sort of half admitted that maybe she doesn't always do it on a Friday, and then he has Saturday night off his dialysis, so you can easily imagine her not doing anything on Saturday – it is completely understandable, but it is also important.

As a result, the nurse arranged for community nurses to visit to administer the injection:

Nurse: One of the things that we have done with parents is to have community nurses going in to do that, maybe once or twice a week.

Finally, there were examples of children taking responsibility for their own condition and making judgements about the possible cause of changes to their condition. Leslie (phase one) described how he had come to know intuitively that his renal problem had returned when his regular urine checks showed that he had blood in his urine, even though he had been at home with no symptoms for several months:

Leslie: First of all you, aren't sure if its back but then you develop an instinct...well it just comes natural type of thing, you look and you think Oh, Oh we'd better get to the hospital, you know? we ring them up and tell them we're on the way and things like that, I say Mam, there's something wrong with me kidney.. if it's [test for blood in urine] still four pluses, we'll get in touch and say 'Look it's four pluses' [the result shown on the urine testing stick that indicates a high level of blood is present in the urine]

This account, therefore, suggests that David and his parents knew intuitively that his condition had returned and they were sufficiently empowered to act autonomously.

## **Autonomy**

By comparing accounts of professionals, children and parents it emerged that in practice there may be a tension between the need to recognise and respect the child's right to autonomous decision-making and the need to protect the child's right to optimum and

often life saving care and treatment. It was clearly necessary that professionals initiated discussions about investigations, technical aspects of care and administration of medication. Where possible, however, children were supported to manage aspects of their care if that was their preferred option. For instance, in the following account, Carol (phase two) explained what was involved in caring for her central venous line:

Carol: ...it is not just mam who has had to learn stuff, I had to as well. I had to learn how to clean my dressings [central venous line] and everything because it is not just like going into the shower and getting your sponge and wash it – you can't do that, you have got to go into the shower and get washed, and then come out, take the dressing off that is on it now, and then clean around it with this brown stuff and try and take the little scabby bits off, and then once that is all clean and everything, you go back in the shower and clean that off and dry it with like gauze because you can't dry it with the towel in case there is any little infections living on the towel – you don't know they will harm you but it might harm my leg, and then the gauze and everything, if you drop one, you cannot pick it up again – even if it fell on the floor and you know there is nothing wrong with it – you cannot pick it up.

Int: Why is that?

Carol: Because of all of the germs on the floor, because if you went to pick that up and washed your site, because it is right where it goes into your skin and it [germs] could get sucked in and you could get peritonitis

Despite all of these risks (or maybe because of them), Carol decided to do the dressing herself because *It is mine really, isn't it – it's on my body so I said I wanted to do it.*

Most options available to children were less likely to be about whether or not a certain procedure or treatment actually took place than about the circumstances in which it took place (venue, time, approach). There were many examples in the different data sources of adults listening to children to determine what their views and preferences were. There were examples in which children were seen to participate in decision making and achieve an outcome that was based on their finding a satisfactory balance between the *necessities* and *preferences* as discussed in the previous section. Sometimes children, parents and professionals had lengthy discussions about the possible options available to combine *preferences* with *necessities* before a decision was made. In these circumstances, decisions were negotiated as well as often autonomous. These were examples of the consumer model of partnership portrayed by Cunningham and Davis (1985) and discussed in chapter 2 (see page 21) .

## Negotiation

Although negotiation is a recurring theme in relation to family centred care, it is not clear whether negotiation is always attempted by professionals (Callery and Smith, 1991; Hutchfield, 1999). In the current study, however, there were several examples of decision-making that followed a negotiated process. For instance, Carol (phase two) and her mother described the difficulty associated with meeting Carol's nutritional requirements when she was discharged home with a nasogastric tube in place. The following account by her mother appears typical of the approach often adopted by the renal team in trying to help the child and family participate in the decision making process:

Mother: [The nurse] went to school to explain what was wrong with her [Carol], because first of all she had a nasal tube, feeding her, but she didn't take to that very well and it was making her sick all the time – it [the feed] was vanilla, and she doesn't like vanilla things, it was horrible and she was sick all the time and then she went on [another flavour] but she didn't really take to that either, so every time she was sick

Meanwhile, a renal nurse, in one of her own interview accounts, explained that she goes out to all the schools concerned so that every child who has a condition that may affect them at school gets a school visit at diagnosis, at change of treatment and change of school. This involves the nurse in speaking to whoever the school identifies as the most relevant person. It might be a helper, a nursery nurse, the headteacher or the school nurses but primarily it involves the person who the school identifies as the person with the day to day contact with the child:

Nurse: Contact with school is very important. I talked to her [Carol's] head of year or the tutor...discussed at length about her medical condition and explained about her treatment and the things in particular that might effect her at school, such as the nasogastric tube. Yes, I mean if kids have got a tube coming out of their belly and they are wanting them to do PE, they [school] are a bit scared that they are going to do something wrong....and [dietician] just had a word with her [Carol] and then she gave her some Duocal [high calorie drink] which she mixed in with milk to give her some calories.

The dietician corroborated this description:

Dietician: What I did with Carol – her mum had her on a great diet, she was on a lovely diet, you know, avocados and prawns and all sorts, so in order to get her to eat it, you know, nothing in the written information had enough of the food she liked to eat, so we did potassium exchanges, so instead – if she missed potatoes out of the meal, she would have this much avocado, because she is so anorexic and she loved the avocado, so we tried to help her have what she likes [while maintaining her nutritional needs]

Below is a memo recorded by me after interviewing the dietician which helps to explain the way in which I used memos and the Conditional. Consequential Matrix (Figure 14) in arriving at the category Interacting and the sub-category of negotiation:

**Memo relating to an interview with the dietician:**

The process of negotiation is implicit in this discussion - interaction is coming through as an essential part of the learning process, this interaction is not implicit in other reported accounts of learning by families in which there seems to be an emphasis on learning being one-way although there is much discussion about negotiation taking place...but not in relation to family learning (eg Newton 2000), mainly about professional learning (eg Eraut 1998). **But**, what is coming through here is the explicit efforts on the part of professionals, as described here by the dietician, to recognise and respond to the learning needs of families by moving through a process of decision making to encouraging autonomy in families, to families actually becoming autonomous. The Conditional Consequential Matrix (Figure 14) helps to explain how, as Strauss and Corbin (1998:183) explain:

*“...action/interaction may be taken in response to multiple conditions, some of which occurred in the past, some of which are happening in the present and/or some of which are anticipated in the future”*

In the preceding quote, therefore, the dietician is heard to describe action which occurred in the past: “Mum had her on a great diet...nothing on the written information had enough of the food she liked”, some which are happening the present: “so we did potassium exchanges [which are in place at the time of the interview as I confirmed through the casenotes], some of which are anticipated in the future: “so we tried to help her have what she likes [while maintaining her nutritional needs].

Although the quote cited here uses the past tense because the respondent was talking after the events we were discussing, the analysis revealed her discussion was moving between past, present and future which allowed me to capture the development of this category and sub-category.

In phase one, Leslie’s mother discussed her dilemma when faced with a decision about whether or not to have her son’s stoma reversed:



Mother: He got this stoma done with the bags on his side, I mean I know it was a chew [local term meaning a nuisance]. But it was worth the chew because he was well for a long time, and then they decided because he was older last year, what did we think about reversing it?. But they couldn't guarantee that it would be a success, I was a bit - not annoyed but like he [the surgeon] was saying to me 'What do you think about having it reversed?'. You know, and I mean he was the doctor and I needed him to tell me 'If you do this, this will happen' and he like, wouldn't he said....well it's up to you, it's up to you, and I was getting myself upset, so I asked if I could see [nephrologists]. And straight away he [nephrologist] said to us, 'Look, if it was my son, I would get it done tomorrow' and since getting it reversed we have never looked back and touch wood ...he's weeing properly out of his tail.

This account corresponds in its intensity with the description of the mind-numbing decisions faced by parents as '*the stuff of nightmares*' (Anderson and Hall, 1995:15). First, parents find that major and minor treatment decisions are intertwined and indistinguishable. Next, they discover that the rules keep changing regarding which decisions are theirs to make. Finally, and as reported by the mother in the preceding account, when parents locate the strength to make an actual decision, they often find themselves dangling unsupported.

## Summary

Mutual acknowledgement of expertise and the existence of trusting relationships was found to have a positive influence on families' participation in decision making. Intuition was a significant aspect of this process for children, parents and professionals. The issue of autonomy was important in relation to children feeling empowered to make decisions on their own behalf, although professionals and parents sometimes experienced difficulty in achieving a balance between ensuring the child's condition was managed safely while trying to respect their right to autonomy. Implicit in this was the need for negotiation that was also an important part of the decision making process for professionals and parents. Using examples from my own memos written during data collection and analysis as well as an example of a Conditional, Consequential Matrix has helped to enhance the description of the findings. The next section will use two Cases as examples of the type of issues that arose within this category.

## Cases

### Lucy- two months (High to moderate intervention)

During pregnancy, Lucy's mother (Kate, who was 21 yrs old) was told after her antenatal scan that there was a strong possibility that her baby would be born with a very rare type of nephropathy that would require high levels of intervention after birth. She was

introduced by the obstetrician to the paediatric nephrologist who has a particular interest in this type of nephropathy. He told Kate (who was with her own mother at the hospital) that it was approximately 99% likely that the post natal course would involve the baby being in hospital for 1-2 years during which time she would require continuous infusions of albumin followed by removal of one kidney with the possibility of renal failure requiring dialysis and subsequent transplant. Kate was quite certain she did not wish to terminate her pregnancy. Lucy was born naturally and was diagnosed with a milder version of the condition than anticipated.

#### *Knowledge use and application*

Lucy was Kate's first child, she had no previous experience of looking after a baby, therefore, she had been particularly anxious about how she would cope after the birth. She was resident throughout Lucy's inpatient stays and received regular support from her parents and sister, although they were 40 miles away in Kate's home town. Soon after her baby was born, Kate had to learn to adjust her expectations of the seriousness of Lucy's condition:

Kate: They told me [antenatally] she wouldn't feed, she wouldn't grow, she'd have drips all over her, she wouldn't open her bowels, but fortunately, touch wood, Lucy was strong and she was feeding on her own, and she was opening her bowels and having a wet nappy. She did have all the drips in her though, at first, so it was really about learning about it all.

Kate learnt to flush, clean and apply sterile dressings to Lucy's central venous line, that was essential as Lucy was at risk of developing thrombosis. Kate also learnt, under supervision from the nurses how to infuse albumin through Lucy's central line so that she could do this when they were discharged. The following quotation by Kate was made soon after she and Lucy were discharged home for the first time:

Kate: It is a good thing because we are out of hospital [sooner than expected] and we thought we were going to be in there for the first year of her life, and she is a normal baby, except she has had medicines and a central line because it was through a main vein into your heart and I was having to clean that line every day and to check that it was not clotted, and if Lucy is ever ill to make sure she does not get any infections and the doctors at [Children's Kidney Unit] only want them to touch it, or me to touch it.

This indicates the level of knowledge that Kate had acquired by the time Lucy was discharged, meaning that she was trusted by the professionals to deal with these aspects of her care at home.

### *Trust*

Initially, Kate learned to carry out the different aspects of Lucy's care by observing the nurses caring for Lucy and through that by interacting in a special type of social process associated with a kind of participation framework designated as legitimate peripheral participation. This requires a trusting relationship and is a feature of practice that has been described by Lave and Wenger (1991) in which people co-participate to a limited extent, thereby gaining access to modes of behaviour not otherwise available to them, eventually developing skills adequate to certain kinds of performance. To participate in this way a mutually trusting relationship was needed. This was, in part, based on the type of communication between Kate and the renal team. The following quote helps to illustrate how Kate used a trusting relationship with the ward-based nurses to help her learn to understand what the doctors decided on the daily ward round:

Kate: Well, the nurse comes round with the doctors and obviously after that round I'm not always sure what they meant, plus obviously they [nurses] are more trained, they are clearer about reading the notes so they know what that is, they can chat to you and say 'right, this is what we think it is'... and even 'we're not 100% [sure] but we will find out for you'...

Int: So they are almost like a go-between to start with, are they?

Kate: Well, yes, they are friends as well.

This socialised learning and brokering (discussed in more detail in the next chapter) that Kate experienced is consistent with that described by Lave and Wenger (1991), who suggest that as an aspect of social practice, learning involves the whole person; it implies not only a relation to social communities [such as a ward and the health care team], it implies becoming a full participant or member. This in turn helped Kate to begin participating in decision making about aspects of Lucy's care.

### *Decision-making*

Initially, Kate lacked the confidence to contemplate any involvement in decision-making but after learning from working with the nurses as they cared for Lucy and through talking to more experienced mothers, she began to understand how to ask questions:

*Kate:* Because I was in Newcastle, not a lot of my friends and family were able to be there because they work, so I was on the ward for three weeks and getting home at the weekend and I was taking a lot in as the nurses talked aloud when they were doing Lucy's dressing and line and giving her medicines [to help in decision making]... and my mam was great, she came up a lot and she was on the phone to me every night, in the morning after the doctor's rounds. I used to cry to her if I didn't understand what they said about her so she told me off - said 'She's your baby, you've got to ask them to tell you'.

These acts of coaching provided a form of scaffolded learning and, combined with the fact that Lucy felt she was accepted into the community of practice, these helped her to develop skills that were later useful when she and Lucy were at home. Soon after discharge, Lucy developed a high temperature with diarrhoea and vomiting and so, following instructions from the doctors at the Children's Kidney Unit, Kate took her to the local District General Hospital so they could withdraw blood from the central line to test for infection and kidney function. However, the staff there were unfamiliar with the central line technique and so were reluctant to take blood. As a result, Kate took the blood and the results indicated that Lucy's kidneys were failing and she needed intravenous therapy:

*Kate:* ...Yes, they finally put her on a drip because I stood there and I insisted that he did something for her because she was dying,

The confidence to act decisively in this way was nurtured as a result of her participation in the care Lucy received while an inpatient in the Children's Kidney Unit.

### **Nina – 15 years (Moderate intervention)**

Nina lives with her parents and two older brothers aged 20 and 22 years. Nina had been found to have a kidney disease during a routine antenatal scan. Several family members (including Nina's paternal cousins and an uncle) have also been diagnosed in the past with the same condition. As a baby, Nina was prescribed prophylactic antibiotics until she was five years old when the treatment was discontinued and her parents were told that her kidneys were clear. She had no further kidney related treatment until two weeks before the study commenced when she was admitted to her local hospital with severe abdominal pain and subsequent investigations revealed that her kidneys were covered in cysts and that her blood pressure was elevated. Following this, she was transferred to the Children's Kidney Unit and her father and two brothers were also investigated for the same condition. Nina was commenced on medication to

treat her hypertension, given dietary advice and advised to attend the Children's Kidney Unit clinic for regular blood pressure monitoring.

*Knowledge use and application*

Nina and her parents were very concerned about the fact that she had been diagnosed with a chronic kidney condition and initially Nina demonstrated anxiety about the fact that she received so much information at the beginning of the disease course:

Nina: Too much information, you like get told that you have it [renal condition] and they just tell you loads of stuff.

Int: So what do you think is the best way?

Nina: Don't get told everything all at once, it's too frightening...it's just so scary, the scary bits were first [crying while explaining this]

Mother: I must admit they [doctors] didn't hide anything from her, they didn't keep anything from her as such, they talked to her as an adult, you wouldn't want to be treated as a child would you [to Nina]?

Nina: No.

Mother: ...and they did ask if Nina understood what it was she had and she said yes and they said well tell me what it is so they knew that Nina understood exactly what it was, and when Nina told them they said 'Yes that's right', but I think it is too much to tell them straight away

The approach used in delivering information to Nina and her parents at this stage is consistent with guidance from Rolland (1994) and Ewles and Simnett (1999). In advising professionals about giving information to families so that they can fully understand the rationale for care and why it is necessary, Rolland (1994) maintains that children should not be deprived of an understanding of their condition and Ewles and Simnett (1999) recommend that the most important things should be said first, stressed and repeated so that they are remembered. As in Nina's Case, however, this can present a dilemma for professionals when trying to deliver '*the most important things*' first when those important things are also perceived by the patient as '*scary and too much at once*'. This dilemma is further intensified when the patient is an older child or young person. In keeping with the philosophy of family centred care that promotes open communication with young people, Nina was a full participant in the consultation.

### *Trust*

Information giving is often seen as the key to empowerment. As discussed earlier in the chapter, in order to feel empowered, families need to feel that they can trust the professionals caring for the child and that the professionals in turn trust them. This reciprocity in the relationship is a critical factor in the process of families learning to manage the chronic disease. In particular, Nina valued the way that the doctors and nurses directed most of their communication to her even when her parents were present. She felt that this showed that:

Nina: They must know that I can understand what is going on as well as Mam and Dad, I like that and I think it means they will always be honest with me.

Repeat visits to hospital during the course of this study led to Nina demonstrating a growing confidence in the way she interacted with professionals. In regular out patient consultations with a doctor, Nina believed that diagnostic and treatment information were primarily directed at her and as an in patient she was pleased when the doctor came to her with new information about her condition. These findings are, however, divergent from those of Young, Dixon-Woods, Windridge *et al* (2004), who reported that consultations were largely carried out between parents and professionals and seemed to leave the young person without a voice. In the present study nevertheless, Nina's growing confidence led to her articulating her views in subsequent interviews about the best way to relate complex information to young people with a chronic disease.

### *Decision making*

Young, Dixon-Woods, Windridge *et al* (2004) also identified the fact that parents were often involved in setting information boundaries and in censoring or filtering what young people were told. This is consistent with the findings of the current study but in this study, there was also a disagreement between Nina's parents (during a research interview) about the most appropriate way for this early communication to be handled. The following dialogue between Nina's parents helps to illustrate some of the tensions that can arise between parents of young people with chronic disease:

Father: She is not a child but she is not an adult but some of the things that were said, she shouldn't have been there...it would have been better if we were just there on our own and the doctor came in and told us what could happen. I think we would probably have been better explaining it to her. The worst side of it, not all of it

Mother: I disagree with you on that...I don't think we are qualified to tell her how serious it is, I think it is best coming from the doctor because if she asks anything the doctor is there to answer, well, we couldn't answer her could we?

Father: But not all in one go, she had all this information given in one bit.

It appears then that, while the needs and preferences of some young people with chronic disease and their parents regarding knowledge use and application may be discordant (Young, Dixon-Woods, Windgridge *et al* 2004), there is also a previously under explored area of communication that has been highlighted by this study. This involves the possibility of discordance between individual parents in communicating vital information. That neither of Nina's parents had explained their differing views about information boundaries and censoring to the doctor is an example of 'unarticulated knowledge' that was identified earlier in this chapter in relation to Kevin's Case. However, over the course of Nina's disease course, Nina's parents described how they both adjusted their approach to information provision towards a partnership-based model with their own and Nina's roles becoming more equal. This finding supports Rolland's comment that when beliefs about competency in chronic disease management can be sustained flexibly then decisions about communication are less apt to produce tension.

## Conclusion

In this chapter, the type of interaction between families and professionals was seen to be pivotal to the way in which children and families learned to manage chronic conditions. The accounts of knowledge and expertise, trust and decision making revealed some helpful conclusions about the way in which they interact. Primarily respondents expressed the opinion that through sharing knowledge and expertise they each gained access to modes of behaviour not otherwise available to them. Professionals legitimately entered the personal and private worlds of children and families while families also entered the worlds of professionals. Nevertheless, all of the interactions described initially involved highly asymmetric forms of co-participation. In the professional world families could and did participate in decision making but ultimately professionals held control of the power base. Similarly, where professionals entered the private world of the

family they were still the main decision makers. These interactions, however, had the potential to transform the relationship between participants and lead to the development of trusting relationships and thus more symmetric forms of co-participation that were further developed and utilised during episodes of decision making. Where this transformation did not take place it appeared to be because co-participation remained asymmetric and the interaction between families and professionals has not yet facilitated a form of co-participation that is conducive to fully trusting relationships.



## **Chapter 7: Synthesising Worlds of Chronic Disease**

The previous two chapters have explored and discussed the categories of assessing and interacting in relation to children and families learning to manage chronic disease. The approach adopted in this study required a methodology that could capture the multiple realities that characterise the world of chronic disease and acknowledge that different participants use and adapt different language styles in an attempt to make sense of their world. The interpretative approach has, therefore, given emphasis to the differing perspectives of family members and professionals and has highlighted the two-way process that can exist in optimum health care relationships. This third and final chapter of findings considers the emergent concept of synthesized learning across the disease course. In this chapter, the interrelated concepts of 'communities of practice', 'cultures, and 'learning' within the category of 'synthesising' will be addressed from the perspective of families and professionals. Synthesis occurs when a new unified whole results from the combination of different ideas, influences or experiences (Allen, 1990).

### ***Communities of practice***

Within the data from this study, there was evidence of the practice that families and professionals had developed together and of the cultural resources they produced in the process, in order to be able to manage their respective roles in relation to the children's conditions. It is in this sense that they constituted communities of practice. In considering the ways in which families learn about chronicity, it appears that the process of learning promotes consideration of the reproduction cycles of communities of practice through the concepts of identities, brokering and legitimate peripheral participation. These will now be explored more closely in relation to the data from this study.

### **Identities**

There was evidence in this study of a connection between practice and identity, with identity being viewed as a significant part of membership of communities of practice. Participants viewed learning and identity as not merely conditions for membership of the respective communities of practice but also as evolving forms of membership. According to participants' accounts, in practice the negotiation of identities were often not made explicit yet in the research interviews it emerged that families and sometimes professionals talked directly about the issue. It appeared that the focus of discussion in the research interview served as a transformative process in which participants articulated what had previously been unarticulated. For instance, Carol (phase two)

described a situation in which the issue of identity emerged implicitly during practice. She had been told that she would probably receive a transplanted kidney from her father and had decided that:

Carol: I want to get my exams [GCSE] out of the way first, then I've got the whole summer to get the kidney and get over it before going back to school.

However, her father was later found to be an unsuitable donor so she was told she would need to go on to the donor list:

Nurse: Carol is no longer going to have one of her Dad's kidneys so she will go on the [donor] list instead, but she's determined to get her exams over first and then go on the list, she doesn't want to miss any more school than she needs to, she knows exactly what she wants, does Carol.

Carol's full involvement in the discussion can be explained by the fact that, as a member of the community of practice, she had learnt certain ways of engaging with other people. She had, through assessment and interaction earlier in her disease course, learnt to develop certain expectations about how to interact, how people treat each other and how to communicate with the various professionals caring for her. She had developed an identity that led to her occupying a significant position in decision making about her condition and its planned management course. In this way, the temporal dimension of identities was found to be central and yet at no time had explicit discussions taken place about the actual identity that Carol or her mother had in the community of practice. Nevertheless, Carol had defined her identity through participation in the community of practice of the renal team.

Carol, her mother and the nurse all reported the way in which Carol had participated in extensive discussions with professionals about the timing of her planned kidney transplant. These discussions also give credence to the notion proposed by Wenger (1998) that identity can be defined by who we are, where we have been and where we are going on the learning trajectory. According to the definitions in chapter 2 (Figure 3), Carol had commenced her disease course on an inbound trajectory in the community of practice but by the time she reached the stage of discussing her proposed transplant, she had entered a boundary trajectory that had been brokered by the renal nurse. Like other children in this study, her perception of her own identity meant she believed herself to be central to the discussions with parents and professionals about her conditions.

This is in direct contrast with findings from a recent qualitative study investigating communication with children suffering from cancer and their parents, which found that children saw themselves as occupying a marginal position in consultations. Consultations were largely carried out between parents and professionals and seemed to leave the young people without a voice (Young *et al.*, 2004).

## Brokering

In the current study, children reported that they felt comfortable enough to be able to admit if they did not understand information they were given. In this way, appropriate forms of communication were adapted between the child, parents and professionals and a brokering role could emerge. This was especially evident in the accounts of children requiring moderate or high levels of intervention. For example, Nina (phase two) described the way she discovered the results of a kidney scan:

Nina: I asked about another scan on my kidneys and [doctor] said that I wouldn't need one because that just shows us what they look like and they know that anyway. But [doctor] told us that my kidneys were working just as good as anybody else's which I have never been told before. And that [information] had been there for ages, it was in the results from months ago but I had never been told

Int: So they can tell from the bloods?

Nina: Yes, and [doctor] said that they could tell from the bloods that they had taken this time as well so they were still working the same.

Int: So what else did they say to you about that? How do they know that your kidneys are working okay?

Nina: Because the kidneys are filtering the blood and it is just the same as anybody else's blood.

Int: So how do you feel about that?

Nina: Happy! Yes, because I thought that when they said they had lost the cysts and that, [maybe] they weren't working very well. And now they tell us that they are.

Int: So what do you think about the fact that nobody had told you?

Nina: I would have liked to know but I didn't know it was in the notes. Yes - it is about me and they should have told me about it.

Int: Did you feel that you could say that to [doctor]?

Nina: I can talk to [doctor] – it's like 'Nina! Nina! Come on!' – I mean, is just very jolly with me.

Int: And do you like that?

Nina: Yes

In this instance, the doctor fulfilled the role of broker through translating the information in the notes and relaying it in a way that could be understood by Nina. The following dialogue helps to illustrate how David's mother (phase two) also performed the role of broker:

Mother: Yes, and we showed David it [information folder about plasma exchange] as well, so it wasn't like a big shock when we turned up at this machine and started attaching him to it and that sort of thing.

Int: So is it written in a way that children could understand as well?

Mother: Oh, yes. There are photographs of children on the machine and what have you, and it describes what the machine does. I asked if I could keep hold of it to show my oldest and he understood it as well.

Int: And what sort of difference has that made now that he has seen the pictures of what's happening, because he won't always see what is happening to David?

Mother: Well I think he finds it a help – I mean, he has been up once when David has been on the machine because I thought that was necessary to bring him up just so that knew that David was fine when he was on the machine, nothing gross was happening so I brought him up on the first weekend.

Acting as a broker was, therefore, a significant part of helping to move newcomers' towards full participation into the world of healthcare, as was granting legitimate peripheral participation. The job of brokering is complex as it involves processes of translation, coordination and alignment between perspectives. It requires the ability to manage carefully the coexistence of membership and non-membership of the community of practice, yielding enough distance to bring a different perspective while having the legitimacy to be listened to.

## Legitimate peripheral participation

The move of children with chronic disease and their families toward full participation in the community of practice that represents the Children's Kidney Unit (and conversely the move of professionals into the community of practice of the family) did not take place in a static context as the practice itself was in motion. On the one hand, they each needed to engage in the existing practice that had developed over time in order to understand it, participate in it and to become members of the community. On the other hand, they each had a stake in the development of the particular practice as they began to establish their own identity. In the Children's Kidney Unit and the other communities of practice surrounding the children with chronic renal problems, reification (described previously by Wenger, 1998:58 as a 'shortcut to communication') took a variety of forms (such as a blood sample used for analysis, a hand written drawing by a doctor showing a child where the kidneys are situated, a dimercapto succinic acid scan showing a child's damaged kidney and reduced kidney function or a mother's personal diary of significant events in her child's chronic disease).

The importance of these forms of reification is that they were only the 'tip of an iceberg' but for children and families they provided a medium for aiding understanding or a point of focus around which the negotiation of meaning became organised. Their character as reification is not only in their form but also in the processes by which they are integrated into practice. The products of reification are thus reflections of these practices and tokens of human meaning (Wenger, McDermott and Snyder, 2002). This increased understanding of the significance of relationships, their impact on the negotiation of meaning for families and the place of reification in care was echoed by some of the professionals.

Nurses' assessments of families' ability to manage the demands of this is based on years of accumulated experience of carrying out the skills themselves and of teaching colleagues and families to carry out the skills. Nurses described the strategies they adopt to assess families' potential to learn and manage the skills. These strategies included: observing; questioning; asking them to describe as if telling another child or parent; drawing upon personal experience; recounting anecdotes from other families' experiences and admitting their own anxieties when first learning to do peritoneal dialysis on a sick child while acknowledging that it would be very different to have to do it in their own child. This is an example of the brokering role adopted by nurses and is further illustrated by the following quote:

Nurse: The first time I set up a [peritoneal dialysis] machine in someone's bedroom it was really bizarre, I can remember it very vividly, really bizarre doing something that I had a million times in hospital, little things like that are things to pass onto parents...I hope that it might relieve some of the fears that they might have while doing this at home.

There was a need for families to feel that they were legitimate participants in the management of the chronic disease and one important aspect of this was the ability to understand the differences in status between professionals, in particular doctors and nurses. In acquiring this understanding, parents especially learned to distinguish between the differing roles of doctors and nurses. Arriving at this knowledge sometimes involved a steep learning curve, however. Lucy's mother, Kate (phase two) illustrates the difficulty she first encountered in trying to understand the various positions that exist within the renal team and how they interact amongst themselves and with families. She explained that she thought it was excellent that she could stay with Lucy but that, as a new mother, she found it hard to just sit there and watch all the different interactions going on. She wanted to feel that she was able to fully participate in as many aspects as possible of Lucy's care.

Similarly, in phase one Nancy's mother alluded to the way in which encounters with health care professionals can sometimes be likened to a play on a stage. She used a theatrical metaphor to explain how she used to watch the professionals talking to each other and listen to the words they used and the way they interacted. This was particularly significant at the beginning of Nancy's disease course when she [the mother] was very unsure about all aspects of the disease. Like Lucy's mother she recalled how the ward round was a time when she tried to understand how best to become involved in discussion with professionals in order that she could participate effectively in managing the condition. She was motivated by a strong desire to be able to participate in her daughter's care:

Mother: I used to think it [the discussion between professionals during the ward round] was a bit like watching a programme on TV, you know a drama, and I felt I wanted to be part of the programme but realised I didn't know some of the words and things. I think I realised quite early that if I didn't use the words they [professionals] used they wouldn't let me play [laughs] you know a bit like the kids won't let someone else play their games if they don't quite fit in

This blending of metaphors (theatrical and children's play) used by Nancy's mother gives some support to the view that learning is not merely situated in practice, as if it were

some independent process that just happened to be located somewhere but that it is an integral part of social practice. Therefore, data in this study corresponds with the ideas of Lave and Wenger (1991) and Wenger (1998) who maintain that learning and legitimate peripheral participation involve the whole person forming not only a relationship to specific activities but also a relation to social communities.

In addition, parents found it difficult to relinquish control of aspects of care that they were previously managing independently, such as peritoneal dialysis, when their child is transferred to haemodialysis that is managed entirely in hospital by the nursing and medical staff. This change in their child's management leads to a change in role and status for the parents. As a result, many try to compensate for this by holding onto the aspects of care that are usually viewed as part of the traditional parenting role, such as managing the child's food intake. A nurse cites a general example [anonymised] of the father of a child who is not a participant in the study who is concerned because she is not putting on weight while she is on haemodialysis although this is not a concern for the clinicians:

Nurse: I think that he feels that it [feeding and monitoring her weight] is among his parenting skills, because they [parents] don't have any control on kidney dialysis now because we do their dressings, we access their lines, we put them on the machines, we take them off the machines and do their observations – the parents don't really have that much hands-on experience, whereas with PD [peritoneal dialysis] they are taught how to do everything, they give injections, they give medication, they put the children on the machines, they do the dressings and basically they are the main care-giver to their children.

Lave and Wenger (1991) remind us that granting legitimate participation to newcomers with their own viewpoints potentially introduces tensions into any community of practice

## **Summary**

As part of the social practice of chronic disease management, learning by families relates not only to specific activities but also to a type of social community that is health care. For learning to occur, family members and professionals need to become full (although often transient and temporary) members of the alternative communities of practice. Activities, skills, decisions and understandings do not exist in isolation but as part of a broader system of relations where they have meaning and where people construct identities for themselves and each other. Therefore, regarding learning as legitimate peripheral participation means that learning is not just a condition for membership of the community of practice but is in itself an evolving form of membership.

## **Cultures**

Families of children with chronic renal problems typically found that although they sought to understand the culture of health care practice, the initial transition into a relatively unknown and often alarming world was a huge culture shock. Children, even the older ones, seemed to base their own reactions to this exposure to new environments on the attitude of the adults in the family. Several of the principles of family-centred care that were outlined in chapter 2 were implicit in the experiences described by families. These include collaboration, negotiation, empowerment, support through teaching and advocacy and sharing in an open and honest environment. The extent to which these principles are promoted depends on the prevailing infrastructure and the characteristics of the individuals concerned. An overarching definition of family-centred care has been articulated as:

*The professional support of the child and family through the process of involvement, participation and partnership underpinned by empowerment and negotiation. (Smith et al., 2002a:22)*

The main distinction to emerge in the data in relation to cultures was regarding efforts to retain family cultures as an attempt to normalise the situation and when that became unsustainable, then respondents talked about redefining cultures to accommodate the consequences of the condition. The next two sections, therefore, discuss the concepts of 'retaining' and 'redefining' cultures in relation to learning in chronic childhood renal disease.

## **Retaining**

Efforts to retain the distinct characteristics of family life were evident in the accounts of several participants in phase one and all the Cases in phase two. The issue also kept re-emerging as families moved across the disease course. Early in the disease course, all families entered a state of 'limbo' that was characterised by a period of uncertainty, vulnerability and preoccupation about the whole experience. Regardless of the level of intervention required by the child's condition, it became a severe stressor and caused strain in a wide range of areas including physical, emotional, social and financial. An abiding aspect of coming to terms with this culture shock was to try, whenever possible, to retain familiar aspects of the family culture. By attempting to retain as much as possible the customary aspects of life before the disease course began, while learning to accommodate the disruption caused by the child's condition, parents in particular, sought to normalise the situation in which they found themselves and their family. This attempt



to normalise the situation was described by Milly's mother (phase one) as a form of denial:

Mother: I think at first I was in such a state of shock that I went into a kind of reverse gear, or at least stood still, I tried to pretend that as a family we could just go on as before, school, housework, a birthday party, the lot really. I just didn't want to admit that I, well all of us really, was in a different world now.

Kevin's father (phase two) in the first interview described the resentment he felt about the necessary changes to daily life:

Father: Already I just know that our life will never be the same again, I have to keep taking time off work to go to the hospital. But it's the little things as well, I mean the bairn [pointing to the younger sibling of the affected child] we should have gone to a little school play and couldn't because of all the to-ing and fro-ing to hospital.

These accounts are similar to those presented by Clarke-Steffan (1993) who recognised the 'state of limbo' amongst families coping with childhood cancer and Robinson (1993) who found that the construction of the story of life 'as normal' with a chronic condition was a balancing act. In addition the many forms of diversity within family structures that are created by the many alternative lifestyles that co-exist in modern society have been alluded to by Mountain (2002) and may be relevant to the way in which families achieve the balancing act of striving for normalisation. For instance in phase one, Keith's mother reported how an already complex family situation where she has to manage all aspects of family life alone was made even more complicated when Keith was diagnosed four years previously, as a small baby, with a condition requiring high levels of intervention:

Mother: It's a balancing act keeping everything right, hospital trips, medicines and all as well as everything else he needs, especially now I'm on my own.

For those parents able to draw on the resources of friends or relatives, this helped retain some aspects of the usual culture of the family and made a significant difference to the way in which they could concentrate their own energy on learning about the condition. In this way, others were able to maintain the routines of home life or as one mother described it '*keep the home fires burning while we are at the hospital*'. The type of supportive resources parents valued included child minding, financial support and help with daily tasks such as housework and shopping. An example of the type of support parents described included a family friend collecting the sick child's siblings from school when the parents were at the hospital and taking them back to the family home. This

meant they could play with their friends and sleep in their own bed. This concurs with earlier findings from research into family management styles in which the preferred or dominant story for many individuals and families managing a chronic condition is one of maintaining the family status quo despite the situation (McCubbin *et al.*, 1983) and normalisation, that is essentially seen by the family members as normal people leading normal family lives (Knafl and Deatrck, 1986). Families that adapt best to a childhood disorder are, according to Rolland (1994) those who maintain a balance between the illness and the rest of family life. Nevertheless, the difficulty in maintaining this balance and managing the often complex needs of chronic renal disorders has been well articulated by families in this study.

Sometimes parents trying to retain the many aspects of usual family life, relied on someone to provide transport whenever needed. For example, Ann's mother (phase one) described how her own father helped to keep life as normal as possible:

Mother: And me dad always comes to hospital, there's always me and me dad so I'm not alone coz Mick [her husband] can't get there because he's at work. Me dad's always there.

Although negotiation was very often implicit in the accounts of parents, children and professionals in this study, there were very few explicit references to it. Nevertheless, when the issue was raised in interviews by using a different terminology (such as 'did you feel your point of view was welcomed by staff?' or 'did you and the staff ever reach an agreement about an aspect of care through discussion and compromise?') all families in phase two acknowledged that negotiation did feature to a greater or lesser extent in their interaction with professionals. This has been referred to in the previous chapter when discussing decision making, indeed, a significant feature of family centred care is the concept of negotiation between family members and professionals (Valentine, 1998; Hutchfield, 1999).

In addition, there were examples in the data of extensive collaborative efforts between family and staff members to integrate health care needs into the usual patterns of family life. For instance, as Carol (phase two) moved through the disease course her home-based peritoneal dialysis treatment was altered to hospital-based haemodialysis, that meant she needed to attend the hospital three times a week (Monday, Wednesday and Friday) for her dialysis. The nursing staff communicated with the school to arrange for Carol to leave school as late as possible in the afternoon and organised transport to

collect her from school and take her to the hospital for the dialysis. When the transport proved to be unreliable, it meant the Carol often had to wait at the school reception for long periods that meant missing classes related to her forthcoming GCSE exams:

Carol: So the nurses contacted the Transport Manager and asked them to make sure that the transport arrived at the arranged time. When it didn't improve, one of the doctors wrote to the Transport Manager to emphasise the importance of the transport arriving on time. So it has got a lot better

This example of negotiation helped to retain as much as possible aspects of the normal family culture.

### **Redefining**

Despite the considerable effort described by families to help them retain normal family function, the enduring nature of the child's condition often meant that at some point in the disease course families needed to relinquish some of their routines and replace them with the routines of the health care environment. It was only by accepting the inevitability of this transition that it would be possible to achieve positive adaptation to the condition and to optimise the child's wellbeing.

The following dialogue between Kevin's mother and stepfather was obtained in the third research interview, by which time the family had spent a great deal of time in hospital and had encountered many different professionals. However, disenchantment with the service and fear about Kevin's vulnerability were evident. There was evidence in the casenotes and from accounts of nurses that a supportive relationship was being cultivated. For instance, a nurse made the following comment:

Nurse: ...she [Kevin's mother] hasn't had things to do on a day to day basis with the kidney nurses ... she is alright now but she had quite a bad time a couple of months ago, she came to the clinic, she was really upset and he was better, we were feeling confident about him but she was really upset. She was saying things like 'You said he would go bald and he never did' and things like that, so whether she was annoyed that we had given her all these details and it didn't actually happen?

There was no account by them of negotiation, collaboration or empowerment:

Stepfather: I mean maybe it might just be us, I don't know...

Mother: Well, it's not, because remember when we first went in [to a ward] – you go in, and they give you a bed and they tell you to do this and do that, and they are really, really friendly but once you have been in for a couple of hours, they will come back and they will do your obs [child's observations] and that is it, and it is going to get to the point obviously, with me having her to look after [gestures to one of her daughters], and he is back in hospital, he is going to be in hospital by himself and that scares him.

In contrast, David's mother (phase two) described in the first interview how the whole family had made efforts to retain some normality in their lives. This proved to be more difficult than they imagined, as she articulated in the following quotation:

Mother: A fortnight ago, when my husband went back to work, we thought we would try to get into a routine of what it was going to be like every day, but it is difficult, I suppose, especially now that he is at work because I am like the sole carer for David, so it has been hard. I take the oldest one to school in the morning, come straight up to the hospital... as I say, now that he [David] is going back to school, I'll probably just be sitting by the phone waiting for someone to phone[laughs at own anxiety].

In the same way, David's grandparents had found it difficult to understand the implications of the condition because they had little personal experience of hospitals. Nevertheless, because of negotiation and collaboration between the family and members of staff, the family were able to redefine their usual culture in order to help with the process of adaptation. This involved learning new strategies to manage situations. David's mother explained how she would usually discuss with her friends concerns about her children's minor acute conditions such as colds or ear infections. However, she realised by the second week of the disease course that it would be more difficult to discuss David's condition with them because they do not have a similar experience for her to compare with and:

Mother: I feel it's been hard, because the only contact that I have had with my friends is trying to explain it [chronic condition] over the phone and it is hard to explain it to them, really. Like they cannot really understand – I mean it is really quite hard to explain to people what has gone wrong.

As a result, she spoke with other ward based mothers and nurses because:

Mother: Well, one or two of them [mothers] have children having treatment a bit like David's, it's just as if we understand what each other is going through. And the nurses know David now and can help us decide what's best for him because they have the experience.

This corresponds with findings from Thorne's study (1993) in which one mother of a chronically ill child chose not to talk to her friends about what was happening with her child but did choose to talk with other parents in the hospital because 'you probably wouldn't see them again'. Thorne's analysis of this comment was to speculate that this strategy was adopted by the mother as a means of 'pushing or pacing' to ensure that the self presented to outsiders to see is a normal self with limitations or differences masked. In contrast, in this study my interpretation placed on the mother's choice to speak to other hospitalised parents is that she was acknowledging the need to redefine her usual family cultural practice in order to integrate into the health care environment.

## **Summary**

Maintaining the patterns of family life while struggling to adjust to the changes brought about by a child's chronic disease, regardless of the level of intervention, led to families adopting differing strategies. Retaining family cultures involved a combination of resourcefulness and flexibility. Friends, relatives and indeed professionals often became allies in the attempt to retain the familiar aspects of family culture. Where this did not work then families again learned to adjust and adapt. A compensation arising from this process of adaptation was the resulting integration into or articulation between communities of practice so that professionals and families could begin to discover their commonalities and come to terms with their mutual dependence.

## **Learning**

The preceding discussion in these findings chapters has considered the social perspective on learning in health care for children with chronic disease. Learning has been observed as an integral and ongoing part of the daily existence of children, and professionals, at home as well as in hospital. It is not a separate activity to be picked up and put down according to a predetermined timetable. It is not the same as coping with chronic disease although it is an integral part of coping; yet coping is an integral part of learning. Nevertheless, learning is too important to be allowed to occur in a purely ad hoc and unstructured way. Learning is a social activity involving a constant realignment of experience and competence. It transforms the identities of those it involves and it involves multiple forms of participation in many different learning communities. It is

pivotal in health care and yet the children and families who need to learn are committed to the learning experience through necessity rather than choice. There is a level of emotional investment in the learning by families of chronically sick children that is unlikely to be paralleled in any other type of learning encounter. There is huge responsibility and sometimes fear of failure. There is great satisfaction in the smallest achievement and there is the weariness that comes from knowing that roles people are given and the positions they adopt and are attributed, are likely to persist for a long time.

Participants' accounts have illustrated the many 'ups and downs' of learning and competence development in these often challenging and emotional situations. Families described a variety of types of participation in the Children's Kidney Unit and associated learning outcomes that characterised their learning about the chronic condition. Comparative analysis across the Cases in phase two revealed three main patterns of learning by families: parallel learning; integrated learning and synthesised learning. These patterns varied in the extent to which families participated in the community of practice and achieved learning outcomes relating to the condition. These are discussed in more detail below using excerpts from the data to help illustrate key points.

### **Parallel Learning**

Parallel learning was characterised by a side-by-side approach to unpicking the signs and symptoms, seeking explanations for them and dealing with the consequences. At this stage, interaction was superficial and usually focused on the immediate focus of the learning situation. Where the child required low intervention, this stage could involve a fragmented approach to intervention with a variety of investigations being conducted in different settings by different individuals. If the family were anxious about interactions with health care professionals, either because of previous difficult encounters or because of lack of confidence to deal with the situation, then learning could be very superficial as the following quote from a mother in phase one illustrates:

Mother: At first you know, I had trouble grasping what the doctor was saying about Jane's illness, we'd not had much to do with hospitals at that stage, I felt I only really understood the surface information you know?

Int: Do you think that could have been made any easier for you?

Mother: Well I remember it helped me when they drew a picture of the kidneys and showed me exactly where the problem was, so maybe that would have been a good thing to have started with

This often occurred in the early days of the disease course until the process of mutual assessment had informed the individuals concerned what to expect and who to trust. In these early days, professionals held the power and with total responsibility for managing clinical situations, often had to act quickly on the minimum of information in order to establish the cause of symptoms and treat the child accordingly:

Nurse: Sometimes we just have to do something quite quickly, when a child is new and very sick, like taking blood and putting in a naso-gastric tube-that can be really hard for the child and family.

Parents were often 'immobilised' by the uncertainty of the situation while at the same time being galvanised into action to try to minimise the stress for the child. The concept of family centred care is now well known amongst health care professionals yet many parents will not have heard of this and indeed may not learn about it explicitly even during long involvement with the health service. Yet the concept is implicit in every aspect of care. The profile of the acutely ill child in hospital has, according to Rennick (1995), changed markedly and so the concept of family centred care needs to be socially reconstructed to be responsive. Rennick points out that as the nature of childhood disease shifts from hospitalisation because of short-term acute diseases to a situation where acute diseases are increasingly replaced by chronic diseases with often acute exacerbations of symptoms, then the need for research that reflects this changing epidemiology is growing more urgent. The following excerpt from an interview with a dietician helps to illustrate the way in which parallel learning occurs from a professional perspective. The respondent is describing how early assessment of families where a child has a chronic renal problem may be carried out:

Int: So you are sort of doing an informal assessment on an ongoing basis really?

Dietician: Yes, if they are people that I am very concerned about and what their level of understanding is, they will do it in their own time but I have a different level of approach, I have quizzes, so I go through some quizzes and from that I gauge how much they have understood and make it a bit of fun.

Int: And how do they go down?

Dietician: They go down very well...but I do the quizzes – they are sitting down with the questions but it is taking that information in every day but education has to be as you know [individual] some of them don't understand the literature...

Int: And the written information that you give them, is it stuff that you have developed within the department?

Dietician: Yes.

Int: So it is tailor made?

Dietician: Yes, I developed it from trial and error and bits of it worked and bits of it hadn't so bits had to be taken away, but through trial and error.

Int: So how do you decide whether it has worked or not then?

Dietician: For example, some people were taking potassium carbonate with their meals but were having high phosphate foods in between their meals so I developed a list of snack foods that didn't have any phosphate in them and then another list of foods which had potassium carbonate...and that was as a direct result of patient feedback. I have always believed it is my job to allow the patients to understand. The onus is not on the patient to understand, but if they don't understand then it is my job to think of a way that they do understand, so we have actually broken things down into just pictures and that if their understanding is limited, I must come up with something that that patient can use. So I wouldn't just stop at what I have got, you know, and say, That's it – if it wasn't suitable then I have to come up with a way of presenting it differently.

This is an example of the way in which the professional as a teacher aims to act as a facilitator to enable the learners (or children and families) to become autonomous. It is conceded that to become autonomous, learners may need the context of a highly supportive and respectful environment to help them recognise and explore individual learning needs (Cottrell, 2001). This is the context described above. In order for this transformation to autonomy to take place, however, current thinking suggests that there is not an essential 'autonomous student' waiting to get out but the autonomous individual needs to be constructed (Boud and Garrick, 1999). Cottrell points out that this construction is situated within social and cultural contexts. This is consistent with the dimension of practice described by Wenger (1998) as 'mutual engagement':

*Each participant in the community of practice finds a unique place and gains a unique identity...these identities become interlocked and articulated with one another through mutual engagement, but they do not fuse. (Wenger, 1998:76)*

Of particular significance to this study is the fact that individuals are likely to need different types of teaching approaches to reflect the fact that they come to the situation with a variety of different learning abilities and experiences. But, most importantly, the individuals are likely to be emotionally distressed by the consequences of the condition



and this will need to be taken into account by the facilitator. By the end of the Cases, all families had progressed beyond the stage of parallel learning although Kevin's parents had only just made the transition, after eighteen months, to a state of integrated learning.

### **Integrated learning**

Integrated learning was characterised by an ability for families to initiate interaction with professionals and to act independently in seeking new information or coordinating aspects of care without supervision from a professional. This is consistent with the dimension of 'joint enterprise' that Wenger describes as:

*...a collective process of negotiation that reflects the full complexity of mutual engagement...it is defined by the participants...it is their negotiated response to their situation...it is not just a stated goal but creates among participants relations of mutual accountability that become an integral part of practice.*  
(Wenger,1998:78)

Four families moved beyond this phase but one family (Eric's phase two) entered this pattern early in the disease course and remained in this phase until the end of the data collection period. The following excerpt from the first interview with his mother described events that occurred the day she and Eric were admitted prior to him having major kidney surgery next day:

Mother: The first thing when we arrived at the hospital, we had to arrive the day before his operation, and they asked us to arrive in the middle of the afternoon. I actually asked if we really needed to be there in the middle of the afternoon, was there any reason why, and they said we could come a bit later than they had originally said. So we did arrive later, and I think it was only about 4pm when we got there, and I didn't see a doctor or anybody until late that night in the end.

Int: Did you get any information on why you were waiting?

Mother: No, I think he was probably called in to do an emergency operation. And that was what happened that night – so many things happened on so many different nights! Yes, I think he had been called away so he was unable to come down, and I didn't really feel it had been necessary, we could have just arrived at 6 or 7 that evening – I mean we did need to be there the night before, yes, but we didn't really need to be there for that length of time. Luckily my husband was home so we turned up with him and we just played, really because there was nothing else to do.

Because of the nature of Eric's condition, his care was shared between the nephrologists and the kidney surgeons and most of his care was managed as an outpatient apart from the episode mentioned in the previous excerpt when Eric was admitted to a surgical

ward prior to kidney surgery. Eric's mother said she had little experience of the health service but, as a teacher, she believed she was much more confident than many other parents in asserting herself to find out about Eric's condition. Because of the fragmented nature of Eric's care, the family did not have regular contact with any members of staff so although interaction took place it did not lead to a situation of synthesised learning.

Parents' assessments of their own and each other's competence to manage the condition were graphically articulated in both phases and were often closely aligned to their assessment of the professionals who taught them. Mothers and fathers were at pains to reassure each other, during the interviews, that they were able to carry out the clinical and technical skills needed to support their child's condition. For instance the parents of Leslie (phase one), who was diagnosed in the antenatal period with a condition that required high levels of intervention after his birth, spent a considerable part of the interview explaining what this meant for them:

Mother: Learning everything was easy because they [nurses] showed us things in steps, they showed us how to NG tube [pass a nasogastric tube]. Once you'd figured out how to do that, it's uncomfortable and horrible, and I do know people who still don't do that but...

Father: ...the thing is as well though L [mother], you're intelligent, [turns to interviewer] she is intelligent she picks things up very quick, and whether it's the same for other people or not? She reads something and it sort of sticks.

Mother: What I found really hard about doing the tube was because P [father] wasn't here, he was working away, and at the beginning I felt like you needed two people to do it. When I was on the ward I had [Nurse] with me so if Leslie would start flailing around then she would hold his head still for me while I done it. While I was at home I had nobody to do that.

By the end of phase two, four families had moved beyond this pattern of learning and were demonstrating the characteristics of synthesised learning.

### **Synthesized learning**

Within this pattern of learning families were able to demonstrate significant confidence in their negotiations with professionals. This was based on a combination of knowledge of the condition, confidence in their own knowledge of the child and mutual respect that had emerged over time through the development of trusting relationships. To some extent this pattern was more evident in those families where the child's condition required a

moderate or high level of intervention. However, it was only possible to observe the shift from one pattern of learning to another in phase two because of the longitudinal nature of data collection and only one child in that phase had a condition requiring a low level of intervention. Therefore, the data may not be widely representative of all levels of intervention in relation to the different patterns of learning.

Nevertheless, there are several examples of the way families were able to demonstrate significant confidence in their ability to negotiate with professionals. Some of these have already been discussed in chapter six in relation to decision making. However, other examples which are consistent with synthesised learning include situations relating to Carol and Lucy in phase two. Carol and her mother both demonstrated an ability to negotiate aspects of her care from a well informed perspective, for instance a nurse explained the way in which Carol became more and more competent in understanding the consequences of her condition as the disease progressed:

Nurse: I mean when you are talking about the disease at first you tell them what you expect for the future, but you see you start off with it being just straightforward – ‘she has got [name of condition], this is the cause, this is what happens, this is what you can expect but there are no guarantees from any of us but this is what we expect to happen over time’. Then eventually it just dawns on people that this is really quite complicated, what lies ahead and maybe she could have a transplant. So the impact of that can be quite hard to take in over time she and her mother became really well informed and started to talk with us about how we will do the treatment, we all talk together about it

Int: So is there any particular type of support you think families need in a situation like this?

Nurse: Oh yes, well we arrange for them to see the transplant psychologist, just to talk around what is happening and just to acknowledge that she [referring to Carol] doesn't just have to take it on the chin, which is what she does, everything she just takes it...she is very resilient

Correspondingly Carol and her mother told me independently that they had talked to the psychologist and had found it helpful, but that because they felt so integrated into the care team they knew that any anxieties would be dealt with by open discussion and that they were happy to initiate this and to negotiate with the professionals before they led to Carol feeling the effects of the stress.

There were also examples in the data of parents demonstrating the social aspects of learning within this pattern of learning. Initially, families found it difficult to discuss the condition and its consequences with professionals because they did not possess the

vocabulary of professional language. However, as they accumulated more experience and information through watching and listening to professionals in different settings, they could begin linking this to their own situations and gain a greater understanding of what they were involved with. Children and families appeared to learn most effectively when they were integrated into the community of practice surrounding the renal team and in particular if they had access to a broker who could translate and interpret for them. When a broker drew their attention to situations that were meaningful then family members were more likely to learn from and remember the facts. This is illustrated by the quote below from Lucy's mother in phase two:

Mother: So the nurses kept saying to me when they were showing me how to clean her central line ' so we do this in steps and as long as we follow the steps we don't miss out anything important, so just remember the steps and you'll be fine.

Following such encounters there was also more evidence of intramental learning as being given a structure within which to learn a skill helped participants to internalise the knowledge and so use it in future practical situations. For example, Lucy's mother went on to say that whenever she was cleaning the central line on her own without a nurse supervising her, she would imagine an internal voice, that of one of the nurses, explaining the procedure. Sometimes she even thought out loud while doing the procedure which also helped her to internalise the skill and so accommodate some of the vocabulary and the concepts linked to that:

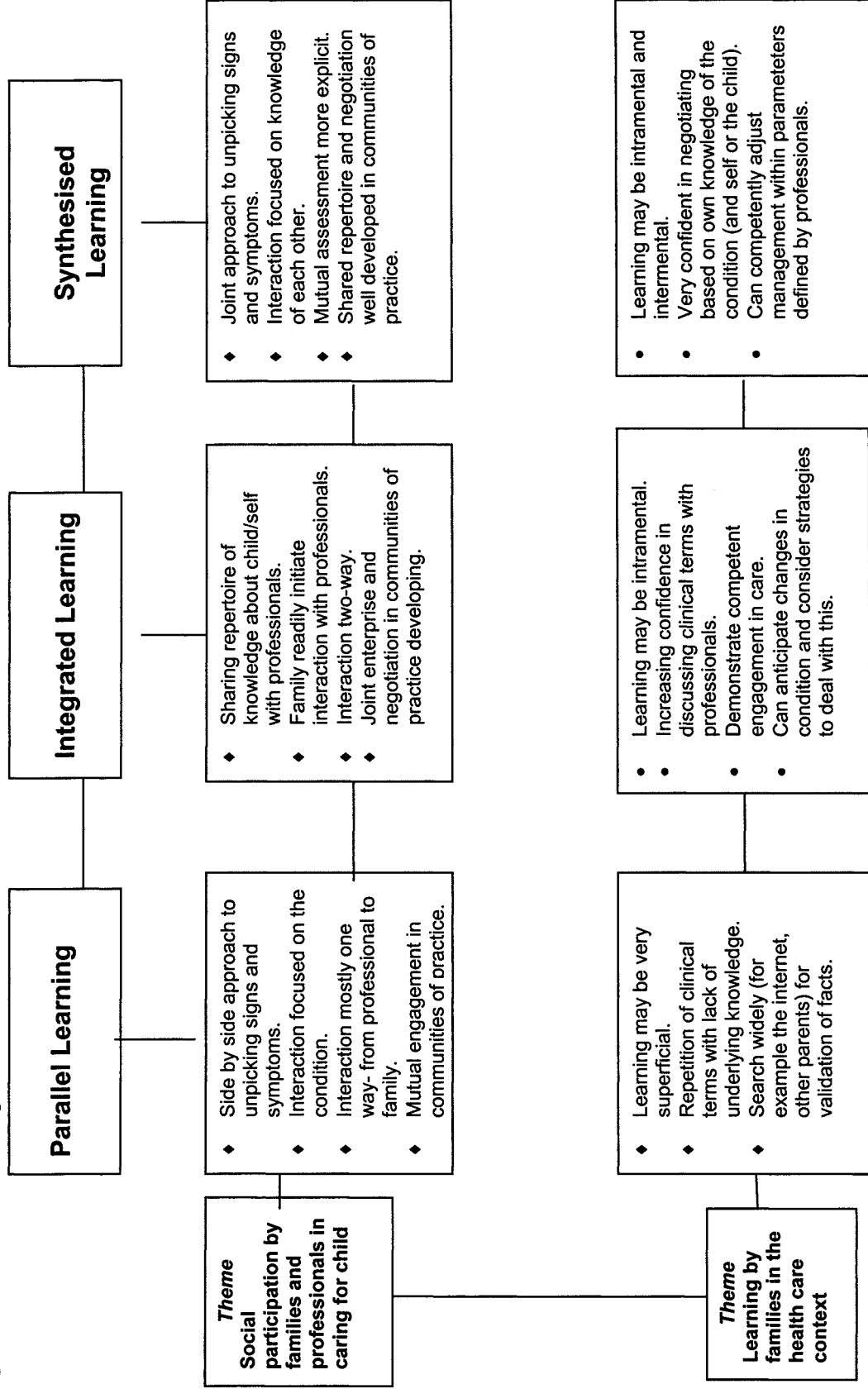
Mother: When I first went home I used to talk out loud to myself while doing it, just because it helped me visualise what I was doing and gave me more confidence. Now thought I can do it without thinking-well almost!

Within this pattern of learning children and parents could often demonstrate the ability to independently manage aspects of the condition and make judgements about changes to treatment, but always based on the presence of clear boundaries that had been determined by doctors or nurses. This was an important point that was raised by professionals when discussing the way in which families learn. Ultimately the family need to know what the boundaries of their responsibility are and how to know the limits of their responsibility and where to gain advice if they need it. Through repeatedly performing the different clinical skills required by the chronic condition, however, family members reported that they began to see patterns emerging in their experience and so built up a stock of their own knowledge.

## **Summary**

Three patterns of learning have emerged during respondents' accounts. These may occur simultaneously or consecutively, some families demonstrate all three patterns while some only demonstrate parallel learning or integrated learning. Dimensions of practice as the properties of communities of practice are closely aligned to the three patterns of learning. These are mutual engagement, joint enterprise and shared repertoire. An overview of the main characteristics of the three patterns of learning as they relate to the two main themes of the thesis is presented below in Figure 18. Two further Cases have also been used to explicate the patterns of learning as they arose within those Cases, these are outlined below following Figure 18.

Figure 18: Patterns of learning in relation to themes of the thesis



## **Cases**

### **Eric 3 years (Low to moderate intervention)**

Eric lives with his mother, father and 5-year-old sister. He was transferred to the Children's Kidney Unit after having a series of unsatisfactory urinalyses that led to him being treated for a urinary tract infection. Some of his renal investigations at the local District General Hospital were unsatisfactory because Eric was uncooperative, but those that were successful indicated that he had a chronic renal condition requiring low to moderate intervention. Further investigations were arranged at the Children's Kidney Unit and were carried out successfully. He was commenced on regular prophylactic antibiotic therapy and an appointment made to see the renal surgeons with a view to having an operation at the regional centre to correct the problem with his kidneys and ureters. As Eric lives 100 miles away from the Children's Kidney Unit, each outpatient visit for investigation or consultation meant a long journey by car. When he was admitted for his operation his mother was concerned about some aspects of information provision and the fact that arrangements were sometimes changed without her being informed of the reasons for this:

#### *Culture/Brokering*

Eric's mother demonstrated that she was confident enough to approach the consultant and ask for information if she had not been given the information she wanted previously. She recognised that some parents do not have the same level of confidence, however. In particular, she described the way that one of her friends:

Mother: ...just accepts everything she's told without asking any questions, she has been waiting ages to have her little boy seen at the hospital and just waits and waits without trying to find out what's happening. I always chase things up now if I think things are taking too long.

However, in a subsequent interview later in the study, she explained that her parents were the people who had advised her and her husband how to communicate with health care professionals. In the following quote, she explains what happened the night after Eric's operation:

Mother: No, the first night, it got to the middle of the night and we were on the main ward with lots of other people, well, with other children, and he was just screaming and crying, he had me up every hour wandering up and down the corridors. By the morning I was just in tears, I was on the phone to my parents saying I couldn't do this anymore – no-one seemed to be able to do anything for him and he was in agony and nothing really changed, he just gradually, very slowly, got a bit better.

Her mother advised her what to say to the nurses and doctors and how to ask for pain relief. So, although her mother was not resident in the hospital, she acted as a broker indirectly by administering reassurance and advice.

### *Communities of practice*

Having been told to arrive in the afternoon on the day prior to his operation so that Eric could be prepared for surgery, his blood sample was not taken until 10:30 pm. From the standpoint of a participant in the community of practice on the ward, although she acknowledged that everyone was busy and the staff were pleasant to her and Eric, she did not believe she had received the information she would have liked or that there were adequate explanations about expected delays to planned investigations:

Mother: Well, my parents came up [and stayed with little girl at home 100 miles away] and he [husband] stayed as long as he could [at the hospital], he stayed until nine pm and then he had to go because he had told Laura he would be home and things, and we hadn't seen anyone. I mean, the nurses had been round and chatted to us and so on, in the end he had a blood sample taken at 10:30 at night.

Int: Oh

Mother: And I really thought that was unnecessary and I was quite upset about that. You know, he should have been asleep at that time, and they said they had decided they needed blood. I was really annoyed!

Int: Did you tell her that you were annoyed?

Mother: Well, I think they knew because I said Is that really necessary? and they said Well, so-and-so says it really needs to be done – we had been there all afternoon and I asked them if we could please get it done when my husband is there, could they get it done and they said they were waiting for so-and-so to arrive.

Int: So you were waiting for the doctor who was operating?



Mother: No, we were waiting for somebody else for that who wasn't available either. I mean, they did it very quickly but he was pretty upset and everything and the other thing that happened that first night, well the sleeping arrangements were strange because we were on the main ward that first night and so I asked, because obviously they knew I was staying with him and so they said I could sleep on the bed opposite because it was free – although I am not quite sure what would have happened if it hadn't of been, otherwise I suppose I would probably have had to sleep in a chair or something.

Int: That often happens, does it?

Mother: Yes, well I saw other people doing that, but I don't think they got much sleep though. Anyway in the end I got in with him because he wanted me, so I got in with him and we had quite a good night's sleep, amazingly – I am not sure how. But just before we went to bed, I noticed that one of the doctors had come down – one of the consultants had come down and was looking at the X-rays and things and I heard E's name mentioned, so I went over and I said If they are Eric's X-rays, would you mind going through them with me because I have never seen them?

Her own reflections on this experience led her to the conclusion that:

Mother: You have to let them [professionals] know that you expect to be informed of what's going on, everyone was very nice but I don't think they all expected you [parents] to ask what's happening...

### *Learning*

Eric's mother, therefore, demonstrated integrated learning as she was able to initiate communication with consultants through their secretary, as she explained in the following description:

Mother: Yes, that was at Newcastle, and we had a problem with the results from that one because I was told I could phone up and I spoke to [surgeon's] secretary and she said He has dictated the notes for me to send out the letters, when it came to Eric's he said he would speak to you at your next meeting and I was annoyed because the meeting wasn't until the 26<sup>th</sup> November, a whole month later, well it was almost six weeks, so that was a long time to wait for results, so she said the fact that he had not said anything probably meant it was a good thing, it probably meant things were fine otherwise if it was something urgent, he would have to tell me, obviously. So that was why we had to wait.

After this, she learned to contact the secretary each time information had been promised but was overdue

### **Carol 15 years (High intervention)**

Carol lives with her mother and was admitted to the Children's Kidney Unit from her local hospital following a three-month history of increasing lethargy, nausea and vomiting, reduced appetite and weight loss. Immediately prior to admission she began to complain of headaches and abdominal pain. Following admission, a renal biopsy was performed (histology indicated a chronic condition requiring high levels of intervention) and a peritoneal catheter was inserted to facilitate peritoneal dialysis. A wide range of investigations was carried out and a central venous line was inserted in order to commence Plasma Exchange. Carol was, therefore, commenced on a very heavy immunosuppressive regime involving intravenous and oral medication as well as plasma exchange and subsequently peritoneal dialysis. This led to a gradual improvement in her condition.

However, after three months and while still in hospital she suffered multiple generalised seizures and was seen by the neurosurgeons who recommended further plasma exchanges. This was discontinued (and her immunosuppressant therapy increased) when she developed severe gastro intestinal bleeding. Carol began to respond quite well and her peritoneal dialysis was well established. She was eventually discharged home on peritoneal dialysis that her mother was taught to manage. In addition, she needed regular blood pressure monitoring, a carefully controlled diet and fluid intake as well as several oral medications all of which her mother took responsibility for. In addition, Carol took responsibility for dressing her central line site using an aseptic technique. During the period of the study, Carol was informed that she would eventually need a kidney transplant and her peritoneal dialysis was changed to haemodialysis, which meant that she had to come into the ward three times a week to receive this treatment. Because Carol faced months or years of very intensive treatment, she was referred to see a Child Psychologist who spoke to both Carol and her Mum. Carol's mental state was found to be good, with no symptoms of emotional disturbance. Carol and her Mum talked of 'just getting on with it' with regard to how they coped with the condition and acknowledged the practical and emotional support from the maternal grandmother and the extended family and friends as needed.

#### *Brokering*

Carol and her mother were required to learn a vast range of skills and subsequently needed to acquire an increasing knowledge base to support these skills. From the

beginning of the disease course, there was evidence in the accounts of processes of translation, coordination and alignment between perspectives. There was remarkable convergence of accounts between the family and professionals with regard to the way in that Carol and her mother learned about the various aspects of care. The doctor reported in a discharge summary letter to the General Practitioner that peritoneal dialysis went extremely well and that Carol and her mother were involved in the connecting and disconnecting. The doctor went on to report that home and school visits have taken place [by a renal nurse to inform staff about Carol's condition] and that all essential changes that were going to be needed in the home environment for a sink [for hand washing before peritoneal dialysis connection] to be placed in Carol's room were pending.

Meanwhile, a renal nurse recorded the progress being made by Carol and her mother with regard to learning to connect and disconnect peritoneal dialysis in preparation for discharge. The following are excerpts from the nursing notes made at this time:

Figure 19: Excerpt from nursing notes regarding Carol's mother's preparation of the peritoneal dialysis machine

27th August Observed Mum make [prepare] machine and connect Carol. Still very unsure of blood pressure recordings even though technically correct. Good connection and awareness of machine, very safe doing machine connections but still needs to be watched at times.  
Evaluation pm - Mum connected Jasmine [practice doll] to dialysis, absolutely fine.  
28th August Observed Mum connect Carol to machine - done well, no prompting.  
29th August Observed Mum set up machine - still needs extra practice with connections. To put Carol on tonight on her own.  
9th September Observed Mam doing machine...technique was excellent.  
1st October Watched Carol do exit site dressing for first time in shower...good all round technique.

In discussing the way in which new skills were learnt, Carol's mother reported:

Mother: I found it hard to do the PD [peritoneal dialysis] at first, well I did it at Crawford House [family accommodation at the hospital which can be a transitional stage between hospital and home] and I did sometimes on the ward, just to make sure I was doing it right really, and so it is three weeks that we have been left on our own doing it. And you think you can do it, and then you think eeh, well, this is alright when you are in hospital and everybody is around, you know, but when you are at home, well it is alright setting it up and that but when it gets to night time and you think Will I hear it? And I don't hear it, it's not until Carol shouts to say that it is beeping

Int: And what does it beep for?

Mother: It beeps because it has got a kink and it cannot flow through or it gets blocked or something.

Carol: It is just a horrible thing – it just beeps because it is an eejit!

Mother: An eejit!

Carol: Yes because it wants your attention, doesn't it? It doesn't even want anything, you go up to it and it says 'Check patient' – there is nothing wrong and then all of a sudden it just stops speaking, I think it just beeps to let you know that it is there!

From these accounts, it is possible to see the full complexity of brokering. It provides a participative connection because what brokers are the connections provided by people who can introduce elements of one practice into another.

#### *Communities of practices*

Carol and her mother alluded to several communities of practice relating to her condition in addition to the ones associated directly with the health care setting. For instance, Carol referred to her teachers who helped her to catch up with school work so that she did not miss her GCSE exams despite spending such a long time in hospital. In a later interview, she also talked about her friends who always make sure that their social life is organised in such a way that Carol is not excluded because of her dietary restrictions:

Carol: Oh they [friends] think it is mint!

Mother: The chemo [chemotherapy] – they had a talk with [nurse], she talked to them and they were really good, just sort of when Carol went back to school really, so that they would keep an eye on her.

Int: Did you mind that?

Carol: No because my closest friends knew anyway.

Int: So do they keep an eye out for you?

Carol: Yes, cos when I go out they are always asking Are you allowed that? and I say Yes, I know what I am allowed! and they say Yes, but your mam said you can't eat that and things like that.

Int: So it hasn't cramped your style in anyway?

Carol: No!

Mother: I think some days she tries to do too much because she is so tired. We try to tell her that...

Carol's grandmother is also very involved in aspects of her management as Carol and her mother discussed:

Mother: Like-Carol's grandma, she is older again, and she took it really badly –in fact she got shingles because of the worry and everything, but she is an even older generation where they didn't have that contact with the doctors and she thinks it is amazing the way that the doctors and the nurses go on now, I mean she is 80 so she has seen a lot, but she says now it is amazing what they do. ...she was there when the dietician came, because we have had to have talks with the dietician and everything to do with her food, and she was here then, because her grandma is usually here after school for to give her her meals and that, so she had to like learn that bit of it, but she forgets, doesn't she Carol, and she keeps saying to Carol Are you allowed that?.

Carol: I can't stand it – I just don't say anything – she says Are you allowed this? and I tell her, like yesterday, I said Grandma, I am allowed this and she comes up and says Are you allowed this? and I said Grandma, I have already told you! and then half an hour later, she will say Eeh, Carol, were you allowed that that you have just eaten? and I said Right grandma, I am not speaking to you because you are asking me the same question a thousand times!

Mum: But it is just the generation gap, isn't it?

### *Learning*

Carol and her mother demonstrated patterns of parallel learning early in the disease course, as can be seen in the following illustration of mutual engagement:

Mother: It's funny now, but on that day it was awful, you know, it's the sort of thing that happens to somebody else but it doesn't happen to you, and it wasn't until the next day when I spoke to [nurses] and they said that [named nurse] was going to be Carol's renal nurse, and I asked if her kidneys would be better again and she said no, once they are bad, they are always bad, you get acute and chronic, and with acute she said they do come again, and with chronic, that's it, you can't mend them.

Subsequently her mother described the dimension of joint enterprise that is a characteristic of integrated learning. Wenger explains that the enterprise is joint in that everybody believes the same thing or agrees with everything but that it is communally

negotiated. Negotiating a joint enterprise gives rise to relations of mutual accountability among those involved. These relations of accountability include what matters and what does not, what is important and why it is important, what to do and not to do. This communal regime of mutual accountability plays a central role in defining the circumstances under which individual members feel concerned or unconcerned. For instance, Carol's mother explained:

Mother: So I asked what would happen, and they asked if she had ever been unwell, and [doctor] said to me that he thought it had been happening since she had been born and her kidneys had failed all the way through life until she has reached puberty and then they had stopped.

Finally, she described some of the characteristics of synthesised learning when talking about a shared repertoire:

Mother: But when she went down to theatre, she had to have a kidney biopsy when she had her line put in, and the next day, by this time Joe [Carol's father] was up, and he [doctor] took us into the room and he explained that it was not what they had first thought, it was not genetic, it was [high intervention condition], which is a really rare auto immune disease that attacks your own body and it is something so rare that they had never seen it. I mean, they knew about it but normally in children it attacks your kidneys and your lungs but it was only a slight shadow –she had to go to theatre again to get a line because she had to have plasma exchange to wash the antibodies out, and when she went down for that operation, the other consultant came up and said Would you mind doing a lung wash so we can see how far the antibodies had gone into her lungs? and there was only a slight trace.

## **Conclusion**

As part of the social practice of chronic disease management, learning by families relates not only to specific activities but also to a type of social community that is health care. For learning to occur, family members and professionals need to become full (although often transient and temporary) members of alternative communities of practice. Activities, skills, decisions and understandings do not exist in isolation but as part of a broader system of relations where they have meaning and where people construct identities for themselves and each other. Therefore, regarding learning as legitimate peripheral participation means that learning is not just a condition for membership of the community of practice but is in itself an evolving form of membership.

Within this chapter it can be seen that maintaining the routines of family life while struggling to adjust to the changes brought about by a child's chronic disease, regardless

of the level of intervention, led to families adopting differing strategies. Retaining family cultures involved a combination of resourcefulness and flexibility. Friends, relatives and indeed professionals often became allies in the attempt to retain the familiar aspects of family culture. Where this did not work then families again learned to adjust and adapt. A compensation arising from this process of adaptation was the resulting synthesis between communities of practice so that professionals and families could begin to discover their commonalities and come to terms with their mutual dependence. Three patterns of learning (Parallel, Integrated and Synthesised Learning) have emerged during respondents' accounts. Learning patterns may occur simultaneously or consecutively. Some families demonstrate all three patterns while some only demonstrate parallel learning or integrated learning. Dimensions of practice as the properties of communities of practice are closely aligned to the three patterns of learning. Finally, two further Cases have been used to explicate the patterns of learning as they arose in this chapter.

## Chapter 8: Discussion and Final Conclusions

*Ultimately it [learning] belongs to the realms of experience and practice. It follows the negotiation of meaning; it moves on its own terms. It slips through the cracks; it creates its own cracks. Learning happens, design or no design. And yet there are few more urgent tasks than to design social infrastructures that foster learning. This is true not only of schools and universities, but also of all sorts of organisations in the public and private sectors, and even of entities not called organisations, like states and nations. (Wenger, 1998:225)*

This study had two main aims: to gain insight into the ways in which children and their families learned to manage a chronic disease from the point of referral into the Children's Kidney Unit, and to explore the impact of relationships between families and professionals on the way learning occurred. Because of the dearth of previous research into the issue of families' learning in childhood chronic disease, the literature informing this study was drawn from the areas of clinical and psychosocial contexts of childhood chronic disease and the broader literature on social learning and teaching. These issues were covered in chapter 2. Chapters 3 and 4 have outlined the philosophical, methodological and ethical focus of the study as well as describing and discussing the research design.

A major challenge for qualitative researchers is knowing what features of the analysed data to focus on from a large and complex body of data generated through the entire research process (Strauss and Corbin, 1998). In chapters 5, 6 and 7, therefore, I sought to give prominence to the accounts of children and families within the three categories that make up the social theory of learning in childhood chronic renal disease. Interpretation of these accounts helped to meet the first aim. The two way process of social interaction that was implicit in these accounts made it important, at times, to also portray the voices of professionals. Sometimes professionals' accounts served to mirror those of family members, at other times they contradicted them. Interpretation of these dual perspectives helped to meet the second aim, and so provided insight into the impact of health care relationships on the way families learned.

In pulling together some of the main issues that have been discussed in the previous chapters, this final chapter explores and discusses the notion of learning as social participation in childhood chronic renal disease and considers some of its implications for theory, professional practice, care delivery and further research. In reflecting upon the theoretical implications, consideration is given to the use of symbolic interactionism in developing the current theory. Then, the provenance of the social theory of learning



proposed by Wenger in 1998 is explored; the current theory is compared against that and then used to appraise existing literature relating to families' learning and competence development in childhood chronic disease. This critical analysis of the social theory of learning in childhood chronic renal disease includes detailed discussion of the three emergent and interrelated categories of assessing, interacting and synthesising identified by this study. Next, the implications of the theory for practice and policy are addressed from the perspective of children and families learning to manage chronic disease. The two main themes of this thesis, social participation by families and professionals in caring for the child, and learning by families in the health care context are highlighted throughout the discussion.

The study supports a conceptualisation of family learning that stresses: not acquisition of a static subject matter but interaction in developing an ongoing practice; not merely intrapersonal learning but also interpersonal learning, and not just acquisition of skills but the formation of identities in a social context where the skills are learned. It is recommended that educators of health care professionals emphasise in curriculum the significance of family learning approaches when teaching the management of childhood chronic disease, and that practitioners recognise children and families as co-learners as well as co-clients in care delivery. Subsequently, the implications for research are considered. Methodological considerations of this study include discussion of the appropriateness of theoretical concepts used in the sampling process (age at referral, level of intervention and time since diagnosis) and strengths and limitations of the current study are identified. Finally, recommendations for future research that arose from this study are proposed. The next section, therefore, considers the theoretical implications of the present study, beginning with discussion of the appropriateness of symbolic interactionism as a theoretical perspective.

### ***Implications for theory***

#### **The appropriateness of symbolic interactionism in developing the theory**

In chapter 3, the branch of interpretivism known as symbolic interactionism, with its emphasis on eliciting and understanding the way meaning is derived in social situations was introduced. The decision to use this approach in the current study has also been justified in that chapter. In this section, I consider whether this was actually the most appropriate choice of approach for the study. First, I explore the three basic premises of

symbolic interactionism presented by Blumer (1969:2), in relation to the current study. Then I discuss some of the criticism of symbolic interactionism before finally concluding that this was the best approach to achieve the research aims.

The first of Blumer's (1969:2) premises is that 'human beings act toward things on the basis of the meanings that the things have for them'. This is evidenced in chapter 5 in this thesis, when parents reported the way in which they acted towards professionals on the basis of the meaning that the professionals had for them. In assessing ability of staff, in particular during the early disease course, they also assessed social positioning; the staff's position as expert (or not) and their own position in the health care of their child, as professionals ascribed it to them. Similarly, in the process of synthesising (Chapter 7), professionals acted as brokers, in particular for children requiring a moderate or high level of intervention. In this way professionals used their experience as members of several different communities of practice (eg the nursing workforce, the multi-professional team on the Children's Kidney Unit and the family in their home) to identify the meaning that a clinical intervention such as an injection had for a family.

Thus, within the basic social process of interacting, a nurse explained in chapter 6, during general discussion about approaches to care within the renal team, how she had acted towards a child's treatment in a way that benefited the child while recognising the meaning the situation had for the mother. Recognising that the mother had not been administering the injection as needed because of her anxiety about the child's distress, the nurse tactfully arranged to administer it herself. This is congruent with Blumer's philosophy that the meanings that things have for human beings are central in their own right and to ignore the meaning of things towards which people act, is seen as falsifying the behaviour under study. In this situation, the nurse based her meaning on a hunch gained from previous experience with other families, physiological information obtained from the child's routine investigations and discussions with members of the renal team.

The second premise states that 'the meaning of such things is derived from, or arises out of, the social interaction that one has with one's fellows' (Blumer 1969:2). Symbolic interactionism sees meaning as arising in the process of interaction between people. The process of interaction emerged as the central category within the social theory of learning in childhood chronic renal disease and manifested in particular, in relation to knowledge exchange, decision-making and trust. Wenger (1998) used the term 'negotiation' to convey a flavour of continuous interaction, of gradual achievement and of 'give and take'. This is similar to Blumer's suggestion that the construction of meaning

is not produced out of thin air. In the current study, whilst the negotiation of meaning involved language it was not limited to it. It included social participation and social relationships between children, family members and professionals as factors in the negotiation of meaning. For instance, staff in the current study often played a critical role in mediating family participation in decision-making that led to meaning arising out of the social interaction for both the family and the professionals involved.

The third premise is that 'these meanings are handled in, and modified through, an interpretative process used by the person in dealing with the things he encounters' (Blumer 1969:2). Accordingly, interaction in this study was not regarded as a mere automatic application of established meanings but as a formative process in which meanings were used and revised iteratively for the guidance and formation of action. For instance, in the process of synthesising three patterns of learning were identified, each pattern involving different degrees of interaction between families and professionals. In relation to parallel learning, families and professionals demonstrated mutual engagement in which membership of respective communities of practice occurred but only on a superficial level. An example of this is from Kevin's mother who spent a great deal of time in hospital with Kevin during the early part of his disease course but reported that she was not involved in negotiated enterprise while she and Kevin were recipients of care from professionals. Despite the high level of involvement with the Children's Kidney Unit community of practice Kevin's family interpreted their position as being peripheral.

In contrast, Eric's mother described how she used an interpretive approach in dealing with encounters with professionals and subsequently learned to negotiate with professionals on his behalf and so demonstrated characteristics of integrated learning. Eric's family remained on the boundary, most of their involvement with the Children's Kidney Unit being as outpatients. Eric's and Kevin's disease courses were very different, both requiring differing levels of intervention but the most distinct difference between the two families was that Eric's mother identified a broker (her own mother) who helped her and her husband to interpret the situations they encountered while Kevin's parents believed themselves to be isolated in their involvement with the Children's Kidney Unit. Meanwhile, the remaining families in phase two described synthesised learning in which interpretative processes were used and that led to a shared enterprise with professionals.

The preceding discussion has illustrated the way in which symbolic interactionism had accounted for many of the processes implicit in the social theory of learning in childhood chronic renal disease. Nevertheless, alternative interpretative approaches to the study could have been used. For instance, a phenomenological approach would have enabled me to focus on describing the lived experiences of children and families. It has been cited as a most appropriate approach for the study of concepts and issues within nursing whose meanings have remained unclear or unexplored (Darbyshire, 1994). However, Darbyshire also pointed out that while phenomenology's concerns seem more individualistic (although not exclusively so), grounded theory with its origins in symbolic interactionism more specifically addresses issues of social processes, identities and shared experiences. Critics of symbolic interactionism refer to an absence of any attempt to gain an overview of social organisation with an accompanying neglect of social stratification (Kuhn, 1964; Meltzer, Petras and Reynolds, 1975). However, interactionists have developed concepts that connect individual behaviour within societal structures (LaRossa and Reitzes, 1993). Therefore, the main tenets of the symbolic interactionist tradition and their emphasis on deriving meaning from social interactions through an interpretative process were regarded as the most fitting approach to achieve the aims of this study, wider societal concerns featuring in so much as they were experienced by the individuals in the study.

By virtue of symbolic interactionism, human group life is, therefore, a formative and dynamic process and not a mere arena for the expression of pre-existing factors (Blumer 1969). Thus, what was available to be known of participants' behaviour was negotiated between them and me as the researcher. This led to a shared understanding of the relationship between the families and the phenomenon of learning in chronic disease, in particular in relation to the social theory of learning in childhood chronic renal disease and the processes of assessing, interacting and synthesising. Therefore, this approach was used in the current study to help uncover the socially constructed meanings that formed the realities of children, families and professionals as they learned across the disease course and 'learning' became an object for the participants in this study. The next section provides a critique of the social theory of learning in childhood chronic renal disease in relation to the two main themes of the study, social participation by families and professionals in the child's care and learning by families in the care context.

## **The Social theory of learning in childhood chronic renal disease: a critique**

The social theory of learning in childhood chronic renal disease constitutes a coherent level of analysis. It also yields a conceptual framework from which has been derived a consistent set of general principles and recommendations for understanding and enabling learning in childhood chronic disease. The theory helps to explain some of the differences between families' learning as they move through the disease course of chronic renal problems and to highlight the significance of relationships between families and professionals in the learning process.

Wenger defined the social theory of learning in 1998. He proposed the theory as a new conceptual framework for thinking about learning, that would be of value to theorists but also to teachers, students, parents, health practitioners, patients, managers and all who:

*In one way or another must take steps to foster learning (our own and that of others) in our relationships, our communities and our organisations.*(Wenger, 1998:11)

The theory builds on earlier work (Lave and Wenger, 1991) that distilled a number of ethnographic studies of apprenticeship in groups such as tailors and midwives and an ethnographic study of communities of practice in a medical claims processing centre in America. The ethnographic study was later described in detail by Wenger (1998). The authors' purpose was to articulate what it was about apprenticeship that seemed so compelling as a learning process. They used the concept of legitimate peripheral participation to characterise learning. They aimed to broaden the traditional connotations of the concept of apprenticeship, from a master/student or mentor/mentee relationship to one of changing participation and identity transformation in a community of practice. Thus, the concepts of identity and community of practice became Wenger's main entry point into the social theory of learning.

In discussing the potential for discovering new theory from existing theory, Strauss (1987b) argues that this is entirely feasible, providing only that the extant theory was carefully grounded in research. The social theory of learning was undoubtedly grounded in research and according to Wenger is relevant to a number of disciplines including anthropology, sociology, philosophy and educational theory and practice but in particular it belongs to the tradition of social theory such as that proposed by Giddens (1979). A social theory of learning, therefore, must integrate the components necessary to

characterise social participation as a process of learning and knowing (these components are meaning, practice, community and identity). As can be seen below, the social theory of learning in childhood chronic renal disease does integrate these components. Wenger's definitions of these components are presented in italics and followed by summaries of the way in which these components are articulated by the theory that emerged from this study:

- *Meaning: a way of talking about our (changing) ability—individually and collectively – to experience our life and the world as meaningful*
  - Illustrated by the category assessing and the concepts of assessing ability, social positioning and disease course
  
- *Practice: a way of talking about the shared historical and social resources, frameworks and perspectives that can sustain mutual engagement in action*
  - Illustrated by the category interacting and the concepts of knowledge use and application, trusting and decision making
  
- *Community: a way of taking about the social configurations in which our enterprises are defined as worth pursuing and our participation is recognisable as competence*
  - Illustrated by the category synthesising and the concepts cultures and communities of practice
  
- *Identity: a way of talking about how learning changes who we are and creates personal histories of becoming in the context of our communities*
  - Illustrated by the category synthesising and the concepts communities of practice and identities

The theory identified in the present study is, therefore, consistent with Wenger's definition of a social theory of learning. This section has considered the origins of the substantive theory that evolved from this study. Further development of the social theory of learning in childhood chronic renal disease and its usefulness in caring for children with chronic renal problems is indicated by this study. The next section will appraise existing empirical literature on families' learning in relation to the social theory of learning in childhood chronic renal disease.

### **Families and professionals interacting in childhood chronic disease**

Some concepts from the social theory of learning in childhood chronic renal disease parallel concepts emerging from other studies. The literature suggests that previous attempts to understand the way in which families learn about childhood chronic disease (Robinson, 1985; Jerrett, 1994; Gibson, 1995) have given us limited insight into the

social interaction that underpins this process of learning. There was some congruence between the process of interacting in this study and two components from Gibson's (1995) concept of participatory competence (taking charge and holding on). The process of interaction in this study also corresponds with Wenger's second dimension of practice as a source of community coherence, which is the negotiation of joint enterprise. However, this study's findings suggest that unlike the mothers in Gibson's study, families' interactions with professionals across the disease course led to interpersonal as well as intrapersonal learning in ways that were characterised through the interrelated concepts of knowledge and expertise, trust and decision making. There was evidence of a relationship between learning and the social situations in which it occurred that has not been previously described in this area.

In this study, there was remarkable similarity between the accounts of parents from both the retrospective and prospective phases regarding the process of interacting. Parents' accounts suggested that their previous sense of parenting competence was initially dismantled with each new interaction and they relied heavily on intuition at these times as they sought to understand what their own position was in the care of their child and what the implications were for the child. Most parents in this study reported the way in which the uncertainty of the situation initially created an immobilising effect upon their coping processes. Consequently they found it difficult to articulate to professionals the personal and private information they held about their child. This finding is supported by another study (Mishel, 1983) that found that uncertainty was a major perceptual variable that impeded parents in their psychological management of the chronically ill child. This proposition found support in the work of Cohen (1995) who developed Mishel's work. Cohen indicated that the current interest in uncertainty is an evolutionary process in response to biomedical and technological advances in the treatment of disease. These advances have changed the nature of disease experience for many children with previously fatal diseases and have increased the likelihood of long-term survival without the assurance of a cure. According to Cohen, this has produced a 'medically fragile population' whose future quality of life is unpredictable and whose parents have to cope with the resulting and sustained uncertainty.

Some of the findings reported in Chapters 5, 6 and 7 in this thesis showed how families coped with the sustained uncertainty and unpredictability associated with the chronic renal problem. I suggest also that this research reveals an alternative to the coping processes described by Cohen. This was the process of interaction and in some cases synthesising in which family members demonstrated evidence of mutual engagement,

joint enterprise and shared repertoire with professionals. There were examples of parents valuing professionals who recognised parental expertise while being willing to share professional expertise with them. The value of this mutual engagement, joint enterprise and shared repertoire was also highlighted by the accounts given of its absence. For example, the account from Kevin's parents and a nurse in chapter 7 about information giving, showed how mutual engagement had deteriorated into reproachfulness and mutual wariness. Instead of a shared repertoire there was a discourse of alienation and lack of confidence.

Cohen (1995) also described the concept of 'existential uncertainty' in which parents of a child with a newly diagnosed chronic disease sought information from professionals about what the disease meant for the child's survival and quality of life. These questions were usually answered with generalisations or reference to statistical probabilities thus emphasising the uncertain prognosis for the child. When information was available that was critical to a realistic appraisal of the impact of the disease, it had the potential for maximising the parents' perception of existential uncertainty. This is consistent with the way in which Kevin's parents in phase two of this study reacted to the information they received about his condition early in the disease course. However, some strategies used by children and parents in this study differed from those in Cohen's study and led to a reduction in existential uncertainty.

For instance Lily's mother in phase two described how support from the ward-based nurses and one of the other resident mothers helped her to make sense of the situation in which she found herself. Nevertheless, relationships with medical staff were initially tense until she learnt to understand their language. This is consistent with Wenger's concept of participation in which participants shape each other's experiences of meaning. By assessing the social positioning of doctors, for instance through use of a theatrical metaphor (seeing the ward round as a play in which only the doctors know the full script but the parent have to watch the script unfold to understand it) Lily's mother eventually developed more trusting relationships with medical staff.

On the other hand, if Lily's mother had been a student nurse on a ward she would have previously acquired, through classroom based teaching and workplace mentoring, some understanding of her own and others' social positioning within the workplace that would have assisted her in each new encounter. However, for parents in particular, the relationship with each different professional they encountered was a new hurdle to overcome and they relied heavily on intuition to help them manage these unknown and



uncertain situations. Families repeatedly said that they often did not know exactly what position individual staff held or what position they themselves were expected to hold. Polanyi (1967) considered the concept of intuition in relation to nurse education and claimed that initially nurses often know more than they can tell in the clinical setting. Polanyi distinguished between explicit knowledge that is codified through written words, pictures or diagrams and tacit knowledge gained through interaction that connects the knower with the world. In this way, a clearer idea of the 'big picture' develops through repeated interaction with the world and sorting of clues and information.

Polanyi's approach confirms the importance of personal factors such as beliefs and values, assuming them to be essential to the development of tacit knowledge. This is consistent with Gibson's use of intuition in the process of developing participatory competence. However, the findings of this study suggest that unlike the mothers in Gibson's study, families' learning was a process that took place in a participatory framework and not only in individual minds (intermental as well as intramental learning). This meant for instance that learning was mediated by the differences of perspectives amongst co participants.

The process of relationship building continued to be a significant issue in research interviews across the disease course. In part this was in response to questions I asked in interviews about the way in which families came to understand 'who is who?' and what is expected of families when they enter the world of chronic disease. However, for the most part, parents in particular, made unsolicited comments about their relationships with professionals. This was evident within the category of assessing but also in relation to the categories of interacting and synthesising. Families' accounts indicated that interactional processes that occurred early in the disease course (such as a conversation with doctors and nurses in Children's Outpatient Department or at the bedside of the sick child, or a nurse showing a mother and her child the pictures of a peritoneal dialysis machine before the child was attached to the machine) provided a stepping off point for future interactions. However, parents talked of the maelstrom of new faces, information, anxiety and uncertainty about the child's condition and unmet commitments at home and work.

Other examples of interactional processes that emerged as significant to families in this research are scaffolding, involvement in decision making and learning from professionals or other families. Engaging in social interaction was implicit in the way participants constructed assessments of each other's ability and the need for mutual assessment

was inherent in the relationships between professionals and families. If the child's condition required moderate or high levels of intervention early in the disease course then this involved professionals using points of focus such as blood biochemistry results, blood pressure readings or the outcome of urine microscopy to communicate to the child and family the significance of symptoms and treatment plans.

It was instruction through modelling and legitimate peripheral participation that allowed parents to imitate a set of clinical skills (such as urine testing or blood pressure monitoring) that helped them to move towards participatory competence. Interaction is clearly very significant in relation to situated learning and the concept of positioning has been used in this analysis as a dynamic alternative to a more static concept of role that has previously been the main focus of interaction in the work of Gibson (1995). This approach is more cognisant with the emphasis made by Wenger on the second characteristic of practice as a source of community coherence that is the negotiation of a joint enterprise. The implication of social positioning in the joint enterprises between families and professionals regarding families' learning is that we can most usefully focus, not upon the skills learned themselves or the roles that individuals hold in learning and teaching the skills but on the dynamic and interactive processes involved in the community of practice. In this section the process of interacting has been explored and discussed in relation to the prevailing literature and the findings from the current study. Interaction, as the central category has also been related to the other two categories and there are indicators to it in all the Cases in phase two. The next section will appraise the category of assessing against the existing literature.

### **Assessing the world of chronic disease by families and professionals**

Assessing was a process that occurred at all stages of the learning process and as described in chapter 2, learning can be viewed from several different perspectives. For children and families assessing was often a more invisible activity than it was for professionals. In this section of the thesis prominence is given to the processes of assessing ability, social positioning and disease course because, through using the coding device of a conditional/consequential matrix previously described in chapter 4, it emerged that these sub categories most effectively illustrated the structure and process (micro and macro) of participants' accounts within this category (Strauss and Corbin, 1998). There was some congruence between families' accounts in the category of assessing and two components of the concept of participatory competence reported by Gibson (discovering reality and critical reflection). In addition there was similarity with

the dimension of 'mutual engagement' described by Wenger (1998) in relation to the development of communities of practice:

*Each participant in the community of practice finds a unique place and gains a unique identity...these identities become interlocked and articulated with one another through mutual engagement, but they do not fuse. (Wenger, 1998:76)*

In the current study, however, this engagement without fusion was demonstrated through a combination of a process of assessing ability, learning about the positions held by professionals and families and critical reflection on the disease course. These have been defined in this study as 'parallel learning'. Unlike the mothers in Gibson's research, the process of assessing for family members in the current study was associated with the connection between identity and practice and was dependent on negotiation of meaning between families and professionals. The nature of relationships between families and professionals was very significant for families. This is reflected increasingly in child health literature (Callery, 1997a; Coleman, 2002a). In addition the phenomenon of relationship building is becoming recognised as a precursor to the process of empowerment (Coleman, 2002a) and is entirely consistent with Kieffer's findings (1984) in relation to the phases of 'entry' and 'advancement' into the process of empowerment. The iterative nature of the grounded theory approach used in the current study permitted a view of respondents' experiences that illustrates the temporal nature of relationship development as participants described the way professionals helped them to learn about the condition as they moved through the disease course. As relationships developed family members became co learners with professionals, the family learnt about the condition while the professionals learned about the family. This is similar to the situated learning described by Lave and Wenger (1991) in relation to apprenticeship.

Thus Wenger (1998) argues that implicit in the concept of situated learning is the relationship between intermental (interpersonal) and intramental (intrapersonal) learning that were first promoted by Vygotsky (1987). Although Vygotsky did not give priority to either approach it appears from translations of his work that he regards them as mutually dependent (Kozulin, 1986). Vygotsky suggests that interpersonal learning can only be studied and understood in its own terms in light of the social and cultural context in which a specific interpersonal activity is embedded. This includes the cultural setting in which individuals are in action as well as the way they participate in the creation of their own and others' understanding as they interact in the social world around them. These contextual dimensions of social and cultural forms of organization will necessarily then shape the outcome for intramental learning. In the same way, in the current study

families talked, wrote and read (for instance using the internet) about the condition and the context of care. According to Vygotsky, intramental learning promotes higher mental functions of problem framing and solving. This process has parallels with deuterolearning which focuses on learning how to learn (Argyris and Schon, 1978; Clarke, Reed, Wainwright, McClelland, Swallow, Harden and Walsh, 2004). Practitioners can encourage deuterolearning amongst family members by helping them identify their preferred learning styles, examine the effects of these and learn effective strategies for enhancing them.

Assessing social positioning and the disease course were also implicit in the way participants assessed each other (Davies and Harre, 1990). The classic dramaturgical model has focussed on 'role' as the determining basis of action. In the dramaturgical model people are construed as actors with lines already written and their roles determined by the particular play they find themselves in. However, they do not have much choice as to how to play these roles in any particular setting but learn how to take up a particular role through observation of others in that role (Tanner and Timmons, 2000). Families were usually more covert than professionals in the way they performed their assessments. This was particularly evident early in the disease course. This was consistent with the emotional, cognitive and behavioural responses of mothers in Gibson's study. This finding was similar to that described by Darbyshire (1994) when investigating parents' experiences of living in hospital with their sick child. He reported that parents' participation in their child's care was a subtle, dynamic yet frequently unarticulated social phenomena created by the expectations, approaches and strategies of both nurses and parents. These findings are in contrast to previous studies that characterised parent participation in terms of power as an external force, imposed and controlled by professional and organisational dominance (Robinson, 1985).

Wenger (1998) meanwhile has argued that we not only produce our identities through the practices we engage in, but we also define ourselves through the practices we do not engage in. When children and families discussed their involvement in staged learning about clinical knowledge and technical 'know how' they talked freely about the practices they engaged in because they felt able to do so. Sometimes they discussed the practices they did not participate in because they were not ready to or because it was not something they were expected to do.

## **Synthesising worlds of chronic disease**

As discussed previously, the product of this study (a social theory of learning in childhood chronic renal disease) corresponds with Wenger's proposal that a social theory of learning must integrate the components necessary to characterise social participation as a process of learning and of knowing (ie community, practice, identity and meaning). These components have underpinned the discussion in the previous two sections concerning the categories of assessing and interacting and will also underpin the forthcoming discussion about synthesising worlds of chronic disease. Synthesising is, therefore, the third and final category in the theory of social learning in childhood chronic disease and represents an extension of the concept of participatory competence defined by Kieffer (1984) and later redefined by Gibson (1995). It also corresponds with Wenger's third dimension of practice as a property of a community that is 'shared repertoire'. In keeping with the philosophy of grounded theory, however, and following the approach used in the previous two sections, the discussion also provides examples and possible explanations for dimensional extremes and statements about the relationships between categories.

A key part of synthesised learning was the way in which children and families learned how to take up a particular role through observing others in that role. In child health care it is widespread practice to talk about becoming partners in care with children and families. It is expected that families will become informal carers for the condition. In my own practice it has sometimes occurred to me to wonder what would happen to a chronically ill child who requires intervention of any sort, if the family were unwilling or unable to deliver the care that is required. During one of the later interviews with a nurse I posed this question in a general context. After some reflection she told me about a child who used to attend the Children's Kidney Unit and who needed high levels of intervention but whose parents had a learning difficulty. This proved to be a great challenge to the renal team who needed to constantly readjust their teaching and who were unable to discharge the child as early as usual. In addition, when the child was eventually discharged the staff needed to give extra support and also to train community staff to support the family at home.

This individualised approach is reflected in Mountain's observation (2002) where he reminds us that working in partnership with families is not always easy and involves making a key contribution to the care and management of their child's health and social

care. In order to do this effectively the practitioner needs to apply powers of observation and analysis and engage with the child and parents so that true partnership approaches can be facilitated in an appropriate and meaningful manner. This challenge was recognised by the nurse who told me about the child whose parents had a learning difficulty. This nurse acted as a broker for the family. However, Kevin's family did not describe any brokering relationship but seemed to wish to be independent.

The repertoire of a community of practice includes routines, words, tools, ways of doing things, stories, gestures, symbols, genres, actions or concepts that the community has produced or adopted in the course of its existence and that have become part of its practice. Wenger (1998) claims that practice is associated with the formation of communities and proposes three dimensions of the relation by which practice is the source of coherence of a community. The first characteristic of practice as a source of coherence of a community is the 'mutual engagement' of participants. Practice exists because people are engaged in actions whose meanings they negotiate with one another. Membership of a community of practice is, therefore, a matter of mutual engagement. Each participant in a community of practice finds a unique place and gains a unique identity that is both further integrated and further defined in the course of engagement.

The second characteristic, 'joint enterprise', is a process not a static agreement. It is the result of a collective process of negotiation that reflects the full complexity of mutual engagement. The participants in the very process of their joint enterprise define it. It is their negotiated response to their joint situation and thus belongs to them in a profound sense in spite of all the forces and influences that are beyond their control. Even when some members have more power than others do, the practice evolves into a communal response to the situation. Negotiating a joint enterprise gives rise to relations of mutual accountability among those involved. Over time the joint pursuit of an enterprise creates resources for negotiating meaning. The third characteristic of practice as a source of community coherence is outlined by Wenger (1998) as the development of a 'shared repertoire'.

Lave and Wenger (1991) asked about the kinds of social engagements that provide a proper context for learning to take place, rather than asking about the kinds of cognitive processes and conceptual structures that are involved. They claim that this means that learning is mediated by the differences of perspectives amongst co participants. Therefore, it is the community, or at least those participating in the learning context, who

learn under this definition. Practices evolve as shared histories of learning, history being neither merely personal or collective experiences but a combination of participation and reification intertwined over time (Wenger 1998). They interact but they do not fuse although they do continually converge and diverge. They exist, through time in different realms. The dual modes of existence of participation and reification in this study can be explained using the example of Carole's mother's participation in Carole's peritoneal dialysis at home. She maintains a record of all stages of the dialysis including any unusual occurrences, what actions she took to deal with them, what communication (if any) she had with the Renal Nurses and what the outcome was. If, for example Carol's mother was unable to continue managing Carol's peritoneal dialysis for any reason or if the renal team need to monitor Carol's progress during her time at home, then the information she entered into the record is reified and so available for others to refer to.

These findings are also consistent with those of Spouse (2003), who observed that for student nurses being coached by an experienced practitioner whilst undertaking new skills helped them to reach their existing level of potential and to transfer 'knowledge in waiting' to 'knowledge in use'. This helped prepare them for a further cycle of learning and a new zone of proximal development. The zone of proximal development was a social aspect of learning conceptualised by Vygotsky (1987) and refers to the distance between problem-solving abilities exhibited by a learner working alone and that learner's problem-solving abilities when assisted by or collaborating with a more experienced person (Lave and Wenger, 1991). Thus the act of becoming familiar with nasogastric tube insertion described by Lucy's mother suggests that her learning was situated in a form of social co-participation where social engagement provided the optimum context for learning to take place. Like other participants she talked of situations when a professional would talk about a procedure as she was doing it so that she understood better what was happening and drew upon this understanding when carrying out the procedure herself. This type of 'voice over commentary' was described by Vygotsky (1987) as a supportive mechanism in teaching new skills to learners.

Central to this approach is the need to provide reassurance by creating the sense of 'support without presence' or the possibility that collaboration from the professionals is 'invisibly present' while the families are coping with the technical aspects of care at home. Vygotsky (1987) refers to the idea of 'virtual support' or 'invisible support' when describing the way in which a schoolchild solves a problem at home on the basis of a model that he has been shown in class. He claims that it is a solution accomplished with the teacher's help. This aspect of collaboration, Vygotsky maintains, is invisibly present.

It is, therefore, contained in what looks from the outside like the child's independent solution of the problem. This reassurance is similar to that provided by a craftsman who works alongside an apprentice, while at the same time inculcating into the apprentice an ability to anticipate, a sense of what can feasibly occur within specified contexts and an insight into what it means for knowledge to be portable. In the same way, children and parents acquire (or are given) portable knowledge by the nurses when taught to perform technical aspects of the child's care at home. This is designed to empower them to act independently when away from the direct support of the professionals.

In summary, therefore, the preceding section has considered the theoretical implications of the current study. The appropriateness of symbolic interactionism as a theoretical perspective to illuminate the way in which families learn across the disease course has been confirmed. A discussion of the evolving social theory of learning in childhood chronic renal disease has illustrated that the theory develops and extends that proposed by Wenger in 1998. A critique of the theory in relation to current literature on competence development has demonstrated that the current theory extends the concept of empowerment proposed by Gibson (1995) in two distinct ways. First, the current study, unlike Gibson's research, highlighted the fact that a sense of participation in a community of practice involving facilitation by professionals, in particular nurses, was critical to learning and empowerment by children and families. Second, participation can be very effective in fostering both interpersonal and intrapersonal learning by families who must apply their learning in different contexts both at home and in hospital. The following section considers some of the main implications of this research for health care practice.

### ***Implications for practice***

This study contains rich descriptions and interpretations of participants' accounts that may be recognisable to other families and professionals involved in chronic disease management. These may help to increase mutual understanding of the significance of social participation by families and professionals as a process of learning and knowing, and may help professionals to recognise that families are co-learners as well as partners in care. The research has opened the door to ideas that further our understanding of the way in which families learn across the chronic disease course and has highlighted the importance of professionals recognising and valuing the two way process of learning that occurs in child health care. Data from the study indicate three specific aspects of chronic disease management that can influence the way in which families learn. First,



families' learning results not simply from acquisition of a static subject matter, but also from interaction in developing an ongoing practice. Second; competence development is not merely the result of interpersonal or intrapersonal learning but needs to be a combination of both. Finally, learning by children and families involves not just the acquisition of skills but also the formation of identities in the social context of health care where the skills are learned. The implications of these for practice and practitioners can be considered within the two broad areas of relationships in chronic disease management and learning by families in chronic disease, which relate closely to the aims of this study. The following section explores these and then considers some of the implications for practice.

### **Relationships in childhood chronic disease management**

The findings of this study reflect the views and experiences of a cohort of families and professionals associated with a specific group of chronic childhood disorders and a single children's kidney unit where care is managed. Therefore, the conclusions can be transferred to a wider population providing, only that the differences between the two populations are taken into account. However, it is the depth rather than the breadth of the findings that are of most importance for practice. As such, the interpretations placed on the findings may have relevance to the wider population of families and professionals dealing with childhood chronic disease. The current study conceptualises family learning as stressing, not merely acquisition of a static subject matter but interaction between families and professionals in developing an ongoing community of practice in which children can receive optimum care. Supporting children and families in learning about chronic disease management is a challenge for professionals. The longitudinal phase of the study reported in this thesis (phase two) lasted eighteen months and was preceded and informed by an earlier, retrospective phase involving a different sample of children and families who participated in 'one off' interviews. In phase two, moving to a kind of normality meant families making significant efforts to retain the usual aspects of family cultures and adapting to the challenges of the condition. This was especially evident in the accounts of families at times when intervention was moderate or high.

It appears from Kevin's story, for instance, that his family were on a peripheral trajectory within the community of practice of the Children's Kidney Unit for most of the study period. This was partly through his mother's choice. She eventually volunteered the information that she disliked hospitals because of her experience with another hospital many years ago when her father had been very ill. However, Kevin's parents also

believed from their interpretation of interactions with some of the professionals that they were excluded from the community of practice. Wenger (1998) emphasises the importance of newcomers to a community of practice being granted enough legitimacy to be treated as potential members. He points out that in order to be on an inbound trajectory the community must grant newcomers this legitimacy. If the community rejects (or appears to reject) the newcomer for some reason then that person will have a hard time learning. Legitimacy can have many forms and in this study these included situations where families believed themselves to be trusted by professionals because of the way they were positioned by them, or the way in which professionals involved children and parents and worked in partnership with them to negotiate aspects of care. Working in partnership with families is not always easy for professionals (Mountain, 2002). It involves helping, facilitating and enabling the child and parents to make a key contribution to the care and management of the child's health and social care.

Brokering is a common feature of the relation of a community of practice with the outside. Brokers are able to make new connections across communities of practice, and enable coordination. However the job of brokering is complex as it involves processes of translation, coordination and alignment between perspectives. It requires sufficient legitimacy to influence development of a practice, mobilise attention and deal with conflicts of interest (Wenger, 1998). Brokers in particular, are able to connect practices because of their experience of multi-membership and the possibilities for negotiation that are implicit in participation. Therefore, in family centred care brokering often entails ambivalent relations of multi-membership and so requires the ability to manage carefully the complexity of the situation to ensure that there is enough distance between the broker and the community in order to bring a different perspective but also enough legitimacy to be listened to.

There were many examples in the current study where partnerships between professionals and family members were directly associated with an improved quality of life for the child concerned. For instance in chapters 5 and 6, Carol's mother and David's mother described in individual interviews how the family worked with professionals to re-adjust to the demands of the condition on a daily basis, in order to minimise the effect on the child. Carol's parents are separated and her father lived several hundred miles away but her mother stressed that both her and Carol's father tried to retain as many aspects of normal family life as possible in order to support Carol during the disease course. Carol and her mother had described at length the efforts they and the doctors and nurses in the Children's Kidney Unit had made to ensure that positive links with the

school and with her friends were maintained in order that the effects of her condition on her education and friendships were minimised. In contrast, Kevin's mother and stepfather discussed their communication difficulties with professionals in front of Kevin during research interviews, including him in their discussion about this. His mother did not accept my offer of an individual interview and during a short unaccompanied interview with Kevin, he spent most of the time repeating what he had heard his mother saying about her previous communication difficulties in hospitals.

This study suggests, however, that learning is another important dimension of partnership. Because of the complex interweaving between parenting and caring for a chronically ill child, partnership can only really be achieved when the importance of learning is underscored. The two way process of communication is implicit in partnership working but for successful learning to occur within that partnership it requires the active intervention of a broker. In Edward's position, his grandmother acted as broker in order to facilitate the learning of his mother. In some families, such as Lucy's, there were several brokers including members of the nursing staff and her maternal grandmother. Indeed there were many other examples of brokering in the study, in particular brokering by professionals. Since nurses spend more time than other professionals with families in chronic disease management (for instance when listening to, assessing, showing, testing) then it is evident that they are very well placed to adopt the brokering role and help families to become 'insiders' in the communities of practice that comprise the child's health care environment.

The families in this study who demonstrated a pattern of synthesised learning (Carol, Lucy, Nina and David) all identified at least one person, a nurse or doctor who became a broker for their process of empowerment. It was this synthesising of different ideas and influences within a social-ecological approach that led to the new unified whole of synthesised learning and which subsequently supported these families' transition into participatory competence. Wilson (2001) in discussing the Expert Patient Policy (DoH, 2001a) suggests that people with chronic disease may be subtly coerced into self-care and self-management processes in order to prevent deterioration and reduce the demand on resources. In the present study, however, there was no evidence in five of the Cases of families being coerced into self-care although in the sixth study, Kevin's parents' accounts in the first three interviews suggest that they did at times feel coerced. A key message to emerge from this study is that nurses and other professionals can help to promote synthesised learning in child health care by recognising and promoting the value of a broker to act as facilitator of learning. This demonstrates an extension to

Gibson's conceptualisation of participatory competence (Gibson 1995) as a key finding from that study was that most mothers did not have a facilitator to mentor them along their path to empowerment.

Therefore, Gibson recommended nursing interventions directed at facilitating the interpersonal element of empowerment as well as research efforts to understand the process of empowerment in mothers who have such support. It appears that the renal team who participated in this study have already developed such a nursing intervention for supporting families at times of high intervention. Nevertheless, the gap is still evident in relation to families whose care requires low or moderate intervention. Clearly there is a resource issue here, as providing appropriately experienced and trained staff in a specific area is likely to create additional expense. Ongoing debate in practice settings will help to raise awareness of this issue. In addition we need to introduce staff to the concept of brokering in partnership care, during professional education and apply and integrate the concept to the practice setting.

Over time the joint pursuit of an enterprise between most families and professionals created resources for negotiating meaning and a shared repertoire. The practice of families and professionals as they moved along the disease course reflected their attempts to create a negotiated enterprise. Negotiation has been described as a key element of family centred care (Smith *et al.*, 2002a) and previous discussion in this area is adequate but not sufficient as it fails to address the process of learning by families in chronic disease management. If negotiation is to continue to be such a key part of family centred care in the changing context of health care, then to disregard the significance of the way in which families learn risks the possibility that we will understand only part of the picture. In the same way that the boundaries between work and learning are beginning to dissolve for professionals (Boud and Garrick, 1999; Swallow *et al.*, 2004) so too are the boundaries between professional and lay knowledge and roles in child health are changing (Callery, 1997b).

Today, we see children with chronic disease and their families extending their capabilities in self-management. At the same time this creates new opportunities and challenges for professionals who care for them and who share their skills with the families. In this prevailing climate, families' learning has become too important to be left unexplored and an important aspect of their learning in this study was linked to the way in which they created identities for themselves and each other. Identity is something we constantly renegotiate within communities of practice (Wenger, 1998) and as people go

through a succession of forms of participation in communities of practice, their identities form trajectories.

The critique of recent literature on social-ecological perspectives in chronic disease has provided a useful framework within which these findings have been further explored. Conceptual models have been promulgated that consider the complexity and multiple determinants of family life and these aim to be inclusive rather than reductionist (Thompson and Gustafson, 1996). The emerging literature in this area recognises the need to broaden approaches to chronic disease management to include the psychosocial without sacrificing the clear advantages of the biomedical approach. The social-ecological systems-theory perspective of human development (Bronfenbrenner, 1979; 2005) is the most influential in this area and is defined as a study of the relationship between developing humans and the settings and contexts in which they are involved. This theory proposes a series of concentric circles (with the child at the centre) that represent settings that have bidirectional influences on the child. The closer circles represent family and other smaller settings (for instance in this study this would include Kevin's school, Carol's youth club, Lily's mother having a night out with mothers of other chronically ill children) and the more distant circles represent society and cultures (or in this study, for instance, family centred care or the Department of Health).

In this perspective the child was not viewed as a passive recipient of the socialisation processes of the family and the larger environment but as an active participant in shaping his or her own environment. Two major features of the social-ecological theory include:

- Reciprocity-not only does the environment affect the child but the child also affects the environment. This has been typified in Carol's Case when she influenced the decision about when she would begin preparation for her kidney transplant. Nina also demonstrated an ability to influence her immediate environment by coaching her friends in first aid so that they would know how to react if she became unwell when they were out together. Even younger children such as David and Kevin influenced their environment through the actions of their parents who acted as brokers between them and nursing staff when the nurses did not appear to understand what their wishes were at times of moderate or high intervention.

- Transitions, that is successive shifts in role and setting across the life span may have developmental significance (Bronfenbrenner, 1979). For instance Lily's mother demonstrated during repeated research interviews the way in which she made transitions from parallel learning, early in the disease course, through integrated learning to synthesised learning by the time she was discharged home with Lily. During this process she also demonstrated a transition from a peripheral trajectory, through an inbound trajectory to an insider trajectory where her position involved interaction in shared enterprise with professionals.

This corresponds with aspects of the Family Transition Model described by Clarke-Steffan (1993) in relation to family transition in response to the diagnosis of childhood cancer. Clarke-Steffan described a transition that was characterised by a 'fracturing of reality', a period of 'limbo' after the diagnosis and the subsequent use of strategies to 'reconstruct reality' and a 'new normal' for the family. The transition process emerged from a longitudinal study that covered a period of five months following diagnosis of the chronic condition. Clarke-Steffan reports that the transition process continued for the five-month course of the study and extended beyond the study period. All participants in Clarke-Steffan's study had adopted strategies to reconstruct 'new normal' by the end of the five-month study. By this point all children were in a state of remission and while uncertainty about the child's ultimate survival was still present, this had been defined and contained into the outlook on life of family members so that it became more tolerable.

In contrast, professionals only rarely alluded to the nature of relationships. Families enter the professional's domain of practice because of the child's condition, often without even knowing what exactly the condition is, what it entails and what effect it will have on the child and family. Family members may have previous experience as users of the health service and this may influence the assessments they make in a positive or negative direction. Alternatively they may have no such experience so will have fewer preconceived ideas but may have expectations of what will occur based on lay knowledge from a wide range of sources.

Nurses who provided specialist renal support for families requiring moderate or high levels of intervention were often described by adults and children alike rather like a benevolent parent or facilitator. They helped evoke latent strengths, nurture independent action and support autonomous experimentation in un-practiced skills. In the same way, the more participants understand about the condition and its consequences, the more motivated they were to continue to act. The more they continued to act the more

proactive they were. There is considerable resonance between the analysis of family members' accounts in this study and the findings from Kieffer (1984) who drew parallels between the development of relationships with those holding positions of power in community organisations and the confidence and maturity that comes with later childhood. Further support for this understanding of the significance of health care relationships was presented in chapters 6 and 7 in this thesis. There were positive and negative examples.

In assessing each other's ability differing strategies are adopted. In assessing the child's clinical condition, professionals ask questions of the child and family, often quite searching and intimate questions about clinical, social, psychological and economic factors. Clinical assessment, examination and investigation are a source of critical information about the clinical problem. These are also a focus for interaction and a means by which professionals can assess and document their impression of the family's likely ability to learn about the consequences of the condition. The child and family are respondents in the situation at the early stages and have relatively little control over the direction of enquiry. Nevertheless, family members seemed to use every encounter to assess the ability of the professional(s) concerned to care for their child. Relationships between family members and professionals were usually influenced by the early encounters.

Meanwhile, Callery and Smith (1991) examined and compared accounts from senior and junior nurses about their relationships with parents in hospital and found the balance of power to be weighted in the nurses' favour. In particular there was evidence of a pattern of categories of response related to the grade of the respondent. The results suggested a stratification of responses, moving from a tendency for enrolled nurses to describe themselves responding to parents with encouragement, through to staff nurses who described themselves responding with explanations or advice, to ward sisters who responded to parents by negotiating. These relationships may be a function of the roles of the different grades of staff or of their individual characteristics. However, the authors suggested that the direction of movement from encouragement, through explanation/advice to negotiation appeared logical, the movement being from a more rigid set of expectations to a less rigid one.

In summary, the preceding discussion about the importance of interaction between family members and professionals in cultivating a community of practice indicates that psychosocial care in practice should be directed towards the family unit as well as the

child. Negotiation and partnership working are important in enabling families to learn about the complexities of chronic disease. This study offers practitioners telling insights into the worlds of families, therefore, I suggest that staff introduce children and parents slowly to the social positions that individuals (staff and family members) are expected to adopt. In addition, the findings of this study suggest that satisfactory interaction is a critical precursor to the formation of identities in the context of families learning. Thus staff may need to find new ways of balancing the clinical needs of the child with the need for satisfactory interaction with families, including those who do not readily adopt the characteristics of synthesised learning. The implications for practice of families' learning are explored in more detail in the next section.

### **Learning in childhood chronic disease management**

In this study, children and parents' accounts of the way they assessed the ongoing situation mostly demonstrated an expectation that they would be involved in all aspects of care. In the same way that Darbyshire (1994) reported the way in which parents in his study could not contemplate a situation where they did not stay with their sick child in hospital, all parents in this study, whatever level of intervention was required, said that they intended to be fully involved with the child's management and took it for granted that they would be full participants in the child's care. There was little evidence of coercion by professionals and little evidence of reluctance by families. Because of the prevailing philosophy of family centred care in child health care, involvement by families is encouraged as it is usually believed to be in the best interests of the child (Smith *et al.*, 2002a).

Family members in the present study learned to manage the condition by using differing strategies, but a key determining factor in the success of these strategies was whether or not there was a broker involved. In chapter 7 for example, Carol and her mother positively recounted the 'brokering' role of the nurses who taught them about the many technical aspects of Carol's care. Nurses reified the progress being made by Carol and her mother with regard to learning to connect and disconnect peritoneal dialysis in preparation for discharge, by recording the progress in nursing notes. These were retained and taken home by Carol where recording continued jointly between the nurse and Carol's mother. The nurse made entries when she visited the home to monitor the condition, its treatment and the family's progress in managing these. Carol's mother meanwhile maintained a record of peritoneal dialysis progress and noted any



unexpected occurrences. This included the fact that she may have contacted one of the nurses for telephone advice if an unexpected event arose or that she may have made an autonomous decision to deal with such an event herself but maintained a record so that the nurse would be able to assess Carol's clinical and psychological progress, even though she was not present all the time. In this way, the relationship of facilitator/learner was given form (or reified) and this form became a focus for the negotiation of meaning between the family and the health care team who the nurse represented.

For parents and children, being on a learning trajectory was an important part of their identity development for two main reasons. Firstly, most of them appeared to believe that any improvement in their understanding of the condition, the health care setting and the different individuals they encountered would lead to the professionals who care for the child trusting them and helping them to move to an insider trajectory. Secondly, they appeared to believe that identity was something they constantly renegotiated as they moved through the disease course. Thus, being seen as competent to manage peritoneal dialysis at home was a continual challenge to prove to professionals that they were able to deal appropriately with demands of the treatment. Central to helping family members to establish identities and subsequently form trajectories is the activity of brokering. As discussed in the previous section, brokering provided a participative connection between the community of practice of the Children's Kidney Unit and the community of practice that was the family. In this study brokering was often a feature of the role of either a professional (nurse, doctor or dietician) or a family member. This concept will be discussed in more detail in this section in relation to the formation of identities.

In this study, the one reported account of any reluctance to be fully involved was by Kevin's mother (phase two) when she described her difficulty in understanding his medication regime and did not like the assumption by professionals that she could repeat a list of his medications each time she was involved in an outpatient consultation. She was anxious to maintain her role as his mother but not be viewed also as a nurse who held a professional knowledge base. This distinction between personal and professional roles was not so evident in other parents' accounts. It is significant then that unlike the other families in phase two, Kevin's family were found to retain most of the characteristics of parallel learning (for example: Learning was very superficial, Interaction was mostly one way from professional to family, There was mutual engagement in communities of practice) until very near the end of the study when there was a shift towards the pattern of integrated learning. His mother's desire to be viewed primarily as

his mother who did not understand or recall the names of his medications, and not as a nurse, can be interpreted as an example of an act of 'self-positioning' through which one adopts the position of one who is 'helpless'. It may be that she would like to have been empowered to take some responsibility for recalling his medication regime but because she did not have a facilitator or enabler then this did not happen. Shields (1995) found that an internal sense of self emerges during an empowering process that moves people to take action. In addition Shields found that a salient theme of connectedness with the environment ran throughout the empowering process, thus suggesting that mentorship and peer relationships are important. In the absence of a mentor or facilitator Kevin's mother did not demonstrate such connectedness with the environment and did not demonstrate participatory competence as defined by Gibson (1995).

For children with chronic disease and their parents, learning that the child has a chronic disease is often the event that puts an end to one set of uncertainties whilst creating a whole new set of uncertainties. For many families in the current study the disease course began a long time before they were referred to the Children's Kidney Unit and this process will have often exposed the family to interaction at several stages of the disease course. This is just as significant if the condition requires low intervention as it is if the condition requires high intervention. A feature of many chronic conditions that was evident in this study is that the level of intervention can vary across the disease course. While some children's trajectories will start at one stage of the intervention continuum and stay there indefinitely, others will fluctuate across the disease continuum meaning that the amount of interaction between families and professionals will usually fluctuate accordingly. Acquiring the competence to manage the condition in these often unpredictable circumstances was contingent on both intrapersonal and interpersonal learning. The implications of these are discussed in more detail below.

In traditional apprenticeship models, the sponsorship of a master is usually required for apprentices to be able to have access to the practice. If learning through a cognitive apprenticeship model they relied on the expertise of an experienced practitioner facilitating the learner's development into 'communal enterprise'. This approach is regarded by some as little more than the 'sitting by Nellie' model used in nursing education many years ago (Chalmers *et al.*, 2004). However, the success of legitimate peripheral participation in this study is related to the introduction of a novice into a health care setting but also relies upon an expert making explicit the strategies by which the novice can become competent (Lave and Wenger, 1991; Cope *et al.*, 2000). This in turn

helps to foster deeper approaches to learning that according to (Ramsden, 1992:81) are encouraged by:

*Stimulating and considerate teaching, especially teaching which demonstrates the lecturer's personal commitment to the subject matter and stresses its meaning and relevance to the students.*

Kolb (1984) places most emphasis on the process of learning as opposed to the behavioural outcomes and suggests that learning is a continuous process grounded in experience where knowledge is continuously derived from and tested out in the experiences of the learner. The social nature of learning was uncovered by Jerrett (1994) using a phenomenological approach which found that the caregiving experience exposed parents of children with arthritis to learning on many levels. As primary carers they were expected to implement complex treatment plans. The process of coming to know the child's disease was based on the practical knowledge that came from experience of caring for the child at times of illness. These parents, like some of the families in this study, challenged the widely held assumption that the family is a passive recipient of 'expert advice'. Nevertheless, the findings suggested that parents' relationships with professionals were 'far from ideal' (Jerrett 1994:1055).

Professionals use most encounters with children and families to share their own expertise in explicit or implicit ways. Recognising mutual expertise in childhood chronic disease is a critical precursor to learning by families and professionals. It seems unlikely, however, that lay and professional definitions of expertise will concur and this can lead to potential confusion or dissent and may even influence the way in which individuals assess the disease course projection. This in turn may adversely affect the way families learn during the disease course. During research interviews professionals often reflected upon the way they had acquired their present level of expertise.

Parents might be helped to support their child by, for example, acquiring the behavioural skills needed to alleviate their child's anxiety before a medical intervention, or to help the child deal with separations caused by hospitalization. Work with families where one child requires treatment for a chronic disease has demonstrated that the adjustment of well siblings can be affected (Williams *et al.*, 2002) and research with families where one child requires a bone marrow transplantation has shown significant levels of posttraumatic stress in both sibling donors and non-donors. Professionals, however, do often have personal experience of being a health care 'user' and those working in the area of child health may also have experience of parenting and/or knowledge of the user

perspective from discussions with close relatives, friends and acquaintances. Nevertheless, according to Schon, health care professionals hold the superior position in the relationship with patients and tend to carry an aura of certainty associated with their professional knowledge base (Schon, 1987). Staff working with families living with chronic renal disease could help to initiate families into their own communities of practice through explicit introductions to working practices and routines and by regularly reiterating information and checking that family members are aware of their own position in the care of the child.

In summary, consideration of the implications of the social theory of learning in childhood chronic renal disease indicates that staff can become increasingly aware of the fact that learning is not just the acquisition of subject matter but also interaction in developing an ongoing community of practice. Health professional education courses, therefore, should include discussion of the concept of children and families being learners as well as partners in care. In addition, practitioners need to be involved in ongoing discussion about the similarities and differences between learning by families whether a child's condition requires a low, moderate or high level of intervention as well as the importance of recognising the fluctuation between these.

### ***Implications for research***

#### **Strengths and weaknesses of the study**

Despite being unable to achieve the full complement of sample in relation to age at diagnosis and level of intervention this did not have major implications for the study. In future research in this cognitive area there is a need to collect more data from children in age range 11-15 and 4-11 in order to represent the broadest possible range of developmental perspectives. In addition the views of fathers were only represented in 4 families, therefore, further research would benefit by the inclusion of more fathers, especially as the fathers who did take part in the study reported here were found to be very involved in learning about and delivering aspects of care to the child but also often differed from mothers in their assessment of the best way to support the child.

As discussed elsewhere in the thesis, a key strength of the study has been the attention to quality and rigour as has been demonstrated by the use of reflexivity and relationality, in particular in relation to the co-construction of knowledge and meaning with

participants. In addition, the issues of credibility, trustworthiness and transferability have been addressed.

### **Reviewing the aims of the study**

The way in which children and families learned across the disease course from the point of referral into the Children's Kidney Unit has been described as it occurred for participants in this study. The social theory of learning in childhood chronic renal disease comprises three categories or processes that help to illuminate the way in which learning occurred. The core category, interacting, has the ability to account for the considerable variation within the three categories but also has the ability to pull the other categories together to form an explanatory whole of the process of learning. In this way the first aim has been achieved. Implicit in this theory is the significance of interaction and, therefore, the impact of two-way relationships between families and professionals has been highlighted. In this way the second aim has been achieved. The novel findings from this study could be strengthened by further research such as that recommended below:

### **Recommendations for further research**

- Test the theory in other patient groups (chronic renal populations in other centres or other chronic conditions in Newcastle and other centres including a wider range of children's ages) taking the whole family as a unit of analysis.
- Explore differences between mothers and fathers in learning about childhood chronic disease through separate interviews.
- Consider the possible influence of prior educational status of parents and/or children.
- Evaluate the impact of friendship groups on adolescents' learning.
- Conduct more focussed 'case study research' exploring the minutiae of teaching and learning partnerships between nurses and children and/or parents.
- Build on the present study, taking the whole family as the unit of analysis.

New steps are being taken to capture the family as a unit of analysis in childhood chronic disease research. Knafli and Deatrick have a well established programme of research around families' management of their child's chronic disease, with families sometimes being the unit of analysis in studies (Knafli and Deatrick, 1990; Knafli *et al.*, 1996). Hayes (1997) points out that studies such as these contribute significantly to our understanding of family life with a chronically ill child but that even so they only scratch

the surface of what health care professionals and families need to know to design effective care. Researchers and clinicians are reported to be working in relative isolation from each other and Hayes points out that we know very little about how families function. This isolation may be compromising coordinated attempts to develop a knowledge base. The findings from the study reported in this thesis, therefore, contribute an innovative perspective on childhood chronic disease in relation to the way children and families learn to participate in the day-to-day treatment and management of the condition.

### ***Final conclusions***

As discussed in the introduction, my motives for carrying out this stuffy were twofold. I sought to contribute to the knowledge base at a time when boundaries between families and professionals are becoming increasingly blurred, and to enhance my own understanding in clinical practice about the way in which families learn. As a clinician and an academic I have been particularly interested in the way in which nurses can assist or hinder families as they learn. However, I am also fully committed to the concept of team-working and, therefore, recognise that whilst this research was initiated by a nurse, the findings can have relevance to the other professional groups who care for and teach children and families about chronic disease. The conceptualisation of learning amongst families in childhood chronic disease that emerged from this study is distinct from the conceptualisations of learning or competence development that have been depicted in the literature. A pervasive finding of this study was that learning is a fundamentally social phenomenon that is influenced by three main factors. First, families' learning results not simply from acquisition of a static subject matter but also through interaction in developing an ongoing practice. Second, competence development is not merely the result of intrapersonal or interpersonal learning but a combination of the two. Third, learning is not just the acquisition of skills but also involves the formation of identities in a social context where the skills are learned. Further development of the social theory of learning in childhood chronic renal disease and its usefulness in caring for children with chronic renal problems is indicated by this study. The theory helps to explain some of the differences and similarities between families' learning as they move through the course of chronic renal problems and to highlight the significance of relationships between families and professionals in the learning process.

Completing the study has helped to inform my own understanding of the way in which children and families learn in childhood chronic disease and so has answered some of the questions that triggered this study. As Wenger points out in his quotation at the beginning of this chapter '*learning happens, design or no design*'. If we allow learning in childhood chronic disease to happen in an ad hoc manner, with no input into its design, or the design of the infrastructure within which it occurs, we run the risk that care delivery will be negatively affected and that the future of children with chronic disease may be disadvantaged. In striving to improve care for these families, the significance of learning as social participation in health care has previously been overlooked. The social theory of learning in childhood chronic renal disease, therefore, has important implications for all families and health care professionals living and working with chronic disease.

*Appendices*

*Appendix 1: Approval from the Local Research Ethics Committee*



Newcastle and North Tyneside   
Health Authority

JOINT ETHICS COMMITTEE

Newcastle & North Tyneside Health Authority  
University of Newcastle upon Tyne  
University of Northumbria at Newcastle

Benfield Road  
Newcastle  
NE6 4PF

Your Ref:

16 March 2001

Ms V Swallow  
Senior Lecturer  
University of Northumbria at Newcastle  
Coach Lane Campus  
NEWCASTLE UPON TYNE  
NE7 7XA

Dear Ms Swallow

**Learning To Manage Chronic Renal Disease: The Experience Of Children And Families**

(Min Ref: 2001/66)

Your application in respect of this study was considered at the March meeting of the Joint Ethics Committee.

Before reaching a final decision in respect of your application the Committee wished:

- (i) to suggest that the initial approach to subjects should come from Dr Lambert rather than from yourself;
- (ii) to suggest that the Information Sheet should indicate that tapes made at interviews will be erased at the end of the study; and
- (iii) to have your confirmation that this study did not commence in January 2000 as indicated in the protocol.

swallow

tel: (0191) 219.6009  
fax: (0191) 219.6066

In view of delayed responses from some applicants previously experienced by the Committee your reply within three months is requested. Where a response is not received within this period applications will be considered to have lapsed and further consideration of study proposals will require a new application.

Yours sincerely

*A. Taylor*  
*(Committee Coordinator)*  
*pp* Mr W M Ross  
Acting Chairman  
Joint Ethics Committee

Newcastle and North Tyneside   
Health Authority

JOINT ETHICS COMMITTEE

Newcastle & North Tyneside Health Authority  
University of Newcastle upon Tyne  
University of Northumbria at Newcastle

Benfield Road  
Newcastle  
NE6 4PF

Your Ref:

20 March 2001

Ms V Swallow  
Senior Lecturer  
University of Northumbria at Newcastle  
Coach Lane Campus  
NEWCASTLE UPON TYNE  
NE7 7XA

Dear Ms Swallow

**Learning To Manage Chronic Renal Disease: The Experience Of Children And Families**  
(Min Ref: 2001/66)

Thank you for your communication of 19 March addressing the issues identified by the Joint Ethics Committee when it considered your application in respect of this study.

In the light of your response I can now confirm the grant of ethical approval in respect of your research study application.

Yours sincerely

  
(Committee Coordinator)  
 Mr W M Ross  
Acting Chairman  
Joint Ethics Committee

*Appendices*

*Appendix 2: Approval from the Head of Research and Development, Newcastle upon Tyne Hospitals NHS Trust*

**Veronica Swallow**

---

**From:** Mackerness, Craig [Craig.Mackerness@nuth.nhs.uk]  
**Sent:** 18 November 2005 10:10  
**To:** Veronica Swallow  
**Subject:** RE: Appendix 2: Learning to manage chronic renal disease: the experiences of children and families

Dear Vera

Yes, can confirm that we were aware of the project, which has full Trust approval to proceed.

Kind regards

Craig

Dr Craig Mackerness  
Head of Research & Development  
Clinical Research Facility  
4th Floor Leazes Wing  
Royal Victoria Infirmary  
Newcastle upon Tyne  
NE1 4LP  
Phone 0191 282 5213  
Fax 0191 282 0064

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This message has been scanned for viruses and dangerous content by the NorMAN **MailScanner** Service and is believed to be clean.

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09/01/2006

Appendices

Appendix 3: Relationship between levels of intervention, chronic conditions and skills/competencies required by families

| Level of intervention | Typical conditions                   | Skills/competencies required by families   |
|-----------------------|--------------------------------------|--|
| Low intervention      | Vesicoureteric reflux                | <ul style="list-style-type: none"> <li>Communication with professionals</li> <li>Urine collection</li> <li>Negotiating urinalysis with General Practitioner's surgery</li> <li>Giving antibiotics</li> <li>Taking temperature</li> </ul>   |
| Moderate intervention | Steroid Sensitive Nephrotic Syndrome | <ul style="list-style-type: none"> <li>Communication with professionals</li> <li>Testing urine for protein</li> <li>Monitoring fluid intake</li> <li>Monitoring weight</li> <li>Monitoring diet</li> </ul>   |
| High intervention     | End Stage Renal Failure              | <ul style="list-style-type: none"> <li>Communication with professionals</li> <li>Dialysis</li> <li>Peritoneal Dialysis</li> <li>Urinalysis, urine collection</li> <li>Administering Growth Hormone or erythropoietin by injection</li> <li>Managing intravenous therapy, Weight &amp; Dietary monitoring</li> <li>Administering oral medications</li> <li>Regular inpatient/outpatient visits</li> <li>Care after transplantation</li> </ul> |

Appendix 4: Consent form (parents/children)

Headed paper

Addressee

LEARNING ABOUT LONG-STANDING KIDNEY CONDITIONS: THE EXPERIENCES  
OF CHILDREN AND FAMILIES

Even if you do not want to take part, please complete and return this form so that we can update our records. We will not bother you again about this. Deciding not to take part will not affect your child's management in any way.

I have read the attached letter and information leaflet and understand the purpose of the project. I understand that I can withdraw my consent at any time without giving a reason and that doing so will not affect my child's treatment in any way.

\*I am willing to take part in the project

\*I am not willing to take part in the project

(\*cross out which does not apply)

Please complete the following details:

Name .....

Address .....

..... Post Code

Day time telephone number .....

Evening telephone number .....

Suitable/Best time to contact you.....

SIGNATURE ..... DATE .....

PLEASE RETURN THIS FORM IN THE PREPAID ENVELOPE PROVIDED WHETHER  
OR NOT YOU HAVE AGREED TO TAKE PART.

THANK YOU VERY MUCH FOR YOUR HELP

*Appendix 5: Consent form (professionals)*

Headed paper

Addressee

LEARNING ABOUT LONG-STANDING KIDNEY CONDITIONS: THE EXPERIENCES  
OF CHILDREN AND FAMILIES

Even if you do not want to take part, please complete and return this form so that we can update our records. We will not bother you again about this. Deciding not to take part will not affect your child's management in any way.

I have read the attached letter and information leaflet and understand the purpose of the project. I understand that I can withdraw my consent at any time without giving a reason and that doing so will not affect my child's treatment in any way.

- \*I am willing to take part in the project
  - \*I am not willing to take part in the project
- (\*cross out which does not apply)

Please complete the following details:

Name .....

Address .....

..... Post Code

Day time telephone number .....

Evening telephone number .....

Suitable/Best time to contact you.....

SIGNATURE ..... DATE .....

PLEASE RETURN THIS FORM IN THE PREPAID ENVELOPE PROVIDED WHETHER  
OR NOT YOU HAVE AGREED TO TAKE PART.

THANK YOU VERY MUCH FOR YOUR HELP



Appendix 6: Letter to participants (parents/children)

DATE

Dear

Learning to manage long term kidney conditions: the experiences of children and families

We are writing to ask if you are willing to take part in a project currently being carried out jointly between the Children's Kidney Unit at the RVI and the University of Northumbria at Newcastle. We have received approval from the Newcastle and North Tyneside Joint Ethics Committee to conduct the study.

The project will be carried out in two phases; we are writing to ask if you are willing to take part in phase one. Our aim is to learn more about the way in which children and families learn to manage long term kidney conditions. This will provide valuable information to staff caring for children in the UK as well in other countries.

We enclose an information leaflet about the project. If you are willing to help by taking part in phase one, Veronica Swallow, the research Nurse responsible for the study, will contact you to arrange to come and talk to you.

If you would like to ask any questions about the study before you decide whether or not to take part, please contact Veronica on 0191 215 6047.

Please return the enclosed consent form by (date) whether or not you decide to take part. A pre-paid envelope is included, no stamp is needed

Thank you for taking the time to read this.

Yours sincerely

Veronica Swallow  
Research Nurse/  
Senior Lecturer

Heather Lambert  
Consultant Paed/  
Head of Dept

*Appendix 7: Letter to participants (professionals)*

DATE

Dear

Learning to manage long term kidney conditions: the experiences of children and families

We are writing to ask if you are willing to take part in a project currently being carried out jointly between the Children's Kidney Unit at the RVI and the University of Northumbria at Newcastle. We have received approval from the Newcastle and North Tyneside Joint Ethics Committee to conduct the study.

The project will be carried out in two phases; we are writing to ask if you are willing to take part in phase one. Our aim is to learn more about the way in which children and families learn to manage long term kidney conditions. This will provide valuable information to staff caring for children in the UK as well in other countries.

We enclose an information leaflet about the project. If you are willing to help by taking part in phase one, Veronica Swallow, the research Nurse responsible for the study, will contact you to arrange to come and talk to you.

If you would like to ask any questions about the study before you decide whether or not to take part, please contact Veronica on 0191 215 6047.

Please return the enclosed consent form by (date) whether or not you decide to take part. A pre-paid envelope is included, no stamp is needed

Thank you for taking the time to read this.

Yours sincerely

Veronica Swallow  
Research Nurse/  
Senior Lecturer

Heather Lambert  
Consultant Paed/  
Head of Dept

*Appendix 8: Information sheet phase one*

We will arrange an appointment to come and talk to you at a date and time convenient to you. This will take between one and two hours. We will be asking you to tell us about things that were important to you when you were learning to manage the condition.

There are no right or wrong answers. It is your experiences we are interested in. The discussion will be tape recorded but the tapes will be erased at the end of the project. Any information you give will be treated in strict confidence.


---

If you do not wish to take part, this will not affect your management in any way and we will not contact you again about this project.

---

If you would like to discuss any aspect of the study after taking part please contact Veronica Swallow Lead Researcher on 0191 215 6047

Faculty of Health, Social Work & Education

UNIVERSITY of  
NORTHUMBRIA  
at NEWCASTLE  
  
Coach Lane Campus  
Coach Lane  
Benton  
Newcastle upon Tyne  
NE7 7XA

---

## A RESEARCH PROJECT

*Learning to manage chronic  
childhood illness: the experiences  
of children & families*

*Patient Information Sheet for Phase  
One*

---

Department of Paediatric Nephrology  
Royal Victoria Infirmary, Newcastle upon  
Tyne, NE1 4LP  
**and**  
Nursing, Midwifery & Allied Health  
Professionals R&D Unit,  
Northumbria University

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## WHAT IS THE PROJECT?

---

The Project is being carried out jointly, by the Children's Kidney Unit at the Royal Victoria Infirmary, Newcastle upon Tyne and the Nursing Research and Development Unit at the University of Northumbria.

Our aim is to learn more about the issues, which are important to children/young people and families when learning how to manage a long-term kidney condition.

---

---

## WHY IS IT BEING CARRIED OUT?

---

Families often play a very big part in many different aspects of care for children with long term health problems.

Through families and professionals working in partnership, we can ensure that children/young people have the best possible experience of health care.

By listening to families' experiences, we hope to gain information to inform staff when looking after children.

---

---

## WHAT WILL IT INVOLVE?

---

The Project will be carried out in two phases. We are writing to see if you are willing to take part in Phase One – we will talk to children/young people (and/or their parents) who were referred to the RVI with a kidney condition between one and five years ago.

If you agree to take part, we will contact you again soon after you return the consent form.

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*Appendix 9: Information sheet phase two*

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In this way I will be able to learn from you as you gain experience in managing the condition. There are no right or wrong answers. It is your views and experiences we are interested in. Any information you give will be treated in strict confidence.

If it seems appropriate I will also ask your permission to talk to any other person who you think is likely to be very involved in looking after your child/ giving care relating to the condition

I will ask them to tell me what they think are the important areas we need to know about when learning about a long term kidney condition.

---

If you decide you do not wish to take part this will not affect your child's care in any way and we will not contact you again about this project.

If you would like any more information please contact me, Veronica Swallow, Research Nurse on 0191 215 6047 Mon-Fri



**School of Health, Community & Education Studies**

Coach Lane Campus  
Coach Lane  
Benton  
Newcastle upon Tyne  
NE7 7XA

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## A RESEARCH PROJECT

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# LEARNING TO MANAGE LONG TERM KIDNEY CONDITIONS: THE EXPERIENCES OF CHILDREN AND FAMILIES

*Information Sheet for Phase Two*

Children's Kidney Unit,  
Royal Victoria Infirmary,  
Newcastle upon Tyne  
and  
Nursing Research and Development Unit

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## WHAT IS THE PROJECT?

---

The Project is being carried out jointly, by the Children's Kidney Unit at the Royal Victoria Infirmary, Newcastle upon Tyne and the Nursing Research and Development Unit at Northumbria University

Our aim is to learn more about what children and families see as important issues when they are learning to manage a long-term kidney condition.

---

## WHY IS IT BEING CARRIED OUT?

---

Families play a very big part in many different aspects of care for children with long-term conditions.

Through families and professionals working in partnership, we can ensure that children have the best possible experience of health care.

By listening to families' experiences, we hope to gain new information to inform staff when looking after children.

---

## WHAT WILL IT INVOLVE?

---

If you agree to take part, I will arrange to come and talk to you for a short time at a date, time and place convenient to you. This might for instance be arranged to fit in with a clinic visit, or you might prefer to arrange it for another time/place. I will ask you to tell me what you believe are the important things you need to learn and understand about the condition. This is not in any way a test of what you know but simply a chance for us to learn from you about what it is like learning to manage a long term kidney condition. If you agree I would like to talk to you again on one or two occasions over the next year.

---



## *Appendix 10: Summary of topic guides*

Introductions, recap on aims and purpose of study, details of referral/diagnosis, when, how long it took to arrive at diagnosis, who gave information and how; What needed to learn following referral/diagnosis: Technical knowledge e.g. meaning of the condition, treatment and management, disease course projection; Systems knowledge e.g. who's who in the team, how the service operates, what is expected of families, where to go for information/support; Social Knowledge e.g. who's who, how to approach different interactions with professionals, what you do if you feel you are not being listened to; How you approached learning/who assisted you/what they did or said to help this. What you would do differently if you were to embark on this again?; Advice to others in a similar situation.

### **Topic guide children (Adjusted) (phase one)**

Adaptations of topics above according to age and stage of cognitive development.

### **Topic guide families (phase two)**

First interview as phase one plus introduction and exploration of maelstrom effect, intuition and playing the game.

Subsequent interviews development of categories from previous interviews and follow up on developments since previous interview (in 2<sup>nd</sup> interview discuss issues in reflective diary, in 3<sup>rd</sup> interview discuss these in relation to analysis of content).

Explore notions of socialised and situated learning, scaffolding, communities of practice (using appropriate language) in particular how respondent thinks they are learning to manage the condition; Explore categories of assessment, interaction and synthesising.

### **Topic guide professionals (phase two)**

First interview introduction and exploration of maelstrom effect, intuition and playing the game.

Referral/diagnosis, when, how long it took to arrive at diagnosis, who gave information and how.

What family needed to learn following diagnosis: Technical knowledge; Systems knowledge; Social Knowledge.; How you approached teaching/learning/assessment/what you did or said to help this; What, if anything, would you do differently another time?

Subsequent interviews -development of categories from previous interviews and follow up on developments since previous interview; Explore notions of socialised and situated learning, scaffolding, communities of practice (using appropriate language) in particular how respondent thinks family are learning to manage the condition.; Explore categories of assessment, interaction and synthesising.

*Appendix 11: Stages towards participatory competence (Kieffer 1984)*

| Phase                | Characteristics of Phase  |
|----------------------|---|
| Era of Entry         | <ul style="list-style-type: none"> <li>• Entry to the community grassroots organisation preceded by a mobilising episode which has particular significance for the person involved (such as violation of personal property, direct threats to family members).</li> <li>• Commitment to self-reliance, a sense of integrity in their perceived self-identity and daily lives</li> <li>• Participation in the organisation is exploratory, unknowing and unsure</li> <li>• Through awkward initial 'trial and error' efforts participants begin to develop their first sense of themselves as active political beings</li> <li>• The reorientation of self in relation to authority is the central developmental demand and usually follows a 'mobilising episode' and ultimately provokes an empowering response</li> </ul> |
| Era of advancement   | <ul style="list-style-type: none"> <li>• Major aspects of empowering evolution in this phase are the centrality of a mentoring relationship, the enabling impact of supportive peer relationships and cultivation of a more critical understanding of socio-political relations</li> <li>• Often described much like a benevolent parent the enabler helps evoke latent strengths, nurtures independent action and supports autonomous experimentation in un-practiced skills.</li> <li>• The more participants understand the more motivated they are to continue to act, the more they continue to act the more proactive they are - parallels the development of later childhood-</li> <li>• The cultivation of rudimentary strategic capabilities constitute this phase's essential developmental task</li> </ul>       |
| Era of Incorporation | <ul style="list-style-type: none"> <li>• Self concept, strategic ability and critical comprehension substantially mature, similar to adolescence</li> <li>• Participants confront and learn to contend with the permanence and frustration of institutional barriers to self-determination</li> <li>• Organising skills are sharpened, leadership skills are honed and survival skills, of necessity, are constructed</li> <li>• The transition on this phase is reported as being similar to growing up. This transformation ushers participants into a more mature state of empowerment</li> </ul>  |
| Era of commitment    | <ul style="list-style-type: none"> <li>• Those who develop a fully realised participatory competence are those who succeed in reconstructing their sense of mastery and awareness of self in relation to the political world</li> <li>• Participants continue to struggle with integrating new personal knowledge and skill into the reality and structure of their everyday life worlds</li> <li>• In this phase participatory competence attains its adulthood</li> </ul>   |

Appendix 12: Components of the process of empowerment (Gibson 1995)

| Component                  | Characteristics of components   |
|----------------------------|---|
| <i>Discovering reality</i> | <ul style="list-style-type: none"> <li>• <b>Emotional responses:</b> The diagnosis legitimated their concerns but they were bewildered, shocked and confused. Experienced arrange of feelings as part of the process of accepting the situation and realising that crucial aspects of it could not be changed.</li> <li>• <b>Cognitive responses:</b> Sought out as much information as possible and found even distressing information was better than none at all, relied on health care professionals to make the right decisions, initially were recipients of care rather than active participants in their child's care</li> <li>• <b>Behavioural responses:</b> assumed responsibility for the child's health, did not consider any other option. Own feelings of sadness, remorse and anger were channelled into resignation'. Quickly able to discern problems, interpret symptoms and possibly recognise solutions. Frustrations (within the family: mother carrying burden, with health care system; with self) were powerful forces and evoked ongoing cycles of critical reflection</li> </ul> |
| <i>Critical reflection</i> | <ul style="list-style-type: none"> <li>• Escalation of frustrations forced mothers to evaluate themselves and examine situation critically which helped to initiate the empowerment process. Meanwhile developed confidence in own knowledge and abilities to care for their child.</li> <li>• Were self evaluative to determine where difficulties lay, what they could do about them in terms of their attitudes and behaviours.</li> <li>• Employed positive thinking by making downward comparisons which enabled them to see their own situation more favourably</li> <li>• Most converted negative energy into positive energy and problem-solving to make their situation better</li> </ul>  |
| <i>Taking charge</i>       | <ul style="list-style-type: none"> <li>• No longer subordinated their judgements and perspectives to those of others, learned to assert themselves and in so doing their growing sense of confidence was reinforced</li> <li>• Felt compelled to advocate for the child and to deal efficiently with the health care system, for instance by contacting familiar professionals</li> <li>• Learned to write down their questions to ensure they got the information they wanted or enlisted the help of a nurse to help gain information or persevere to get the best care for their child.</li> </ul>   |
| <i>Holding on</i>          | <ul style="list-style-type: none"> <li>• As a result of mothers' awareness of their strengths, competencies and capabilities were able to maintain their own sense of power even during changing circumstances</li> <li>• Through ongoing cycles of critical reflection became cognisant of the dynamics in situations and so tried to be understanding when outcomes were not as anticipated</li> </ul>  |

## References

Abercrombie, N., Hill, S. and Turner, B. S. (1984) *The Penguin Dictionary of Sociology*. Middlesex, UK: Penguin Books.

Alderson, P. (1990a) *Choosing for Children: Parents' Consent to Surgery*. Oxford: Oxford University Press.

Alderson, P. (1990b) 'Parents and Paediatric Anaesthesia - a Prospective Survey of Parental Attitudes to Their Presence at Induction', *Annals of the Royal College of Surgeons of England*, 72(4) Jul, pp. 272-272.

Alderson, P. (1997) 'Children as research subjects: Science, ethics and law', *Nursing Ethics*, 4(2) Mar, pp. 174-176.

Alderson, P. (2005) 'Designing ethical research with children', in Farrell, A. (ed.) *Ethical Research with Children*. Maidenhead: Open University Press.

Allen, R. E. (1990). *Oxford English Dictionary*. Oxford, Clarendon Press.

Allmark, P. (2002) 'The ethics of research with children', *Nurse Researcher*., 10(2) pp. 7-19.

Alsop-Shields, L. (2002) 'The Parent-staff Interaction Model of Pediatric Care', *International Pediatric Nursing*, 20 pp. 113-117.

Anderson, B. and Hall, B. (1995) 'Parents' perceptions of decision making for children', *The Journal of Law, Medicine and Ethics*, 23(1) p. 15.

Argyris, C. and Schon, D. A. (1978) *Organisation Learning: A Theory of Action Perspective*. Reading, MA: Addison-Wesley.

Arthur, V. A. M. (1995) 'Written patient information: A review of the literature', *Journal of Advanced Nursing*, 21, pp. 1081-1086.

Atkin, K. and Ahmad, W. I. U. (2000) 'Family care-giving and chronic illness: how parents cope with a child with a sickle cell disorder or thalassaemia', *Health & Social Care in the Community*, 8(1) Jan, pp. 57-69.

Atkinson, T. and Claxton, G. (2000). *The Intuitive Practitioner: On the value of not always knowing what one is doing*. Maidenhead, Berkshire, Open University Press.

## References

Audit-Commission (1993) *What seems to be the matter: communication between hospital and patients*. London: HMSO

Audit-Commission (2003) *Services for disabled children. A review of services for disabled children and their families*. London: Audit Commission

Aynsley-Green, A. (2000) 'Who is speaking for children and adolescents and for their health at the policy level?' *British Medical Journal*, 321 pp. 229-232.

Backett, K. and Alexander, H. (1991) 'Talking to young children about health: methods and findings', *Health Education Journal*, 50(1) pp. 34-38.

Bandura, A. (1997) *Self efficacy: The exercise of control*. New York: W H Freeman.

BAPN (1995) *The provision of services in the UK for children & adolescents with renal disease*. London: British Association for Paediatric Nephrology

BAPN (2002) *Registry Report*. London: British Association of Paediatric Nephrology

Barlow, J., Harrison, K. and Shaw, K. (1998) 'The experiences of parenting in JCA', *Clinical Child Psychology & Psychiatry*, 3(3) pp. 445-463.

Barnett, R. (1994) *The Limits of Competence*. Buckingham: The Society for Research into Higher Education and Open University Press.

Bartlett, E. E. (1984) 'Effective approaches to patient education for the busy paediatrician', *Pediatrics*, 74(920-923).

Beauchamp, T. L. and Childress, J. F. (1994) *Principles of Biomedical Ethics*. Oxford: Oxford University Press.

Becker, P. (1993) 'Common pitfalls of published grounded theory research', *Qualitative Health Research*, 3(2) pp. 254-260.

Becker, P. T. (2002) 'Family centred care: Concept, theory and practice', *Journal of Advanced Nursing*, 40(6) Dec, pp. 747-747.

Beckett, D. (1999) 'Past the guru and up the garden path: the new organic management learning', in Boud, D. and Garrick, J. (eds.) *Understanding Learning at Work*. London: Routledge.

## References

Beecher, H. (1966) 'Ethics and clinical research', *New England Journal of Medicine*, 274 pp. 1354-1360.

Benoliel, J. Q. (1996) 'Grounded Theory and Nursing Knowledge', *Qualitative Health Research*, 6(3) pp. 406-428.

Beresford, B. (1996) 'Coping with the care of a severely disabled child', *Health and Social Care in the Community*, 4(1) pp. 30-40.

Beresford, B. A. and Sloper, P. (2003) 'Chronically ill adolescents' experiences of communicating with doctors: a qualitative study', *Journal of Adolescent Health*, 33(3) 2003/9, pp. 172-179.

Blaikie, N. (1993) *Approaches to Social Enquiry*. Cambridge: Policy Press.

Blumer, H. (1969) *Symbolic Interactionism: Perspective and Method*. New Jersey: Prentice-Hall.

BMA (2001) *Consent: Rights and Choices in Health Care for Children and Young People*. London: BMJ Books.

BMJ (1996) 'The Nuremberg Code', *British Medical Journal*, 313 p. 1448.

Bond, J. and Bond, S. (1986) *Sociology and Health Care: An Introduction for Nurses and Other Health Care Professionals*. New York: Churchill Livingstone.

Boud, D. and Garrick, J. (1999). *Understanding Learning at Work*. London, Routledge.

Boud, D. and Solomon, N. (2001). *Work-based Learning A New Higher Education?* Buckingham, The Society for Research into Higher Education and Open University Press.

Bourgue, T. D. and Crompton, J. L. (1982) 'Time sampling as a field technique', in Burgess, R. G. (ed.) *Field Research: A sourcebook and Field Manual*. London: Allen and Unwin.

Bowlby, J. (1953) 'Some pathological processes set in train by early mother-child separation', *Journal of Mental Science*, 99 pp. 267-272.

Bowling, A. (2002) *Research Methods in Health: Investigating Health and health services*. Buckingham: Open University Press.

## References

- Boyd, M. D. (1987) 'A guide to writing effective patient education materials', *Nursing Management*, 18 pp. 56-57.
- Boyle, C., Decoufle, P. and Yeargin-Allsopp, Y. (1994) 'Health Impact of developmental disabilities in US Children', *Pediatrics*, 93(3) pp. 399-403.
- Bradford, R. (1991) 'Staff accuracy in predicting the concerns of parents of chronically ill children', *Child : Care Health and Development*, 17 pp. 39-47.
- Bradford, R. (1997) *Children, families and chronic disease: psychological models and methods of care*. London: Routledge.
- Breitmayer, B. J., Gallo, A. M., Knafl, K. A. and Zoeller, L. H. (1992) 'Social Competence of School-Aged Children with chronic illnesses', *Journal of Paediatric Nursing*, 7(3) pp. 181-188.
- Bridgeman, J. (1999) 'How do nurses learn about family-centred care?' *Paediatric Nursing*, 11(4) pp. 26-29.
- Bronfenbrenner, U. (1979) *The ecology of human development*. Cambridge, MA: Harvard University Press.
- Bronfenbrenner, U. (2005) *Making Human Beings Human: Biological Perspectives on Human Development*. Thousand Oaks.
- Brykczynska, G. (1994) 'Implications of the Clothier Report: the Beverly Allitt case', *Nursing Ethics*, 1(3) pp. 179-181.
- Bryman, A. (1988) *Quantity and quality in social research*. London & New York:: Routledge.
- Bryman, A. and Burgess, R. G. (1994). *Analyzing Qualitative Data*. London, Routledge.
- Buckens, P. and Boerma, J. (2001) 'Maternal and child health', in Coop, C., Pearson, C. and Schwarz, M. (eds.) *Critical Issues in Global Health*. Jossey Bass: San Francisco, pp. 196-202.
- Burke, S. O. (1999) 'Assessment of stressors in families with a child who has a chronic condition', *MCN, The American Journal of Maternal/Child Nursing*, 2498-106, p. 2.

## References

Burke, S. O., Harrison, M. B., Kauffmann, E. and Wong, C. (2001) 'Effects of stress-point intervention with families of repeatedly hospitalized children', *Journal of Family Nursing*, 7(2) May, pp. 128-158.

Burnard, P. (1985) *Learning Human Skills : A guide for nurses*. London: Heinemann.

Burton, L. (1975) *The family life of sick children*. London and Boston: Routledge & Kegan Paul.

Bury, M. (1982) 'Chronic illness as biographical disruption', *Sociology of health and illness*, 4( 2) pp. 167-182.

Bury, M. (1991) 'The sociology of chronic illness: a review of research and prospects', *Sociology of health and illness*, 13(4) pp. 451-468.

Callery, P. (1997a) 'Caring for parents of hospitalized children: a hidden area of nursing work', *Journal of Advanced Nursing*, 26(5) Nov, pp. 992-998.

Callery, P. (1997b) 'Maternal knowledge and professional knowledge: Co-operation and conflict in the care of sick children', *International Journal of Nursing Studies*, 34(1) Feb, pp. 27-34.

Callery, P. (1997c) 'Paying to participate: financial, social and personal costs to parents of involvement in their children's care in hospital', *Journal of Advanced Nursing*, 25 pp. 746-752.

Callery, P., Milnes, L., Verduyn, C. and Couriel, J. (2003) 'Qualitative study of young people's and parents' beliefs about childhood asthma', *British Journal of General Practice*, 53(488) Mar, pp. 185-190.

Callery, P. and Smith, L. (1991) 'A Study of Role Negotiation between Nurses and the Parents of Hospitalized Children', *Journal of Advanced Nursing*, 16(7) Jul, pp. 772-781.

Canam, C. (1993) 'Common Adaptive Tasks Facing Parents of Children with Chronic Conditions', *Journal of Advanced Nursing*, 18(1) Jan, pp. 46-53.

Carter, B. D., Urey, J. R. and Eid, N. S. (1992) 'The chronically ill child and family stress: family developmental perspectives on cystic fibrosis', *Psychosomatics*, 33 pp. 397-403.

Casey, A. (1995) 'Partnership Nursing - Influences on Involvement of Informal Carers', *Journal of Advanced Nursing*, 22(6) Dec, pp. 1058-1062.



## References

- Caughey, D. (1989) 'Patient communication and effective rheumatology', *Journal of Rheumatology*, 16 pp. 5-6.
- Chalmers, H., Swallow, V. and Miller, J. (2004) 'The theoretical perspective of work based learning', in Swallow, V., Chalmers, H. and Miller, J. (eds.) *Partnerships in work based learning*. Newcastle upon Tyne: Northumbria University Press.
- Charmaz, K. (1983) 'Loss of self: a fundamental form of suffering in the chronically ill', *Sociology of health and illness*, 5 pp. 168-195.
- Charmaz, K. (1990) "Discovering' chronic illness: Using grounded theory', *Social Science and Medicine*, 30 pp. 1161-1172.
- Chenitz, W. C. and Swanson, J. M. (1986) *From Practice to Grounded Theory: qualitative Research in Nursing*. Menlo Park, California: Addison-Wesley.
- Clark, P. and Bowling, A. (1989) 'Observational study of quality of life in NHS nursing homes and a long stay ward for the elderly', *Ageing and Society*, 9 pp. 123-148.
- Clarke, C. (1995) *Who needs problems? : finding meaning in caregiving for people with dementia*. University of Northumbria
- Clarke, C., Reed, J., Wainwright, D., McClelland, S., Swallow, V., Harden, J. and Walsh, A. (2004) 'The discipline of improvement: something old, something new?' *Journal of Nursing Management*, 12 pp. 85-96.
- Clarke-Steffan, L. (1993) 'A Model of the Family Transition to Living with Childhood Cancer', *Cancer Practice*, 1(4) pp. 285-292.
- Clarke-Steffan, L. (1997) 'Reconstructing reality: family strategies for managing childhood cancer', *Journal of Paediatric Nursing*, 12(5) pp. 278-287.
- Clawson, J. A. (1996) 'A child with chronic illness and the process of family adaptation', *Journal of Paediatric Nursing*, 11(1) pp. 52-61.
- Cocks, A. (2000) 'Respite care for Disabled Children: micro and macro reflections', *Disability and Society*, 15(3) pp. 507-519.
- Coffield, F. (2000). *Differing Visions of a Learning Society: Research Findings Volume 2*. Bristol, The Policy Press.

## References

- Cohen, M. H. (1993) 'Diagnostic closure and the spread of uncertainty', *Issues in Comprehensive Pediatric Nursing*, 16 pp. 135-146.
- Cohen, M. H. (1995) 'The triggers of heightened parental uncertainty in chronic life threatening childhood illness', *Qualitative Health Research*, 5 pp. 63-77.
- Cohen, M. H. (1997) 'The stages of prediagnostic period in chronic life threatening childhood illness: a process analysis.' *Research in Nursing and Health*, 18 pp. 39-48.
- Coleman, V. (2002a) 'Empowerment: Rhetoric, Reality and Skills', in Smith, L., Coleman, V. and Bradshaw, M. (eds.) *Family-Centred Care*. Basingstoke: Palgrave.
- Coleman, V. (2002b) 'The evolving concept of family-centred care', in Smith, L., Coleman, V. and Bradshaw, M. (eds.) *Family-centred care*. Basingstoke: Palgrave.
- Compass, B., Worsham, N. L. and Ey, S. (1992) 'Conceptual and developmental issues in children's coping with stress', in LaGreca, A. M. S., Wallander, L. J. and Walker, J. L. (eds.) *Stress and Coping in Child Health*. New York: The Guildford Press.
- Conrad, P. (1987) 'The experience of illness: recent and new directions', in Roth, J. A. and Conrad, P. (eds.) *Research in the Sociology of Health Care*. Greenwich: Conn:Jai Press, pp. 1-31.
- Conrad, P. (1990) 'Qualitative research on chronic illness: a commentary on method and conceptual development.' *Social Science and Medicine*, 30 pp. 1257-1263.
- Cooper, C. (1999) *Continuing care of sick children: Examining the impact of chronic illness*. Salisbury: Quay Books.
- Cope, P., Cuthbertson, P. and Stoddart, B. (2000) 'Situated learning in the practice placement', *Journal of Advanced Nursing*, 31(4) Apr, pp. 850-856.
- Copeland, L. G. (1993) 'Caring for children with chronic conditions: model of critical times', *Holistic Nursing Practice*, 8 pp. 45-55.
- Copeland, L. G. and Clements, D. B. (1993) 'Parental perceptions and support strategies in caring for a child with a chronic condition', *Issues in Comprehensive Pediatric Nursing*, (16) pp. 109-121.
- Corbin, J. and Strauss, A. L. (1987) 'Accompaniments of chronic illness: changes in body, self, biography and biographical time.' *Research in the Sociology of Health Care*, 6 pp. 249-281.

## References

- Corbin, J. M. (1998) 'The Corbin and Strauss Chronic Illness Trajectory Model: An Update', *Scholarly Inquiry for Nursing Practice*, 12(1) pp. 33-41.
- Corbin, J. M. and Strauss, A. (1991) 'A nursing model for chronic illness management based upon the trajectory framework.' *Scholarly Inquiry for Nursing Practice*, 5 pp. 155-174.
- Cormack, D. (2000) *The Research Process in Nursing*. 4th edn. Oxford: Blackwell.
- Cottrell, S. (2001) *Teaching Study Skills and Supporting Learning*. Basingstoke: Palgrave.
- Coulthard, M. G. and Crosier, J. (2002) 'Outcome of reaching end stage renal failure in children under 2 years of age', *Arch Dis Child*, 87(6) December 1, 2002, pp. 511-517.
- Court, S. D. M. (1976) *Report of the Committee on Child Health Services*. London: HMSO
- Cowan, F. J., Warner, J. T., Lowes, L. M., Riberio, J. P. and Gregory, J. W. (1997) 'Auditing paediatric diabetes care and the impact of a specialist nurse trained in paediatric diabetes', *Archives of Disease in Childhood*, 77(2) August 1, 1997, pp. 109-114.
- Cox, S. (1994) 'How I coped emotionally with diabetes in my family', *Professional Care of Mother and Child*, 4(5) pp. 139-141.
- Coyne, I. T. (1995) 'Parental Participation in Care - a Critical-Review of the Literature', *Journal of Advanced Nursing*, 21(4) Apr, pp. 716-722.
- Coyne, I. T. (1996) 'Parent participation: A concept analysis', *Journal of Advanced Nursing*, 23(4) Apr, pp. 733-740.
- Coyne, I. T. (1998) 'Researching children: some methodological and ethical considerations', *Journal of Clinical Nursing*, 7(5) Sep, pp. 409-416.
- Craft, A. (2004) 'Children with complex health care needs - supporting the child and family in the community', *Child Care Health and Development*, 30(3) pp. 193-194.
- Crawford, D. (1992) 'Putting parents in the picture', *Nursing Times*, 88 pp. 41-42.
- Crotty, M. (1996) *Phenomenology and Nursing Research*. Melbourne: Churchill Livingstone.

## References

- Cunningham, C. and Davis, H. (1985) *Working with parents: Frameworks for Collaboration*. Milton Keynes: Open University Press.
- Darbyshire, P. (1989) 'Communication and Medical-Practice - Social-Relations in the Clinic - Silverman,D', *Journal of Advanced Nursing*, 14(6) Jun, pp. 510-510.
- Darbyshire, P. (1990) 'The Clinical Nurse Specialist in Theory and Practice', *Journal of Advanced Nursing*, 15(2) Feb, pp. 241-241.
- Darbyshire, P. (1993) 'Parents, Nurses and Pediatric Nursing - a Critical-Review', *Journal of Advanced Nursing*, 18(11) Nov, pp. 1670-1680.
- Darbyshire, P. (1994) *Living with a sick child in hospital: The experiences of parents and nurses*. London: Chapman and Hall.
- Darbyshire, P. (1995) 'Family centred care within contemporary British paediatric nursing', *British Journal of Nursing*, 4(1) pp. 31-33.
- Davies, B. and Harre, R. (1990) 'Positioning: The discursive production of selves', *Journal for the Theory of Social Behaviour*, 20(1) pp. 43-63.
- Davies, B. and Harre, R. (1999) 'Positioning and personhood', in Harre, R. (ed.) *L van-Langenhove*. Oxford: Blackwell.
- Davies, D. and Zerchykov, R. (1978) *Citizen participation in Education*. Boston: Institute for Responsive Education.
- Deatrick, J. A., Dickey, S. B., Wright, R., Beidler, S. M., Cameron, M. E., Shimizu, H. and Mason, K. (2003) 'Correlates of Children's Competence to Make Healthcare Decisions', *The Journal of Medical Ethics*, 14(3) pp. 152-163.
- Denzin, N. K. (1989) *The Research Act: A Theoretical Introduction to Sociological Methods*. Englewood Cliffs: Prentice Hall.
- Desguin, B. W., Holt, I. J. and McCarthy, S. M. (1994) 'Comprehensive care of the child with a chronic condition. Part 2-Primary Care Management', *Current Problems in Pediatrics*, 24 pp. 230-248.
- Dewar, B. J. and Walker, E. (1999) 'Experiential learning: issues for supervision', *Journal of Advanced Nursing*, 30(6) pp. 1459-1467.

## References

Dewey, J. (1938) *Experience & Education*. New York: Touchstone.

DfES (2003) *The Victoria Climbié Inquiry: Report of an Inquiry by Lord Laming*. London: Department for Education and Skills

Dibben, M. R. and Lean, M. E. J. (2003) 'Achieving compliance in chronic illness management: illustrations of trust relationships between physicians and nutrition clinic patients', *Health, Risk & Society*., 5(3) Nov, pp. 241-258.

DoH (1987) *The Family Law Reform Act*. London: The Stationery Office

DoH (1989) *The Children Act*. London: The Stationery Office

DOH (1991) *The Patients' Charter*. London: Department of Health

DoH (1996) *The Patient's Charter: Services for Children and Young People*. London: HMSO

DoH (1997a) *The New National Health Service : Modern, Dependable*. London: The Stationery Office

DoH (1997b) *Third report health services for children and young people in the community home and school report, together with annexes and the proceedings of the Committee*. London: The Stationery Office

DoH (2001a) *The Expert Patient: a New Approach to Chronic Disease Management for the 21st Century*. London: Department of Health

DoH (2001b) *Report of the Inquiry into Children's Heart Surgery at the Bristol Royal Infirmary (Kennedy Report)*. London: Department of Health

DoH (2001c) *Research Governance Framework for Health and Social Care*. London: Department of Health

DoH (2004) *The National Service Framework for Renal Services (Part One) Dialysis and Transplantation*. London: Department of Health

DoH/DfES (2004) *Every Child Matters-National Service Framework for Children, Young People and Maternity Services*. Nottingham: Department for Education and Skills

## References

Douglas, J. (1976) *Investigative Social Research: individual and Team Field Research*. Beverley Hills, CA: Sage Publications.

Dreyfus, H. and Dreyfus, S. (1985) *The power of human intuition and expertise in the era of the computer*. New York: Free Press.

Duffy, M. E. (1987) 'Methodological triangulation: a vehicle for merging quantitative and qualitative research methods', *Image the Journal of Nursing Scholarship*, 19 pp. 130-133.

Eiser, C. (1986) 'Issues in the Care of Children with Chronic Illness -', *British Journal of Medical Psychology*, 59Dec, pp. 393-393.

Eiser, C. (1990) *Chronic Disease: An Introduction to Theory and Research*. Cambridge: Cambridge University Press.

Eiser, C. (1993) *Growing up with a Chronic Disease*. London: Jessica Kingsley Publishers.

Eiser, C. (2001) 'Long term consequences of surviving childhood cancer', *Psycho-Oncology*, 10(4) Jul-Aug, p. A13.

Eiser, C. and Havermans, T. (1992) 'Mothers and Fathers Coping with Chronic Childhood-Disease', *Psychology & Health*, 7(4) pp. 249-257.

Eiser, C., Kopel, S., Cool, P. and Grimer, R. (1999) 'The Perceived Illness Experience Scale (PIE): reliability and validity revisited', *Child Care Health and Development*, 25(3) May, pp. 179-190.

Eiser, C. and Morse, R. (2001) 'A review of measures of quality of life for children with chronic illness', *Archives of Disease in Childhood*, 84(3) Mar, pp. 205-211.

Eraut, M. (1994) *Developing Professional Knowledge and Competence*. London: Falmer Press.

Eraut, M. (1997) 'The challenge of competence: Professionalism through vocational education and training', *Studies in Higher Education*, 22(1) Mar, pp. 99-103.

Eraut, M. (2000) 'Non-formal learning and tacit knowledge in professional work', *British Journal of Educational Psychology*, 70 pp. 113-136.

## References

- Erikson, E. H. (1950) *Childhood and Society*. 2nd(Rev 1963) edn. New York: WW Norton.
- Etzioni, A. (1969) *The Semi-professions and their Organisations*. New York: Free Press.
- Evans, M. (1994) 'An investigation into the feasibility of parental participation in the nursing care of their children', *Journal of Advanced Nursing*, 20 pp. 477-482.
- Ewles, L. and Simnett, I. (1999) *Promoting Health: A Practical Guide*. 4th edn. London: Bailliere Tindall.
- Faux, S., Walsh, M. and Deatrck, J. (1988) 'Intensive interviewing with children and adolescents', *Western Journal of Nursing Research*, 10(2) pp. 180-194.
- Feeg, V. D. and Hunter, J. (2002) 'British Paediatric nurses and American Pediatric nurses: how well do we know each other?' *Journal for Specialists in Pediatric Nursing*, 7(1) pp. 16-23.
- Fielding, D. (1985) 'Chronic Illness in Children', in Watts, F. (ed.) *New Perspectives in Clinical Psychology*. Leicester: British Psychological Society Books.
- Florian, V. and Krulik, T. (1991) 'Loneliness and social support of mothers of chronically ill children', *Social Science and Medicine*, 32 pp. 1291-1296.
- Foley, P. (2001) 'The development of child health and welfare services in England (1900-1948)', in Foley, P., Roche, J. and Tucker, S. (eds.) *Children in Society*. Basingstoke: Palgrave.
- Fraley, A. M. (1990) 'Chronic sorrow: a parental response', *Journal Of Pediatric Nursing*, 5(4) pp. 268-273.
- Franck, L. S. and Callery, P. (2004) 'Re-thinking family-centred care across the continuum of children's healthcare', *Child Care Health and Development*, 30(3) May, pp. 265-277.
- Franz, T. T., Lawrence, J. C., Somov, P. G. and Somova, M. J. (1999) 'Factors in hospice patients length of stay', *American Journal of Hospice & Palliative Care*, 16(2) pp. 449-454.
- Gallo, A. M., Breitmayer, B. J., Knafl, K. A. and Zoeller, L. H. (1993) 'Mothers' perceptions of sibling adjustment and family life in childhood chronic illness', *Journal Of Pediatric Nursing*, 8(5) pp. 318-324.

## References

Gallo, A. M. and Knafl, K. A. (1998) 'Parents' reports of "tricks of the trade" for managing childhood chronic illness', *Journal of the Society of Pediatric Nurses*, 3(3) pp. 93-100.

Gibbs, G. (1992) *Improving the quality of student learning*. Bristol: Tech & Ed Services Ltd.

Gibson, C. H. (1995) 'The Process of Empowerment in Mothers of Chronically Ill Children', *Journal of Advanced Nursing*, 21(6) Jun, pp. 1201-1210.

Gibson, C. H. (1999) 'Facilitating critical reflection in mothers of chronically ill children', *Journal of Clinical Nursing*, 8(3) May, pp. 305-312.

Giddens, A. (1979) *Central problems in Social Theory: Action, Structure and Contradiction in Social Analyses*. Berkeley: University of California Press.

*Gillick v West Norfolk & Wisbech Area Health Authority Gillick* 1986

Gittell, M., Hoffacker, B., Rollins, E. and Foster, S. (1979) *Citizen organisations: Citizen participation in educational decision making*. Boston: Institute for Responsive Education.

Glaser, B. G. (1978) *Theoretical Sensitivity*. Mill Valley, California: Sociology Press.

Glaser, B. G. and Strauss, A. L. (1967) *The Discovery of Grounded Theory: Strategies for Qualitative Research*. New York: Aldine de Gruyter.

Glasper, E. A. and Ireland, L. (1997) 'Is the quest for evidence-based care detrimental to children's nursing?' *British Journal of Nursing*, 6(21) pp. 1253-1255.

Goffman, E. (2003) *Impression management: the presentation of self in everyday life*. New York: Free Press.

Grave, M. E. and Walsh, D. J. (1998) *Studying Children in Context: Theories, Methods and Ethics*. London: Sage Publications.

Gravelle, A. (1997) 'Caring for a child with a progressive illness during the complex chronic phase: parents' experience of facing diversity', *Journal of Advanced Nursing*, 25 pp. 738-745.

Grey, D. E. (1993) 'Perceptions of stigma: parents of autistic children', *Sociology of Health & Illness*, 15(1) pp. 103-120.



## References

- Grey, M. and Thurber, F. W. (1991) 'Adaptation To Chronic Illness In Childhood: Diabetes Mellitus.' *Journal Of Pediatric Nursing*, 6 pp. 302-309.
- Griffiths, C., Foster, G., Barnes, N., Eldridge, S., Tate, H., Begum, S., Wiggins, M., Dawson, C., Livingstone, A. E., Chambers, M., Coats, T., Harris, R. and Feder, G. S. (2004) 'Specialist nurse intervention to reduce unscheduled asthma care in a deprived multiethnic area: the east London randomised controlled trial for high risk asthma (ELECTRA)', *BMJ*, 328(7432) January 17, 2004, pp. 144-.
- Gross, J. G. and Howard, M. (2001) 'Mothers' Decision-Making Processes Regarding Health Care for Their Children', *Public Health Nursing*, 18(3) pp. 1525-1446.
- Guba, E. G. and Lincoln, Y. S. (1989) *Fourth generation evaluation*. Newbury Park: Sage.
- Hagenhoff, B. D., Feutz, C., Conn, V. S., Sagehorn, K. K. and Moranville-Hunziker, M. (1994) 'Patient Education Needs As Reported By Congestive Heart Failure Patients And Their Nurses.' *Journal of Advanced Nursing*, 19 pp. 685-690.
- Hagenhoff, B. D., Feutz, C., Conn, V. S., Sagehorn, K. K. and Moranvillehunziker, M. B. (1994) 'Patient Education Needs as Reported by Congestive-Heart-Failure Patients and Their Nurses', *Journal of Advanced Nursing*, 19(4) Apr, pp. 685-690. [Online] Available at <Go to ISI>://A1994ND76600010
- Hall, W. A. and Callery, P. (2001) 'Enhancing the rigor of grounded theory: Incorporating reflexivity and relationality', *Qualitative Health Research*, 11(2) Mar, pp. 257-272.
- Hammersley, M. and Atkinson, P. (1995) *Ethnography: Principles in Practice*. 2nd edn. London: Routledge.
- Harper, M. and Hartman, N. (1997) 'Research paradigms', in Smith, P. (ed.) *Research mindedness for practice: an interactive approach for nursing and health care*. London: Churchill Livingstone.
- Harre, R. and Van-Langenhove, L. (1976) 'Varieties of Positioning', in Harre, R. and Secord, P. F. (eds.) *The explanation of social behaviour*. Oxford: Blackwell.
- Harre, R. and van-Langenhove, L. (1999) 'The dynamics of social episodes', in Harre, R. and van\_Langenhove, L. (eds.) *Positioning theory: moral contexts of intentional action*. Oxford: Blackwell.
- Hayes, V. (1997) 'Families and Children's Chronic Conditions: Knowledge Development and Methodological Considerations', *Scholarly Inquiry for Nursing Practice: An International Journal*, 11(4) pp. 259-290.

## References

- Hendrick, H. (1990) *Child Welfare England 1872-1898*. London: Routledge.
- Hetherington, E. and Parke, R. (1986) *Child Psychology: a Contemporary viewpoint*. 3rd edn. New York: McGraw Hill.
- Hilton, B. A. (1992) 'Perception Of Uncertainty: Its Relevance To Life-Threatening And Chronic Illness', *Critical Care Nurse*, 12 pp. 70-73.
- HMSO (2004a) *Child Poverty Review*. London: The Stationery Office
- HMSO (2004b) *The Children's Bill*. London: The Stationery Office
- Hoffman, M. A., Levy-Shiff, R., Sohlberg, S. and Karishif (1992) 'The Impact of stress and coping: developmental changes in the transition to adolescence', *Journal of Youth and Adolescence*, 21 pp. 451-469.
- Holloway, I. (1997) *Basic concepts for Qualitative Research*. Oxford: Blackwell Science.
- Holloway, W. (1984) 'Gender difference and the production of subjectivity', in Henriques, J., Holloway, W., Urwin, C., Venn, L. and Walkerdine, V. (eds.) *Changing the subject: Psychology, Social Regulation and Subjectivity*. London: Methuen.
- Holstein, J. and Gubrium, J. (1997) 'Active interviewing', in Silverman, D. (ed.) *Qualitative Research: Theory, Method and Practice*. London: Sage.
- Horner, S. D. (1997) 'Uncertainty in mothers care for their ill children', *Journal of Advanced Nursing*, 26(4) pp. 658-663.
- Horowitz, M. J. and Kaltreider, N. B. (1980) 'Brief psychotherapy of stress response syndromes', in Karasu, T. and Bellak, L. (eds.) *Specialised techniques in individualised psychotherapy*. New York: Brunner/Mazel.
- Hutchfield, K. (1999) 'Family-centred care: a concept analysis', *Journal of Advanced Nursing*, 29(5) pp. 1178-1187.
- Hutchins, E. (1995) *Cognition in the Wild*. Cambridge, MA: MIT Press.
- Hutchinson, S. A. (1992) 'Nurses who violate the Nurse Practice Act: transformation of Professional Identity', *Image the Journal of Nursing Scholarship*, 24(2) pp. 133-139.

## References

Hutchinson, S. A. (1993) 'Grounded theory: the Method', in Munhall, P. L. and Oiler-Boyd, C. (eds.) *Nursing Research: A Qualitative Perspective*. New York: National League for Nursing.

Inman, C. (1991) 'Analysed interaction in a Children's oncology Clinic: The Child's View and Parent's opinion of Medical Encounters', *Journal of Advanced Nursing*, 16(7) pp. 782-793.

Jacoby, A. (2002) 'Stigma, epilepsy, and quality of life', *Epilepsy & Behavior*, 3(6) Dec, pp. S10-S20.

Jerrett, M. D. (1994) 'Parents' experiences of coming to know the care of a chronically ill child', *Journal of Advanced Nursing*, 19 pp. 1050-1056.

Judson, L. (2004) 'Global Childhood Chronic Illness', *Nursing Administration Quarterly*, 28(1) pp. 60-66.

Katz, K. S., Baker, C. and Osborn, D. (1991) 'Home-Based Care For Children With Chronic Illness.' *Journal Of Perinatal And Neonatal Nursing*, 5. pp. 71-79.

Kavsek, M. J. and Seiffge-Krenke, L. (1996) 'The differentiation of coping traits in adolescence', *International Journal of Behavioural Development*, 19 pp. 651-668.

Kennedy, I. and Grubb, A. (2000) *Medical Law*. London: Butterworth.

Kieffer, C. (1984) 'Citizen Empowerment: A Developmental Perspective', *Prevention In Human Services*, 3 pp. 9-36.

Kieffer, C. H. (1981) *The emergence of empowerment: The development of participatory competence among individuals in citizen organisations*. University of Michigan

Knafl, K., Breitmayer, B., Gallo, A. and Zoeller, L. (1996) 'Family response to childhood chronic illness: description of management styles', *Journal of Pediatric Nursing: Nursing Care of Children and Families.*, 11(5) Oct, pp. 315-326.

Knafl, K. and Gilliss, C. (2002) 'Families and Chronic Illness: a Synthesis of Current Research', *Journal of Family Nursing.*, 8(3) pp. 178-198.

Knafl, K. A., Ayres, L., Gallo, A. M., Zoeller, L. H. and Breitmayer, B. J. (1995) 'Learning from stories: parents' accounts of the pathway to diagnosis', *Pediatric Nursing*, 21(5) pp. 411-415.

## References

- Knaf, K. A. and Deatrick, J. A. (1986) 'How families manage chronic conditions: an analysis of the concept of normalization', *Research in Nursing & Health*, 9(3) pp. 215-222.
- Knaf, K. A. and Deatrick, J. A. (1990) 'Family management style: concept analysis and development', *Journal Of Pediatric Nursing*, 5(1) pp. 4-14.
- Koch, T. (1999) 'An interpretative research approach: revisiting phenomenological and hermeneutical approaches', *Nurse Researcher.*, 6(3) pp. 20-34.
- Kohlen, C., Beier, J. and Danzer, G. (2000) "They don't leave you on your own': A qualitative study of the home care of chronically ill children', *Pediatric Nursing*, 26(4) pp. 364-371.
- Kolb, D. A. (1984) *Experiential Learning: Experience as the source of learning and development*. New Jersey: Prentice-Hall Inc.
- Kozulin, A. (1986). *Thought and Language: Leo Vygotsky*. London, MIT Press.
- Krippendorff, K. (1980) *Content analysis: an Introduction to its methodology*. Newbury Park, California: Sage.
- Kubler-Ross, E. (1969) *On Death And Dying*. New York: Macmillan.
- Kuhn, M. (1964) 'Major trends in symbolic interaction theory over the past twenty-five years', *Sociological Quarterly*, 5 pp. 61-84.
- Kvale, S. (1996) *Interviews: An Introduction to Qualitative Research Interviewing*. Thousand Oaks, CA: Sage.
- LaGreca, A. M., Siegal, L. and Wallander, J. L. (1992) *Stress and coping in child health*. New York: Guildford.
- Lamprill, J. (2002) 'Asking for children's assent to take part in clinical research', *Good Clinical Practice Journal*, 9(8) pp. 1-4.
- LaRossa, R. and Reitzes, D. C. (1993) 'Symbolic interactionism and family studies', in Boss, P. G., Doherty, W. J., LaRossa, R., Schumm, W. R. and Stenmetz, S. K. (eds.) *In Sourcebook of Family Theories and Methods: a Contextual Approach*. New York: Plenum Press, pp. 135-163.

## References

- Lave, J. and Wenger, E. (1991) *Situated Learning: Legitimate Peripheral Participation*. Cambridge: Cambridge University Press.
- Lazarus, R. S. and Folkman, S. (1984) 'Coping And Adaptation', in Gentry, W. G. (ed.) *Handbook Of Behavioural Medicine*. London.: Guilford.
- Legard, R., Keegan, J. and Ward, K. (2003) 'In-depth interviews', in Ritchie, J. and Lewis, J. (eds.) *Qualitative Research practice*. London: Sage Publications.
- Leventhal, H. (1993) 'Theories of compliance and turning necessities into preferences: Application to adolescent health action.' in Krasnegar, N. A., Epstein, L., Johnson, S. B. and Yaffe, S. J. (eds.) *Developmental aspects of health compliance behaviour*. Hillsdale, NJ: Erlbaum.
- Lewis, J. (1984) *Women in England 1870-1950: Social Divisions and Social Change*. Brighton: Wheatsheaf.
- Liaschenko, J. and Fisher, A. (1999) 'Theorising the knowledge that nurses use in the conduct of their work', *Scholarly Inquiry for Nursing Practice: An International Journal*, 13(1) pp. 29-41.
- Long, S. (1997) 'Being together as a family', *Pediatric Nursing*, 9(6) pp. 25-28.
- Lowes, L. (1996) 'Paediatric nursing and children's autonomy', *Journal of Clinical Nursing*, 5(6) Nov, pp. 367-372.
- Lowes, L. and Lyne, P. (1999) 'A normal lifestyle: parental stress and coping in childhood diabetes', *British Journal of Nursing*, 8(3) p. 133-139.
- Lowes, L. and Lyne, P. (2000a) 'Chronic sorrow in parents of children with newly diagnosed diabetes: a review of the literature and discussion of the implications for nursing practice', *Journal of Advanced Nursing*, 32(1) Jul, pp. 41-48.
- Lowes, L. and Lyne, P. (2000b) 'Your child has diabetes: hospital or home at diagnosis?' *British Journal of Nursing*, 9(9) pp. 542-548.
- MacDonald, H. (1995) 'Chronic Renal Disease: The Mother's Experience', *Pediatric Nursing*, 21 pp. 503-507.
- MacDonald, H. and Callery, P. (2004) 'Different meanings of respite: a study of parents, nurses and social workers caring for children with complex needs', *Child Care Health and Development*, 30(3) May, pp. 279-288.

## References

- MacLean, W., Perrin, J., Gortmaker, S. and Pierrs, C. (1992) 'Psychological adjustment of children with asthma: effects of illness severity and recent stressful life events', *Journal of Pediatric Psychology*, 17(2) pp. 159-172.
- Maier, H. W. (1969) *Three theories of child development*. London: Harper International.
- Majomi, P., Brown, B. and Crawford, P. (2003) 'Sacrificing the personal to the professional: community mental health nurses', *Journal of Advanced Nursing*, 42(5) pp. 527-538.
- Maltby, H. J., Kristjanson, L. and Coleman, M. E. (2003) 'The parenting competency framework: learning to be a parent of a child with asthma', *International Journal of Nursing Practice*, 9(6) Dec, pp. 368-373.
- Manfredi, C., Czaja, R., Buis, M. and Derk, D. (1993) 'Patient Use Of Treatment-Related Information Received From The Cancer Information Service.' *Cancer Nursing*, 71 pp. 1326-1337.
- Marks, J. and McQueen, D. (2001) 'Chronic Disease', in Koop, C., Pearson, C. and Schwarz, M. (eds.) *Critical Issues in Public Health*. San Francisco: Jossey Bass, pp. 117-126.
- Marshall, C. and Rossman, G. (1995) *Designing Qualitative Research*. 2nd edn. London: Sage Publications.
- Marshall, C. and Rossman, G. R. (1999) *Designing Qualitative Research*. 3rd edn. London: Sage Publications.
- Mason, J. (1994) 'Linking qualitative and quantitative data analysis', in Bryman, A. and Burgess, R. (eds.) *Analysing qualitative data*. London: Routledge.
- Mathews, J. H. and Candy, P. C. (1999) 'New dimensions in the dynamics of learning and knowledge', in Boud, D. and Garrick, J. (eds.) *Understanding learning at work*. London: Routledge.
- Mattson, A. (1972) 'Long-Term Physical Illness in Childhood: a Challenge to Psychological Adaptation', *Pediatrics*, 50 pp. 801-811.
- Mays, N. and Pope, C. (1996) *Qualitative Research In Health Care*. London: BMJ Publishing Group.
- McCann, T. V. and Clark, E. (2003) 'Grounded Theory in Nursing', *Nurse Researcher*, 11(2) pp. 7-18.

## References

- McCormick, J., Fleming, D. and Charlton, J. (1995) *Morbidity statistics from General Practice 1991-2*. London: Office of Population Census and Surveys
- McCubbin, H. I., McCubbin, M. A., Patterson, J. M., Cauble, A. E., Wilson, L. R. and Warwick, W. (1983) 'Chip - Coping Health Inventory For Parents: An Assessment Of Parental Coping Patterns In The Care Of The Chronically Ill Child.' *Journal Of Marriage And The Family*, pp. 359-370.
- McGivney, V. (1999) *Informal learning in the community: a trigger for change and development: Report of a short DfEE-funded study that focuses on the role of informal learning in starting people on a learning pathway*. Leicester: NUACE
- Meiers, S. J. and Tomlinson, P. S. (2003) 'Family-nurse co-construction of meaning: a central phenomenon of family caring', *Scandinavian Journal of Caring Sciences*, 17(2) pp. 193-201.
- Meltzer, B. N., Petras, J. W. and Reynolds, L. T. (1975) *Symbolic Interactionism: Genesis, Varieties and Criticism*. Boston: Routledge & Kegan Paul.
- Miles, I. (1986) 'The emergence of Sick Children's Nursing Part 1. Sick Children's Nursing before the Turn of the Century.' *Nurse Education Today*, 6 pp. 82-87.
- Miles, R. (1987) 'Experiential Learning in the Curriculum', in Jolley, P. A. a. M. (ed.) *Nurse Education*. New York: Croom Helm.
- Miller, F. J. W. (1997) 'Sir James Spence Professor of Child Health (1928 -1954)', *Journal of Medical Biography*, 5 pp. 1-7.
- Milliken, P. J. and Schreiber, R. S. (2001) 'Can you 'do' Grounded Theory Without Symbolic Interactionism?' in Schreiber, R. S. and Stern, P. N. (eds.) *Using Grounded Theory in Nursing*.
- Mishel, M. H. (1983) 'Parents' Perception Of Uncertainty Concerning Their Hospitalized Child', *Nursing Research*, 32 pp. 324-330.
- Montessori, M. (1916) *The Montessori Method*. 1964 edn. New York: Schoken Books.
- Mooney, C. G. (2000) *Theories of childhood*. St Paul: Redleaf Press.
- Morrow, V. and Richards, M. (1996) 'The ethics of social research:The United Nations Convention on the Rights of the Child', *Children & society*, 10(2) pp. 90-105.

## References

Morse, J. (1997) 'Considering theory derived from qualitative research', in Morse, J. (ed.) *Completing a qualitative project: details and dialogue*. Newbury Park, California: Sage.

Morse, J. (2001) 'Situating Grounded Theory', in Schreiber, R. and Stern, P. (eds.) *Using Grounded Theory in Nursing*. New York: Springer Publishing Company.

Mountain, G. (2002) 'Parenting in Society: A Critical Review', in Smith, L., Coleman, V. and Bradshaw, M. (eds.) *Family Centred Care: Concept, Theory and Practice*. Basingstoke: Palgrave.

MRC (1991) *Working party on research on children*. London: Medical Research Council

Murgatroyd, S. and Woolfe, R. (1993) *Coping with Crisis: Understanding and Helping People in Need*. Milton Keynes: Open University Press.

Murphy-Black, T. (2000) 'Longitudinal Research', in Cormack, D. (ed.) *The Research Process in Nursing*. Oxford: Blackwell Science.

Neill, S. J. (2000) 'Acute childhood illness at home: the parents' perspective', *Journal of Advanced Nursing*, 31(4) pp. 821-832.

Nevin, R. S., Mccubbin, H. I. and Birkebak, R. C. (1983) 'Assessment Promotion Of Family Coping With Stressors In Disability.' *Pediatric Social Work*, 3 pp. 23-30.

Newacheck, P. W. and Taylor, R. W. (1992) 'Childhood Chronic Illness: Prevalence, Severity, And Impact', *American Journal of Public Health*, 82 pp. 364-371.

Oduntan, S. (1995) 'Gender differences in childhood mortality and morbidity', in Wallace, H., Giri, K. and Serrano, C. (eds.) *Health Care of Women and Children in Developing Countries*. Oakland, California: Third Party Publishing Co., pp. 70-78.

OPS (2004) *Mid-year Population Statistics for the United Kingdom*. London: Office of Population Statistics

Palmer, S. J. (1993) 'Care of a sick child by parents: a meaningful role', *Journal of Advanced Nursing*, 18 pp. 185-191.

Parsons, T. and Shils, E. A. (1962) *Towards a general theory of action*. London: Oxford University Press.



## References

- Patton, M. Q. (1990) *Qualitative Evaluation And Research Methods*. California: Sage.
- Perrin, J., Maclean, W. and Perrin, E. (1989) 'Parental perceptions of health status and psychologic adjustment of children with asthma', *Pediatrics*, 83(1) pp. 26-31.
- Phillips, D., Fawns, R. and Hayes, B. (2002) 'From personal reflection to social positioning: the development of a transformational model of professional education in midwifery', *Nursing Inquiry.*, 9(4) Dec, pp. 239-249.
- Piaget, J. (1954) *The construction of reality & the child*. New York: Basic Books.
- Platt, H. (1959) *The welfare of children in hospital: report of the committee*. London: Ministry of Health
- Pless, I. and Perrin, J. (1985) 'Issues common to a variety of illnesses', in Hobbs, N. and Perrin, J. (eds.) *Issues in the Care of Children with Chronic Illness*. San Francisco: Jossey Bass.
- Polanyi, M. (1967) *The tacit dimension*. London: Routledge and Kegan Paul.
- Porter, S. (1993) 'Nursing research conventions: objectivity or obfuscation?' *Journal of Advanced Nursing*, 18 pp. 137-143.
- Radley, A. (1994) *Making Sense of Illness: The Social Psychology of Health and Disease*. London: Sage Publications.
- Ramsden, P. (1992) *Learning to Teach in Higher Education*. London: Routledge.
- Rappaport, J. (1981) 'In praise of paradox: A social policy of empowerment over prevention', *American Journal of Community Psychology*, 9(1) pp. 1-25.
- Ray, L. D. and Ritchie, J. A. (1993) 'Caring For Chronically Ill Children At Home: Factors That Influence Parents' Coping', *Journal Of Pediatric Nursing*, 8 pp. 217-225.
- RCN (2003) 'The Royal College of Nursing Research Society: nurses and research ethics', *Nurse Researcher.*, 11(1) pp. 7-21.
- RCN (2004) *Research Ethics: RCN Guidance for Nurses*. London: Royal College of Nursing

## References

- RCPC (2000) 'RCP (Royal College of Paediatrics and Child Health) Ethics Advisory Committee', *Archives of Disease in Childhood*, 82 pp. 177-182.
- Rennick, J. (1995) 'The Changing Profile of Acute Childhood Illness: A Need for the Development of Family Nursing Knowledge', *Journal of Advanced Nursing*, 22:58-66, p. 2.
- Reynolds, J., Garralda, M., Jameson, R. and Postlethwaite, R. (1988) 'How parents and families cope with chronic renal failure', *Archives of Disease in Childhood*, 63 pp. 821-826.
- Richman, J. and Skidmore, D. (2000) 'Health implications of modern childhood', *Journal of Child Health Care*, 4(3) pp. 106-110.
- Ridley, U. (1956) *The Babies Hospital*. Newcastle upon Tyne: Andrew Reid & Company Ltd.
- Ritchie, J. and Spencer, L. (1994) 'Qualitative Data Analysis For Applied Policy Research', in Bryman, A. and Burgess, R. G. (eds.) *Analyzing Qualitative Data*. London: Routledge, pp. 173-194.
- Robbins, M. (1991) 'Sharing the care', *Nursing Times*, 87(8) pp. 36-38.
- Going to hospital with mother (film)* (1958) Directed by Robertson London: Tavistock Institute of Human Relations
- Robertson, J. (1953) 'Some responses of young children to the loss of maternal care', *Nursing Times*, 49 pp. 382-386.
- Robertson, J. (1955) 'Young children in long-term hospitals', *Nursing Times*, 23(Sept) pp. 63-65.
- Robinson, C. (1993) 'Managing Life With a Chronic Condition: The Story of Normalisation', *Qualitative Health Research*, 3(1) pp. 6-28.
- Robinson, C. A. (1985) 'Parents of hospitalised chronically ill children: Competency in question', *Nursing Papers*, 17(2) pp. 59-67.
- Robinson, I. (1988) 'Reconstructing Lives: Negotiating The Meaning Of Multiple Sclerosis. In Living With Chronic Illness.' in Anderson, R. and Bury, M. (eds.) *The Experience Of Patients And Their Families*. London: Unwin Hyman Ltd, pp. 43-66.

## References

- Robson, C. (2002) *Real world research*. 2nd edn. Oxford: Blackwell.
- Rolland, J. (1987) 'Chronic Illness and the Life Cycle: a Conceptual Framework', *Family Process*, 26 pp. 203-221.
- Rolland, J. (1988) 'A Conceptual Model of Chronic and Life-Threatening Illness and Its Impact on Families', in Chilman, C., Cox, F. and Nunnally, E. (eds.) *Chronic Illness and Disability*. Newbury Park, California: Sage Publications Inc.
- Rolland, J. S. (1994) *Families, Illness and Disability*. New York: BasicBooks.
- Rueschemeyer, D. (1983) 'Professional autonomy and the social control of expertise', in Lewis, R. D. a. P. (ed.) *The Sociology of the Professions: Lawyers, Doctors and others*. London: Macmillan.
- Rutter, D., Quine, L. and Chesam, D. (1993) *Social Psychological Approaches to Health*. London: Harvester: Wheatsheaf.
- Rutter, M., Tizard, J. and Whitmore, K. (1970) *Education, health and behaviour*. London: Longmans, Green.
- Sameroff, A. J. and Chandler, M. J. (1975) 'Reproductive risk and the continuum of caretaking causality', in Horowitz, F. D., Hetherington, M., Scarr-Salapatek, S. and Siegal, G. (eds.) *Review of Child Development*. Chicago: University of Chicago Press, pp. 187-244.
- Sartain, S. A., Clarke, C. L. and Heyman, R. (2000) 'Hearing the voices of children with chronic illness', *Journal of Advanced Nursing*, 32(4) Oct, pp. 913-921.
- Schmidt, S., Peterson, C. and Bullinger, M. (2003) 'Coping with chronic disease from the perspective of children and adolescents-a conceptual framework and its implications for participation', *Child Care, Health and Development*, 29(1) pp. 63-75.
- Schon, D. (1987) *Educating the Reflective Practitioner: How Professionals Think in Action*. New York: Basic Books.
- Schatz, M. and Walker, R. (1995) *Research as Social Change: New Opportunities for Qualitative Research*. London: Routledge.
- Schreiber, R. S. (2001) 'The 'How To' of Grounded Theory: Avoiding the pitfalls', in Schreiber, R. S. and Stern, P. N. (eds.) *Using Grounded Theory in Nursing*. New York: Springer Publishing.

## References

Schreiber, R. S. and Stern, P. N. (2001) *Using Grounded Theory in Nursing*. New York: Springer Publishing.

Schwandt, T. A. (1994) 'Constructivist, interpretivist approaches to Human Inquiry', in Denzin, N. K. and Lincoln, T. S. (eds.) *Handbook of qualitative research*. Thousand Oaks: Sage.

Scott, J. E. S. (1987) 'Ureteric Reflux: The Present Position. In Recent Advances', in Hendry, W. F. (ed.) *Urology/Andrology*. Edinburgh: Churchill Livingstone, pp. 89-108.

Scott, J. E. S. and Stansfield, J. M. (1968) 'Ureteric Reflux And Kidney Scarring In Children', *Archives of Disease in Childhood*, 43 pp. 468-470.

Scott, J. E. S., Swallow, V., Coulthard, M. G., Lambert, H. J. and Lee, R. E. J. (1997) 'Screening The Newborn For Familial Ureteric Reflux.' *The Lancet*, 350 pp. 396-400.

Scullion, J. E. (2004) 'A specialist nurse led liaison model of care reduced unscheduled care for acute asthma in a deprived multiethnic area', *Evidence-Based Nursing.*, 7(3) Jul, p. 77.

Seale, C. (1999) *The Quality of Qualitative Research*. Oxford: Blackwell.

Seed, A. (1995) 'Conducting a longitudinal study: an unsanitised account', *Journal of Advanced Nursing*, 21(5) pp. 845-852.

Shakespeare, T. and Watson, N. (1998) 'Theoretical perspectives on research with disabled children', in Robinson, C. and Stalker, K. (eds.) *Growing up with disability*. London: Jessica Kingsley.

Shields, L. (1995) 'Women's Experiences of the Meaning of Empowerment', *Qualitative Health Research*, 5(1) pp. 15-35.

Shields, L. and Twycross, A. (2003) 'Why we need ethics committees', *Paediatric Nursing.*, 15(10) Dec, p. 19.

Silverman, D. (1998). *Qualitative Research: Theory, Method and Practice*. Sage Publications, London.

Skinner, B. F. (1974) *About Behaviourism*. New York: Knopf.

Sloper, P. (1999) 'Models of service support for parents of disabled children: What do we know?' *Child: Care, Health And Development*, 25 pp. 85-99.

## References

Sloper, P. and Lightfoot, J. (2003) 'Involving disabled and chronically ill children and young people in health service development', *Child Care Health and Development*, 29(1) Jan, pp. 15-20. [Online] Available at <Go to ISI>://000180430500002

Smith, F. (1995) *Children's Nursing in Practice: The Nottingham Model*. Oxford: Blackwell Science.

Smith, L. (1991) *Experiential learning*. Curriculum Planning in Nurse Education. London: Edward Arnold.

Smith, L., Coleman, V. and Bradshaw, M. (2002a). *Family Centred Care: Concept, Theory and Practice*. Basingstoke, Palgrave.

Smith, L., Coleman, V. and Bradshaw, M. (2002b) 'Family-Centred Care: A Practice Continuum', in Smith, L., Coleman, V. and Bradshaw, M. (eds.) *Family-Centred Care: Concept, Theory and Practice*. Basingstoke: Palgrave.

Spence, J. C. (1946) *The Convocation Lecture: The purpose of the family: a guide to the care of children*. London. Oxford University Press.

Spence, J. C. (1947) 'The care of children in hospital', *British Medical Journal*, 1(4490) pp. 125-130.

Spence, J. C. (1950) 'Family studies in preventive paediatrics', *New England Journal of Medicine*, 243 pp. 205-210.

Spencer, L., Ritchie, J., Lewis, J. and Dillon, L. (2003) *Quality in Qualitative Evaluation: a Framework for Assessing Research Evidence*. London: Government Chief Social Researcher's Office

Spirito, A., Stark, L. J. and Gill, K. M. (1995) 'Coping with everyday and disease related stressors by chronically ill children and adolescents', *Journal of the American Academy of Child and Adolescent Psychiatry*, 34 pp. 283-290.

Spouse, J. (2003) *Professional Learning in Nursing*. Oxford: Blackwell Publishing.

Stein, R. and Jessop, D. (1982) 'A Non-categorical approach to chronic childhood illness', *Public Health Reports*, 97 pp. 354-362.

Stern, P. N. (1980) 'Grounded theory methodology: Its uses and processes', *Image the Journal of Nursing Scholarship*, 12(7) pp. 20-23.

## References

- Stern, P. N. (1994) 'Eroding grounded theory', in Morse, J. (ed.) *Critical Issues in Qualitative Research methods*. Thousand Oaks: Sage.
- Strauss, A. (1987a) 'Health-Policy and Chronic Illness', *Society*, 25(1) Nov-Dec, pp. 33-39.
- Strauss, A. (1987b) *Qualitative Analysis for Social Scientists*. Cambridge: Cambridge University Press.
- Strauss, A. and Corbin, J. (1990) *Basics of Qualitative Research: Grounded Theory Procedures and Techniques*. Newbury Park: Sage.
- Strauss, A. and Corbin, J. (1998) *Basics of Qualitative Research: Techniques and procedures for developing grounded theory*. 2nd edn. Thousand Oaks: Sage.
- Strauss, A. and Glaser, B. (1975) *Chronic illness and the quality of life*. St Louis: Mosby.
- Strauss, A. L., Corbin, J., Fagerhaugh, S., Glaser, B. G., Suczek, B. and Weiner, C. L. (1984) *Chronic Illness And The Quality Of Life*. 2 edn. St Louis: Mosby.
- Streubert, H. J. and Carpenter, D. R. (1999) *Qualitative Research in Nursing: advancing the Humanistic Imperative*. 2nd edn. New York: Lippincott.
- Swallow, V. (1990) 'The Children's Outpatient Department', *Paediatric Nursing*, 2(9) pp. 20-24.
- Swallow, V. (1997a). Mothers' coping with chronic congenital childhood renal disease. York, NHSExecutive Conference for Research Training Fellows.
- Swallow, V. (1997b) *A Study to Determine Mothers' Coping in Chronic Childhood Illness*. MMedSci. University of Newcastle upon Tyne
- Swallow, V. (2001). Looking back: the experiences of children and families learning to manage chronic illness. Copenhagen, International Council of Nurses Bi-annual Conference.
- Swallow, V., Chalmers, H. and Miller, J. (2004). *Partnerships in Work Based Learning*. Newcastle upon Tyne, Northumbria University Press.

## References

- Swallow, V. and MacFadyen, A. (2004) 'Communication skills in nursing: effective qualitative research tools?' *Paediatric Nursing*, 16(5) pp. 20-23.
- Swallow, V., Miller, J. and Chalmers, H. (2001) 'Accredited work based learning for new nursing roles: nurses' experiences of two pilot schemes', *Journal of Clinical Nursing*, 10(6) pp. 820-822.
- Swallow, V., Newton, J. and Marshall, C. (2003) 'How to manage and display qualitative data using 'Framework' and Microsoft Excel', *Journal of Clinical Nursing*, 12 pp. 610-612.
- Swallow, V. and Thompson, L. (1991). Setting up a parents' asthma support group with the local community. Durham, RCN Nursing Research Conference.
- Swallow, V. M. and Jacoby, A. (2001a) 'Mothers' coping in chronic childhood illness: the effect of presymptomatic diagnosis of vesicoureteric reflux', *Journal of Advanced Nursing*, 33(1) Jan, pp. 69-78.
- Swallow, V. M. and Jacoby, A. (2001b) 'Mothers' evolving relationships with doctors and nurses during the chronic childhood illness trajectory', *Journal of Advanced Nursing*, 36(6) Dec, pp. 755-764.
- Swallow, V. M. and Thompson, E. (1992) 'Children's Asthma Support For Parents: A Parent Support Group', *Paediatric Nursing*, 4(1).
- Tanner, J. and Timmons, S. (2000) 'Backstage in the Theatre', *Journal of Advanced Nursing*, 32(4) pp. 975-980.
- Tates, K. and Meeuwesen, L. (2001) 'Doctor-parent-child communication. A (re)view of the literature', *Social Science & Medicine*, 52(6) Mar, pp. 839-851.
- Thompson, R. J. and Gustafson, K. E. (1996) *Adaptation to chronic childhood illness*. Washington, DC: American Psychological Association.
- Thomsen, S. (1999) 'Making family-centred care a reality', *Nursing New Zealand*, 5(4) pp. 14-16.
- Thorne, S. E. (1993) *Negotiating Health Care: The Social Context of Chronic Illness*. London: Sage Publications.
- Thorne, S. E., Nyhlin, K. T. and Paterson, B. L. (2000) 'Attitudes toward patient expertise in chronic illness', *International Journal of Nursing Studies*, 37 pp. 303-311.

## References

- Thorne, S. E. and Robinson, C. A. (1988) 'Health Care Relationships: The Chronic Illness Perspective', *Research in Nursing and Health*, 11 pp. 293-300.
- Thorne, S. E. and Robinson, C. A. (1989) 'Guarded alliance: health care relationships in chronic illness', *Image: Journal of Nursing Scholarship*, 21(3) Fall, pp. 153-157.
- Turner-Henson, A., Holaday, B. and Ogletree, G. (1994) 'The experiences of discrimination: challenges for chronically ill children', *Pediatric Nursing*, 20(6) pp. 571-577.
- Twigg, J. and Atkin, K. (1994) *Carers Perceived: Policy and Practice in Informal Care*. Buckingham: Open University.
- UN (1959) *United Nations Declaration of the Rights of the Child*. New York: United Nations
- UN (1989) *United Nations Convention on the Rights of the Child*. New York: United Nations
- UNICEF (1989) *A new charter for children*. London: United Nations
- Valentine, F. (1998) 'Empowerment: family-centred care', *Paediatric Nursing*, 10(1) pp. 24-27.
- Valsiner, J. and Leung, M. (1994) 'From intelligence to knowledge construction: a sociogenetic process approach', in Sternberg, R. J. and Wagner, R. K. (eds.) *Mind in Context: Interactionist Perspectives on Human Intelligence*. Cambridge: Cambridge University Press, pp. 202-217.
- van der Voort, J. H., Edwards, A. G., Roberts, R., Newcombe, R. G. and Jones, K. V. (2002) 'Unexplained extra visits to general practitioners before the diagnosis of first urinary tract infection: a case-control study', *Arch Dis Child*, 87(6) December 1, 2002, pp. 530-532.
- van-Langenhove, L. and Bertolink, R. (1999) 'Positioning and assessment of technology', in Harre, R. and van-Langenhove, L. (eds.) *Positioning theory: Moral Contexts of Intentional Action*. Oxford: Blackwell.
- Varni, J. and Wallander, J. (1988) 'Pediatric chronic disabilities: haemophilia and spina bifida as examples', in Routh, D. (ed.) *Handbook of Pediatric Psychology*. New York: Guildford Press.



## References

Vernon, S. (1995) 'Urine Collection From Infants: A Reliable Method', *Paediatric Nursing*, 7 pp. 26-27.

Vila, G., Nollet-Clemencon, C., de Blic, J., Mouren-Simeoni, M. C. and Scheinmann, P. (2000) 'Prevalence of DSM IV anxiety and affective disorders in a pediatric population of asthmatic children and adolescents', *Journal of Affective Disorders*, 58(3) Jun, pp. 223-231.

Vygotsky, L. (1987) *The collected works of LS Vygotsky*. New York: Plenum Press.

Wallander, J. (1996) 'Adaptation to chronic childhood illness - Thompson,RJ, Gustafson,KE', *British Journal of Health Psychology*, 1 pp. 378-379.

Wallander, J., Feldman, W. and Varni, V. (1989) 'Physical status and psychological adjustment in children with spina bifida', *Journal of Pediatric Psychology*, 16 pp. 39-58.

Wang, K. and Barnard, B. (2004) 'Technology-dependent children and their families: a review', *Journal of Advanced Nursing*, 45(1).

Watson, D., Townsley, R. and Abbott, D. (2002) 'Exploring multi-agency working in services to disabled children with complex healthcare needs and their families', *Journal of Clinical Nursing*, 11 pp. 367-375.

Weindling, P. (1996) 'Human guinea pigs and the ethics of experimentation: the BMJ's correspondent at the Nuremberg medical trial', *British Medical Journal*, 313 pp. 1467-1470.

Weithorn, L. A. (1980) *Competency to render informed treatment decisions: A comparison of certain Minors and Adults*. Pittsburgh: University of Pittsburgh.

Welch, J. L. and Austin, J. K. (1999) 'Factors associated with treatment-related stressors in hemodialysis patients', *ANNA Journal.*, 26(3) Jun, pp. 318-326.

Welch, J. L. and Austin, J. K. (2001) 'Stressors, coping and depression in haemodialysis patients', *Journal of Advanced Nursing.*, 33(2) Jan, pp. 200-207.

Wenger, E. (1998) *Communities of Practice: Learning, Meaning and Identity*. Cambridge: Cambridge University Press.

Wenger, E., McDermott, R. and Snyder, W. M. (2002) *Cultivating Communities of Practice*. Boston: Harvard Business School Press.

## References

While, A., Cornish, J. and Citrone, C. (1996) 'Study of care management arrangements for dying children', *British Journal of Community Health Nursing*, 1(5) Sep, pp. 290-294.

WHO (2002) *Expert Consultation on Diet, Nutrition and the Prevention of chronic Diseases*. Geneva: WHO

Whyte, D. A. (1992) 'A Family Nursing Approach To The Care Of A Child With A Chronic Illness', *Journal of Advanced Nursing*, 17 pp. 317-327.

Williams, P., Williams, A., Graff, J., Hanson, S., Stanton, A., Hafeman, C., Liebergen, A., Leuenberg, K., Setter, R., Ridder, L., Curry, H., Barnard, M. and Sanders., S. (2002) 'Interrelationships amongst variables affecting well siblings and mothers of families of children with a chronic illness or disability', *Journal of Behavioral Medicine*, 25 pp. 411-424.

Williams, P. D., Lorenzo, F. D. and Borja, M. (1993) 'Pediatric Chronic Illness: Effects On Siblings And Mothers', *Maternal-Child Nursing Journal*, 21 pp. 111-121.

Williams, S. J. (2000) 'Chronic illness as biographical disruption or biographical disruption as chronic illness? Reflections on a core concept', *Sociology of health and illness*, 22(1) pp. 40-67.

Williams., G. (1984) 'The Genesis Of Chronic Illness: Narrative Re-Construction', *Sociology of health and illness*,(6) pp. 175-200.

Wilson, P. M. (2001) 'A policy analysis of the Expert Patient in the United Kingdom: self-care as an expression of pastoral power?' *Health Soc Care Community*, 9(3) May 01, 2001, pp. 134-142.

Wilson, S. J., Bladin, P. F. and Saling, M. M. (2004) 'Paradoxical results in the cure of chronic illness: the "burden of normality" as exemplified following seizure surgery', *Epilepsy & Behaviour*, 5(1) Feb, pp. 13-21.

WMA (2000) *Declaration of Helsinki: Ethical Principles for Medical Research Involving Human Subjects*. Helsinki: World Medical Assembly

Wood, D. (1998) *How children think and learn*. London: Blackwell.

Woods, L. (2003) 'Grounded theory explained', *Nurse Researcher*., 11(2) pp. 4-6.

Yin, R. K. (1994) *Case Study Research: Design and Methods*. 2 edn. London: Sage Publications.

## References

Young, B., Dixon-Woods, M., Windridge, K. C. and Heney, D. (2004) 'Managing communication with young people who have a potentially life threatening chronic illness; Qualitative study of patients and parents', *British Medical Journal*, 326(7384) Feb 8, 2003, p. 305.