Final Report, The Teaching Parents Study: Pan-Britain, mixed methods study of multidisciplinary teams teaching parents, and parents learning to manage, home based care of long-term childhood kidney conditions

The University
of Manchester

MANCHESTER
1824

Greater Manchester,
Lancashire & S Cumbria
mcrn
Medicines for Children Research Network

The Teaching Parents Study

FINAL REPORT JULY 2012

Pan-Britain, mixed methods study of multidisciplinary teams teaching parents, and parents learning to manage, home based care of long-term childhood kidney conditions

Kids Kidney Research

Document Title	The Teaching Parents Study: A pan-Britain, mixed methods study of multidisciplinary teams teaching parents and parents learning to manage home based care of long-term childhood kidney disease
Authors	Veronica Swallow, Ruth Nightingale, Davina Allen, Julian Williams, Trish Smith, Jean Crosier, Heather Lambert, Leila Qizalbash, Lucy Wirz, Nicholas JA Webb, Cat Mercer, Laura Crowther.
Publisher	University of Manchester
Target audience	Paediatric clinical teams, policy makers, families managing home-based clinical care for children with CKD and other long term conditions, service developers, service providers, parent charities and support organisations
Funded by	Kids Kidney Research
Key words	Parents, children, professionals, multidisciplinary teams, MDTs, learning, teaching, CKD, long term conditions, clinical roles, management.
Contact details	Email: veronica.swallow@manchester.ac.uk and ruth.nightingale@gosh.nhs.uk
Suggested citation:	Swallow V, Nightingale R, Allen D, Williams J, Smith T, Crosier J, Lambert H, Qizalbash L, Wirz L, Webb NJA, Mercer C, Crowther L. The Teaching Parents Study. Final Report. Kids Kidney Research, 2012

Authors' affiliations

Dr Veronica M Swallow, Senior Lecturer in Children's Nursing[1,2] (VS),

Ms Ruth Nightingale, Clinical Research Practitioner (Phase II) [1, 6] (RN),

Professor Davina Allen, Health Foundation Improvement Science Fellow,

Professor Julian Williams, Professor of Mathematics Education & lead of the Socio-cultural interest group[5],

Mrs Trish Smith, Clinical Nurse Specialist Nephrology [2],

Mrs Jean Crosier, Clinical Nurse Specialist Nephrology[3],

Dr Heather Lambert, Consultant Paediatric Nephrology[3],

Ms Leila Qizalbash, Paediatric Renal Dietician[3],

Dr Lucy Wirz, Clinical Consultant Psychologist (Nephrology)[3],

Dr Nicholas JA Webb, Consultant Paediatric Nephrologist [2],

Mrs Cat Mercer, Clinical Researcher, (Phase I)[1,2,] (CM),

Miss Laura Crowther, Senior MCRN Research Administrator[7] (LC).

[1] *School of Nursing, Midwifery and Social Work, University of Manchester, Oxford Road, Manchester, M13 9Pl, UK*

[2] *Royal Manchester Children's Hospital, Central Manchester University Hospitals NHS Foundation Trust, Oxford Road, Manchester, M13 9WL, UK*

[3] *The Great North Children's Hospital, Newcastle upon Tyne Hospitals NHS Foundation Trust, Queen Victoria Road, Newcastle upon Tyne, NE1 4LP, UK*

[4] *Cardiff School of Nursing and Midwifery Studies, Cardiff University, Newport Road, Cardiff, CF24 0AB, UK*

[5] *School of Education, University of Manchester, Oxford Road, Manchester, M13 9PL, UK*

[6] *Great Ormond Street Hospital, London*

[7] *NIHR Medicines for Children Research Network*

In addition to the members of the research team, the project steering group comprised:

Mrs Helen Walker and Mr Graeme Walker, parents

1.1 Executive Summary

Background: Care of children and young people (children) in the 12 children's kidney units in England, Scotland and Wales is managed by multidisciplinary teams (MDTs) comprising professionals such as clinical psychologists, dieticians, doctors, nurses, pharmacists, play workers, social workers, and therapists. Within the constraints of treatment regimens it is in children's best interests for them to be cared for at home whenever possible[1-4].

Professionals therefore, spend considerable time teaching parents from diverse socioeconomic and educational backgrounds, with different health care experiences and learning needs, to deliver home-based clinical care to their children. Often isolated and overwhelmed, parents may look to health professionals for help with care, while professionals often act as teachers as well as care providers[5-7].

Although studies of chronic disease management acknowledge issues such as: normalisation [8], the 'work' associated with parental care giving[9], the ways families adjust[10], and the fact fathers would like more time to learn about disease management[11], there is little research evidence on the ways parents actually learn to take responsibility for and deliver clinical care at home, or how professionals teach parents to do this.

Nevertheless, parents:*…perform the vast majority of care-giving, including tasks that are complex and demanding*[12:13]. If they are unsure they may not maintain treatment regimens or recognise subtle clinical changes[13 14] so negative outcomes such as undetected urinary tract infections, damaged kidneys, impaired kidney function, relapse of the condition, and transplant rejection may occur. All of these carry significant emotional, physical and financial costs for families [4 15], and have financial implications for the NHS[12].

Aim: to obtain a detailed understand of the ways: MDTs teach parents and carers to become home-based clinical carers, and parents learn to care for children's long term kidney conditions.

Methods: A mixed method, longitudinal, two phased design allowed us to achieve depth and breadth in our analysis.

Phase I, strand i: An administered questionnaire (a survey designed to map the shape of current services and approaches to teaching parents).

Phase I, strand ii: Individual or group focussed qualitative interviews with 112 MDT members to explore with them the range of care-giving skills/ and information they relay to parents, and the formal/informal teaching interventions they use.

Phase II: Using an ethnographic approach we undertook six observational case studies of children with long term kidney conditions whose parents were learning new clinical skills to deliver at home. Children were purposively sampled to achieve maximum variation in regard to age, gender and ethnicity. After parents (and where appropriate children or other informal carers) were recruited, we used snowball sampling to identify and recruit 28 professionals (nurses, doctors, dieticians, play specialists, social workers, therapists, pharmacists) who were involved in managing the children's clinical care, and teaching parents the skills needed for home based management. Each case study lasted six months and data obtained included:

- 86 observations
- 41 interviews
- Field-notes
- Case-note reviews

Survey data were managed using Excel to produce descriptive statistics. Qualitative data were analysed using Framework Technique.

Key findings:

- In **Phase I** most professionals were involved in both teaching parents and reinforcing other professionals' teaching.

- Eight disciplines (clinical psychologists, dieticians, doctors, nurses, pharmacists, play workers, social workers, therapists) described how they share discipline-specific knowledge with parents to promote safe and effective home based clinical care

- When discussing parent education professionals described two distinct identities: the inter-disciplinary 'we' (e.g. social workers or doctors) and the intra-disciplinary 'we' (i.e. as the MDT)

- Distributed expertise was evident within all of the MDTs accounts, this:
    - Means that different professionals offer different kinds of expertise to the co-management of a child's condition;
    - Explains the team's capacity (rather than just the individual's) to care for the children's CKD.

- Three parent-educative functions were identified in professionals' retrospective accounts:
    a) Initiating parents' knowledge and skill development;
    b) promoting and monitoring parents' knowledge and skill development, and
    c) multidisciplinary team working

    these informed Phase II data collection/analysis

- In **Phase II** a wide range of teaching processes, and interactions between professionals, children, parents/carers were observed; and discussed during qualitative interviews

- Four categories emerged as responses to shared MDT/parent management:
    1-MDTs promoting parents' clinical roles;
    2-Parents cautious acceptance of clinical responsibilities;
    3-Blended expertise around the child;
    4-Ambivalence within teaching and learning encounters

- There was evidence that professionals acknowledged parents' expertise around their own child, and actively promoted parents' clinical expertise.

- Although there was little evidence of professionals negotiating with parents about taking on clinical responsibilities, there were examples of parents being offered choices about specific aspects of care, e.g. in-centre dialysis vs. home dialysis; or inserting the NG tube at home vs going to local hospital

- Professionals worked hard to try to accommodate parents' learning needs and care delivery preferences within the constraints of the clinical regimen.

- Although parents appeared to 'cautiously accept' clinical care as part of their 'parenting role', their clinical expertise was generally developed through necessity rather than choice.

- Professionals were often challenged by the need to determine parents' individual learning needs, and individualise skill development.

- Parents valued professionals' efforts to continually tailor teaching activities to parents' individual needs.

- Parents and professionals experienced some ambivalence when engaging in teaching and learning, this arose early in the case studies and continued to appear around a variety of issues.

Recommendations:

Professionals and parents have developed considerable expertise which ought to be harnessed and made available to support those who are new to renal care. The following would offer professionals an optimum, evidence based understanding of the way parents learn to manage CKD, and, offer parents evidence based material to assist their clinical roles,:

1. A sequence of exemplar case studies could be developed from our anonymised data; these could help share the experiences of parents with professionals, and vice versa. Their purpose would be to support parents and professionals to develop a rounded understanding of the experience of living with CKD and its consequences (e.g. 'taking a dialysis machine home', using an NG tube to feed your child)

2. A series of 'top teaching tips' and 'top learning tips' leaflets could be developed from the data for circulation to wards, clinics, parent web sites and possibly the KKR web site?. These could include 'typical medical language you might hear and what it means' or 'common turns of phrase [e.g. colloquialisms, metaphors, analogies] that are used in CKD management, and what they mean'

3. A leaflet/web based resource explaining the range of 'distributed expertise' within the renal MDT, what the roles and titles mean for families

4. Parents ought to be routinely sign-posted to resources when available

5. A range of UK workshops where professionals and family members could jointly generate educational material and action plans for tailoring support to parents. Materials could include: e.g. parents' experiences of the clinical role, symptom management, recognising when to seek help, how to seek help

6. A national conference/seminars for local health care staff who might need to support management of a local child with CKD; these could draw on our data and enable discussion with interested staff who are able to attend

7. Staff in higher education institutions responsible for developing curriculum for the professionals represented in our data could be provided with key findings from the study in order that the evidence can be fed into practice via new recruits

8. Further research is needed that builds on this study, working with families and MDT members to develop and evaluate a parent learning-needs assessment tool that could promote a standardised, MDT approach to assessing parents' individual learning needs and preferences

9. Further study is needed to assess the cost effectiveness of home vs hospital care and the cost to parents

10. A small body of literature focuses on measuring parent-child shared management of chronic conditions [16], but children with CKD were not represented, data collection was limited to an un-validated, postal questionnaire and data did not explore parent-professional interactions, as our study has done. Therefore, a large mixed methods study is needed to measure shared parent-child management in CKD care.

11. More detailed research is needed that investigates the individual contribution each discipline makes, the wider impact of renal MDT support on parents' clinical role development, and a time line to illustrate the processes by which MDT members teach and parents learn.

1.2   Acknowledgements

Contents

1.3 Table of Figures

1.4 Table of Appendices

1.5 Glossary of terms and abbreviations used in the report

BP: Blood pressure, Pressure blood exerts on the walls of blood vessels. This is expressed in two numbers, such as 120/80. The systolic (top) number is the pressure when the heart is contracting. The diastolic (bottom) number is the pressure when the heart is at rest

CKD: Chronic kidney disease

Dialysis: Cleansing the body of unwanted toxins, waste products and excess fluid by filtering them from the blood through a semi permeable membrane.

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

GFR: Glomerular filtration rate is a measure of how well kidneys are filtering waste from the blood

Grand round: Ward round involving health care professionals

Infection: Invasion of the body by disease - producing organisms and the reaction of the tissues to their presence.

Kidneys: Two bean-shaped organs located at the back of the abdominal cavity, one on each side of the spinal column. Kidneys maintain the body's chemical balance by excreting waste products and excess fluid in the form of urine

Nasogastric (NG) 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.

MDT: Multidisciplinary team

Renal: Referring to the kidneys

PEG: Percutaneous endoscopic gastrostomy is an endoscopic medical procedure in which a tube (PEG tube) is passed into a patient's stomach through the abdominal wall, most commonly to provide a means of feeding when oral intake is not adequate

UF: ultrafiltration occurs at the barrier between the blood and the filtrate in the renal corpuscle or Bowman's capsule in the kidneys. The Bowman's capsule contains a dense capillary network called the glomerulus. Blood flows into these capillaries through the afferent arteriole and leaves through the efferent arteriole. The blood pressure in the afferent arteriole is higher than the blood pressure in the efferent arteriole. This is because the efferent arteriole has a smaller diameter than the afferent arteriole. The high pressure forces small molecules such as water, glucose, amino acids, sodium chloride and urea through the filter, from the blood in the glomerular capsule across the basement membrane of the Bowman's capsule and into the nephron. This type of high pressure filtration is ultrafiltration.

Scaffolded learning: When students are learning new or difficult tasks, they are given more assistance. As they begin to demonstrate task mastery, the assistance or support is decreased gradually in order to shift the responsibility for learning from the teacher to the students. As students assume more responsibility for learning, the teacher supports less

Teachable moment: in education, is the time at which learning a particular topic or idea becomes possible or easiest.

1.6　Background

Care of children with long-term conditions in the 12 children's kidney units in England, Scotland and Wales is managed by multidisciplinary teams (MDTs) comprising professionals such as clinical psychologists, dieticians, doctors, nurses, pharmacists, play workers, social workers, and therapists. Within the constraints of treatment regimens it is in children's best interests for them to be cared for at home whenever possible[1-4]. Professionals in the 12 units, therefore, spend considerable time teaching parents from diverse socioeconomic and educational backgrounds, with different health care experiences and learning needs to deliver home-based clinical care to their children.

As part of children's clinical management and disease monitoring some MDT members also visit the family home and/or the child's school to initiate training and provide parents and other carers with ongoing support. Although there is ample anecdotal evidence of the way professionals teach and parents learn to manage the child's condition, currently little research evidence exists to describe the strategies that experienced professionals use when teaching parents, or to inform professionals of the types of teaching and support that parents prefer.

1.7　Parents delivering home-based clinical care

Previous research tells us that although some parents of children with long-term conditions readily accept the care-giving role, and adapt to it by developing competent management styles involving mastery and routinisation of treatment that minimise the intrusiveness of conditions, others experience difficulties, and the condition remains an unwelcome focus of family life[4 8 15 17]. There is also emerging evidence, including from members of the current research team, that from the outset of the condition trajectory some parents are reluctant to acknowledge any learning or comprehension difficulties in case professionals judge them to be incompetent parents and/or do not 'allow' them to take their child home. Moreover, some parents find the relentless requirements of home-based clinical care giving difficult to maintain[15 18-21].

Often isolated and overwhelmed, parents may look to health professionals for help with care, while professionals often act as teachers as well as care providers[5-7]. Although studies of chronic disease management acknowledge issues such as: the 'work' associated with parental care giving[9], the ways families adjust[10], normalisation[8] and the fact fathers would like more time to learn about disease management[11], there is little research evidence on the ways parents actually learn to take responsibility for and deliver clinical care at home, or the ways professionals teach parents to do this.

Nevertheless, parents of children with long term kidney conditions increasingly:…*perform the vast majority of care-giving, including tasks that are complex and demanding*[12:13]. If parents are unsure about aspects of care-giving they may not maintain treatment regimens or may fail to recognise subtle clinical changes[13 14] and negative outcomes such as undetected urinary tract infections, damaged kidneys, impaired kidney function, relapse of the condition, and transplant rejection may occur. All of these carry significant emotional, physical and financial costs for families[4 15], and have financial implications for the NHS[12].

Moreover, the limited evidence of parents' clinical care giving that does exist did not use observational methods and draws on data collected from parents whose care-giving practices were already well established, and who had developed their own unique management styles[19] [22] [23]. However, little prospective evidence exists from parent or professional perspectives to tell us about early development of the parental care-giving role when parents need to learn new skills and knowledge.

1.8 Integrated working between professionals and parents

Delivery of high quality care for children with kidney conditions [24] requires integrated working between healthcare professionals, close working relationships with primary care teams, liaison with other healthcare teams and outside agencies, and the sharing of skills and knowledge between MDTs and parents. Moreover, parents need access to accurate and accessible information in order to make informed decisions in partnership with clinicians, and an agreed care plan that promotes children's best possible quality of life[12].

When managing children's conditions MDTs spend considerable time educating parents about the condition and facilitating their home-based clinical care-giving [5] [15]. Although few data exist relating to MDT management of children's renal conditions a recent retrospective case-note review of 44 American children with renal insufficiency demonstrated better clinical outcomes for those managed in an MDT clinic compared to those managed in a general nephrology clinic [25]. More recently [26] a retrospective MDT quality improvement project of American adults with stage 3 CKD and co morbid diabetes and/or hypertension concluded that MDT care resulted in a slower decline in GFR than usual care. This occurred despite a lack of significant differences for secondary disease-specific measures, suggesting that other differences in the MDT population or care process accounted for the slower decline in GFR in the MDT group. The authors concluded that there may have been inherent differences in either the MDT population or MDT care process compared with the usual care sub cohort that accounted for the slower decline in GFR in the MDT group. There may also be intangible benefits to the informational continuity of care provided through an integrated system compared with receiving nephrology care at an outside site but these were not investigated.

1.9 Links with our previous research

Members of the current research team recently undertook qualitative studies that explored family learning in one children's kidney unit in England. Parents and professionals described the way parents learned to: collect and test urine; understand investigations; administer specialist diets, medications, gastrostomy or naso-gastric tube-feeds; manage peritoneal dialysis; monitor diet and fluids; recognise the importance of subtle clinical changes; record clinical observations; act on observations and results, and accurately communicate observations/actions to professionals [5] [7] [15] [18].

During this shared practice parents adopted the identity of 'students' needing to learn new skills, while professionals such as nurses functioned as 'family learning brokers' who demonstrated five distinct yet overlapping teaching activities: assessing parents' learning needs, creating learning opportunities, implementing teaching strategies, acting as interpreters and brokers, and assessing learning progress. Over time, many parents

successfully and independently managed care giving but some reported negative emotional and physiological responses to the relentless responsibility. Moreover, within couples fathers' and mothers' views were sometimes at variance; these findings extend earlier reports that also highlight the dearth of research focussing on fathers' viewpoints in child-health care, and the fact that fathers' views are often underrepresented in clinical research [11] [27] [28] [11] [29-31].

To generate knowledge about the contributions that both fathers and mothers make to management of children's long-term conditions we later conducted a qualitative study of fathers' and mothers' individual and joint accounts of care giving for a child with a long term kidney condition. We found that fathers and mothers made a significant contribution to management and a key theme identified was 'developing skills' in: information processing, sharing/negotiating care giving, restraining children, adapting to treatment regimens and communicating. Although skill development was often a challenging and uncertain process, fathers and mothers often negotiated care giving with each other to accommodate this while caring for other children, undertaking paid employment and providing mutual practical and emotional support.

Developing skills in holding their child for procedures and treatments was a major concern, but it was fathers who assumed the 'protector' role and worried more about their child's long-term health and well-being, while mothers concerned themselves more with current clinical issues and maintaining relationships with professionals[32]. Fathers also reported a preference for receiving information 'first hand' from professionals rather than 'second hand' from the mother.

As part of this work we also conducted a narrative review of 29 studies involving fathers in health care for their child with a long-term condition. The studies were undertaken in Australia (2), Canada (6), China (1), Israel (1), Taiwan (1), UK (3), USA (14), UK and USA (1). The review demonstrates that fathers' involvement in children's health care can positively impact on fathers', mothers' and children's well-being and family functioning[33]. Both fathers' and mothers' accounts of clinical care giving are therefore, important targets for ongoing research.

A limitation of previous studies, including our own, is that they were retrospective and/or used participants' reports of their experience rather than observational studies, and so were unable to focus on actual encounters between MDT members and parents at times when parents were being trained to become clinical caregivers. Therefore, detailed, prospective research that investigates the ways professionals promote learning from early in the parents' clinical care-giving journey is needed. This has the potential to help inform MDTs about the factors that are seen to be important in professional-parent interactions as professionals teach parents to deliver safe and effective home-based management of children's conditions, thereby contributing to optimum clinical outcomes for children.

1.10 Conceptual framework
Marshall and Rossman [34] use a funnel metaphor to illustrate the complex process of conceptualising a study. Within this approach are three levels of conceptualisation. This metaphorical approach was adapted for the present study (Figure 1).

1. In the first level, the wide end of the (conceptual) funnel contains the general theories the study used. Therefore, social learning theory and distributed expertise provided an interpretive framework and 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 activity theory is introduced, while social learning theory and distributed expertise remain and flow through the entire funnel.

2. In the second level, the wide end represents the MDT teaching parents as part of family centred care. This is guided by a combination of the theoretical and modelling phases of the Medical Research Council Framework for Complex Interventions [35], in particular this study is part of a phased approach towards developing an understanding of the complex intervention of Parent-education amongst Renal MDTs and its possible effects. 'Modelling' refers to the fact that this phase is paper-based and also includes qualitative testing[36]. The study is based on the MRC[36:2] premise that:

   Complex interventions in health care, whether therapeutic or preventative, comprise a number of separate elements which seem essential to the proper functioning of the intervention, although the "active ingredient" of the intervention that is effective is difficult to specify

   Our goal, therefore, is to begin specifying the 'active ingredient' of the 'parent-teaching' intervention in CKD management, and use this as part of a phased approach to developing and evaluating an intervention that can be used by renal MDTs in clinical practice to help them assess parents' learning needs and preferences. Our approach is entirely consistent with current MRC[35:32] guidance which indicates that:

   Involving users in the design and conduct of evaluations, as well as being ethically preferable, has important practical advantages. Recruitment and retention are likely to be better if the intervention is valued by potential participants, concerns about fairness are addressed…. Involving users may also contribute to a better understanding of the process by which change is achieved.

3. In the third level, the wide end of the funnel represents Phase I of this study, a mixed methods survey of the 12 children's kidney units in England, Scotland & Wales, and the narrow, more focused end represents Phase II, the focused observational study involving six case study families in two of the units.
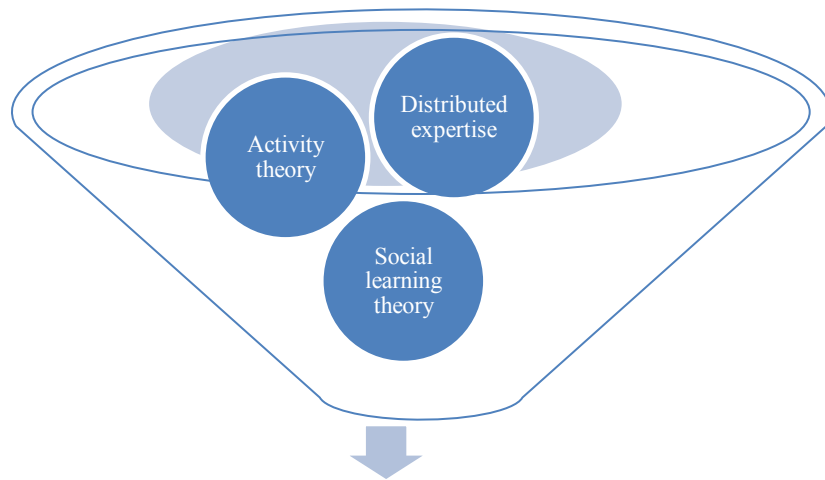
Figure 1: Conceptual funnel level 1

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 [37]. 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 [38]. By contrast, in mixed methods studies such as this 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 new understanding is reached.

1.11 Research aim and objectives

The aim of this study was to obtain a detailed understand of the way MDTs teach parents and carers to become home-based clinical care-givers, and the way parents learn to care for children's CKD.

The objectives were to:

1. Develop a descriptive profile of multidisciplinary team members' parent-teaching interventions in the children's kidney units in England, Scotland and Wales

2. Explore MDT members' detailed accounts of the range of care-giving skills and information they relay to parents, and the formal/informal teaching strategies and interventions they use

3. Obtain a focussed and detailed prospective understanding of professional-parent interactions during observation of planned and ad hoc teaching and learning encounters in one or two units

2   Research design

2.1   Study setting

The twelve children's kidney units in England, Scotland and Wales

2.2   Methodological approach

Parent education is a complex, multidimensional process representing a variety of cultural, cognitive, social and emotional factors so a single methodological approach would not yield meaningful data[39] [40]. To achieve breadth and depth of analysis, therefore, the study used a combination of quantitative and qualitative methods[41]. We used a two-phased process of data collection and analysis, each phase forming a progressive focus on the interactions between MDTs and parents of children with CKD during teaching and learning encounters. To enhance the rigour of our study we regularly reviewed the methods using recognised check-lists for mixed methods and qualitative research[42] [43] [44]. We published the protocol[45]; this can be found at: http://www.biomedcentral.com/1472-6963/12/33i. The two phases of the study are illustrated in Figure 2 and described in detail below.

Phase 1, strand i
- NHS REC Approval granted for Phases I & II
- Trust R&D approval obtained in 12 Trusts for Phase I & II
- Pan-Britain questionnaire survey of the 12 Renal MDTs

Phase 1, strand ii
- Qualitative exploration of MDT members' accounts of their parent-educative functions
- 13 focus group and 7 individual qualitative research interviews
- 112 health care professionals (7 clinical psychologists, 9 dieticians, 30 doctors, 48 nurses, 3 pharmacists, 7 play workers, 6 social workers, 2 therapists) and 1 receptionist.

Phase 2
- 6 Ethnographic family Case Studies
- 28 MDT members
- 86 observations of teaching/learning interactions, 41 individual semi-structured interviews
- Field-notes and case-note reviews

Figure 2: Study overview and methods used

2.3   Phase I: Strand i: Administered questionnaire survey

We developed a questionnaire (Appendix 1) comprising a range of questions to survey: the numbers of professionals from different disciplines in each team, the information and skills individual professionals relay to parents, the teaching and support interventions they use, the existing patient categories by diagnosis, and treatment support needed by parents (e.g. post-transplant care, or management of haemo-dialysis, peritoneal dialysis, dietary restrictions, injections, naso-gastric tube feeding and complex medications), and   the

disciplines represented within the MDTs. Additional questions asked whether individuals teach parents, reinforce information taught by colleagues, or teach and reinforce information.

The principle investigator (PI) in each unit (identified through the British Association for Paediatric Nephrology) or a delegated colleague completed one or two booked telephone interview(s) lasting 15-30 minutes at a convenient date/time. The researcher conducting the interviews entered the data provided by the PI into the questionnaire. Telephone interviews combined with administered questionnaires are an effective means of surveying clinicians[46] [47], and can result in lower 'missing-response' rates and less use of 'don't-know' options than postal questionnaires. Data were managed using Excel to produce descriptive statistics, the derived profile of each unit informed data collection in strand ii.

2.4 Phase I, strand ii: MDT focus groups/individual interviews in the 12 centres

2.4.1 Data collection

To obtain an in-depth understanding of professionals' accounts we adopted an interpretative approach using qualitative methods; this approach stresses the importance of interpretation as well as observation in understanding the social world so was appropriate to address our aims [48] [49]. Individual and/or group focussed qualitative research interviews (lasting on average 50 minutes each) were facilitated by VS and/or CM. Interviews took place in a meeting room in each unit and were supported by a topic guide (Appendix 3) designed to help us explore professionals' accounts of the parent-educative component of their role. The topic guide was based on our knowledge of the literature and included the five teaching activities arising from research previously conducted in the area of paediatric nephrology[5] [7] [15]. Interviews were digitally recorded and later transcribed verbatim. To protect individuals' identity all data were anonymised before reporting.

2.4.2 Data analysis

Data were analysed using Framework Technique which is systematic, rigorous and grounded in the data; it provides an audit trail enabling easy retrieval of data to show others[39] [40] and has an overt policy and practice orientation[48:186] [50] (see Figure 3 below). Framework enables both theme-based and case-based analysis. Transcripts are analysed through five iterative stages: (1) familiarization with the data; (2) identification of a theoretical framework; (3) indexing; (4) charting; and (5) mapping/interpretation. Framework borrows its principles and approach to implementing these principles, from different epistemological traditions within the social science field; it is this eclecticism that has remained its strength throughout its development as an analytical process [39] [49]. Framework's ontological position adheres most closely to subtle realism [51] which accepts that the social world does exist independently of individual subjective understanding but that it is only accessible in qualitative research via participants' interpretations, which may then be further interpreted by the researcher.

Analytical hierarchy: iterative steps from raw data to informing policy and practice	Analytical process
Raw data	
	Data management
• *Closely reading transcripts*	
⇕	
• *Identifying themes/indexing*	⇩
• *Coding/labelling/charting data*	
⇕ • *Summarizing/synthesizing data*	Descriptive accounts (what)
• *Identifying dimensions & categories*	⇩
• *Detecting patterns/clustering*	
⇕ • *Seeking interpretations*	
	Explanatory accounts (why)
Inform policy/practice	

Figure 3: Analytical hierarchy and processes of Framework[18]

Initially, VS and CM, independently read and coded the first transcript, searching for patterns in the data, mapping connections and seeking explanations for patterns before comparing and discussing these. During this stage a data sample from two of the sites was also coded independently by LC (1) and discussed with VS and CM until a consensus was reached; this helped to enhance analytical rigour. As part of the iterative process of data collection/analysis, version 1 of the framework comprised five themes, version 2 comprised six themes and after discussion with co-authors/steering group members we distilled down the themes until the final framework comprising four themes and 12 sub-themes was agreed upon (2).

The framework was then applied (manually) (3) to all transcripts. VS and CM then worked independently with the transcripts, searching for patterns within the data, mapping connections and seeking explanations before comparing and discussing these until achieving a consensus. Each coded transcript was then (4) 'lifted' to a Microsoft Excel spreadsheet for charting where key quotations were labelled and identified for later retrieval when reporting. Stages (4) and (5) were facilitated by coding data from disciplinary datasets across the 12 units.

As data management proceeded, emerging themes supplemented interview topics; this iterative process involved moving backwards and forwards between the five stages of Framework[39 52] (Figure 3). This enabled comparison of data within and between disciplines across the 12 children's kidney units, and rearrangement of the data for more detailed

analysis and interpretation. Working through the raw data with this level of intensity helped us identify the lines of enquiry to pursue during ongoing data collection and analysis.

The main purpose of this process was to scrutinise the content of each theme, to display the data in a way that makes meaningful distinctions between disciplinary accounts across the participating units, and to provide content that illustrates the themes. Constant comparison between transcripts opened up meaning in the text until no new themes emerged. To ensure trustworthiness and credibility, reduce potential bias and enhance theoretical sensitivity we incorporated reflexivity into the data management process regularly considering whether analysis might have been compromised in favour of our own preconceived ideas[39 40]. For a more detailed description of the charting process, and of the way Framework was used in this study, please see published examples from one of our earlier qualitative studies involving fathers and mothers of children with CKD doi:10.1111/j.1365-2214.2011.01219.x [20].

2.5 Phase II: Focussed ethnographic study

2.5.1 **Introduction:**

In this phase, detailed information was gathered on how MDT members supported parents, and how parents learned to develop the skills and knowledge to carry out clinical care-giving tasks with their child. Six observational case-studies were completed in two UK children's kidney units selected during Phase 1 analysis. To protect individuals' identity the two centred are not identified. An ethnographic approach [53-55] was used, involving the "systematic, detailed observation of behaviours and talk" [56:182]. Each case study lasted approximately six months. The data gathered during this phase provides information on how parent-professional interactions were enacted and identifies communication processes which appeared to promote or impede parents' learning. The researcher (an Occupational Therapist who had worked with children and young people and had practiced within the NHS for over 10 years, but who had no experience of renal units) started in post in July 2011 and initially spent time in the two units to become familiar with the settings.

2.5.2 **Sample selection and recruitment:**

A purposive sampling approach was used to achieve maximum variation. This approach means the sample is chosen for a purpose to ensure all criteria of relevance are included[54]

Sampling was based on:

- The age of the child, to allow for a broad range of stages of cognitive development as it has been recognised that differences exist between care needs of children and young people of different ages [57 58].
- Sex of the child
- Ethnicity
- Type of care-giving needed

Additionally, as interpreters were not available to the researcher, parents needed to be able to speak English to a level where they could participate in interviews without requiring an interpreter.

Potential case study patients were identified by the PI in each of the two units. The PIs were a nurse and doctor who worked in the two respective units; as knowledgeable insiders, they acted as gatekeepers and advised and supported the recruitment process. Families selected were about to embark on delivering a new clinical intervention, where the child required regular home-based care-giving such as:

- Administering complex medications, either requiring multiple medications and/or frequent changes to medication
- Dietary supplements
- Gastrostomy or naso-gastric tube feeds
- Setting up/running home dialysis
- Monitoring diet and fluids
- Recognising subtle clinical changes
- Recording clinical observations
- Acting on results

- Accurately communicating observations/actions to professionals

In total, the local PIs identified ten children who met our inclusion criteria during the recruitment phase; we aimed to recruit up to six families. The final selection of six families was based on the potential for maximum variation from the sample available during the recruitment stage, and enabled the researcher (RN) to efficiently manage the significant work involved in setting up and running six case studies across two study sites. The parents of the first six patients selected were therefore, invited to participate; all provided consent after receiving verbal and written explanations about the study. The six case studies each lasted six months and there was no attrition. In total, 18 family members participated in the study, this included children, mothers, fathers and grandparents. Figure 4 provides information about the participating families.

Figure 4: Characteristics of participating families

Families Study identifier	Child's age	Child's Sex	Child's Ethnicity	Care-giving learned by parent(s) and their Experience	Social situation
1	8	Boy	White British	Home dialysis. Parents had previous experience of home-based care-giving.	Parents married, 2 younger siblings. Father works full time, mother worked up to having youngest child, is now primary carer for child. Grandparents involved in child care.
2	11	Girl	White British	Home dialysis. Previous experience of home-based clinical care-giving.	Parents married, 2 older siblings. Father works full time, mother works part time from home and is primary carer for child. Grandparent involved in child care.
3	12	Girl	White British	Dietary restrictions, preparing for home dialysis. Previous experience of home-based clinical care-giving.	Single mother, lives with members of extended family. Mother previously worked full time, now unemployed.
4	15	Girl	South Asian	Understanding new condition, medication, diet, home dialysis. Little experience of home-based clinical care-giving.	Parents married, 3 younger siblings. Parents speak English as second language. Live with grandparents. Father is primary carer, had full time job, stopped working temporarily whilst learning home dialysis, but has resumed job working part time.
5	3		White British	Post transplant (e.g. fluids, medication, diet). Previous experience of home-based clinical care-giving.	Single mother, only child. Child has contact with father. Mother previously worked full time, now unemployed.
6	5 months		White British	Understanding new diagnosis, fluid management, NG tube. Parents had little experience of home-based clinical care-giving.	Parents married. Only child. Father works full time, Mother not currently working. Grandparents involved in child care.

Snowball sampling [1] was initially used to identify the MDT members involved in the management of each index case. With guidance from the PIs, the researcher approached professionals working with each family, who sometimes then identified other colleagues who were also involved with the family. Convenience sampling was also utilised when the researcher came into contact with other professionals involved with the family; for example during clinic appointments. At the start of each case study access negotiations commenced on an individual basis with MDT members involved in the child's care. In total, 28 professionals participated in Phase II, including nurses, doctors, dieticians, therapists, a play specialist, a social worker and a pharmacist. We did not specifically ask if any of these participants had participated in Phase I as we did not want to risk influencing professionals' decision about whether or not to take part in Phase II. Four professionals who were invited did not participate, either because their involvement with the family had ceased since they were referred to the researcher or, because their initial verbal expression of interest was not followed up with written consent within the timescale of the study.

Diagrams in Appendices 7, 9, 11, 13, 15 and 17 provide information about the number and range of professionals who had contact with each of the families during the case studies. As the focus in this study was on the interaction between parents and MDT members more detailed information is provided about this part of the family's network. The diagrams illustrate the disciplines (e.g. social worker, nurse, doctor, dietician, play specialist) and the individual professionals who participated in the study. Information is also provided about the number of contacts that the researcher had with individual professionals in relation to each family. As the diagrams demonstrate, some MDT members had contact with more than one of the study families. The diagrams also indicate of the number of individuals from the same discipline which had contact with a family.

2.5.3 Data collection:

A central assumption of ethnography is that to understand what people are doing and why, "...one needs to understand the meanings involved: how they interpret and evaluate the situations they face, and their own identities" [55:168]. The communications between MDT members and parents were explored, as parents learned selected skills and knowledge that would be needed to undertake clinical care-giving tasks with their child. A combination of methods was used to gather data, including:

A) 86 observations of interactions between parents and professionals from August 2011 – April 2012

- In the clinical setting, including ward based events, outpatient appointments and families' homes.
- Both planned and ad-hoc teaching/learning events were observed.

---

[1] Identification of a small number of individuals with required characteristics who are then used as informants to identify others for inclusion in the study. In turn, these informants are used to identify further participants until sufficient numbers are reached. An example of non-probability sampling.

.

- Observations were focused on key themes arising from a synthesis of Phase 1 data.
- Verbatim field notes, and some digital recordings were made of each event. Field notes are notes taken by the researcher about events which were observed and included information such as communication, behaviour, the context, time, personnel and the environment. See Appendix 19 for an example of an excerpt from a field note.
- The researcher aimed to be minimally obtrusive during each event. See Appendix 20 for further discussion about the role of the ethnographic researcher.
- Tables in Appendices 8, 10, 12, 14, 16 and 18 illustrate the number of events that the researcher observed with each of the families and who was present at each event.

B) 41 individual semi-structured interviews with mothers, fathers and professionals following selected observations between August 2011 – May 2012

- Interviews explored parents' and professionals' views about how parents were being supported to learn to deliver home-based care-giving. This included the effectiveness of the interactions which were the subject of respective observations.
- 39 interviews were carried out face to face, two interviews with mothers were carried out over the telephone as this was more convenient for the participants.
- Interviews were digitally recorded and transcribed verbatim.
- Interviews lasted between 20 – 65 minutes.
- Some participants were interviewed more than once, at the start and the end of the case study, to explore if any changes had occurred over the six month period.
- Participants were offered copies of their interview transcripts to review and asked for their agreement to use anonymised quotations in reporting the study. No one disagreed to quotations being used. Two professionals amended their transcripts. A number of professionals commented on the experience of reading their transcripts, expressing surprise and/or concern about their ability to articulate the teaching and learning encounters they engaged in with families.
- Appendices 21 and 22 illustrate the topic guides used to help structure interviews with parents and professionals.

C) Selected case note reviews

- To gain relevant background information.
- To identify how professionals documented skills teaching and parents' skill and knowledge development.

D) Selected documents review

- Documents used by professionals to support their teaching.
- Documents used by parents to record their home-based clinical management.

As data collection proceeded, the inquiry became progressively focused on specific research questions. This allowed for strategic data collection, especially through the observations and

interviews, which meant answers to questions could be pursued more effectively and tested against existing data and research literature. Discussion with the study steering group about preliminary data also resulted in increasingly focused data collection.

2.5.4   **Data analysis:**

Data management and analysis involved using the Framework Technique [39] and Excel as described in section 2.4.2[52]. Therefore, analysis involved an iterative-inductive approach whereby the researchers moved "forwards and backwards between theory and analysis, data and interpretation" [54:149]. During preliminary analysis an initial coding framework was developed and collaboratively agreed comprising of descriptive and analytic codes. This was applied to the data set (interview transcripts and field notes) and subsequently refined as analysis proceeded. The final coding framework is available in Appendix 23. Data were then sorted and synthesised. In keeping with the Framework principle of Framework the essence of the original material are retained until the later interpretative stage of the analysis, at this stage key terms and phrases were retained as much as possible from participants' own language.

In the later, more abstract categorizations four different classifications began to emerge: the first concerns professionals enabling and promoting parents' clinical role; the second, parents' cautious acceptance of the clinical role; the third, blended expertise around the child; and the fourth, ambivalence in teaching and learning encounters. During this process the substantive content and elements of the categories were identified by looking across all cases and noting the range of perceptions, views, behaviours and experiences that had been labelled as part of the category, and it became clear, for instance, that professionals actively and consistently promoted parents' clinical roles at the same time as they assessed and managed the child's clinical condition.

2.6   **Ethical considerations:**

Ethical approval for the entire study was obtained from the North West 3 Research Ethics Committee (REC) (REC reference: 09/H1002/92) [now NRES Committee North West – Liverpool East], the University of Manchester REC and the participating NHS Trusts Research and Development departments. The CI (VS) was awarded letters of access or an honorary research contract at the participating NHS Trusts for the duration of the study. In Phase I, the researcher appointed (CM) held a substantive contract with one of the participating NHS Trusts and was awarded letters of access in the remaining NHS Trusts In Phase II, the researcher appointed (RN) held a contract of employment with one of the two participating NHS Trusts and was awarded a letter of access by the other participating NHS Trust, both for the duration of the project.

All the parents, and children where appropriate, who were identified by the PIs were provided with written and verbal explanations by RN and had the opportunity to ask any questions. Those parents who agreed to participate, provided signed consent (and children completed assent forms where appropriate). Where possible, professionals were provided with written explanations in addition to verbal explanations prior to being asked to consent; however, this was not always feasible within the context of busy outpatient clinic appointments, and in a few cases written consent was gained retrospectively. As the two

units had participated in Phase 1 and the researcher had spent time meeting with MDT members before data collection started, many professionals had some awareness of the study. Furthermore, we viewed consent as a process rather than a single event meaning it was regularly reviewed with participants during Phase II. Where both parents were involved in learning clinical skills and knowledge, informed consent was sought from each and the assent of children involved in any observed events was sought each time, if they were capable of providing this.

All participants were assured of anonymity and confidentiality. With small sample sizes, maintaining anonymity presents a challenge when reporting qualitative findings, therefore the children's kidney units and individual participants are assigned coded identifiers throughout the report. This is necessary so that participants' identities are not identifiable through the diagnostic or treatment detail presented.

No risks or hazards were anticipated for participating MDT members, parents or children and though it was possible some participants may have felt they were being judged on their performance, assurances were offered that the study was not 'testing' knowledge or 'judging' teaching, parenting or professional care-giving skills. Participants were advised to signal using a coloured card if they became uncomfortable and wanted the researcher to leave an observed situation. Support from a Clinical Psychologist on the research team was available for those who experienced any distress from participating in the study. Neither of these measures were utilised by any participants, though the researcher decided to leave one observed situation when the child was becoming distressed during a clinical care-giving task.

In line with ethical and legal guidance all identifiable personal information is being handled in strict confidence. Parents' and professionals' views were not disclosed to one another or anyone else. The interviews and teaching/learning events which were digitally recorded, were typed up as transcripts by a commercial transcription company. All person identifiable information was removed from interview transcripts and field notes. No one other than the Chief Investigator (CI) and researcher were able to listen to the digital recordings or read the complete collection of notes and transcripts. Anonymised excerpts from field notes and transcripts were discussed with the study steering group, where confidentiality was assured. Though the research team may carry out further data analysis in the future, the findings would always remain anonymous. All data were stored (and will continue to be stored for ten years when they will be destroyed) in a secure locked cabinet or password protected computer and available only to the CI and researcher. The site files, containing information about the study such as consent forms and correspondence, were kept in secure locked cupboards/cabinets with site files from other research studies taking place in the two respective NHS trusts.

3   Findings: National survey

Strand i:

Appendix 2 reports the number of staff from selected disciplines across the 12 units involved in teaching and reinforcing

Strand ii: Professionals' parent-educative functions across the 12 units

A total of 112 health professionals (Clinical Psychologists n=7, Dieticians n=9, doctors n=30 *(28 Consultant Paediatric Nephrologists; 2 Registrars),* Nurses n=48 *(Included the roles of Specialist Nurse, Nurse Consultant, Nurse Specialist, Clinical Nurse Specialist, Associate Nurse Specialist, Advanced Nurse Practitioner, Staff Nurse, Senior Staff Nurse, Junior Sister, Sister, Matron, Ward Manager, Research Nurse, Clinic Nurse, Community Nurse, Ward Nurse, Nurse working in HD, PD or Transplant),* Pharmacists n=3, Play Workers n=7, Social Workers n=6, and Therapists n=2) participated in group (n=13) or individual (n=7) focussed interviews. Three further professionals expressed interest in participation but were unavailable during the data collection period.

Data presented in this section are drawn from professionals' accounts during MDT focus groups and individual interviews in strand ii. Participants spoke at length about their experiences and touched upon a wide variety of topics in describing their parent-teaching activity. Our analysis identified three main themes, these represent three key parent-educative functions demonstrated by MDT members. The themes and their associated sub themes illustrate the retrospective views and experiences of professionals, and form the main output from Phase I: the MDTs' parent-educative model in CKD management. Figure 5 illustrates the explanatory model and Figure 6 the inter-relatedness of the three themes within this model.

Initiating knowledge & skill development
- Establishing parents' prior condition-related knowledge and position on the 'renal journey'
- Determining learning potential
- Prioritising the skills/knowledge to teach
- Defining & meeting individual learning needs

Promoting & monitoring knowledge & skill development
- Teaching in stages
- Using metaphors & tools
- Assessing understanding
- Reviewing learning progress

Multidisciplinary team working
- Role allocation & differentiation
- Sharing information within the team
- Language interpretation
- Acting as ambassadors

Figure 5: MDTs' parent-educative model in CKD management
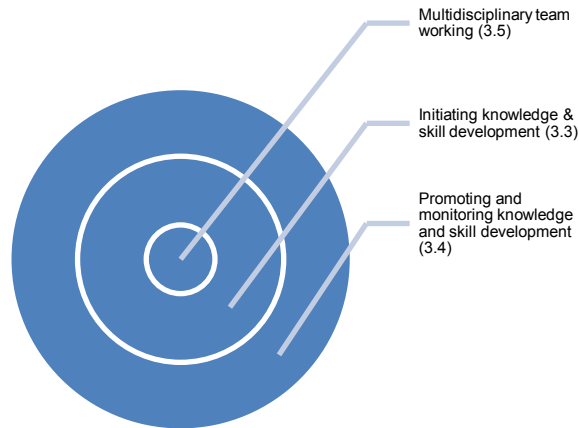
Figure 6: Relationship between the three parent-educative functions

The model is organised in such a way that the essential component of multi disciplinary team working is central to professionals' parent-educative functions; this centrality was evident throughout the research interviews and our analysis. Each part of the model is discussed in this section of the report using selected illustrative quotations according to individual disciplines and across all teams, thereby illustrating how each component of the model connects with and is co-dependent on the other. Direct quotations are presented in boxes as below:

> *with details of the participants' disciplines*

Although there was some overlap between professionals' parent-educative functions, for clarity they are presented sequentially below. Moreover, professionals' accounts highlight the way they move backwards and forwards between the three functions according to the child's clinical status and parents' perceived response to teaching interventions. Supplementary data in the form of additional quotations from the respective disciplines are provided in Appendices 4, 5 and 6.

3.1 Initiating parents' knowledge and skill development.

3.1.1 Introduction:

When reflecting on the parent-education aspect of their roles, professionals were asked to start by talking about the way they approach this with a family they were meeting for the first time. The strategy respondents reported as being the most important to start with was initiating parents' knowledge and skill development. Professionals talked about meeting parents for the first time at different stages of the 'renal journey'; because of this professionals needed to determine where parents were on the 'journey', what information they already possessed about the child's condition, and to clarify roles and responsibilities so that they could decide how to communicate with them. Our analysis identified four main patterns similar across teams: Establishing parents' prior condition-related knowledge and position on the 'renal journey'; determining learning potential; prioritising skills/knowledge to teach and, defining and meeting individual learning need. The intersections between these

four main sub-themes are significant, representing the combination of factors that can make early interactions between MDT members and parents particularly challenging, but also providing rigorous evidence of the way professionals may address these challenges.

3.1.2 Establishing parents' prior knowledge and current position on the 'renal journey':

From the outset, establishing parents' prior knowledge and their position on the renal journey was the issue most frequently described by professionals as being important for them when first meeting parents. Central to this was the need to establish a good 'working relationship' with parents. For instance, a nurse said:

> *If you get it [relationship with parents] wrong in the first few hours, you have many problems really and have to make up for that 'big time'.* (Nurse_68)

Introducing themselves as part of the team caring for the child and outlining their respective roles in the team, especially in acute settings where the child's condition warranted prompt and sometimes invasive investigations or treatments, was important for participants from all disciplines. In addition, professionals emphasised the challenge of finding out what knowledge individual parents already possess about the child's condition, and what parents' expectations are, in order to communicate with them appropriately. For example, two doctors explained:

> *Some [parents] have very high levels of understanding and want to know everything; others won't want that …it's trying to ascertain what level you're working at, and:…the only way to teach is to try to bring them with you when you do it…*(Doctor_ 42 & Doctor_ 66)

Other professionals, such as this pharmacist, gave vivid accounts of the need to identify what knowledge parents had already received from doctors and nurses in the MDT so that they themselves could reinforce this information:

> *I'd find out what they already know, what they been told by medical or nursing staff, what their general understanding of medicines is…* [Pharmacist_ 82]

In addition, clinical psychologists, social workers and therapists talked of providing parents with strategies to help them communicate their questions and concerns to MDT members:

> *I mean [for instance] the lady who if she started [explaining herself to a professional] now it would be an hour later you'd hear [what she was trying to say to the professional] because she didn't have a [suitable communication] style, and sometimes it's just [about us] acknowledging that they are in a horrible position* (Therapist_65)

Meanwhile, a social worker described the way they would try to empathise with parents to try and assist them to learn about the complexities of their child's condition:

> *I introduce myself as somebody who maybe has as little knowledge as they do on the medical aspects of care* (Social Worker_23)

Establishing parents' position on the renal journey and their prior knowledge about the child's condition helped professionals to determine the parents' learning potential.

3.1.3   Determining parents' learning potential:
Participants' accounts indicate that they were sensitive to the need to determine parents' potential to learn by being alert to subtle cues:

> *I visit to see how mum is doing with PD, [although] it might look a bit more social, a cup of tea and how's it going?* (Clinical Psychologist_8)

This quotation emphasises the fact that members of disciplines such as social work, clinical psychology or nursing may routinely make home visits to families to offer additional support and often used this opportunity to tactfully assess parents' learning ability, as a social worker articulated:

> *...lots of little warning signs altogether [that parents are not understanding] might then get us [MDT] to discuss it in a psychosocial meeting, then we'll make a plan…* (Social Worker_89).

Although play workers primarily support the children, they often do this by working with the whole family, so may initially do a:

> *…quick assessment because I have to try and build a relationship quickly…prefer to get to know family, play with the child, understand a bit more how that child works then maybe give [family] some text or something to take away* (Play Worker_63)

Having determined parents' learning potential professionals used this knowledge to help them prioritise the knowledge and skills to teach

3.1.4   Prioritising skills/knowledge to teach:
Each child's management plan will be different and may change frequently throughout the renal journey according to their clinical status. As part of the management plan each discipline has specific knowledge and/or skills to impart to parents..This means that parents need to have some understanding of the different disciplinary knowledge bases as they

relates to their child. Mindful of the fact that parents may have limited, prior condition-related knowledge, and to avoid overwhelming them with new information at what can be a very anxious and stressful time, many individuals described their strategies for prioritising the knowledge and skills they teach:

> *..[parents'] greatest fear is their child's going to die, but it's a fear they don't ask as they're petrified of getting a 'yes'. So often one of the first things I say is (because they've not seen it [kidney condition] before so they think it's new) 'we've seen it before, this is what we're going to do, we're not expecting your child to die'…that's a big anxiety [addressed] and then they're more ready to listen* (Dr_110).

Information was often *'drip fed'* and parent-education *'paced'* by professionals:

> *…teaching them very slowly and not letting them rush…they've really got to know what might happen if you do this, if you do that* (Dietician_6), *while a nurse advocated:.'.try to break it [information] up into small bits such as…'function of the kidney, basic idea of how kidneys work'* (Nurse_87)

Nevertheless, time pressures could pose limitations on professionals' teaching and potentially constraints on parents' learning, as one nurse commented:

> *Because if you've got a set amount of time and you've got some information to get over to them you can find yourself kind of talking at them and never really [checking their understanding]* (Nurse_68).

While a therapist reported that their responsibilities included encouraging parents to learn to recognise the way their own behaviour may adversely affect the child's response to treatment, for instance by pressuring the child to comply with all aspects of treatment, even those that professionals do not regard as a priority:

> *…because it can be very difficult for parents to stand back as obviously they want to make sure their child's doing everything to be as healthy as possible* (Therapist_67)

The decision about which knowledge and skills to initially teach parents informed the way professionals then defined individuals' learning needs, and helped to formulate a plan for meeting these needs

3.1.5 Defining and meeting individual learning need:
Defining and then meeting individuals' learning needs was another challenge reported by professionals, as one doctor explained:

> *My approach would be to try and explain what the diagnosis is, often for kidney patients one has to explain mechanisms because many conditions have no associated physical finding…it's often explaining results of blood tests or scans…explaining about things happening inside..often they're not terribly obvious on the outside (Doctor_103)*

The 'invisible' nature of CKD alluded to in the above quotation was reported by several MDT members as a challenge when explaining a kidney condition and its management to parents.

Another issue in focus group and interview discussions was using appropriate language, as a dietician said:

> *The language you'd use for someone who's not got any medical knowledge is completely different [to that you would use with parents] (Nurse_92)*

Similarly, it was acknowledged that even when communicating with parents who have been users of the health care system for several years:

> *...we shouldn't assume that they know... for example, because they've [child] been on dialysis for ten years they don't know about transplantation... you have to start from scratch with things like that…... (Nurse_108)*

Meeting individuals' learning needs could, therefore, present many challenges for professionals including the need to recognise that kidney conditions are often invisible, and the importance of using appropriate language and vocabulary. In addition it was often considered important to recognise that even for parents who had prior experience of health care it may be necessary to teach them as if they were novice learners

3.1.6   **Summary:**
Initial interactions with parents often start by professionals from up to eight disciplines introducing themselves. This means that for parents, as well as needing to deal with potential concerns about the child's symptoms and any uncertainty related to these, they may also meet a wide range of new individuals with differing roles and responsibilities in the child's management, in an unfamiliar environment. It appears that professionals adopt a variety of strategies to initiate relationships and assess parents' learning potential in order that they can both comprehensively assess and treat the child's clinical condition by drawing on information from the parents, and decide which knowledge and skills need to be shared with parents.

The complexity of this parent-educative function is accentuated by the fact that the child's condition may be 'silent' with few if any 'visible' signs to use as a focus for communication, and that parents present with a wide range of educational and psycho-social backgrounds and varied prior experience of health care. At the initial stage, professionals have few

standardised resources available to them to assess parents' individual learning needs so use a range of approaches to help them promote and monitor parents' knowledge and skill development. These approaches are discussed in more detail in the section below.

3.2 Promoting and monitoring parents' knowledge and skill development

3.2.1 Introduction:

There were a number of key components in how professionals promoted parents' knowledge and skill development, and how they formally or informally monitored this. Given the limited level of initial understanding about parents' potential to learn complex clinical information, as discussed in the previous section, professionals tended to adopt a combination of 'trial and error' and discussion with other MDT members to approach this. They reported four main features that were important in how they performed this parent-educative function, namely: teaching in stages; using metaphors and tools; assessing understanding; and reviewing learning progress. These features are discussed individually below for optimum clarity but in reality professionals often moved back and forth between them

3.2.2 Teaching in stages:

Building on an acknowledgement of the importance of prioritising the skills and knowledge to teach parents, there were many quotations from a range of disciplines emphasising that parents would not be expected to understand everything at the outset. MDT members, therefore, often teach in stages:

> *.. there are things which are essential that parents learn and things that it's nice if they learn which will often help them along the way to mastering what is going on with their child* (Doctor_34)

Following on with this theme of 'mastery', others, like this clinical psychologist observed:

> *…it's really important that parents know they're not always going to understand everything when they're anxious and upset and they can go back and ask again and again* (Clinical Psychologist_29

This could include:

> *Explaining the basics first, if you don't you're not always going to get compliance or understanding of what to do and why* (Dietician_112)

and:

> *I always start with where are your kidneys and what do they do? And how is that impacting on what you're currently doing? So then I can start talking about why we would need to do a transplant because we can say, well, those treatments that we're currently doing are not going to always keep your child well, need to look at alternatives* (Nurse-86)

Some parents would actually request a staged approach to information provision as one professional explained:

> *…teach in stages, some [parents] will say 'Cards on the table, I want to know everything now' some will say 'just tell me what's happening in the next day or so, don't want to think beyond '* (Nurse_101)

'Teaching in stages' was a strategy that professionals reported using to help ensure parents received essential information early in the renal journey, but was also an attempt to avoid 'overloading' them. This was also a response to requests from some parents to pace information provision. This approach was often supported by the use of tools and metaphors as explained in the next sub-section.

3.2.3   Using metaphors and tools:

When responding to individuals' needs, respondents described using a wide range of tools and metaphors to support information provision. Examples of this included metaphors to support explanations of basic kidney function:

> *How the kidney does a lot of work and is made of a whole lot of little factories*
> (Doctor_113)

In addition, tools designed for children were sometimes used as a means of explaining complex information to parents:

> *…using child appropriate pictures: …pictures are used much more among children obviously but some parents I think do benefit from that quite a lot and quite often they have some shared education* (Doctor_97).

Meanwhile, a dietician described how she:

> *Gave them [parents] a set of scales and little exercises…play with the scales…one [parent] had a slightly bigger muscle in his arm, teaching them if they[child] don't eat they break down the muscle mass…list of foods in a green column…list of foods in red column* (Dietician_6)

Several professionals highlighted in focus groups the fact that MDT members' familiarity with the hospital world and language can lead to them forgetting that for parents, the context, and commonly used terminology, need to be more accessible; a play worker described one strategy for addressing this situation:

> *I've got my book of pictures and my dolls [for the children], parents get quite interested in them but sometimes you take then and you're just talking to the adults…when doing transplant [preparation] perhaps, about what's going to happen… everything needs to be simplified ..* (Play Worker_95)

Providing parents with literature to take home as a way of reinforcing vital information was a widely reported strategy, as one pharmacist explained:

> I give all the patients/parents a renal medication book, so they have written information about their medicines, go through what each medicine is for and why they take it and a chart to record doses. [Pharmacist_82]

In addition to providing tools to assist parents' own understanding, professionals also recognised a need to support parents' efforts to explain the condition and its treatments to other adults such as teachers, nannies and child minders. Parents may need to explain the child's management to health care professionals in hospitals near to the family home for occasions when the child may be admitted as an emergency. Local staff may be inexperienced in caring for children with a kidney condition:

> *When [mother] goes to local hospital she has to start from the beginning each time, so she sees a different Dr and they start right back at the first stage and it drives her completely mad. So what we're doing is an [individualised book] where we have all the information from all the different specialities, a contact list of all the MDT, all her medication lists, all her previous history.* (Nurse_90)

Tools and metaphors were used by MDT members to support explanations and they sometimes helped professionals to determine how well individual parents understood the information provided.

3.2.4 **Assessing understanding:**

Many interviewees indicated that MDT members are sometimes puzzled or even frustrated when parents appear not to understand an aspect of their child's management, even though they had received several explanations about the issue. In these instances, often the clinical psychologist, social worker or play worker informally assessed parents' understanding and relayed their impression to other MDT members:

> *…they [parents] don't [understand what they have been told] they haven't for some reason interpreted it in the way we want them to, or they haven't understood it in the way that would be most helpful. So we need to then kind of rethink how we're giving them that information and then we work as a team, I think, to try and inform them in a way that they can take it* (Clinical Psychologist_94).

Several participants described using 'talk back' as a way of assessing the effectiveness of their explanation to parents, as well as assessing the parents' understanding, one nurse for instance described an informal approach to this:

> *...no set strategy but normally I'll talk it through, often I'm teaching with the children as well, so you can ask the children to repeat it back and if they've understood it or if they haven't parents will chip in, so I would often get them to repeat it back and explain it to me to make sure that I've explained myself properly and I know that they've understood* (Nurse_105)

3.2.5 Reviewing learning progress:

Although there was some variation in the data, all disciplines and many participants reported that it is very important to routinely re-assess parents' learning progress. Strategies included using formal and informal or ad hoc means of assessment. There were many accounts of participants being 'opportunistic' in their reviews of parents' understanding; the outpatient clinic appointment was often used for this purpose, as a doctor commented:

> *Families don't remember all those things you've talked about in that two hours [at first admission], come six months later there's lots of things they've often misconstrued or forgotten and I think that is something….you could argue that every clinic is a training opportunity actually, there's always little bits and bobs you talk to people about and suddenly you realise they haven't understood why they're on a certain medicine or they haven't understood something, even though you know for certain, you and others have told them three times before* (Doctor_98)

Similarly, a dietician explained how reviewing learning progress is often an informal but purposeful part of dieticians' ongoing communications with parents:

> *...we don't necessarily do that formally [review learning progress] like if we were teaching health professionals, in terms of we don't get them to sit down and go through a load of questions but we'd probably do that informally every time we sit in clinic with them or have a discussion with them* (Dietician_99)

In contrast, some participants sought to create opportunities for parents to ask questions. However, mindful of the potential challenge for parents needing to learn large amounts of complicated and vital information about their child's condition and treatment regimens, these participants worked hard to identify learning opportunities. Participants described a variety of settings and contexts that presented learning opportunities. For example, a doctor explained:

> *So one of the things that some of the teams do is to go out to see families at home with pictures, so they're in a more relaxed situation, and some teaching will occur with the parents and the children together and sometimes it's separate, with the parents having opportunities to ask questions themselves and to learn things in a different way (Doctor_98)*

Reviewing parents' learning progress could be either a formal or an informal process and involved professionals drawing on both tacit and explicit aspects of their practice knowledge, however, although often conducted discreetly, reviewing parents' learning progress was also purposeful.

3.2.6 Summary:

Professionals described and discussed a wide range of strategies for promoting and monitoring parents' knowledge and skill development. Key features of communication which mediated parents' understanding were: using a staged approach to help parents 'master' the knowledge they needed at the appropriate time; using a combination of tools and metaphors to make new and unfamiliar concepts more meaningful to parents by, for instance connecting what they already know to what they are learning about the condition; and assessing parents' understanding and reviewing learning progress in order to determine what to teach next in a staged, pragmatic but effective way. There are clear links between the teaching strategies discussed in this theme, but implicit within the two parent educative functions already discussed was the importance of multi disciplinary team working. Until now this has received little attention in the report so in the next section we focus on explicit accounts of MDT working; these accounts help to illustrate the central role of MDT working.

3.3 Multidisciplinary team working

3.3.1 Introduction:

The development and growth of renal MDTs in the preceding 20 years was occasionally identified in interviews as a challenging, clinician led process that had gathered momentum over time. Several participants, but in particular consultant paediatricians described the evolution of their respective MDTs. Teams had evolved and grown as part of local and national strategies to create focussed multidisciplinary teams of professionals to deliver care to children with long term kidney conditions. Participants from all disciplines spoke with pride about their teams and the way they collectively facilitate parent learning, thereby contributing to optimum clinical outcomes for children and young people.

3.3.2 Distributed expertise:

The different professionals in the MDTs teach offered different kinds of expertise to the co-management of the children in their care; this includes specialist knowledge and the resources to promote that knowledge, this distributed expertise explains the group's capacity (rather than just each individual's) to learn, act on and transform the problems of practice. One doctor explained how this distributed expertise has evolved over time. To begin with:

> *...there was myself and one renal nurse…over the years we sort of recognised the additional [staff] appointments that we needed and for most of those we ended up making bids for charitable funding. So …we felt we needed a renal dietician, so we got charitable funding to fund that post for a few years. And then the social worker post came that way, the psychology post came that way. And the nursing staff evolved, while constantly battering at Trust's doors. So, yes, from the very beginning really it was about building up a full team. Individual units have been doing that, over the years…*(Doctor_96)

The actions and approaches of each MDT member were believed to impact on parents' experiences of caring for their child and, although our date in Phase I, strand i indicate that the teams differed in the way they were configured, all the MDTs described ways in which they worked hard at supporting parents and promoting individuals' safe delivery of home based clinical care. Though each individual participant differed in their relationship with parents, our data suggest that all appeared committed to working collectively, alongside their colleagues, to support and inform parents in order that children receive optimum care.

To illustrate this issue, without prompting in the interviews, participants frequently described and discussed in detail the way the respective MDT members work collaboratively and what their personal roles in the team involved. There was a sense that team members often supported each other as well as the families, for example a clinical psychologist explained:

> *My role in the team is [also] to help everybody think psychologically about what's happening…support the member of staff who is in touch with the family…take a step back and help everybody think things through about how we work as a team… I think our team works very well together in that we each kind of have input for families for various reasons at different times…*(Clinical Psychologist_15)

Although team cohesion was pivotal in supporting parents' learning, role differentiation was also central to the way participants described their parent-teaching approach. As if to emphasise this, there were many unsolicited accounts from MDT members who stressed the important role of other disciplines within the team, as the following data excerpts illustrate:

> *We all have a role… you know, the nurses get the parents ready for home, you know, NG feeding-first up, can the parents be told how to do it? With the medicines often the nurses would do that and we work as a team and we make sure that, as a team, we're all happy with every aspect of their training before they go home, so they're safe to either be given the medicines, given the certain feeds, know when to call for help* (Doctor_7)

The MDT also functioned to reinforce information, consequently parents may receive the same piece of information from different professionals at different times, or one disciplinary member may reinforce some information they know a member of another discipline had provided to parents. This division of labour coupled with a tacit understanding that each MDT member would 'back up' the other was often reported as being fundamental to the way MDTs operate: *It's very much a multi disciplinary approach… so everyone has their roles* (Doctor).

Participants also often acknowledged the important practical role of the social worker, play worker, clinical psychologist and therapist. For example a nurse from a team that comprised a social, worker, play worker and clinical psychologist but no therapist explained :

> *…with the social worker there is a much more practical element to it, [for instance] they realise they [parents] are going to be stuck with transport, they are going to be stuck getting the child to school and things like that….They [play workers] do an awful lot…we can't do without them sometimes..they can get a different rapport with the child and family, sometimes families just won't open up to you and they would do to the play worker ….We support parents to see the value of the clinical psychologist or social worker, the SW builds up very good therapeutic relationships with families* (Nurse_22).

Moreover, play workers often articulated the essential part that team-working played in supporting parents:

> *Then I go back to the MDT for more information… We work quite well as a team don't we [turns to colleagues in focus group]… very important, I think* (Play Worker_2)

The interviews contained a few examples of the importance of MDTs presenting a 'united front' when working with 'difficult families', for instance a dietician explained:

> *… we had a boy that wouldn't come in, wouldn't even have his height taken, blood pressure taken and working as a team we've got him doing everything now … we've worked at it as a team* (Dietician_26)

Some disciplines also played the role of advocate within families:

> *...sometimes the older children don't want to tell their parents everything and then if we can build a rapport with them when they come in for a while, we find that quite often they'll talk to us about things they're worried about, you know, they don't want to burden their mum, who is really, really tired, you think, they think, 'well… I don't want to worry them any more'* (Play Worker_109).

A pharmacist commended the post-clinic MDT meetings as a forum for professionals to advocate on behalf of parents and cited an example of parents saying something to the pharmacist that suggested they did not fully understand a medication issue; the pharmacist would discuss this with the team on the parents' behalf at these meetings.

Furthermore, the value of role allocation within the team was summarised succinctly by a social worker:

> *...you need different disciplines in the team because you have the medical and the nursing information and then they're picking up…how the families are reacting and I would say to them, how are you doing, like, [names the clinical psychologist] , and other psycho social members of the team are assessing what's going on and I think part of our [social workers] role is to look and say what is causing particular stress* (Social Worker_30)

The respective disciplines complemented and supported each other when managing the child's condition and sharing management with parents. The quality of interaction within the MDT was seen as important, members believed it provided a forum for sharing information with each other as well as with the child and parents.

3.3.3 Sharing information within the MDT:

The data contain numerous examples such as the previous quotation from a social worker of participants' views on the importance of information sharing within the MDT. In this sub section, we focus on this in more detail as many interviewees indicated how this issue is brought into focus around the child's clinical condition, both in managing the condition and also in articulating uncertainty about parents' understanding of the management process.

For example, a clinical psychologist vividly expressed the value of having this mechanism for communicating about individual families:

> *We do talk…I think our team works very well together in that we each kind of have input with families for various reasons at different times. And often it's informally that we assess people's understanding. So I often when I first meet people [parents] will go in and say, "So what's going on for you and what do you understand of what's going on?" And that already kind of gets them saying what they've taken in because I'll know probably that they've been told a lot of what they need to know. But it will also give me the understanding of, okay, they haven't taken that bit on board or they haven't understood that* (Clinical Psychologist_81).

The MDT sometimes also fulfils the function of advocating for parents with another clinical speciality. Children with CKD may need input from a range of other specialist teams such as Urology, Cardiology and Surgery and communication between the specialisms may focus on treatment adherence for example:

> *What we do do amongst the team is that we agree a management plan, so that when we go and see them [other specialists] and if, they say, she's [child's mother] withdrawn care or she should have thought about this or she shouldn't be starting it, we're all in agreement, you know, along a certain path, so we go to these other meetings, we can actually say, you know, we've discussed it amongst the team and we're in agreement, which makes us much more powerful, in that respect, because if you just say, well, I think this is what we should do, they [specialists] tend to conflict sometimes but if you say it as a team, then it does make a difference* (Doctor_110).

The regular MDT meeting was, therefore, an important focus of discussion in many of the interviews, another doctor explained:

> *…we have … once a week, where we discuss our dialysis and transplant patients who have issues and that we feel that the MDT need to be aware of…The focus is psycho-social rather than anything else. So we're there to link up with the social worker, with the play worker… and so on* (Doctor_44).

Another doctor also highlighted the benefit of MDT communication on the ward round:

> *they [parents] know all their management plans are discussed and we come up with a management plan that they're [MDT members] all in agreement with because I think one of the things that they [parents] will worry about, if you're new, you're seeing different consultants each week and your kid's been pretty sick, so you latch onto the first one and you think, oh my god, we're going to get a new one, do they know what's happening, you know, is it going to be different? So, if they know that the [MDT] hand over is a way of dealing with it, they're much, much happier, much happier (Doctor_113).*

Teams might also use their regular communications to raise concerns about parents' concordance with a child's management plan, for instance:

> *We have had where people [parents] have changed their child's treatment so completely [from that prescribed by the MDT]; we have a good social worker on the team and we have said, we are going to have to think about this.... Not in a detrimental way, for some families if they were really struggling, it [highlighting the concern about parents not maintaining the management plan] a very positive thing really (Nurse_47).*

In the same way, the social worker may use MDT meetings as an opportunity to alert the team about possible literacy or numeracy problems that they suspect parents experience:

> *We have a weekly psychosocial meeting where they [families] would be discussed at an early stage…..I would document it, it would be in my notes… sometimes after team discussions we'll get a sense that maybe somebody has got literacy or numeracy difficulties and then it leads to further discussion about we might need to look at it in a different way (Social worker_102)*

Sharing information within the teams was widely reported as an important teaching strategy as well as a way of optimising the team's understanding of any particular communication needs parents may have revealed to individual team members.

3.3.4 Language interpretation:

In an early interview, participants highlighted the challenge of communicating complex information to parents for whom English was not their first language. In subsequent interviews we, therefore, asked participants to comment on this issue and there was considerable discussion in some centres about the challenge this can present to MDTs. Limited availability of translators was a prevailing issue in some centres:

> *I'm glad you've brought up the whole thing about ethnic and minority groups and so on, because I think that that is a big area and certainly for the large cities [names two cities] Asians make up sixty percent of the population and it's [the need for appropriate translators] a big issue, and it's one that certainly in terms of the resource and the funding to address that, we just struggle because it's not there. … [Pharmacist_46]*

Other participants described some challenges of communicating with parents even when translators were available, these can for instance relate to the level of accuracy in the interpretations:

> *I've had a situation where the interpreter has placed their own emphasis of importance on what I said. So, you know, if the parent wasn't taking the information seriously and the interpreter wasn't helping, altered the emphasis…The only way I could sense it was happening was because of the non-verbals. I reinforced, said how important it was, shared with the team, and saw them [parents] with the interpreter again another time,* (Doctor_ 49)

A doctor also explained the difficulty of communicating through an interpreter with a couple whose understanding of English varied:

> *... you're not really sure what's really being said and whether they're both [parents] getting that at the same level, whether something's being kept back... protection... coercion…e.g. 'difficult tubular problem' …the interpreters will sometimes say no, I don't know how to explain that* (Doctor_76)

Working with an interpreter was described as an 'art' by some professionals, as one dietician articulated:

> You might say something quite brief and then there'll be a long discussion… you don't know what's gone on…...we're discouraged from using a family member... never using the child as an interpreter... to be sure that it's somebody independent that's relayed that message…people have different beliefs about foods that are good for you or bad for you…...there's an art when you're working with an interpreter to make sure that you're focusing on the person and not the interpreter because of all that non-verbal…(Dietician_72)

Another challenge when working with interpreters related to maintaining confidentiality:

> *Sometimes the interpreter will be somebody from within the [parents' own] community and that can be difficult, because it means that people in the wider community know the business of the individual* (Nurse_59)

Whilst another communication challenge identified in several interviews related to a combination of the 'protector' role sometimes adopted by fathers, with the fact that English is not the parents' first language:

> *...we make sure that even if we've got a dad that speaks English and a mum that doesn't, we get an interpreter in. Because we have had doubts in the past about dads actually translating what we actually want the mother to know. And that's very important, that the mother knows exactly what the dad knows* (Nurse_50).

The fidelity of what interpreters are actually interpreting, and their familiarity with medical language was a concern for one social worker:

> *...you give a big whole spiel and then they [interpreter] say a couple of words and you think, 'you haven't told them'* (Social Worker_41)

The data also indicate that even parents who have English as a first language can struggle to understand some explanations, as a play worker explained:

'
> *Often I sit on visits, being a non medical person, and hear lots of words that I always think, no one's going to know what that means, but we're so used to it here that we think they do know what it means… it is important to remember that all the time and to simplify the language* (Play Worker_3)

Working with translators was both a helpful and unhelpful teaching approach; discussion around this was also often associated with accounts of the professionals' roles as brokers

3.3.5 **Acting as brokers:**
When asked about this it was clear from participants' accounts that MDT members frequently act as brokers for parents in a range of contexts in and out of the hospital setting. This doctor's comment was typical of the range of views expressed on this topic:

> *...it's really important, as [nurse also participating in focus group] said, to have someone with you when you talk to them [parents], partly because you get two opinions as to how that family are dealing with information and partly because I think it should ideally be a nurse, in a situation where the nurses have enough time… I think we do take that very seriously, actually, maybe more so than other such specialities here* (Doctor_ 9)

This brokering role could take many forms, including for a clinical psychologist:

> *I did quite a few phone calls on her [mothers] behalf to the special educational needs coordinator in the secondary school* (Clinical Psychologist_16)

A Consultant Paediatric Nephrologist described informing junior medical staff about the MDT benefits for parents*:*

> *I tell them [junior Drs] to take into consideration the psychological situation of the child/family* (Doctor_14)

For dieticians, brokering can involve teaching the school [on the parents' behalf] about special diets [for a particular child]…meeting with a community nurse, a [school] cook and a class teacher. Some nurses also visit schools:

> *I've recently been to a local school...reassuring the school and the teachers. Parents aren't going to keep coming into school, no one has that expectation, I will go back and just check what they are doing and then we can sign off, say the schools are fine.* (Nurse_91)

Another nurse explained the challenge of going into schools and not knowing what level of cooperation they can expect for staff supporting children with special medical needs in school:

> *You have to be able to think on your feet …you might walk in to school to be teaching staff members but some of them … they don't really want to learn this [clinical care-giving for a child] and don't want to be doing it.* (Nurse_57)

Social workers, meanwhile, may need to lobby quite hard on behalf of parents or liaise with employers and building societies on their behalf, or with banks to ask them to keep the

mortgage payments going while parents are in hospital with their very sick child. One social worker explained how they would:

> *…ask if they could have few months respite from paying [e.g. household bills]…organising disability living allowances for families: It's incredibly boring, but it's actually a very good way of getting to know the family…we've written lots of letters, immigration, to get a suitable house for a family…* (Social worker_39)

MDT members often act as learning brokers for parents within and outside of the team, as well as in the hospital environment and in the community. This brokering role related to practical and theoretical aspects of clinical care giving and served a dual purpose as it was also a good way of getting to know a family better, this in turn helped professionals to better understand parents' learning needs.

3.3.6 Summary of Phase I

Drawing on the concept of Distributed Expertise[59] [60], helped us to capture the idea that different professionals offer different kinds of expertise in the co-management of a child's condition; this includes specialist knowledge and the resources to promote that knowledge with parents. The concept suggests that professional knowledge is not just a stable body of knowledge that can be acquired through participation in accepted practices, but that it can be reconstructed dynamically as individuals work together, this includes individuals taking into account historic values as well as new problems to be dealt with. In our data professionals considered the national, historical development of renal MDTs, as well as the way MDTs continuously address new challenges in order to help parents provide optimum clinical care for children.

Distributed expertise also promotes understanding of the range of individually held knowledge bases (e.g. medicine, nursing, pharmacy) in the MDTs, and individuals' experience in specific situations (e.g. administering complex medications to children, inserting an NG tube), as well as the scope for negotiating the use of expertise in complex situations (e.g. negotiating with parents about where, when and how to be taught; decision making around specific aspects of management). Therefore, DE explains the MDT's capacity (rather than just the individual's) to learn, act on and transform the problems of managing CKD and sharing clinical care with parents.

The concept of 'identity' helps to interpret the significance of professionals' accounts of sharing individual and collective expertise with parents. In our data, two different professional identities were seen to co-exist within MDTs. Professionals frequently used the term 'we' when reflecting on their parent teaching activity; the concept of identity helps us interpret this as the intra-professional 'we', e.g. 'As social workers we aim to…' and the inter-professional 'we', e.g. 'In our multidisciplinary team we provide….' . Wenger suggests that there is a profound connection between identity and practice [61] [62] [63] and the social theory of learning assumes that engagement in social practice is the fundamental process by which we learn and so develop our identities.

The formation of intra-professional identity is shaped in part by a novice's construction of the 'others' on the team; as they engage with other team members novices acquire implicit and powerful cultural knowledge of professional roles and relationships. Potentially this is where inter-professional identities are developed as in multi-disciplinary teams[64:549]:

> *…differences potentially "collide" as boundaries around specialisms are broken down. At this point, implicit knowledge must often be made explicit. Professionals have to find a common language to make knowledge accessible to their colleagues from other disciplines.*

In Phase I data there were no examples of implicit disciplinary' knowledge being made explicit to other MDT members, this suggests that boundaries around specialisms had already been broken down and that professionals had found a common language that makes knowledge accessible to colleagues from other disciplines. However, what is still unclear is whether that common language is accessible to parents.

The final concept, Activity Theory is situated in the field of knowledge creation and exchange, and may help to explain how professionals find a common language to make knowledge accessible to colleagues from other disciplines. Activity Theory [65] [66] proposes that conflict is inevitable as tasks are redefined, and re-distributed within changing teams. To create new knowledge, team members must work through "expansive learning" processes of openly articulating differences, exploring alternatives, modelling solutions, examining an agreed model and implementing activities. Our data provide no examples of professionals openly articulating differences, on the contrary, participants were very specific about the positive aspects of communication within teams. Activity Theory also emphasizes that human activity is mediated by tools that are created and transformed during the development of the activity itself and carry with them a particular culture, i.e. the historical remains from their development. This may help explain the value of the tools and resources that professionals use to support parent learning.

As previously stated, the aim of this study was to obtain a detailed understand of the way MDTs teach parents and carers to become home-based clinical care-givers, and the way parents learn to care for children's long term kidney conditions. In Phase I we have addressed our first two research objectives, these were to:

1. Develop a descriptive profile of multidisciplinary team members' parent-teaching interventions in the children's kidney units in England, Scotland and Wales

2. Explore MDT members' detailed accounts of the range of care-giving skills and information they relay to parents, and the formal/informal teaching strategies and interventions they use

In line with the iterative and inductive approach used for this study, the output of phase I, the MDTs Parent-Educative Model in CKD Management, and our data interpretations, were used to inform Phase II data collection and analysis. Findings from Phase II are presented and discussed below.

4 Findings: Ethnographic Case Studies

When exploring the experiences of participating parents and professionals four main themes emerged: teaching and learning processes; teaching and learning facilitators; teaching and learning barriers; and ambivalence within teaching and learning encounters. This initial themed description of findings led to a later conceptualisation of parent and professional experiences as existing in a 'mutually dependent, child-focussed clinical domain'. This domain is characterised by four key categories that comprise the Parent-MDT Teaching and Learning Model; this explanatory model is described in Figure 7 below:

Figure 7: Parent-MDT Teaching and Learning Model
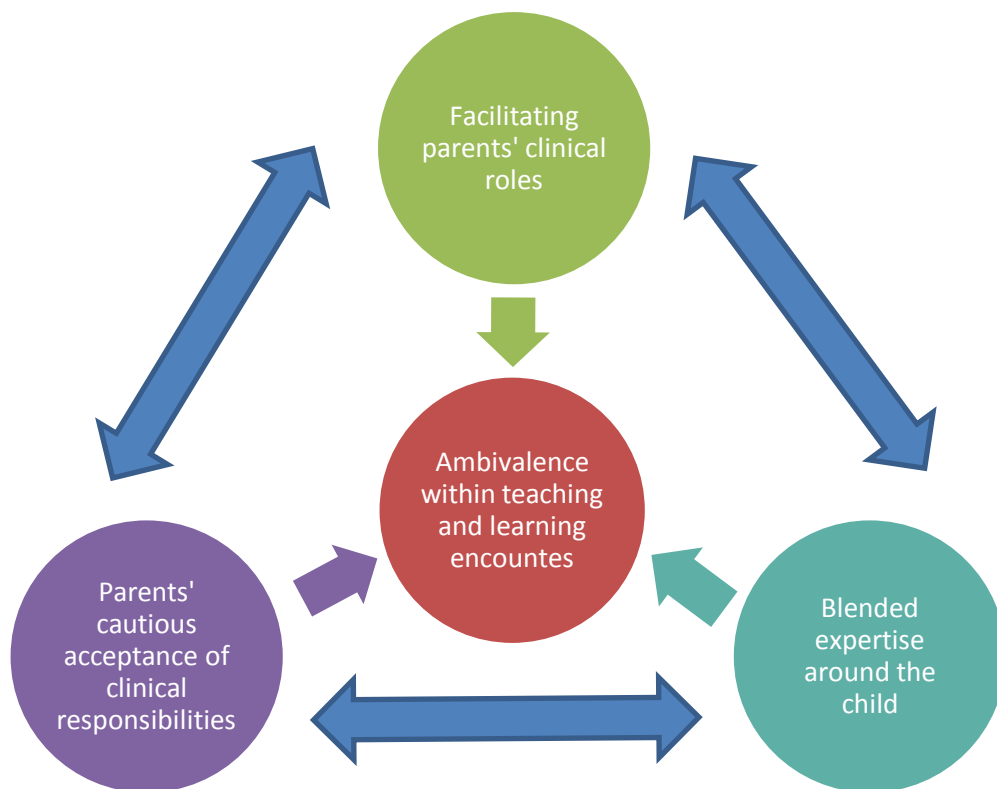
Within each of these categories there are several dimensions. The following ethnographic material helps to illustrate these categories and dimensions, and through them, the day to day experience of parents and professionals sharing the child-focussed clinical domain. Because of the small sample size, participant confidentiality is maintained and anonymity protected in the reporting by the use of family role descriptors (e.g. father, mother) or professionals' disciplines with a study identifier (e.g. doctor_4, social worker_27) only, and through the omission of identifying details such as children's case study numbers, diagnoses, certain modes of treatment or other contextual material about the families which could lead to their easy identification by readers.

Throughout this section:

> *Data from direct quotations are presented in this format*

and

> *Data from field notes are presented in this format.*

4.1 Facilitating parents' clinical roles

4.1.1 'High stakes'

Professionals emphasised the 'high stakes' sometimes that can be associated with renal care; in particular if parents do not maintain treatment regimens as this could have a negative effect on the child's clinical outcomes. To mitigate against these risks, professionals regarded information provision and clear explanations as an essential part of facilitating parents' clinical roles. Professionals were frequently observed explaining to parents about their child's condition and how to carry out the clinical role, while parents were observed explaining to professionals how the child had been at home and how condition management had been for them.

In Phase I (section 3.1.2) we highlighted the fact that some professionals said that they reinforce information that was provided to parents by another member of the team; in the current phase this reinforcement process was captured vividly in our data, and is an example of how professionals worked collectively to minimise potential risks that might arise through parents not understanding the full extent of their clinical responsibility. For example, some professionals reported in post-observation interviews that they had a role in supporting parents' learning by re-explaining what another professional had already said, but using different, and often more accessible, language.

Furthermore, some parents talked to the researcher about the potential risks of them delivering home-based care, but believed they had no option but to manage their child's condition. According to one mother the fact that there was *'no room for failure'* when managing the child's condition helped her to *'focus the mind'* while learning the skills and knowledge needed, this issue of accepting the clinical role through necessity rather than choice is discussed in more detail in section 4.2.1.

4.1.1.1 Checking understanding

Within the dimension of 'high stakes', talk back (i.e. asking parents to explain back what they had been told by another professional) was a technique often used by professionals to establish how much information a parent understood as this nurse described:

> *It was generally through asking them to explain to me what their understanding of [child's name] disease was and what they'd been told. Especially not just ask 'what have you been told?', because many people can repeat that, but how they then understood that and what impact that had on him?* (Nurse_3)

Professionals also used direct questioning that related to a parent's own experience of a phenomenon in order to get a sense of whether the parent had understood what they had been taught; this nurse explained that she might ask a parent:

'Can they remember how you would feel if you were dehydrated?', for example. So you might start with some basic informal questioning to try and assess did they grasp it…(Nurse_1)

During observations RN documented several examples of professionals asking questions of parents; examples of these are presented in Appendix 27 and they help to indicate the diversity of professionals' questions and how their motivation for asking questions varied; for example, to assess parents' understanding, to gain information and to encourage a parent to verbalise what they were doing whilst carrying out a practical task.

During interactions with parents MDT members' using a combination of formal medical language, and informal colloquialisms when explaining or providing reassurance, as the data in Appendix 28 help to illustrate. Phase II data (4.1.1.1) also illustrate this. In promoting parents' clinical roles, professionals were observed 'in action' in Phase II working with parents to emphasise the high stakes associated with clinical care giving, while also providing essential information. This serves to emphasise the reports of professionals in Phase I (section 3.1.2) who said how important it was to establish parents' prior knowledge and their position on the 'renal journey' when starting clinical teaching.

In Phase II parents and professionals alike described the importance of using questioning, for example, this seemed particularly important when learning a new clinical intervention as this father explained:

The main thing I glean is, this is a lot at the start, don't be afraid to ask questions (Father)

This quotation suggests that the father was becoming aware of the high stakes involved in his clinical role.

Parents, as their understanding of potential clinical risks developed, clearly valued professionals' openness to answering their questions, and professionals encouraged parents to ask whatever questions they felt were necessary to assist their understanding. Appendix 26 illustrates examples of situations where parents asked questions of professionals. In addition parents liked to receive feedback and reassurance as this mother explained when describing how a nurse reassured her:

She's very good because she does praise you and she does tell you when you've done alright, which you do need to know. You need to know that you're not putting your child at risk and she's very good at that

There was significant variation in the range of and motivation for questions posed by parents; for example: requesting information, wanting feedback and reassurance, and

seeking to clarify understanding. At times, parents used techniques such as repeating their question to the same professional, rephrasing a previous question, or repeating the information that they had received to the professional as a way of clarifying and checking their understanding.

4.1.1.2   Intra- and inter-disciplinary knowledge:

It was clear that professionals drew on both intra-disciplinary (e.g. pharmaceutical or dietetics) and inter-disciplinary (i.e. multidisciplinary) knowledge when promoting parents' understanding of the high stakes associated with their clinical role. This finding both builds on and reinforces the concept of Distributed Expertise within MDTs that was highlighted in Phase I. In the current phase, the range of parent-educative roles that MDT members described included a wide range of clinical tasks that are described below, but also helping parents to find their way through the "maze of services" such as health care and other statutory and voluntary agencies (e.g. Social Work), and offering support to parents to come to terms with, and deal with this complex information (e.g. Clinical Psychology; Therapy):

> *It's just giving the space for the emotional side of information; which on one level is just a series of facts and predictions about what's going to happen; but they have huge implications for people's lives and what's going to happen to them and what's going to happen to their other children.*(Therapist_1)

Professionals who engaged in 'formal' as opposed to 'informal or ad hoc' teaching, for example supporting a parent to learn home dialysis, noted a distinction between the theoretical knowledge and practical skills that a parent needed to learn. Professionals supported parents to learn and develop specific practical skills; these included administering feeds and renal diets orally and via naso gastric tubes and PEGs, replacing NG tubes, giving complex oral medications and providing home dialysis. Teaching around home dialysis for example usually started with a "theory session" (e.g. about blood pressure), a nurse explained why she thought this was important:

> *… teaching blood pressures, understanding the theory behind what is happening in the body with blood pressures and then being able to safely correctly monitor blood pressures I think is the biggest thing the family has to do at home* (Nurse_1)

Doctors, meanwhile, were the most likely to highlight the challenge of 'fear arousing' communications with parents:

> *Certainly some of the information we have to tell them, which we do have to, from a legal point of view, can be quite hard to hear. So things like, the complications of the medications can be horrific and there's an increased risk of malignancies in the long term, not so much in the short term and although it's not common, it's serious enough that, from a legal point of view, we're obliged to say that.* (Doctor_8)

MDT members' also acknowledged an overlap between the content of what each discipline supported parents to learn. When describing the pharmacists' role in helping parents to understand their child's medication, this overlap was described:

> *If anything is a funny administration, I would answer questions and talk it through, but because the nurses do it [administer medications] in practice, it makes sense for them to do it [respond to parents' questions about this], you know, flushing tubes after[administering a drug through a NG tube], the timing of it [drug administration], all of that, it seems to make more sense.* (Pharmacist_1)

During both inter- and intra-disciplinary communications, the dimension of demonstration, practice and repetition was also evident.

4.1.1.3 Demonstration, practice and repetition:

Parents valued opportunities to initially observe staff as they carried out procedures on their child:

> *They show me machine and, then, after that, another few sessions, they were going to say, they teach the machine. They're going to watch then with [name of the nurse], I had to make the machine in [name] ward and [name of the nurse] used to watch* (Father)

Practising a clinical skill under supervision was very important for parents as it helped them to develop the confidence to later undertake the task without supervision. A father who was learning home dialysis used an analogy to explain the benefits of repeatedly doing a task until it became almost habitual:

> *It's like all things, familiarity is going to help a great deal…you know in the Army they make you take your rifle apart and clean it so many times that you can do it in your sleep almost. I suspect, it's going to have to be one of those processes that gets like that*

Professionals were observed emphasising the importance of practicing clinical skill as demonstrated by these data from a session where the nurse was teaching parents to home dialyse:

> *The nurse advises the parents about the need to practice at hospital, and to practice doing dialysis unsupervised whilst still in hospital. The nurse emphasises it is important for the parents to gain increased confidence. She explains to the parents about another mother of a child on home dialysis, who the parents know, who did this. The nurse suggests to the parents they could practice setting up the [dialysis] machine over the weekend. The nurse says: 'You are definitely on the home straight. You need a bit more practice on the machine. Get more confident. You need to work out the UF [Ultra Filtration], make sense of the numbers, understand the process and the numbers'*

Professionals' accounts suggest that repetition had several functions, they often described the importance of repeating information with parents; these functions included emphasising that the information was important, assisting parents to learn, and checking parents' understanding. MDT members acknowledged that parents often received a large amount of information and so perhaps would not "hear it" the first time they were told something.

Situations were described and observed where the same professional reiterated information they had already provided, and where a professional reinforced what another MDT member had already said. A play worker discussed this:

> *The majority is going over what's already been given to them, although they may think it's new sometimes…So it's not new information, but it might be perceived by them, as new information or the way it's given to them, because it's visually backed up* (Play Worker_1)

The processes of demonstration and repetition were viewed as particularly important by professionals when working with parents whose first language was not English; professionals might adjust their explanation to ensure the parents understood:

> *What I find, when I teach a family with another language, is that whenever I say something, then I'm asking them to say back to me what they heard and did they understand…whereas, if English is their first language, I wouldn't do that as much, I would always make sure that they understood but maybe just not so often"* (Nurse_8)

4.1.2 Safe to take on the clinical role?

Parents and professionals described the process of competence development in order to be safe to take on the clinical role. This process appeared to be both an end point (e.g. a parent becoming competent in taking their child's blood pressure accurately) but also a spectrum where parents could continue to develop their knowledge and skills in an area, though they had already been assessed as safe to carry out a care-giving task with their child. Professionals described how parents gained skills, knowledge and experience in looking after their child over the course of the child's condition trajectory, and reflected on how this influenced interactions:

> *She [mother] uses me much more now to phone up and say 'oh, this and this happened' or 'can I do this or can I do that?' And that's great. So she's really taken on board what we have talked about"* (Nurse_3)

Various techniques were used by professionals to support the parents' competence development, including parents giving their child's medication whilst they were still on the ward instead of the nurses, and a gradual reduction in support so the parent progressively carried out more of the task on their own. This approach of 'scaffolding' practical or theoretical knowledge to help parents become safe in their clinical role was evidenced widely in our data. One father, describing how the nurse had taught him to set up a dialysis machine, explained how over time she reduced support to the point where she would only intervene if he made a mistake:

> *After two, three days, she was watching, before I can ask, 'am I doing right or wrong?'. Then, I think, four times she said, 'I'm going to stay in here, if you do anything wrong, then I'm going to stop you'…when I doing something, if I look at her, you know, she just carry on"* [father demonstrates how nurse was doing something else in the same room whilst watching him, just letting him get on with setting up the machine as if she wasn't there]

This suggests that professionals sometimes made quite subtle changes to their behaviour and/or communication as part of the teaching process. Assessing parents' competence occurred in different ways. At times it appeared a more formal process was adopted, in these instances the professional had a document listing the care-giving tasks which needed to be learnt, and they "signed off" the parent once they had been observed carrying out the task safely and accurately (See Appendix 24). In some situations, participants were seen to have explicit conversations about this process as illustrated in the following field note data:

> *The parents are with their child on the renal ward. The nurse is showing them how to give medication to their child. Nurse is showing them the drug chart used on the ward: 'This is the drug chart. When you go home you'll have a nice print out, an A4 sheet. Whilst in hospital we use the chart….Once you know how to do it, you will be signed off. This means we put a sticker on the front of the drug chart and you do the meds whilst you are still in hospital'…Later on during the interaction, the mother asks the nurse: 'And the A4 sheet, do we have to sign it?' The nurse explains: 'No, that's just information, it's more like a recipe. Whilst you're in hospital you would sign the chart. At first, we'll watch you, and then once you're competent, you can then do it and then you'll sign the chart'.*

The difference between the two types of chart seemed to confuse the mother.

However, at other times, the process was less formalised and more about parents feeling confident. The differences seemed to be linked to the issue of 'high stakes' and the levels of risk associated with the clinical task. For parents, having the skills and confidence to carry out the task and recognition from professionals that they were competent, was significant:

> *I am impressed that they've allowed us…entrusted us to be able to do the medical side of things and the pump and, so, it gives me that independence"* (Mother)

The move towards independence was clearly significant for parents.

The processes by which professionals assessed parents' as competent in clinical care-giving were clearly an important part of the teaching and learning encounter, both for professionals and parents. As described in this section, these processes happened in different ways; sometimes they were formalised and made explicit, whereas at other times, they were informal and more subtle. However, the decision that a parent had acquired the skills to

safely deliver clinical care was essential in preparing the family to take on clinical responsibilities at home.

4.1.3   Readiness for 'going solo'

Both MDT members' and parents' described processes of preparation to ensure parents were ready to take on an independent clinical role and 'go solo'. This took different forms; for example, parents were prepared for take on an aspect of home-based care through discussions and being given information. A pharmacist described one of the techniques used to support parents to learn about their child's medication, whilst their child was on the ward:

> *I will try to print off the sheet a few days before they go, so they have the chance to…while the nurses are giving meds, watch what they're doing, get familiar with the medicines and the sheets* (Pharmacist_1)

Professionals acknowledged that the time available to prepare parents to learn a new clinical intervention varied greatly, depending on the child's clinical needs. For example, teaching and learning encounters differed when there was time to plan that a child would start on home dialysis, in comparison to situations where a child needed dialysis urgently. A doctor described the benefits of having time to prepare:

> *It makes a massive difference to help them come to terms with what's going on. The fact that they've had the chance to learn how to do blood pressure and wash their hands and see the machine and talk about it and go through it, there's a lot less upset and a lot less resistance to what's happening and a lot more acceptance as to what's happening than someone who's suddenly been thrown in the deep end* (Doctor_3)

Though having time to prepare was valued, professionals questioned what the optimum time needed was. They acknowledged that in some situations, such as preparing for transplant, it could be difficult to know when it was the 'right time'. Whilst parents learned how to carry out care giving in the clinical setting, the professionals and parents would often plan how care giving would be carried out at home. This would include practical issues like space, timings and equipment as well as how care giving would fit in with family life. See Appendix 31 for examples from field notes from one of the study families about some of the preparations taking place so the family could return home and start home dialysis. As the data demonstrate, some of these preparations were initiated by parents and some by professionals.

4.1.3.1   Contingency planning

A key part of parent preparation was contingency planning; parents were often prepared by professionals, and sometimes prepared themselves, to think about how they should respond at home in the event of something unplanned or unexpected happening; Appendix 25 demonstrates how scenarios were used as part of this contingency planning. Possible unexpected events included an aspect of a child's treatment not going to plan (such as a

transplanted kidney being rejected, infections from home dialysis, or side effects from medication).

There was discussion about how parents were prepared for unexpected clinical events; for example by professionals putting the potential risk in context (e.g. how many children this had happened to). Professionals appeared to think very carefully about how to have these discussions with parents and acknowledged that parents could find it difficult to hear such information. There appeared to be some ambivalence about how much information should be provided to parents especially when the possibility of something going wrong was actually very unlikely. A mother explained how she felt about contingency planning:

> *You know that there is a chance that they could happen. But there's also a chance that they might, that they probably won't happen. So it's better to know…but at least you know that if it does go wrong you deal with it and that's it. And it can be dealt with if it does go wrong. So it's better to know I think, definitely.*

As if to emphasise the importance of contingency planning taking place in a supported environment, professional participants reported using situations during a planned teaching event such as parent making a mistake or something unexpected happening, as a 'teachable moment'. Professionals for instance drew on unexpected events to demonstrate to parents how to respond to certain clinical scenarios, both in terms of practical skills but also through modelling behaviours (e.g. keeping calm, acting quickly but not panicking). In some situations, professionals would be aware that a parent was about to make a mistake and decide not to intervene immediately, as a means to promote the parent's clinical reasoning skills whilst in this supportive environment (e.g. problem recognition and problem solving), thereby preparing them for the home based clinical role.

This approach required professionals to make judgements and perform 'risk assessments' about the safety implications of potential mistakes being made, and how the parent might respond to making a mistake. However, when used in context, parents valued being able to make mistakes in a supported environment as this provided opportunities for reflection and enhanced their learning:

> *You can make those mistakes or go to make them and she'll say, 'think about it, why are you doing it?' And that's what I like, she always says to you, 'why are you doing it? What have you got to do to get to that?' So it makes you think about the system of what you are trying to do* (Mother)

As illustrated by the discussion above, preparation was one of the key processes occurring within teaching and learning encounters; as a key part of this process professionals used a variety of educational media to facilitate parents' preparation

4.1.3.2 Educational media:
In Phase I professionals described some resources and tools they used to facilitate parents' learning. In Phase II we gathered actual evidence of a range of educational media being

used as an essential part of preparing parents to 'go solo'; see Appendix 30 for more examples of these

4.1.3.2.1 Written information
Written information was used widely, both in providing specific knowledge (e.g. medications, condition) as well as instructions on how to carry out a clinical task (e.g. set up a home dialysis machine, make a feed). As this mother explained:

> *They [written resources] were really good. I don't tend to look at them [at home] now, but yeah, I wouldn't have been without them at first. And at least we've still got them if ever I need to look back at something.*

Participants talked about the value of parents receiving a copy of a clinic letter (or report) following an appointment with a MDT member; these helped by summarising discussions, confirming advice given to parents and sometimes served a more therapeutic purpose of making a family's situation appear tangible rather than abstract, and encouraging reflection. Written information was sometimes translated into different languages, but there was some discussion about how useful this was. MDT members also talked in principle about working with parents' who had literacy difficulties and having to adapt care-giving tasks which utilised written information; for example, replacing a medication sheet which would usually list the names of the child's medications with a system of numbers and/or colours. See sub section 4.3.3 for further exploration of this issue.

4.1.3.2.2 Visual resources
Visual resources were often used to help promote parents' understanding, these included prepared resources and drawings of the kidneys or other parts of the body made spontaneously by professionals during a conversation. Visual resources were used widely, but more so when parents' first language was not English. Some professionals joked about their drawing ability (or lack of!) and explained how this could be a source of humour during interactions with parents:

> *I think, because, you know, I'm not particularly good at drawing!   And it kind of brought a little bit of humour into it as well, so it was a little bit light hearted"* (Nurse__8)

For some disciplines, the use of visual resources was central to their interactions with families, as this play specialist explained:

> *I have, like, photograph books, dolls, bits and pieces like that. So mum and [name of the child] joined me for the first couple of sessions and then, we just work through and then I would answer any questions that either of them had* (Playworker_1)

4.1.3.2.3 Equipment

Equipment was used in different ways to support parents learning; it was demonstrated to parents to supplement verbal explanations about what the care-giving task would involve, for example, parents preparing to learn home dialysis were shown the dialysis machine:

> *I've seen the machine as a picture. To see it for real, as well, definitely helped. It's a lot smaller than we thought it would be…"* (Mother)

Equipment was used by parents when learning to deliver the care their child needed. This involved using the equipment to practice as well as actually delivering care to their child, initially under the close supervision of professionals. Sometimes 'dummies' were used so a parent could practice a task (e.g. dressings, cleaning the central line exit site) before they carried out the same task on their child. Professionals thought this approach was less "scary" than starting by delivering care to their child, and was a means for the parent to develop their skills and confidence.

4.1.3.2.4 Metaphors and analogies

Some professionals used metaphors and analogies to help explain concepts to parents. Examples included comparing blood vessels and blood pressure to a garden hose, the different strength dialysis bags to concentrated and diluted squash, and the immune system and an army as described below:

> *"I always explain an army and a hundred soldiers and you take your immunosuppression and it drops to fifty".* (Pharmacist_1)

This discussion provides a brief overview of the many educational media used and indicates how they were used and their value. Participants also talked about the processes used when both a child's parents were learning to become home-based caregivers

4.1.4 Learning alone or together?:

There was evidence of negotiation between MDT members and parents' around which parent would be the initial focus for teaching certain skills. The following field note data indicate how some professionals approached this:

> *1. A nurse is with the father; both parents will be learning home dialysis. The nurse asks the father how the parents learn best e.g. together or separately. Father tells the nurse that he would like to learn to set up the [dialysis] machine on his own initially.*
>
> *2. A nurse is teaching parents how to give medication to their child. The nurse asks: 'Who will be doing the meds at home?' The mother answers:*
>
> *'It will mostly be me, but [name of father] will do some. Nurse explains: 'I'll focus teaching today on mum but dad will also need to be taught'*

The decision on which parent would be the primary clinical caregiver was often based on practical issues such as who was the child's main carer usually, and parents' availability (e.g. if one parent had work commitments). However, where possible, professionals aimed to eventually teach both parents together where both were to be involved in clinical care:

> *So I always try to encourage when I'm introducing anything new that it's done together so that they can both see that you're teaching the same thing and you don't miss anything out and that they're hearing the same thing together."* (Nurse_1)

Professionals often emphasised the importance of assessing how each parent learned independently as well as how both learned together. It was acknowledged, that at times, it was important to meet with each parent individually to get a true picture of how they would manage with carrying out care giving alone. MDT members explained some of the challenges when each parent had different learning needs and when they needed to teach members of the wider family (e.g. grandparents).   This issue is explored more in sub sections 4.3.3 and 4.3.4.

Supporting the child to learn was mentioned by several participants, and though the focus of this study was on parents' learning, some MDT members' explained how through teaching the child, the parents' understanding seemed to be developed.

> *"If I'm going through what's wrong with them and why they are unwell and what's wrong with their kidneys I aim it at the kids and try and get them to understand. In full knowledge actually, I suspect the parents don't understand. When I start sometimes doing that, the parents will seem to be listening more avidly than the child, that I would be aiming it at"* (Doctor_3)

This section has presented and discussed data detailing the many processes evident in facilitating parents' clinical roles. In the next section we explore and discuss the category that considers the way parents accommodate clinical responsibilities into day to day family life

4.2　Parents' cautious acceptance of clinical responsibilities

From early in the trajectory, parents' attitudes towards the clinical care-giving aspect of their parenting role seemed to be one of 'cautious acceptance'. Their accounts suggest that they accepted the fact that day to day responsibility for clinical management would become part of their own routine, and of the child's in the future, and that they were doing 'nothing special' through providing clinical care.

4.2.1　**Developing clinical skills: necessity rather than choice?**

Parents' cautious acceptance of the clinical role seemed to be based on necessity rather than choice. There is no evidence in our data of discussions between professionals and parents around whether or not parents would actually take on clinical responsibilities. However, there were occasions when negotiations took place about what parents needed to learn and professionals worked very hard to identify and accommodate parents' needs and preferences, for example:

> *Nurse: 'Shall I put it on the other side?'' [The nurse is replacing the child's NG tube and asking the parents if she should put the tube on the other side of the child's face]*
>
> > *Mother: 'What do you think?'*
> >
> > *Nurse: 'I think so, it will protect the skin a little bit'*
> >
> > *Father lies the child down on the plinth.*
>
> *Nurse removes old NG tube from child's nose: 'Take him up and give him a cuddle. (Father does this). It doesn't hurt taking it out; it's just a weird sensation'.*
>
> *Father lies child down again on plinth, and nurse inserts a new NG tube. Child is crying a lot. Father is physically holding child, whilst mother and nurse talk to child to try and soothe him.*
>
> > *Mother says to father: 'You hold his head and I'll hold it' [means the NG tube]*
> >
> > *Nurse finishes: 'There, have a cuddle'. Mother picks up child and cuddles him*
> >
> > *Nurse to parents: 'Thanks for helping'*
> >
> > *Mother: 'It's what we do at home, 1 holds it and the other does the tape'*
>
> *Nurse: 'That's teamwork. Are you interested in learning how to do it?' [Insert the NG tube]*
>
> > *Mother: 'Yes, if he's going to need it in the long term?'*
> >
> > *Nurse: 'It's likely. He produces so much urine; he will need the overnight feed'.*

On the whole though, there was little scope for negotiation about whether or not parents would adopt the clinical role as there was no alternative if the child was to return home. Within this context, the overriding goal for professionals was to achieve optimum clinical outcomes for the child, whilst creating and sustaining a supportive learning environment for parents so that they could safely and effectively manage the child's condition at home. This mutual and implicit acceptance of parents' clinical role development was reinforced through the actions of professionals who tried to provide learning opportunities for parents such as

spending time in hospital before skills training started; this they believed could help parents develop confidence and be *'more relaxed'* once they started to learn clinical skills.

Professionals' attitudes towards promoting parents' clinical roles were predominantly facilitative. A flexible and adaptable approach was described where an *'open door policy'* operated, as the following quotations from MDT members indicate:

> *…parents' needs differ so [they are] able to come on a quieter clinic day if they want more time… [we are] there as a support mechanism, can meet with families regularly if needed* (Nurse_7)
>
> *Families' need for support may vary, a case is always open until the child reaches 18* (Social Worker_1)
>
> *Families know professionals are very available and they can ring if they have queries* (Doctor_8)
>
> *I will offer to provide more information about being available….families are usually happy to wait to meet pharmacists for teaching* (Pharmacist_1)

Sometimes professionals commented in interviews about their assessment of parents' suitability to learn; one doctor for example reported that they used… *different ways of approaching different families* when teaching new information. On occasions professionals were observed explaining to parents about the amount and complexity of the information they needed to learn, and offering reassurance about the support the team would provide with this. One nurse told parents who were learning home dialysis: '*It will be a hard few weeks but we'll get there'.*

Our data, therefore, suggest a collaborative approach whereby parents and professionals acknowledged that clinical skills and knowledge would be shared between them so parents could eventually take on clinical responsibilities. Central to this was the child's ongoing wellbeing. During one clinic appointment, a doctor was observed explaining to a child and mother about the process of learning home dialysis:

> *Doctor explains the process about the operation to fit catheter. She asks child to stand up and lift her t-shirt, and points to the area on her abdomen where the catheter will go. The doctor says to the mother: 'So she'll be in for roughly 2 weeks. During that time, we will establish dialysis, and get you and [name of child] trained up. You'll be in a cubicle on your last night, so you'll be doing it on your own, though ward staff will be around if you need help. When you go home, you will have support. It's like taking a new baby home, at first; you don't know what to do!' Later in the appointment, the mother asks the doctor: 'My mum has a Hick's line, the dressing has to be changed weekly. Will the dressing on her [child's] catheter have to be changed every week? The doctor replies: 'Yes, you'll be shown how to do it. You'll become an expert in [name of child's] dialysis'.*

4.2.2 Learning, unlearning and relearning to go 'solo'

In accepting the clinical role and associated responsibilities, parents sometimes talked about unlearning and relearning as well as the initial learning. To support these activities some

parents valued opportunities to initially learn skills away from the ward [such as in an office] but others preferred learning on the ward with their child, *rather than pretend [on a dummy]*. Alternatively, some preferred to practice skills with their child in the patient hotel; one mother commended this[2] where she spent a week with her child before discharge. This arrangement meant that she and her child were in an environment that was more like a home than a ward, but experienced staff were always nearby if she needed help.

Wherever parents developed their clinical skills, a familiar room layout was often important in facilitating skill development; minor changes to the layout, or transfer to a new environment could lead to a loss of confidence in a skill parents were confident with and which they had previously been assessed as competent in by the professional. One father, when discussing the challenge of learning to dialyse his child, vividly recounted how the 'step down' to the patient hotel initially reduced his confidence in his own ability to safely manage the procedure. The unfamiliar room layout meant that positioning himself to set up the dialysis machine after he had put on sterile gloves involved stretching to reach equipment in such a way that he accidentally touched something that was unsterile; he then needed to dispose of the gloves and start again with a new pair otherwise he risked contaminating the equipment and potentially putting his child at risk of acquiring an infection.

> *…and I'm in a process of learning... I think I did quite well, at the end of the last few days in hospital, I was getting comfortable, I didn't have a problem there.*

This experience led to him reflecting on how he would eventually transfer his new clinical skills and knowledge to other environments:

> *I suspect when I move to doing it at home, I've got to be careful for a while as well, until I get used to…just the sets of the things… 'Gloves here, syringes here…machine,' obviously 'there.' And I need the right height to put it on and off, because I don't want to be bent over trying to stretch, and that's when you can occlude a line, and then you get errors on the machine…*

One father anticipated a process of unlearning and relearning with each new environment:

> *For each place you have to physically do this, there's always going to be a small degree of re-learning and developing the right places to position things, and yourself as well. So for instance, if we take the machine to my parents in [city] again we'll have to think quite carefully, 'Now how do we best situate the trays and the machine and the drain?' and all of that, so that it's easy access for us, and so we're not having to do things like this, which is when you will make a mistake and touch something, or drop a line when it's uncovered*

[2]*Step down to the patient hotel: an MDT staged-approach designed to help parents learn to safely deliver a clinical task, such as set up dialysis, in a new environment with minimal support from experienced staff and in preparation for taking the child home and 'going solo' with clinical care*

In one study site, the clinic waiting area was mentioned by parents and professionals as a positive learning and relearning environment. A mother described it as: *a nice waiting room, can talk with other parents…nice place to visit, [child] can play which makes it easier [for mother to concentrate].* Similarly, a nurse and a social worker viewed the waiting area as a place where peer learning often took place as families could learn from each other; or the Play Specialist could occupy the child while parents met the MDT.

The ward environment was regarded as a reassuring place *when the child is unwell* as noted by a doctor, and parents appreciated the ward for care giving and support from professionals, whilst a therapist said that the child being on the ward made it easier for professionals to talk with parents informally. Meanwhile a nurse thought that for parents, being on the ward initially gave them confidence in managing the child's condition before the 'step down' to the patient hotel and eventual discharge home. Alternatively, the family's home was a place where nurses thought it was easier to build a positive teaching and learning relationship with parents, while parents often thought that once they were confident in their clinical role it was easier to get into a routine once the family were at home.

4.2.3 Ideal vs reality:

Participants indicated that sometimes a tension existed between what they perceived as ideal teaching and learning situations and the reality of those situations. These were discussed by parents and professionals.

4.2.3.1 Parents' experiences

The wide range of clinical skills and the complexity of knowledge that parents needed to learn could impinge on parents' experience of taking on clinical responsibilities and some talked in detail about this. When asked which skills were the most difficult to learn one mother said:

> *… the NG (naso gastric) tube, to always remember…to pH test it…whatever line it's on by [child's] nose, that's how much it should be on and if it moves or comes out more or goes in more, then, obviously, you've got to let them [professionals] know…always, when you give milk or medicines, to flush it with just a little bit of water, yeah, it took me a while to get used to doing… because [child] can feel it, and it's probably a little bit uncomfortable*

Although this mother eventually became more confident at managing her child's NG tube, her quotation, obtained early in the case study, also suggests that learning to supplement a normal parenting skill (i.e. to feed, nourish and comfort the child) with a set of complex technical and clinical procedures as part of managing the child's condition, was a particular challenge for her initially when accommodating clinical care into family life .

Once the MDT decided that a child was ready for discharge and that the parents were 'safe' to take on responsibility for day to day clinical care at home, professionals sometimes arranged with local health care staff to provide ongoing support in the home. These arrangements were designed to minimise inconvenience for the family who may live a considerable distance from the children's kidney unit. However, the following quotation

demonstrated that although this seemed an ideal option, one mother had learned to have little confidence in the ability of local health care staff to assess and manage the child's condition if it deteriorated. Experience had taught the mother that local care provision was not actually as specialised as she had thought it would be. Through a process of unlearning and relearning she had found herself in a situation where she needed to instruct local health care staff during an emergency on how to manage aspects of the condition. This relearning subsequently led to her taking independent action:

> *I now refuse to go [to local hospital] anymore and I'm quite happy, like I say, just to phone up [children's kidney unit] …and I'm sure our consultant would be happy enough for us to just come up. He seems that way inclined…a very genuine guy. We've got direct numbers for him as well… if we can't come up here for any reason, then they [kidney unit staff] would phone our local hospital and sort it out.*

The fact that this mother reported a strong preference for accessing support from the renal MDT rather than the local care team, despite the fact that this could involve travelling long distances each time the child needed professional intervention, is an indication of the significance parents attached to consistent clinical assessment and care giving advice.

4.2.3.2 Professionals' experiences

Professionals also identified tensions between ideal teaching and learning situations and the reality that existed in a busy and unpredictable health care context. Issues that impeded professionals' parent-teaching activity were mainly organisational and interpersonal. Organisational issues included the fact that when the ward was particularly busy there may not be time to train parents in the way staff would like to, or to follow up initial training with retraining. In addition, participants found it frustrating if resources needed for teaching were not readily available.

Due to the unpredictable nature of health services, a nurse explained that during one particularly busy period she was involved in providing dialysis training to three families simultaneously, consequently the nurse was unable to spend the optimum amount of time with each family, or be as consistent as she would have liked in her teaching approach. This reinforces the Phase I findings which indicated how time pressures could pose limitations on professionals' teaching and potentially constraints on parents' readiness to take on the clinical role.

4.2.3.3 MDT clinics as reinforcing and relearning opportunities

MDT clinics were often alluded to in the data; as described in Phase I (section 3.4) one advantage of renal MDT clinics is that they present opportunities for each child to be reviewed collectively by several different disciplines at the same time, thereby capitalising on the distributed expertise of the MDT. As clearly demonstrated in the current phase of the study, this collective approach could indeed facilitate the transfer of essential information between families and professionals in a timely way.

Another advantage of MDT clinics is that they minimise the need for families to attend the hospital on several occasions for separate appointments with individual disciplines.

However, data from professionals suggest that in reality some organisational and interpersonal factors associated with MDT clinics could impede their communication with parents about the clinical role. Interpersonal factors described by professionals include:

- Having 'observers' [e.g. visiting professionals from other centres, trainee health professionals, new staff members on induction programmes] in clinics could affect family members' willingness to ask questions about clinical management
- Having insufficient psychological resources available to support parents who professionals think may require such support
- A dearth of up to date written resources to support verbal information provision, or
- Inconsistency between existing written information and the verbal information that individual professionals relay to parents.

Organisational factors identified by professionals included factors relating to the actual clinic appointments such as;

- Lack of space
- Appointment slots being too short to facilitate meaningful teaching and learning
- Interruptions during consultations that disrupted communication between parents and professionals and which could lead to parents losing concentration, and
- The absence of a play worker to distract children while parents and professionals were discussing the child's management.

Another tension between ideal and reality related to the fact that although one function of the MDT clinics is to facilitate shared discussion between MDT members and family members, it was not always possible for all relevant MDT members to be present at every clinic appointment for each child. This could mean that professionals who were present might need to 'fill the gaps' for parents with information and explanations relating to the expert knowledge of absent colleagues; and also, to ensure continuity, professionals needed to work hard to later communicate with absent colleagues about the information they had relayed to parents during the consultation. A doctor described this situation below:

I was with the dietician… she is fantastic and…the dialysis sister, which is fine for the dialysis, but when dad started to talk about transplantation, the transplant nurse wasn't with us. So I will now, having had some open and frank discussion with dad [about transplant]… be able to share that with the team, so everyone is aware where dad is coming from…everybody needs to know everything, but the core team, we need to know where this family is at (Doctor_1)

In the same way that we described how parents sometimes expressed concerns about the lack of consistency between advice provided by home care teams and renal teams, professional participants also provided unsolicited data on this issue. For example, some found it difficult when home-care teams gave parents different advice to that provided by the MDT, or did not have the skills to support the family. This inconsistent approach could lead to confusion amongst parents who could then be unsure about which advice to follow..

Another tension between ideal and reality in the MDT clinic that a professional reported as a barrier to communication with parents, related to situations when the child and parents were together in the clinic. Having both in the consultation could sometimes impede a professionals' ability to assess individuals' understanding about condition management. For instance, a dietician explained this when discussing one of the study families:

> *In the clinic situation, you have both the parents usually and child there, I'm wanting to separate them out to see how they're each getting on separately, and to talk to the parent about how [child] is getting on. But, because of the nature of that clinic, it has tended to be that I've wanted to give [child] the respect of asking her a lot of the questions, rather than going over her head and asking [the parent]… in fact, she came yesterday, I thought…'I wish, in a way, she would leave the room and, then, I could just have a little session with dad and, then, invite her back in', but, that's not how things have gone, there* (Dietician_3)

As the discussion above illustrates, both parents and professionals reflected on tensions that existed between ideal teaching and learning situations and the reality of these situations. Another factor that could have an effect on parents' acceptance of clinical responsibilities was pressure to take the child home.

4.2.4 Pressures to take the child home:

Data from this phase of the study suggest that for the most part, pressures to take the child home came from parents; however, whilst parents usually felt well prepared for taking their child home after learning to deliver often complex, specialised and essential clinical care, parents in one case study felt surprised when told they could go home, as they believed they had had insufficient time to prepare:

> *I would have liked it [training/preparation] to have been done a week earlier… then, I could have got used to it so, when we went home, I wouldn't have been so nervous, I wouldn't have been, like, 'ah, oh my God, what have we got to do?' (Mother)*

Conversely, a nurse was concerned about another study family who were determined to get home [as quickly as possible] but appeared not to take advantage of learning opportunities offered to them. Therefore, they were potentially under-prepared for the additional clinical responsibilities they would face at home. Nevertheless, this nurse and other professionals in the study often acknowledged that parents had many reasons for putting pressure on professionals to discharge the child, including:

- Parents could have problems taking time off work
- Parents being off work could have serious financial implications for the entire family
- Parents being resident at the hospital for long periods could have negative consequences for their other children, or for relatives such as grandparents who may be looking after those children at home

Field notes also help to illustrate how pressures around going home can impede parents as they learn to accept the clinical role and accommodate it into their daily routines:

> *Parents are learning home dialysis. Nurse tells the parents: 'You will need to practice connecting and disconnecting, you need to do this every day. So the plan for tomorrow is we'll cover a new thing, we'll look at the exit site and then practice. Then the plan for Thursday is we will finish and then it's whether you guys remember it.*
>
> *The mother asks the nurse: 'Do you sign off competency?'. The mother appears annoyed that other nursing staff on the ward hadn't signed off the competency list. The mother asks the nurse about when they will get home as they have exhausted all their childcare. The nurse advises discharge home is about the parents competency.*

Professionals recognised that parents could feel 'torn' between caring for their sick child, other children, and neglecting their paid employment and, realised that these factors may contribute to parents' sense of urgency about the child's discharge. Consequently, it was sometimes difficult to find mutually convenient opportunities for planned teaching sessions if the parents could not take time off work for this purpose.

For the same reason if professionals knew that parents did not have time to attend the hospital for skills training more than once, they sometimes felt obliged to give all essential information to parents in one session rather than providing training over several occasions. This flexible and adaptable approach to teaching and learning was often evident in professionals' accounts, and indicates a compromised situation and one which professionals were unhappy with. Similarly, parents such as the following mother reported in research interviews that they were eager to be 'completely discharged' as soon as possible. This mother recounted how having had weekend leave from the ward [with the child and with the aim of practicing self-management with no professional support readily available], she felt that the child's home based clinical care giving had gone well:

> *…we are quick learners, so, we did go home and manage to do it, there wasn't any problems, [child] slept all night, didn't pull his tube out, the pump carried on, medicine was fine, didn't sick it up, or anything…*

Having been told that discharge was imminent, waiting for confirmation of discharge could be frustrating for parents:

> *They [professionals] say to you, oh, yes, we'll come around; we'll do this and this and this in the morning [referring to preparations for parents being able to take the child home], and then, the morning comes … and they say yeah, we'll come and see you early afternoon and, then, it comes, like, later and later and later and you think, oh, come on, I just want to go home!" (Mother)*

However, some parents, whilst wishing to be well prepared for discharge were also eager to take the child home as soon as possible for other reasons such as:

> *The trouble is, being in a hospital, you're going to get bugs and you're going to get ill, because, obviously, there's all different children here as well"* (Mother)

This mother's assessment of the risk of hospital acquired infections for herself and her child was important as she recognised the need to remain healthy in order to care for her child, however, we obtained no other data from parents on this issue.

4.2.5 Tensions between people during teaching and learning:

Tensions between people could sometimes impact on parents' cautious acceptance of the clinical responsibilities. Professionals described how relationships between MDT members' could become strained at times as individuals had different opinions about a child's management, as a therapist explained:

> *… how those different aspects of [MDT] work dovetail is not always straightforward. It's not to say these things are in competition, but it's not always straightforward, because there are priorities around clinical care. [For example] There may be priorities from my point of view thinking about people's emotional and practical wellbeing* (Therapist_2)

The benefits of MDT clinics are discussed elsewhere but it was also evident that tensions could exist within MDTs and it appeared that MDTs found ways to manage these tensions. However, some professionals described challenges in MDT clinic appointments: "*some people [professionals] do shout louder than others and won't wait their turn*" which meant for some it could be difficult to discuss discipline specific knowledge with parents, as members of other disciplines had varying levels of 'interest' in this information:

> *I can well imagine that the mother sitting there is being asked questions from here, there and everywhere. Her child is on the couch with his belly exposed having his dressing done and for the parent it can be a bombardment of information or questions. So it is difficult* (Doctor_1)

Study parents did not raise concerns about tensions amongst the MDT, possibly because the professionals had found ways to successfully manage differences. However, during a series of observations with one family it appeared that the mother was aware of differences of opinion amongst the MDT about whether her child should have day- or night-time feeds:

> *1. On the ward, day of discharge. The child has overnight feeds. Dietician is explaining to the mother about a new feed recipe: 'So if you discard the scoop in the box and use the yellow or blue scoops. I'll speak with [name of nurse] about the bolus [daytime feed]. Mother laughs: 'I'll leave you two to fight that one out!'*
>
> *2. MDT clinic appointment about a week later. Nurse is updating the doctor: 'We did the home visit on Wednesday and have spoken on the phone since then. They are doing extremely well…. The other issue is [name of child] is having all his feed overnight, but should he have a bolus during the day?'*
>
> > *Doctor asks the nurse: 'Did this happen on the ward?'*
> >
> > *Nurse explains: '[Name of dietician] was reluctant'*
>
> *Later on in the appointment the doctor explains to the mother: 'We need a dietician to discuss the feed'. The mother responds: 'She [dietician] seemed reluctant to do it'*
>
> *Later on a different dietician joins the appointment. Doctor asks the dietician: 'We wondered if he could have feed in the day, and a smaller amount at night?'*
>
> > *Dietician asks the mother: 'How would that work for you?'*
> >
> > *Mother: 'It would be OK. We could do the feed after school. The other dietician [name], was concerned about [child's] possible loss of appetite'.*
> >
> > *Dietician asks mother about the child's appetite and they come to an agreement that the child would have a feed during the day.*

As indicated by these field note data, although there were differences of opinion amongst professionals, they were able to negotiate a management plan with the mother.

Tensions within families could also present barriers to parents' acceptance of the clinical role. Though some parents in the study reported that they had a different level of knowledge and/or skills to their partner, this did not appear to cause tensions as it was acknowledged within the family that one of the parents tended to deliver more of the care. However, professionals described how in other families [non participants in this study] relationships between carers could prevent effective teaching and learning from taking place:

> *Sometimes it can almost turn competitive between carers in terms of if one's watching a set up [of dialysis machine] and then they swap and the other person does set up, it amazes me that sometimes the parent will laugh at the other parent: 'haha, you forgot to do that, or oh, I got that bit right'. I don't know if it's the nature of relationships …, but sometimes you see a very supportive role and sometimes you see something that starts off as a joke but if a parent is already feeling very anxious about how they're going to do this and then they're being laughed at it's not the best thing* (Nurse_1)

Professionals tended to value the support that extended family members could provide to parents, however, there was an acknowledgement that on occasions, they could create difficulties in the clinical care domain. A nurse described how in some families, the relationship between parents and grandparents could act as a barrier to the parents learning to confidently accept clinical responsibilities:

Quite a few of the families that grandparents can take over a little bit because they are just wanting to help out…but that also undermines, if the parent is already feeling that they might not quite be doing well enough or living up to even their own expectations of mothering or caring for their child, if you allow the grandparents then to take over, then that just undermines that even further (Nurse_3)

The nurse continued by explaining how these tensions were managed; for example, by asking to see the child and their parent initially on their own, and inviting the other family member into the appointment later on.

This section has focussed on some key issues associated with parents' cautious acceptance of clinical responsibilities. Expertise within clinical roles was a source of much discussion and the next section explores and discusses this in more detail from the perspective of parents and professionals.

4.3 Blended expertise around the child

When reporting Phase I we presented data from professionals who described the different forms of disciplinary expertise they drew on when caring for the child and promoting parents' clinical roles. We also noted that parents, as part of the clinical role they needed to adopt, might be expected to understand aspects of each of the eight disciplinary knowledge bases relating to their child's management. In Phase II we gathered evidence that explains how professionals acknowledged this but also: recognised parents' expert knowledge of their child, found ways to mobilise this knowledge, and wove parents' expertise into the management plan. Parents also spoke of the degree to which their own expert knowledge of their child complemented professionals'. clinical knowledge. This blended expertise comprised four main dimensions:.

4.3.1 Acknowledging and sharing expertise:

As parents and professionals became familiar with each others' knowledge of issues around the child, new relationships developed that helped them recognise mutual expertise.

4.3.1.1 Acknowledging mutual expertise

Individuals' accounts in research interviews often alluded to a mutual recognition of their respective forms of expert knowledge of the child and the child's condition. Part of the expertise of professionals was the ability to enable parents to reveal and work with their own expertise around their child. An example of this is illustrated when a professional asked a parent for advice, and where the parent appeared to take on the professional's role of becoming 'teacher' and/or 'supervisor' for other family members. Field note data from a clinic appointment (during which the child was being dialysed) illustrates how parents were viewed as the expert in some aspects of their child's clinical care:

> *Nurse checks the child's blood pressure and then says to the mother: 'Her blood pressure is 58, how do you manage that at home?'*
> > *Mother: 'I either turn it down or take her off'.*
> > *Mother and nurse agree to take the child off dialysis machine. Doctor says to mother: 'You could teach the girls! We need a dialysis nurse!'*
> > *Mother laughing and says: 'It's too long a commute!'*

Parents have their own knowledge of the child that can be supplemented over time by the expertise that they develop around condition management. Parents and professionals alike discussed parents' experiences of sometimes knowing more than professionals about details of the child's clinical care. This was observed in different settings, for example when a child was admitted to a renal ward and the parent gave advice to ward staff (i.e. timings of medication). Acknowledgement of mutual expertise seemed to be associated with trust, for example, a mother's trust in ward staff freed her up to learn:

> | Interviewer: | *Were you glad in a way that you were away from the ward when you were doing the learning?* |
> |---|---|
> | Mother: | *I think so, because obviously we knew [child] was being looked after on the ward, but at least we could just go down there [to room off ward] and concentrate on what we were trying to learn. If [child] had been there, I'd probably have been keeping an eye on them.* |
> | Interviewer: | *Yeah, you couldn't perhaps focus so much?.* |
> | Mother: | *Yeah. So I knew [child] was fine up on the ward, so it was nice to sort of get away, especially when I'd been there day and night anyway.* |

In addition, parents liked it when ward nurses were friendly and asked how the child and parent were feeling, and particularly liked it if their child was looked after by the same nurse or doctor on different occasions as this meant they got to know the family well and vice versa and helped to reinforce an appreciation of mutual expertise. The renal team were viewed by parents as: *friendly, genuinely caring and not just interested in the medical condition;* with this in mind parents made comments such as:

> *… we thought [dialysis nurse] was brilliant. …. we were expecting it [dialysis training] to be complicated, but I think it was done at the right level for us. Because obviously we're not medically trained so to do something like this is a bit daunting at first, and she made it seem not daunting, said 'we're always here if there's a problem'* (Mother)

Another mother described how she would joke with staff and felt able to let them know that she was initially nervous [about performing a procedure], whilst another described her *'faith and trust in ward staff'* that they would help her learn to undertake clinical care correctly.

The data suggest that professional and parent forms of expertise are shared and blended around the child. Parents made positive comments about the accessibility of certain forms of information such as that developed by professionals. Some parents liked professionals to share all their expert knowledge about the positive and negative aspects of the child's condition at the outset, but others liked to receive this information in stages.

A nurse described a scaffolding approach to teaching parents whereby she might use her expert judgement to decide to initially leave theoretical explanations aside, focussing instead on the practical application of knowledge by explaining, for example, how to set up the dialysis machine. She would then ask the parents to practice setting up the machine and use opportunities when there was a pause (e.g. when waiting for the machine to prime) to re-engage them in discussion about the theory underpinning dialysis. This strategy helped her to determine how much knowledge parents had recalled from previous sessions:

> *So you might start with some basic informal questioning to try and assess did they grasp it, have they started doing the BPs yet, and then your [training] week sort of develops from those two sessions in terms of how quickly they find their feet with the practical skills, how quickly they seem to have grasped the theoretical skills and then you do your balancing, ideally each day, introducing a new bit of information, so some new theory each day while continuing to practice the same practical skills* (Nurse_1)

This flexible and adaptive approach was also evident when professionals might adjust their language if a child was present; indeed another professional said they would sometimes use the child as a *'crutch'* to help parents receive and understand the professionals' expert knowledge, while several professionals described the importance of being able to: *read families and go at their speed.*

This led to discussion about the ways professionals judge how to pitch their expert knowledge to the individual's needs and preferences. At times during observations, professionals appeared to have made an expert judgement that parents were not yet 'ready' to receive more information or it was not the 'right time', even if the parent had asked a question. These field note data illustrate this point:

> *The father is cleaning the child's line in preparation to connect her to the dialysis machine. Father asks the nurse: 'What should we do if the pressures [child's blood pressure] are high? Call you?' The Nurse appears to want the Father to concentrate fully on what he is doing, so answers: 'Yes, I'll teach you later'.*

Other strategies professionals were observed using to help determine how to pitch information included:
- Involving parents in decision making and trying not to be directive
- Responding to questions from parents rather than having their own agenda
- Aiming not to overwhelm parents by gauging how much they have 'taken in'
- Asking parents how much information they wanted
- Assessing if parents are coping and what level to pitch information at
- Changing a feed recipe in clinic if they know that the parent will understand
- Going through the medication sheet with parents and offering to come back and do it again until parents are happy with their own understanding.

Another strategy professionals used to determine the level at which to pitch information was to be guided by parents' questions. One doctor believed that parents' education level was likely to correlate with understanding so would start a conversation with such parents differently according to their understanding of the parents' educational status. On the contrary though, another professional believed that it was important to recognise when for instance working with parents who are health professionals, that they were parents first, and may not wish to be given information in a different way to other parents

Recognising the type of information provision each parent preferred could be challenging for professionals as some parents wanted to know what to do but not why, and some preferred simple instructions to long explanations. Moreover, doctors believed that some information was crucial to give to parents whilst other information was not so crucial. However, professionals thought it became easier to know how to provide information to parents as relationships with them developed.

Participants' accounts indicate that differences could exist between teaching and learning styles and skills and as this section demonstrates these differences could act as barriers to teaching and learning. There was a broad consensus in professionals' data that each parent has individual learning needs the challenge this presented for MDT members cannot be underestimated. When a child was referred to the MDT, whether it was in an outpatient setting or as a planned or emergency admission to the ward, professionals used the wide range of clinical interventions to help them relay their expert knowledge to parents, these interventions included:

- Assessing the child;
- Developing and initiating a management plan;
- Making adjustments to the plan according to the child's clinical response;
- Explaining the condition and plan to the parents, and the child if they were old enough;
- Keeping the child and parents informed about management as adjustments are made to treatment regimens and;
- Making plans for ongoing management.

Because of their specific expertise and the nature of their MDT roles professionals such as social workers and/or therapists might advocate for parents for example during discharge planning discussions. These professionals in particular tended to learn about parents' care giving arrangements and support infrastructures at home which could inform discharge planning.

Throughout these processes, MDT members continuously involved parents by providing explanations to promote their understanding of the consequences for the child. In addition, professionals would prepare parents to share the child's ongoing clinical management where appropriate. As already mentioned, this shared care was likely to involve parents taking on responsibility for a wide range of home based clinical care; the skills and knowledge that parents needed to take on this responsibility could reflect the distributed expertise of the entire MDT. The data indicate that professionals were often concerned about the best way to explain these issues to parents. On the one hand, professionals recognised the child specific expertise that parents brought to the clinical role and wanted to ensure that parents could use this knowledge as they developed the expertise to safely manage their child's condition at home, on the other hand they wanted parents to know when and how to seek assistance with their clinical role

4.3.2 Good working relationships

These data therefore, point to the importance of good working relationships in sharing expertise around the child. Professionals often highlighted in interviews the importance of the developing relationship between the MDT and parents, and identified situations when they would try to promote good working relationships; these included trying to make clinic visits informal with '*minimal rules*'; trying to be approachable; spending time talking to parents about how difficult care can be, '*giving praise*'; and getting to know the family as people in addition to understanding the psychosocial and medical issues. Professionals being friendly and using humour (where appropriate) in an effort to develop positive relationships with parents was observed on many occasions, as indicated by these field note data from clinic appointments:

> *1. Both parents are present, father is holding the child on his lap. The doctor plots the child's height and weight on a growth chart in child's medical file. The doctor says: 'Can I also do your head? [measure the circumference of the child's head with a tape measure]. For some reason they don't like this, the little ones. 43, that's a big head!' Mother jokes: 'We know who he [the child] takes after!' The doctor says: 'I'm not saying anything!'. Mother says: 'Everyone says he looks like [name of father]!'*
>
> *2. Mother gives the doctor a Christmas card. Doctor thanks her and says: 'I think we should give parents cards for letting us play with their children!'*

Home visits were an important part of the process of developing good working relationships between parents, and the professionals whose roles involved this:

> *You are in their home …you instantly start to build a relationship…you can tell them who you are in clinic, answer some questions but I think the relationship really starts there in the home* (Nurse_8)

Play workers often acted as mediators, because they are *'non-medical'* they may be *'more approachable to parents'*; for instance when discussing a study family a play worker said:

> *Mum worries about saying wrong things to [other] professionals but knows me well enough to feel able to ask these questions* (Playworker_1)

While a social worker thought it was important to let parents know that social work support was available, and explained to the researcher that social workers may support parents to develop strategies for communicating their expert knowledge of the child to the MDT. A doctor believed that, as doctors are a constant figure in clinics they developed longstanding relationships with families and so had time to learn how much clinical information parents wanted and to '*get the teaching right'.* A good working relationship was also discussed by a nurse who said that since she knew one of the study families well it meant she had a 'feel' for what information the parent can '*take on board'.* What participants seemed to be describing was the existence of a blended community of experts surrounding the child.

Professionals and parents often referred to the existence of a 'community' in the clinical environment that helped to promote good working relationships. For example a doctor thought that: *letting them [parents] know there was a community to support them* was important, and that it could be useful for parents to talk to someone [such as the Social Worker or Therapist] apart from the medical team, about psychological issues. One doctor believed it was important to reassure parents that they are not on their own and:

> *There are still times when I give parents a hug, if they've been through a difficult time, I say, 'it's fine, come on, we can do it together, you're not on your own'* (Doctor_8)

A mutual understanding of each other's attitudes towards support was increasingly evident within the case studies as data gathering proceeded. As relationships developed and as professionals and parents learned about each other's expert knowledge around the child they developed ways of communicating with each other. The importance of good working relationships was, therefore, closely linked to the notion of expertise.

4.3.3 Working to parents' strengths

Knowing that parents' educational backgrounds and social circumstances varied widely could make it difficult for professionals to determine the most appropriate way to assess parents' learning needs and promote their clinical expertise. However, there is currently no evidence based, reliable means of assessing and monitoring parents' preferred learning approaches, or the level and type of information provision they prefer. Therefore,

professionals tried to play to parents' strengths and used a combination of 'trial and error', intuition, feedback from parents and children, and discussion with other MDT members to determine each parent's potential to understand the complexities of clinical care, and their preferred learning approach. In some instances professionals perceived that parents within couples appeared to want different information and this could make it difficult for professionals to target information appropriately to each parent:

> …sometimes you get couples differing about what they want" (Nurse_1)
>
> nursing staff, what their general understanding of medicines is… [Pharmacist]

Furthermore, professionals were sometimes concerned that limited literacy and numeracy skills could make it difficult for parents to understand complex clinical issues and develop the expertise needed to safely manage their child's clinical regimen. Though none of the study parents experienced difficulties in this area, professionals such as this nurse, believed that this could potentially be a barrier to teaching and learning for some parents:

> I think one of the things that has shocked me [in the past]…is how little general maths a lot of adults have, and we [the MDT] talk about percents a lot…very few people actually understand what a percentage means and so we can be citing off such and such is 65% or 20% rejection rate, or whatever, and you think, they [parents] don't really understand. And not that I'm trying to say, you know, 'maths test them all', but actually, I do think we can end up scaring people…(Nurse_7)

Many professionals described the importance of putting complex information in context for parents; several doctors discussed the challenge this presented when parents' individual learning needs were so variable. The following quotation helps to illustrate this point:

> …you can see that sometimes they can take that [clinical information] onboard more easily than others. Some of them will then just worry…so as much as possible, I try and put it in context, in terms that they can understand. The same with overwhelming infections, then some of the other things that we're starting to pay a lot of attention to.
>
> We know that one of the biggest causes of mortality amongst young and middle aged kidney patients is cardio vascular disease, which they get earlier than the general public and so we do concentrate very much more on blood pressure, cholesterol levels, those sorts of things, and we have to tell them [parents] why, you know, so we have to say, 'our patients are at risk of heart disease and strokes as relative to other adults and that's why we're doing all of this now', you can see, again, some of them like to know that's why we're doing what we're doing; others do just worry enormously about it." (Doctor_8)

Some professionals talked about not having been trained how to teach but having developed expertise in this both in and out of work. They described how parents did not usually talk

about 'learning styles' but drew on their previous experience of learning when talking with MDT members. Professionals were often guided by parents responses on the way they liked to be taught, and used this knowledge to identify 'teachable moments'. Reflecting, during a research interview, on her experience of teaching parents, a nurse noted that she and her colleagues rarely analyse their parent teaching interventions:

> *We don't go back and say [to parents] actually what was useful and was there a specific thing in terms of what we did that made it easier for you to cope with or learn?* (Nurse_3)

Nevertheless, professionals talked about how, as their experience of working with children with CKD increased, they learned from parents; for example, a nurse explained the way some parents described the experience of having a child with a naso gastric tube informed how the nurse then talked with other parents about this. Professionals tended to draw on several years of experience of dealing with patients and concluded that each parent dealt with their child's kidney condition differently:

> *I think different families want to deal with it differently and there are crucial bits of information that somebody must understand. As an example, on dialysis if there is a risk of somebody getting an infection, what signs of infection to look out for and why it is absolutely, crucially important that they report back to us and let us know immediately about it, and I wouldn't overlook that sort of crucial thing. But if somebody doesn't really want to know why each dose of medicine is changed then I wouldn't bore them with the physiology of it* (Doctor_8)

Professionals' own previous experience of caring for children with long term conditions also informed their teaching of parents in the study families. For instance, one nurse explained that the way she taught parents had changed as she had gained expertise in condition management herself, whilst another professional said that she talked with colleagues about long-term conditions and asked questions in order to learn from colleagues' experiences. As a result of their own experience of managing the care of children with long term conditions, professional participants had learned that families' learning and support needs were very variable; for example if a child had been in the health care system for a considerable amount of time then parents were usually well prepared for care giving.

On a few occasions, professionals commented to the researcher during observation events on how they thought study parents were learning, as indicated by this field note data:

> *Parents are learning with a nurse how to complete home dialysis. The mother is practicing connecting the machine. The nurse comments to me [RN] how the session is very informal and relaxed, how the parents are chatting whilst doing tasks. Thinks the parents have learnt quickly and have confidence as they are able to talk whilst doing tasks. Other parents are not usually able to chat and have to keep quiet to concentrate. The father jokes about not being 'normal. Nurse tells parents: 'It's a compliment'.*

This links with discussion elsewhere about how professionals provided positive reinforcement to parents during interactions, and also highlighted issues about the various roles the researcher/RN occupied during observations (see Appendix 20).

Over time, professionals assessed parents' knowledge and skill development and noted in interviews whether parents appeared more confident, relaxed or comfortable when asking questions, for example:

> *[Mum] takes pride in how careful she is…very practical, straightforward, has questions which need answering…good at asking questions and getting what she wants* (Doctor_8)

Parents vividly described the facilitative attitude of professionals, for instance one mother described a nurse as a:*…brilliant teacher, patient, calm, teaches so you remember….* Parents' accounts mirrored professionals' reports of the 'open door policy' meaning parents realised they could always access expert advice, including 'out of hours' when they could call the ward. Moreover, parents were given direct telephone numbers for renal staff and knew that MDT members would liaise with the local hospital on parents' behalf if needed.

Parents were sometimes amazed with their own ability to learn the skills and knowledge needed to expertly and safely care for their child's condition at home. For example one father said that while he had never dreamed he would be doing home dialysis, he now: *…feels good that I can do it as I was scared when I first saw the machine*. Meanwhile a mother explained early in the case study that she had done the [dialysis] training but now needed to be actually able to deliver the dialysis at home, but she later reported that she was *feeling more confident now when making adjustments to the dialysis.*

Whilst parents had to perform most clinical procedures at home, if a child's naso gastric tube was pulled out and needed to be reinserted so the child's feeding regimen could continue, parents had the option to return to the ward for it to be reinserted, have it reinserted at home by a community nurse who they and the child might not know and who might be inexperienced in this procedure, or learn to do it themselves at home.

When developing the expertise needed to take on home based clinical responsibility, parents' sometimes took a pragmatic approach to decision making about this. For example, one mother was not sure initially if she was '*brave enough*' to insert a naso gastric tube into her child but eventually decided that she would learn to do this so she would not have to visit the hospital each time it needed reinserting, she said that she knew she would eventually develop expertise in this and it would get easier. This was another example of a parent developing clinical expertise through necessity rather than choice. As well as recognising and using teachable moments, participants also reflected on their own teaching and learning so this process of self evaluation is explored next.

4.3.4 Self evaluation

When discussing the importance of health professionals involving parents in decision-making that involved drawing on new and expert clinical knowledge, some professionals

evaluated their own experience of receiving new technical knowledge in their personal life. One nurse discussed this with RN:

> *…the guy [central heating engineer] asked me which filter I wanted, well actually, I needed him to make that decision, yes, I wanted the safest, most efficient, cost effective filter. I didn't want to make a decision about the filter for my gas central heating, and in some ways we're asking parents that sort of same thing, you know, what type of this, what type of that and actually, I think if I was doing a reverse, if I was the parent, I'd be saying actually, tell me about them all certainly, but actually I need guidance to make the decision about what is the best for my child* (Nurse_7)

By using a metaphor to reflect on her own experience of being asked to make decisions that required an understanding of the engineer's expert knowledge, and relating that to the experience of parents in the clinical context, the nurse concluded that parents sometimes required specific guidance to help them make decisions about what was best for their child. This provides further emphasis for the point made earlier in this report that parents were often expected to make clinical decisions that depended on them understanding expert knowledge from the full range of disciplines within the renal MDT.

There is evidence in section 4.2 of parents' positive experiences of learning their clinical role, and their appreciation of professionals' facilitative teaching approaches, nevertheless parents sometimes found it difficult to develop new clinical expertise. One father experienced difficulties because English was not his first language and because learning new skills was not something he did regularly *"…learning, you know, something, I don't really that's not my occupation".* The same father found it difficult initially to operate the BP machine but over time, and by 'taking it seriously', he became more confident at using the machine.

Professionals in Phase I discussed the importance of using appropriate language when engaged in teaching activities and this was also raised by parents in Phase II. Communication during ward rounds sometimes inhibited parents' learning, one father described in an interview how teams of doctors initially talked amongst themselves during the ward round using expert medical terms that he did not understand. This man's partner also preferred information that was provided in 'human' terms:

> *I have asked the doctors and, yes, they have explained it to me, obviously, like I say, when they do, then, explain it too in human terms, as well as them telling me the first time, in medical terms, I've taken that in and, then, when they tell me in human terms, I'm, like, ah! And, then, it starts to sink in …and, obviously, I do jot things down, just for my own peace of mind, so I don't forget, because you get told different things and different things happen every day"* (Mother)

Parents within couples also discussed their own preferred learning styles, for example a mother and father explained that whereas the father assimilated information quickly and could then ask questions of the doctors, the mother needed more time to reflect on the information so she could ask questions later. The same mother found it difficult when the

child was seen by different doctors at each clinic. Another mother reported difficulty in learning new skills if three or four different nurses did the teaching, each nurse had their own way of teaching which could be confusing. Confusion was also observed when parents received information from a range of different members of the same discipline as illustrated by these field notes:

> *Parents tell the nurse that the mother has set up the [dialysis] machine twice and father done it once since previous training session with the nurse.*
> *Nurse asks: 'How was it?'*
> *Mother: 'It was fine, though the tape came off it'*
> *Nurse: 'Was [name of nurse on ward who helped parents to set up] helpful? Did it knock your confidence because things were done in a different way?'*
> *Mother: 'Yes, she does the blue one differently'*
> *Father: 'She was quite critical, she told me to wash my hands again because she thought I had touched the bin. I took exception to it. I said 'I don't agree with you', but I washed them again anyway'*
> *Nurse laughs: 'I didn't teach you to be so empowered!'. The nurse explains [the nurse on the ward] is the infection control nurse and is responsible for reinforcing infection control.*

Some parents had prior experience of clinical care such as monitoring the child's temperature, hand hygiene and central line care and one parent had learned 'tricks' from a dietician about getting their child to eat more calories. During observations such as the one below, it was noted that parents and professionals sometimes used parents' previous experience of a long-term condition to help illustrate a point relating to the child's current management:

> *1. The dietician is talking with the mother about how the child's feed has been changed. The dietician says: 'You know how to do the feeds. You've done it many many times before. It's a shame there are so many ingredients'. The mother replies: 'I'm used to it'*
> *2. Nurse is showing parents how to deal with alarms on the dialysis machine. Mother says: 'We've had that with the feed pump. We sort it out, go back to bed and then 3 minutes later we have to get up again. We better make sure we have our glasses. We both wear contact lenses. We could be pressing any buttons!". Later on in the appointment, father is making comparison between using dialysis machine with their previous experiences with child's feed pump. The nurse demonstrates how to check the line and seals on the dialysis fluid bags and advises: 'It's like you do with your feed pump'*

In this section we have considered and interpreted the evidence for blended expertise around the child. The findings point to a clinical domain where professionals and parents try to use their respective expertise to manage the child's clinical needs. However, uncertainties do exist around the interactions between parents and professionals, these are explored and discussed in more detail in the next section.

4.4   Ambivalence within teaching and learning encounters:

Ambivalence within teaching and learning encounters occupies an important position in the Parent and MDT teaching and learning model (see figure 7) as the other aspects of interactions between parents and MDTs that relate to teaching and learning are connected and contribute to it. The pivotal position of ambivalence in the model reflects the sense in the observational and interview data that parents and professionals experienced some uncertainties when engaging in teaching and learning. Ambivalence was often evident at an early stage in the child's trajectory and continued to appear around a variety of issues. Examples of this are presented in the following four sub sections.

4.4.1   **Hospital vs. home routines:**

Parents and MDT members recognised that delivering care to the child in a ward or clinical setting was different to delivering care at home. Differences resulting from the environment were significant including space and access to hand washing facilities. The other commitments of parents, such as looking after other children and paid employment were also acknowledged as having an impact on how home-based care could be carried out. This created some uncertainties, especially for professionals, as they wanted an optimum environment for parents to learn in (e.g. quiet, no distractions) but were aware that parents could be learning in an environment which didn't reflect the reality of what it would be like when the family were at home:

> *It's got to be real, because at home, you can tell their child to be quiet but she's not going to be quiet at home. But at the very beginning stage I want them to concentrate and understand why we're doing something, not have someone going on in the background. I prefer the TV's off. They're going to do it all at home, I'm not naïve to that, but at least I hope by the time that I've got them home that they've had four solid weeks of doing it and really understanding it without having noise in the background* (Nurse_2)

Both parents and professionals appeared to experience ambivalence when engaging in teaching and learning encounters as they described how care-giving routines might be adapted so they could be delivered more flexibly at home. Typically, the adaptations they described were made to help ensure that care-giving fitted in with the other routines of family life, as well as in recognition of the fact that clinical care delivery was more 'regimented' in clinical settings. A nurse described how this process of finding a suitable care-giving routine at home, was negotiated with parents:

> *So we need to find, 'it's up to us really with you to find a way how this can work for you as a family because everybody has to survive'. It's no good us setting a treatment regime that doesn't work for the family, it's pointless because if mum and dad are completely broken within two weeks then nothing's going to work* (Nurse_3)

It appeared that professionals' prior experience had an impact on their attitude towards, and confidence in, creating a more flexible home-based care-giving routine:

> *…some of our registrars may be that bit newer and while they may know the actual theory, it's actually I'm not going to wake up a child at two o'clock in the morning to give them a drug because it has to be every six hours. You don't do that. You've got this treatment, there's transplant, there's life. So the treatment per se has to be followed to a degree but also it has to fit in with life or else what's the point?* (Nurse_7)

Other factors such as the perceived care-giving expertise of the parents also affected how much flexibility existed in home-based care. As discussed in the previous category the content of teaching and learning sessions could alter depending on the individual participants. There was a recognition that care-giving routines could be carried out differently on the ward whilst the child was an inpatient, and this sometimes resulted in ambivalence being experienced. For example, a father who had been learning to make overnight feeds for his child and had done this at home during weekend leave from the hospital, commented how on returning to the ward, he no longer had responsibility for this:

> *…they have a specific milk kitchen, so all the milk is made up by professionals that do it for a living…* (Father)

The differences between the routines at home and in the clinical setting, appeared to become easier for parents to manage as they gained experience and confidence in their interactions with MDT members'; however, these differences continued to result in some uncertainties and doubt. During her child's second admission, a mother described some of the interactions she had with ward staff around her child's care:

> *We can say to them, 'Look, this is how it's got to be,' but because we are here, things are done differently. But as long as we're on the same page, I'm okay, they can do things whatever way they want, but as long as we're on the same page, and it's the same, I don't mind.(Mother)*

As discussed above, the ambivalence around care giving being carried out differently in clinical settings and families' homes was reported by both parents' and professionals and is thought to have an impact on teaching and learning. Another area where ambivalence appeared to exist, was around expertise.

4.4.2 Expertise:

Building on this ambivalence about the routines in hospital and home and the prior discussion of blended expertise around the child, there was also evidence of uncertainty over what the expertise was and who the expert was. For example, there was recognition amongst MDT members and parents that some professionals used different techniques to other professionals when carrying out the same clinical task. For some parents this caused uncertainty, as they were unclear about which technique they should be using:

> *It's not always the same nurse, all nurses do things differently and I've learnt that, but the way we're taught, or the way we've been shown, I'd like to be shown it again. If there's anything shown different and then having to question it , and then because, I get a little bit, well, I don't really want to question it, because they know what they're doing. (Mother)*

This uncertainty appeared to be experienced more by parents who were completely 'new' to home-based clinical care-giving. Some parents who had experience of undertaking clinical care but were now learning a new task, appeared to cope with being shown different techniques, especially if the alternative technique was easier than one they had been shown previously, or if the new technique saved time:

> *When I first started I clamped everything, just to be safe and sure, and then one of the other nurses said 'there's no need to do that, why don't you just do this'. And it was easier, it wasn't as much work, you're clamping to unclamp so I just went with [name of nurse] and she said, 'do it and it's much easier that way'. (Mother)*

MDT members' described how professionals practised differently both across and within the disciplines; for example, a parent might ask a question and receive slightly different answers depending on who they asked:

> *I'm sure you can line up ten consultants or registrars and ten nurses and probably get 25 answers. There's so many different opinions on things* (Nurse_7)

Professionals gave examples of how MDT members might create additional difficulties for parents' learning by using different these approaches; for example providing information about a treatment (e.g. medication) in alternative ways, and assessing whether a family is coping with delivering care-giving depending on their own particular perspective. In some cases it appeared this could create ambivalence within a teaching and learning encounter. Some professionals recognised these ambivalences and reflected on whether it would help parents' learning if professionals' differences could be minimised and their teaching approaches be 'standardised'.

MDT members' described using checklists at certain points with families (e.g. pre-transplant) to ensure that the information given was the same even if the individual professional's way of sharing the information differed; however, professionals acknowledged that the level of information given to the parent could still vary despite the use of checklists. There appeared to be uncertainty amongst professionals' about whether to try to ensure teaching and learning encounters were the same with all families, or whether it was more important to adjust the interaction depending on the specific learning needs of the parents:

> *We're probably bad actually, we don't have a standardised same thing for everybody, some parents, we assume, need more help and more input and others. We know they're very confident and seem to be getting on great with the meds and don't ask any questions or they seem to be just getting on with it. So we probably give the kids that need a bit more help with their meds a bit more time, which is probably the way it should…I don't know what's right or what's wrong to do?"* (Pharmacist_1)

The overlap of roles within the MDT was also evident in interviews and observations. A dietician explained that to be able to effectively carry out their own role it was important for them to demonstrate to parents that they also understood the discipline specific knowledge of other members of the MDT:

> *The strange role of a dietician is that, although we're mainly talking about food and nutrition, one has to bring in the other aspects of the treatment to make it understandable. So, you will be talking about what the medicines are doing and why they need to understand their role, because, quite often, they're interacting with, for example, absorption …which directly involves nutrition* (Dietician_3)

Similarly, a therapist described how MDT colleagues may consider a child's psychological and emotional wellbeing and she would consider a child's medical needs, but that each discipline would "*bring different things to the table".*

Ambivalence around expertise also appeared to be evident as parents learned how to deliver care. Parents seemed to move along a spectrum of skills, knowledge and confidence; they would move on from gaining competence in delivering essential aspects of a task to making some clinical decisions independently from professionals. A dietician described how some families may not follow professionals' advice and would adjust care-giving once they got home (for example, a child's feeds) but acknowledged that parents could be experts because of the experience they had of looking after their child*:*

> *They do fiddle with the timings and various things and they actually know their child better and it's just what suits their…you know, it works that way…The sort of group that do never listen to what you say, but, sometimes actually, the changes they make are quite relevant* (Dietician_4)

Some parents described the experience of developing greater independence, for example one mother who had been learning home dialysis reported:

> Interviewer: "And making the decisions about increasing her weight, is that something you're doing on your own?"
>
> Mother: "I do it. I just let them know what I've done next time I speak to them. The nurse will ring and say, 'what are we up to now?' She leaves it very much down to you".
>
> Interviewer: "How do you feel about having that responsibility"
>
> Mother: "I was so nervous at the start but I'm fine about it now. Because I can see her and I know the signs when she's got fluid there. I don't worry about it because I think, she's looking a bit puffy, I'll just stick her on the machine and let's get rid of it. I don't worry as much as I used to about it"

There appeared to be ambivalence amongst parents about these situations where they seemed to be adopting the role of expert and educator; some parents accepted the role as they acknowledged not all health professionals could be experts in renal care, whereas other parents wanted hospital staff to be able to identify what was wrong with their child and provide treatment, "*instead of me having to explain*".

Parents knowing when to ask professionals for advice was discussed by both MDT members' and parents. Some parents were aware of the limits of their expertise and had developed their own threshold for when they would make a decision independently and when they would seek advice, whereas for some families this threshold was set by the professional. As keeping the child safe was a priority, MDT members appeared to value parents who exercised caution or were not overconfident in terms of managing their child's care at home:

> *It's very nice when you can see them become empowered and able to make those steps in their head without you directing them. And obviously, you want the fine balance that you don't want them running off and doing it all without ever turning to you, but that was never going to be an issue with this family; they would always be cautious* (Nurse_1)

However, as illustrated by the previous quotation, it was important that a balance be achieved where parents did not consider themselves such experts that they stopped consulting with professionals. The difficulties of parents having a role where "*they're part doctor, part nurse, part parent*" was described by professionals, resulting in some MDT members' viewing their own role within teaching and learning encounters as supporting parents to be parents 'first of all'. The ambivalent role of parents as experts seemed to be taken a step further by a therapist when she was asked how she thought one of the families was managing with care giving:

Ambivalence around expertise appeared both in participants' reports and in observations of teaching and learning encounters; this could affect professionals' teaching activity and parents' experiences of learning. Closely related to this, was some uncertainty that seemed to exist in participants' attitudes towards clinical management of the child.

4.4.3 Clinical management:

There was evidence of ambivalence amongst MDT members' and parents around management, especially in relation to the level of acceptance of how the child's condition was being managed. Examples of when parents found it difficult to accept the ambivalence in this area, or questioned how professionals looked after and made decisions about their child's condition were described in interviews, and became evident during observations. This applied to many aspects of management including:

- Parents wanting more teaching input but professionals thinking that parents were not ready to cope with more
- Parents discussing their concerns about whether one professional "*hadn't been very sure what was really going on",* with another member of the MDT
- Parents questioning the benefits of specific techniques, as illustrated by the following field note data where a mother was discussing with a nurse how to take the child's blood pressure:

Mother: 'I spoke with my mum's nurse and asked why we couldn't use one of those machines to record it electronically'.

Nurse: 'We use these [she gestures towards the machine on desk which takes blood pressure manually], not the electronic, as it's proven in research, that if you have abnormal blood pressure, then it tends to be a higher reading on the electronic, it's more accurate to use this one. We need a really accurate reading when you do dialysis. [Nurse turns to child to include her in the conversation}. At the moment your kidneys are working and you are still producing urine, but they may stop and so the machine would have to take off the fluid. We would need a very precise blood pressure reading to make sure enough fluid is coming off'.

Mother: 'My mum's nurse was saying many nurses can't do it this way!' [measuring blood pressure manually rather than electronically]

Uncertainty about management was also evident when professionals and parents had differing views about what support the family needed to help them learn. For example, MDT members' described difficulties when they suggested to parents that they would benefit from support from the psychosocial team (e.g. Psychology, Therapy, and Social Work) but the family did not accept this. Professionals explained how some parents were initially reluctant

to accept that there were *"no guarantees"* after their child had received a kidney transplant and the child might revert to needing dialysis again:

> *And I think she still struggles with that, a little bit, she doesn't bring it up as much now. And I think to a certain point, she has accepted there's going to be long term, or lifelong treatment…she's going to have medical input for the rest of her life (Social Worker_1)*

Both parents and professionals talked about the difficulties of coming to terms with a child's diagnosis and as a result, finding it hard to accept that some treatments were necessary. For parents, the difficulties' accepting that a child needed treatment was sometimes related to the child not appearing ill. For example, a mother described the challenge of learning to manage the condition when the child had few or no visible symptoms:

> *I think it's been hard because she's not ill. You can't see. It's all inside, and the only thing that's happening now is she's tiring, and that's the only thing which…to me, I don't find that hard. I find it hard for [name of child] when she struggles to get up in the morning, and things like that (Mother)*

In Phase I professionals alluded to the invisible nature of CKD and this was reiterated by professionals in Phase II. For example, MDT members described a scenario when a child who appeared well, attended an outpatient appointment for post-transplant monitoring but was subsequently found to need admission because of the results of blood tests taken during the appointment. Professionals recognised that this uncertainty could be difficult for parents to manage. This reinforces the findings discussed in 3.2.5 about how the 'invisible' nature of CKD can prove challenging for MDT members when explaining a kidney condition and its management to parents.

Additionally, there was acknowledgment of a potential ambivalence around clinical management as a result of professionals having different views about a child's treatment. Some professionals thought parents may find these differences difficult to manage, whereas some believed that it was valuable for parents to learn that there could be differences of opinion within the MDT:

> *I think people also need to realise that things are not necessarily black and white …that especially when they are seeing different professionals that things might not be, there isn't an absolute sort of protocol text book answer to everything, that people do respond in slightly different ways to results and situations and there are different ways of doing things – they are not necessarily wrong – one way is not necessarily wrong and one right, far from it actually (Doctor_6)*

However, there was recognition that some parents were able to cope with this ambivalence more easily than others. As a result, MDTs would make a judgement about how much of the

initial discussion between professionals about a child's management took place with the parents present.

There was an indication that ambivalence could exist in situations where it was uncertain if families were having difficulties coping with delivering home-based clinical care. Professionals described challenges when parents did not communicate or demonstrate when they needed more support with the clinical role; although as professionals' relationship with a family developed they would be able to 'pick up' on whether the parents were experiencing any stress. It was evident that parents communicated a need for additional support in various ways, but sometimes this could be quite a subtle communication.

MDT members acknowledged that parents could be concerned about the perceived implications of communicating care-giving difficulties to professionals. For example, parents may worry that professionals will think they need further teaching, or that the child might be re-admitted, or in extreme cases that the child may be 'taken into care'. Because parents may hide these concerns it could be very difficult for professionals to detect them and offer appropriate support. There were suggestions from professionals that it would be helpful if parents could provide "triggers" to indicate when they needed additional support:

> *And a lot of the time it's very difficult if they're showing you the side, the snapshot that 'this is what I need to do while I'm spending two hours in [name of hospital] and then I can go outside and crumble at the bus stop', actually it's very difficult for us to see that. So unless she [mother] does give us concrete methods [do detect this difficulty]…but it generally is a change of behaviour or if they just look exhausted (Nurse_7)*

Examples of situations when it was unclear whether parents were experiencing difficulties with care giving, were also evident during observations. These field note data were gathered during a clinic appointment with a child's grandparents who were attending in the mother's absence. The mother had given the grandparents a list of questions to be discussed with the professionals. The grandparents were explaining to the nurse that they thought the parents needed some additional support to continue with the child's home-based clinical care:

> *Grandmother to nurse: '[Name of mother] is frightened of saying something up here'*
>
> > *Nurse interrupts grandmother: 'In case we think she's not coping?'*
> >
> > *Grandmother: 'She's only young'.*
> >
> > *Grandfather:' It's different when you're our age'*
>
> *Nurse appears to want to reassure grandparents about mother's care-giving : 'I have no concerns whatsoever. She's really doing the right thing, you can tell just from her questions, her list'.*
>
> *Grandfather: 'I think she knows she's doing the right thing, she just needs to be told, and that's OK'*

At times, uncertainties appeared to exist when additional family members were involved in a child's care. The challenges of including a variety of family members and carers within teaching and learning encounters is explored more in sub section 4.1.8. The field note excerpt presented above also demonstrate the challenge for professionals of providing positive reinforcement to parents, and parents recognising they were doing 'a good job'.

MDT members' described how finding out that parents were having difficulties with home based clinical care giving could lead to personal reflection and questioning of their previous interactions with the family:

> *You always think back, when you see that there is a problem and you see somebody who's struggling, you look back and go 'oh, should I have noticed that before, did I miss a sign, wasn't I observant enough or did I not hear what they were saying to me?' I don't know if you ever really find the answer to that one, but I think the fact that you're thinking about it means that you're sort of analysing what's gone on and if you have missed something, then hopefully the next time you come across the same situation you would be more on the ball of picking those signs up. I think often it's something that comes with experience as well, that you can almost feel it, because people don't necessary have to say it. As you look after these children more and more, you sort of get a feel for when people are coping and when they're not (Nurse_3)*

As indicated by this excerpt, although MDT members' were aware that ambivalences could exist in these types of situations, they also valued the reflective opportunities these situations presented as it could lead to them developing new strategies for parent support. This sense of 'picking up' on how parents are coping was a skill that professionals developed as they gained more experience of teaching about and managing long term conditions, this is closely linked with sub sections 4.2.6 and 4.2.7.

The discussion in this sub section has given a sense of how ambivalence around clinical management could affect interactions between parents and professionals. The final ambivalence which appeared to exist within teaching and learning encounters was around the status of the skills which parents needed to learn.

4.4.4 Skills to learn and teach vs. common sense:

Ambivalence was present in both professionals' and parents' views about the skills and knowledge that parents needed to learn. Though the complexity of care giving was discussed during interactions between professionals and parents, there was also emphasis on parents using their common sense. As parents learned the care giving needed and incorporated this into their daily routine, the role of common sense became more prominent as illustrated by a father, *"it is a pretty common-sense application process"*, and a mother:

> *We have been taught a lot and it is all self explanatory, it is all using your common sense (Mother)*

Parents 'working out their own way' of doing a task and it becoming 'natural' was also referred to within interactions, suggesting that professionals sometimes chose to reassure parents by emphasising the less technical aspects of a task. For example, when teaching parents about managing infections which a child could develop whilst having home dialysis, a nurse was observed to offer reassurance by emphasising the value of *"instinct, being the child's parents, and common sense"*. Thus acknowledging the value of using parental 'instinct' when delivering care, it seemed professionals also valued the expertise and experience parents brought to the encounter and reinforces the earlier discussion about blended expertise.

The ambivalence around skills and knowledge being learnt was also evident in participants' understanding of what was 'normal'. It seemed that for some parents, the challenges of 'normal' parenting (e.g. managing a child's behaviour) were more significant than the demands of clinical care-giving. For one of the renal teams in the study, there were explicit discussions about the teams' philosophy around promoting 'normalisation', as described by a doctor during an interview:

> *Please try and think of the child as, you have a normal child who happens to have a kidney problem, don't think of them as a kidney problem with a child attached* (Doctor_8)

MDT members' reported how this philosophy shaped the teaching and learning encounters with parents:

> *It's just normalising things, that's the other thing with [name of mother], you've got to very much normalise things, in terms of 'a lot of children present with these behaviours and these are the things that you could try'* (Social Worker_1)

There was recognition though that the process of normalising home-based care-giving was not straightforward and potentially created contradictions for parents:

> *I think there's a fine balance as well because we are encouraging them to think of this as okay, this is normal, don't make anything big out of it; this is how it's going to be so just get used to it, and normalising it in that kind of way; yes, we've got a chronic disease and yes, he's got an NG tube, but life carries on and they should go to playgroup and you should interact with other people, and we need to structure your day so that you will have time to do all the things that other parents are doing. So I think, in some ways, we are encouraging to play that down, and at the same time it is so difficult. So it is clashing a little bit. But you don't want to make them feel that it's that bad, it's so overwhelming that they can't cope with it"* (Nurse_3)

Though professionals regularly offered feedback, reassurance and praise to parents for delivering care, it seemed that parents sometimes found it difficult to 'hear' or accept this as illustrated by this field note data from an observation of a clinic appointment:

> *Doctor: 'I think you are an amazing mum, you take things in your stride'*
> *Mother: 'I'm just normal'*
> *Doctor: 'No, you're amazing'*

MDT members' described how they thought it important to praise parents but acknowledged that parents might hear and/or respond to the praise only occasionally. A nurse talked about how she gave praise to one of the study mothers:

> *I don't think she takes it in. I think she hears me but I don't think she takes it on board and she is always sort of, "Oh, well, yeah, I'm only doing what I'm meant to do." And I think instinctively…she wants to do the best for her child and she's not seeing that she's doing anything extra, but her way of reacting to it shows me that she's not necessarily listening to everything that I'm saying, especially when I'm praising her. (Nurse_3)*

It appeared that, as a result of the ambivalent status of the skills being learnt, in combination with other factors (e.g. self-esteem), it was difficult for some parents to accept praise.

4.4.5 Summary of Phase II:

Building on the explanatory model from Phase I, in Phase II we developed, explored and discussed the components of the explanatory MDT-Parent Teaching and Learning Model. Through presenting and discussing data gathered from observations of parents and professionals in 'teaching and learning action' and interviews with parents and professionals, we have started specifying the 'active ingredient' of the complex intervention 'parent-teaching in CKD management' Key components of this 'active ingredient' relate to: the way professionals facilitate parents' clinical roles; parents' cautious acceptance of clinical responsibilities; blended expertise around the child; and ambivalence around teaching and learning encounters within the mutually dependent, child-focussed clinical domain.

This section has explored the data by trying to shift the discussion from participants' descriptive accounts and RN's observations (i.e. what?), to an interpretative analysis and explanatory accounts (i.e. why?) (as described in Figure 3). In so doing we have attempted to uncover the meanings that appeared to be present behind the issues in participants' accounts and what the researcher observed in the child focussed clinical domain. As discussed above, ambivalence around four dimensions was evident in our analysis, and as illustrated by the model in Figure 7, this both links to and overlaps with the other categories. The presentation and discussion of findings across the four categories in the MDT-Parent Teaching and Learning Model demonstrates the complexity of interactions between parents and the MDT when parents are learning to become home-based clinical care-givers for their child's CKD. Supplementary data from Phase II are presented in Appendix 30.

5 Discussion

5.1 Links with policy and guidance

At conception of this study national policy and guidance [12][24] acknowledged the essential role that parents of children with long term kidney conditions play in condition management as:*…they perform the vast majority of care-giving, including tasks that are complex and demanding*[12:13]. With a wider goal of developing a framework of support and psychological services for adults and children with kidney disease, the National Renal Workforce Planning Group also acknowledged the significance of the MDT-parent relationship:

> *The diagnosis of a chronic renal illness…impacts on every aspect of a child or young person's life. Like throwing a stone into water, the ripples created by this diagnosis spread out to include parents and carers, siblings, extended family, educational and social networks. An assumed future based on the child's past social, emotional and intellectual development is challenged and replaced with one of uncertainty about everything, a psychological state recognised as potentially leading to stress and anxiety. In this sea of uncertainty the paediatric renal team becomes a focus for the child and family to seek specialist support, advice and guidance in relation to emotional, social and educational issues in addition to the medical care on which the child's well-being is dependent*[24: 54]

In the wider health care context there is growing emphasis on the importance of self management for those living with long term conditions, and initiatives such as the UK Expert Patient Programme are internationally recognised as ways of supporting individuals' self management. However, despite the potential benefits of enhanced self-management, several possible problems are associated with such initiatives. Some authors claim they tend to overstate the evidence for the effectiveness of lay-led self-management programmes, while the varied experiences of those living with a chronic illness mitigates against a 'one model for all'; approach[67][68][69]. A recent study of information provision for children with long term conditions (not including kidney conditions) highlighted the current ideological drivers in policy as being: expert patient, child and family-centred care, information and informed choice, collaborative decision-making, partnership, building resilience and self-reliance, bringing care nearer to home, and children's rights.[70][71]. Moreover, a study [72] of self care support for children with long term conditions (not kidney conditions) suggests that health professionals need the values, attitudes, knowledge and skills necessary to support self-care; the authors do not define these but suggest that a core set of principles for self-care support that was developed for adult care is transferrable to child health so should be an integral part of professional education programmes and practice[73].

Although there is considerable anecdotal evidence of: the ways professionals provide specialist support, advice and guidance; the ways parents learn to manage their child's condition management, take on the clinical role and share their developing clinical knowledge with the growing child and other informal carers; or the types and formats of information provision that parents prefer, there is little empirical evidence of these complex phenomenon as they naturally occur. The existing evidence base is largely based on retrospective accounts and evaluations, thus being reliant on respondents' recall of events

which may be less accurate, reliable and insightful than longitudinal and prospective, observational research.

The purpose of the Teaching Parents Study, therefore, was to begin addressing these concerns by obtaining a detailed, evidence-based understanding of the ways MDTs teach fathers, mothers and carers and the way parents learn to deliver home-based clinical care for children's CKD, by observing live interactions between parents and professionals. In the following discussion we first present a critique of the study, and then locate the findings in the context of the current literature to demonstrate the unique contribution the study makes to knowledge.

5.2 Study design and methods used

The study used a mixed methods approach involving two discrete phases. However, analysis of each phase involved an iterative process whereby Phase I findings informed the selection of units for focussed study and the structure of observations and interviews in Phase II. This mixed-methods approach allowed us to maximise the scope of the study. We used a combination of survey, retrospective qualitative accounts from MDTs, prospective observations of MDT/parent interactions and their qualitative accounts of selected observed events. In previous sections we have presented and discussed findings from the two phases of this study. These phases formed a progressive focussing on the study aims.

The study has contributed to the evidence base on the way MDT members teach parents of children with CKD, and the way parents learn to become home based care givers. The study's primary contribution was in shifting the focus away from that reported in the literature that investigated parents' management of a range of conditions, including sometimes kidney conditions [17 23 74], the work associated with managing chronic illness [9 18 75], information needs [76 77] and parents' roles [2 20 78 79]; notably these studies looked broadly and usually retrospectively at parents' management activity. Consequently, the current study is the first research which elicits data, fosters longitudinal and focussed insights, and reports on the actual parent-professional experience of sharing knowledge and skills around the clinical management of childhood CKD. These insights are generally not as accessible through other research approaches such as those reported in the literature (e.g. quantitative methods or qualitative accounts that are retrospective).

5.2.1.1 Underlying premise for observational research

By using an observational approach to follow teaching and learning experiences over six months for each case study, Phase II has contributed to a significant gap in knowledge related to parent education. Additionally, we were able to begin redressing some of the limitations of other qualitative and quantitative studies that have investigated shared care giving in long term childhood condition management. As previously stated, most existing evidence is derived from studies that used questionnaires or individual interviews and focus groups where participants were asked to recall their experiences of care giving. Only a few of the studies focussed on CKD management[2 15 75]. Furthermore, previous studies mostly drew on data collected from parents whose care-giving practices were already well established, and who had consequently developed their own unique management styles[19 22 23]. There is little evidence of prospective observational research that captures parents' and professionals' experiences when parents are learning new clinical skills and knowledge.

Semi structured, individual or group qualitative interviews are often 'one off' events that can be perceived as socially awkward or intrusive because they can exacerbate the power differential between participants and researchers. Observational research methods, however, aim to create symmetrical relationships between researchers and participants and can be more 'status levelling' than other methods because they:

- Are flexible
- Allow time for relationships to develop between the research participants (e.g. parents and MDT members) and the intervening researcher
- Can be less intrusive
- Draw on multiple data sources
- Incorporate a relational context [54] [55] [80]

Previous ethnographic studies vividly demonstrate the insights that observational techniques can engender, and confirm the conclusion that they may be better suited than other methods to examining complex interventions in acute and long term child health care contexts[81] [82].

Two recent studies used observational methods to explore the experiences of children with renal conditions [83] [84]. Both studies present important new information about children's experiences that were accessible only through ethnographic research. The first study presents a 'renal bubble' of children's experiences, and their views on the physical and social impact of treatment. Compliance/non-compliance rendered children's embodied experience and their labour in managing dialysis, thirst and difficulties with tablet taking as highly relevant. In the second study, young people reported hospital staff as being caring and professional; their biggest virtue being willingness to treat the young people as 'normal'.

However, ethnographic studies that focus on parents' experiences are historically under utilised in child health settings, in particular with research that seeks to understand actual interactions between professionals and parents as they begin to share clinical management; this may be due to ethical concerns about the circumstances needed for obtaining informed consent and safeguarding privacy[80], or gate keeping concerns. These concerns are understandable, however, with careful consideration, discussion with stakeholders, and approvals from the UK National Research Ethics Service (NRES) and NHS Trust R&D Departments, reassurances can be offered about the rigour of observational studies such as ours. Through following the processes outlined in the NRES Research Governance Framework for Health and Social Care[85] we can demonstrate how throughout the study we observed good ethical practice by:

- Protecting the rights, safety, dignity and well-being of research participants and;
- Facilitating and promoting ethical research that is of potential benefit to participants, science and society.

In observational studies the researcher participates in, observes and records naturally occurring sociocultural activities; as described in Appendix 20, RN recorded extensive field

notes on her observations and insights as they related to the study aims. Thus, as a participant observer she had two overlapping roles: as the main instrument for data gathering, and an ongoing analytic role based on her experiential relationship with the data and evolving understanding of the research context[80]. By appointing a researcher who is a Paediatric Occupational Therapist with no prior experience of working with children with CKD, we were assured that although she was familiar with child health care settings at the start of our study and therefore, could adapt quite quickly to the research setting, as she is not a member of one of the disciplines represented in the renal MDTs there was unlikely to be any conflict of interest.

We adhered to the design approved by NRES and regularly reflected upon the implications of our observational research approach in an acute paediatric setting. Additionally, we adhered to MRC guidance [86] that observation in a natural environment which does not allow the identification of participants/non-participants implies minimal risk. Therefore, we have ensured that our reporting processes protect the identity of individual participants.

5.3 Conceptual framework

We developed a conceptual framework that draws on a range of relevant theories, and the MRC frameworks for developing and evaluating complex interventions; 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 [37]. According to the MRC criteria[35][36], parent-education is a complex intervention. Building as it does on earlier work the current study forms part of the modelling phase of developing and evaluating a complex intervention to assess parents' learning needs and preferences. The theoretical basis for the study [5][15][18][20][35][36] combined with our data from parents and professional, forms part of a phased approach to development/evaluation of the complex intervention. We have not found any other studies that used such a conceptual and methodological framework to better understand parent-professional experiences, needs and preferences for teaching and learning in CKD care.

5.4 Comparison with the literature

In this section, building upon the discussion in the data presentation sections we will consider whether we have fulfilled our study aims. In section 3.3.6 we considered the extent to which we addressed the first two study objectives. In this section we consider the third objective:

- to obtain a detailed understanding of the way MDTs teach parents and carers to become home-based clinical care-givers, and the way parents learn to care for children's long term kidney conditions.

Therefore, our discussion here concerns four main areas. The first relates to the way parents' clinical roles are facilitated; the second relates to the way parents cautiously accept clinical responsibilities for their child; the third considers the issue of blended expertise around the child, and the final area of discussion considers the ambivalence that was noted in teaching and learning encounters. Finally we identify key recommendations for the funders and other stakeholders.

5.4.1 Facilitation of parents' clinical roles

Our data demonstrate that professionals use a number of strategies to raise parents' awareness of the high stakes that can be associated with renal conditions. Professionals used both inter- and intra-disciplinary knowledge to: check parents' understanding; assess their need for support; and design a frequently changing 'curriculum' for each parent. This finding was signalled in the Phase I survey and qualitative data, and restated in observational and interview data in Phase II.

Parents for their part, need to develop a good understanding of aspects of the distributed expertise within the MDT in order that they themselves could safely take on the many components of their clinical role. In order to return to 'normal' family life parents need considerable preparation from professionals. This preparation is supported by a range of educational media; contingency planning is an essential part of this so that parents are equipped to deal with the unexpected as well as the expected. In acquiring these skills and knowledge parents become increasingly aware of the potentially 'high stakes' linked to their child's clinical care.

Although limited data exist to inform MDTs about the most effective ways to educate parents on how to care for their child's medical condition at home, a small body of evidence is emerging about a positive relationship between MDT support and clinical outcomes [25][64]. Moreover, previous research that investigated developing interagency responses to the problem of social exclusion for vulnerable children, does indicate that long-term sustained and supported meetings of practitioners from different professions (such as the MDT meetings and clinics described by professionals in this study) established to build trust and to talk about cases, did help to build local networks of responsive support for children [59]. Our study provides further support for this as illustrated by the network of responsive renal support in Britain.

Previous psychosocial studies in chronic disease management have mostly focussed on parent support provided by nursing and medicine, with little evidence of the contribution from other disciplines. We found one recent study that did explore best practice in multi-agency working and the experiences of families of children with complex health needs and this involved several disciplines[87]. However we believe that the Teaching Parents study is the first research to focus on the way entire MDTs facilitate parents' clinical role development using a combination of a pan-Britain study followed by a more focussed approach. Therefore, our research extends the data in this under researched area, but more detailed research is needed that investigates the individual contribution each discipline makes, the wider impact of renal MDT support on parents' clinical role development and a time line to help illustrate this
.

While there is ample research evidence of the way professionals and parents interact around a child's long term condition [16][23][88][89], and some evidence that adds a multidisciplinary and multi agency focus on what works well in managing complex childhood conditions, there is little research evidence of the way professionals in MDTs teach parents to manage. Our study builds on the existing literature by exploring and describing the accounts of health professionals in paediatric renal-MDTS, and suggests a more complex picture of parent education and support than reported in the literature. Although the parent educative

functions identified in our study pertain specifically to management of childhood CKD, some aspects of these functions may be relevant to the management of other long-term conditions; therefore, some of our findings may be transferrable to and have wider implications in other child-health settings.

5.4.2 **Parents cautiously accepting clinical responsibilities**

Parents in our study cautiously accepted clinical responsibility, although more out necessity than choice. As is usual in observational research, the Phase II sample was small so we do not claim that it is representative of the renal population of parents. However, no study parents indicated that they expected to be consulted on whether or not they would take on the clinical role; typically they regarded it as part of usual parenting. A recent literature review recommends that for family-centred care to be a reality: professionals need to negotiate with families effectively; parents need to be able to negotiate with staff on what their participation will involve, and parents should be involved in decision-making[90]. However, numerous studies have shown that significant procedural errors are often made by parents when carrying out complex treatment regimens[91], and compliance with treatment regimens is poor [74 92]. We did not seek to identify errors or evaluate compliance but it may be that an individually tailored approach to shared care-giving such as that which MDTs tried to promote in these six case studies has the potential to reduce errors and enhance compliance.

During the case studies parents often talked vividly about their concerns before and after they returned home after being trained in their clinical responsibilities; these related to practical, emotional and financial concerns. Transitions from hospital to home care for families of children with long term conditions have consistently been found to be periods of intense worry and confusion for family members[17 93]. However, no studies are known to have evaluated the financial and emotional costs for parents sharing CKD management with specialist centres that may be a considerable distance from the home, so further study is needed in this area. The transition from hospital to home is demanding for families having to cope with new clinical responsibilities and [94 95] no matter how good new treatments for CKD are they are not going to produce optimum outcomes if parents and/or children are unable or unwilling to maintain treatment regimens. Although a small body of literature is emerging that focuses on measuring parent-child shared management of chronic conditions [16], children with kidney conditions were not represented, data collection was limited to an un-validated, postal questionnaire and the data did not explore parent-professional interactions as our study has done, thereby suggesting a need for a large mixed methods study to measure shared parent-child management in CKD care.

Our contribution to evidence in this area extends beyond the work reported above and whilst we echo the recommendation of these authors, our detailed work highlights the way parents for the most part appreciated professionals' considerable efforts to teach them at a pace and using an approach that was targeted to their needs and preferences, and valued professionals' attempts to negotiate a manageable plan with them in order to promote safe care giving. However, professionals frequently talked about the challenge of individualising parent teaching. Our research highlights the need and provides a basis for further

collaborative study drawing on the current data set, to develop and evaluate a standardised, multidisciplinary, parent learning-needs-assessment tool that could help promote a an evidence-based, individually tailored approach to parent education in CKD management

5.4.3   Blended expertise around the child

Two distinct dimensions of parental expertise around their child (personal and clinical) were evident in the data; personal expertise was often acknowledged at the outset by professionals who attempted to integrate this into the developing care plan, they then worked hard to promote parents' clinical expertise. Parents appreciated professionals' recognition of their personal and clinical expertise and sometimes used strategies such as 'modelling' to try to replicate the clinical expertise that professionals demonstrated. Our evidence contradicts the long standing and growing body of literature claiming that there is a lack of collaboration between parents and professionals, that parents' expertise is not valued by professionals and that parent-professional relationships are characterised by tension and conflict[79 96 97-99]. In a previous qualitative study involving mothers in a children's kidney unit, the formation of satisfactory alliances with professionals based on mutual respect and good communication early in the trajectory was instrumental in mothers' coping and competence development during the later chronic phase of the trajectory[19]. Further research was recommended to map prospectively the evolution of relationships between mothers and staff across the trajectory. The current study has begun to address this recommendation.

Where tensions were evident in our data this was usually within families or within the MDT, but not between professionals and parents. This finding may be an anomaly of the situation surrounding children with CKD, for instance it may relate to the way in which the responsive network of MDTs in Britain has evolved; or it may be the design of our study that enabled a unique and detailed analysis of the parent teaching and learning context in two children's kidney units. It is also possible that the presence of the researcher altered the dynamics of interactions in some way, or that our participants' responses are an anomaly of the sample. The small sample in Phase II may not represent all the phenomena that affect parents who use health services. Additionally, the findings may differ from other reported findings because previous studies relied solely on respondents' retrospective accounts whilst our approach was prospective. Moreover, the research questions posed in previous studies may have focussed in particular on participants' difficulties and negative experiences.

5.4.4   Ambivalence in teaching and learning encounters

The difference between hospital and home care raised interesting challenges for parents and professionals as they negotiated clinical roles and responsibilities. Moving care closer to home for ill children has become an ideal in recent years and the international evidence on the effectiveness and costs of paediatric home care for children was recently reviewed. Home care may reduce costs for children, in particular those with complex and long term needs[100 101], however children with kidney conditions were under-represented in the review so the findings need to be considered with caution. A recent report from the Royal College of Paediatrics and Child Health (RCPCH) presents guidance on the way structured, formalised networks of care provision for children with renal problems can provide a co-ordinated, high

quality pathway of care, providing as much treatment as possible close to home whilst ensuring the best possible outcome for the child:

> *The care of children with renal disease is not confined to the tertiary centre and many children live long distances from their tertiary centre and have care delivered by local services. Currently there is often fragmentation of, and a lack of expertise in, providing care which compromises patient safety and provision of a high quality service*[102:2]

Our data concur with this statement as parents and professionals alike provided vivid accounts in Phase II of experiences of inconsistency between the specialist support and advice provided by renal MDTs and that provided by local services. Parents account powerfully illustrate their concerns about the negative effect this fragmentation of and lack of expertise can have on their child, indeed one mother (Section 4.3.2.1) within the dimension of 'ideal vs reality' refused to use her local health care provider having encountered a lack of renal expertise which she believed would compromise her child's safety.

Government policies and published research have consistently advocated home-based care for children with long-term conditions as a way of optimising their physical, emotional and social development [1 10 12 103]. Furthermore, our data confirm the RCPCH recommendations for close collaboration within and between multiprofessional renal teams[101]. However, our data also indicate some ambivalence around care giving being carried out differently in clinical settings and families' homes; this was reported by both parents' and professionals and is thought to have an impact on teaching and learning. It may be that a Case Management approach could be considered such as that reported elsewhere[104]; dedicated personnel would liaise with families, MDTs and local care providers to assess families' home situations with regard to adapting treatment regimes so they remain safe and effective, but are achievable and realistic [104]. If this suggestion has potential it may first warrant further investigation to consider whether it is feasible in the UK health care context.

There was evidence in our data of blended expertise around the child, although at times there was some uncertainty around what the expertise was and who was the expert. This supports findings of an earlier exploratory study in which parents of children with CKD appeared to adopt the identity of 'students' as well as parents, and some nurses adopted the identity of family learning brokers[5 7]. Our current data confirm that other professionals (in particular clinical psychologists, play workers, social workers and therapists as well as nurses) functioned as brokers between colleagues and parents.

Ambivalence around clinical management also emerged from parent and professional data. An overlap of roles was identified within renal MDTs but there is little evidence of this in the management of other childhood conditions. These findings may have implications for under-graduate education and continuing professional development for all health professionals. The preparation of new health professionals is predominantly uni-disciplinary, although there are some attempts to incorporate interdisciplinary working into the curriculum. Unfortunately, the dearth of actual data describing both the distinctiveness of each discipline and the potential overlap between disciplinary roles in clinical practice is a limitation in developing an

interdisciplinary focus in curricula. However, anonymised data from the current study have potential value for use as 'teaching vignettes' for guided, scenario based discussions with students of the disciplines represented in the study.

5.5   Strengths and limitations of the study

5.5.1   Strengths

- We believe this is the first study to have used a longitudinal, mixed methods design to explore 'live' communications between MDTs and parents ; the study has started defining the vital ingredients of the complex intervention of parent teaching and learning in renal care
- The results obtained within the national network of children's kidney units can serve as an important exemplar to inform colleagues supporting children with other long-term conditions and their parents; some of our results may therefore, be transferable to other clinical contexts where parents undertake similarly complex, home-based clinical care of other childhood conditions (e.g. cancer or cystic fibrosis services).
- Researchers and clinicians are reported to be working in isolation from each other and this may be compromising coordinated attempts to develop a knowledge base however, a strength of this study is that it was conducted by clinical and research staff in collaboration with parents[105]

5.5.2   Limitations

- In keeping with mixed-methods' traditions and because of the small sample size and the condition-specific focus of the study, the findings are viewed as a 'snapshot' of the situation so will not be generalisable to other clinical specialities.
- The focus of this study is on parents' learning although we do recognise that:
    o Parents and older children may share knowledge about condition management;
    o Some children may also help their parents to understand complex aspects of treatments or may translate for them if parents' first language is not English. Nevertheless, parents are the primary care-givers and for pragmatic reasons they have been selected as the primary focus for this study in order to generate knowledge about the context in which professionals teach parents.
    o Further research is needed to explore the experiences of parents for whom English is not a first language and children and young people living with CKD
- One of the later centres recruited to Phase I, strand ii, requested that the Receptionist who playsan important part in the renal team and worked closely with families, take part in the focus group. The receptionist provided very valuable data but other centres had not suggested this when focus groups were conducted, for consistency of reporting we therefore, decided to omit the receptionst's data from the reporting. However, in future studies involving MDTs we would discuss with local PIs the potential for including receptionists or other key personnel who they thought this was relevent
- In line with qualitative guidelines, Phase II interview participants were invited to read and comment on the transcript of their interviews, some made slight amendments to

these after reflecting on what they had said. However, this was before we commenced data analysis so it is unlikely that it has affected our output. .

5.6   Implications and recommendations

5.6.1   Implications for practice and professional education

The British network of renal MDTs aims to develop supportive partnerships with parents in order to promote their effective clinical care-giving and facilitate children's optimum condition management They do this through a combination of sharing specialist skills and knowledge with parents, initiating and delivering training, and often visiting homes/schools to offer ongoing support and monitor the child's condition [5] [15] [106]. To our knowledge, this is the first project to study the way MDTs teach parents to deliver home-based clinical care for their children in the children's kidney units in England, Scotland and Wales. The outcome of this study is a detailed, in-depth analysis of professionals' parent-teaching strategies. This provides a description of the cases investigated and two explanatory models that may inform practice and professionals' educational preparation These outcomes will inform a phased approach to developing and evaluating an intervention that meets parents' learning needs.

These insights will provide new evidence to inform professionals' parent-educative roles. The study provides a new understanding of MDT members' contributions to parents' learning in CKD management[24].   The project worked with all children's kidney units in England, Scotland and Wales and will make the findings widely available to these units through a summary leaflet and meetings with MDT members.. The findings have the potential to be useful for future parent-teaching interventions and to inform the promotion of parents' competence. In addition, the outcomes will be made widely available to colleagues who educate health professionals. Our dissemination includes a funder's report, conference and meeting presentations, papers in peer-reviewed journals and materials for distribution through parent networks such as the UK fatherhood Institute (with whom we already have established links in the form of a web page on the research area of their web sitehttp://www.fatherhoodinstitute.org/2011/fathers-contribution-to-the-management-of-their-childrens-chronic-disease/   and Mums Net. http://www.mumsnet.com/

5.6.2   Implications for research

This study is part of a phased approach to developing and evaluating a complex intervention that helps MDTs identify parents' learning needs and individualise teaching interventions. We will seek future funding so that in the next phase of development a multi-disciplinary parent-teaching questionnaire can be developed from the data presented in this report in collaboration with parents and MDT members from the 12 children's kidney units. Subsequently this will be subjected to feasibility testing and piloting[107] prior to evaluation through a randomised controlled trial, as indicated in guidance provided by the Medical Research Council on the development and evaluation of complex interventions.

Additional future research should produce concrete recommendations for developing a child and young person friendly questionnaire to help parents and professionals manage the transfer of responsinilities from parents to children as they mature and take increasing responsibility for managing their own kidney conditions.

The explanatory models produced from this study have potential for further theoretical application and development in the NIHR Research for Patent Benefit funded, Online Parent

Information and Support (OPIS) study in childhood CKD that is currently underway (Swallow et al 2012) [108]

5.7 Conclusions

This longitudinal study used mixed methods to investigate multi-disciplinary teams' parent-educative functions in the 12 children's kidney units in England, Scotland and Wales. The findings present a unique and detailed insight into the context in which professionals teach parents, and parents learn to share clinical responsibilities with professionals. This new insight will inform parent education, health professionals' educational curricula and health care policies. The conceptual framework underpinning the study has helped us understand the way teams construct solutions to the challenge of teaching parents, through discussion, while still retaining disciplinary knowledge and identity; the experiences of parents, and the different identities that parents and professionals adopt during shared care.

5.8 Recommendations

Professionals and parents have developed considerable expertise which ought to be harnessed and made available to support those who are new to children's renal care. If the following actions could happen, professionals would have an optimum, evidence based understanding of the way parents learn to manage childhood CKD, and parents would have access to evidence based material to assist their clinical roles, for example these could include:

- A sequence of exemplar case studies could be developed from the anonymised data presented in the report; these could help share the experiences of parents with professionals, and vice versa. These could potentially be made available as paper based and electronic media. Their purpose would be to support parents and professionals to develop a rounded understanding of the experience of living with CKD and its consequences (e.g. 'taking a dialysis machine home', using an NG tube to feed your child)
- A series of 'top teaching tips' and 'top learning tips' leaflets could be developed from the data for circulation to wards, clinics, parent web sites and possibly the KKR web site?. These could for example include 'typical medical language you might hear and what it means' or 'common turns of phrase [e.g. colloquialisms, metaphors, analogies] that are used in CKD management, and what they mean'
- A leaflet/web based resource explaining the range of 'distributed expertise' within the renal MDT, what the roles and titles mean for families
- Parents ought to be routinely sign-posted to the resources in 1-3 when available
- A range of UK workshops where professionals and family members could jointly generate educational material and action plans for tailoring support to parents. The materials could include: e.g. parents' experiences of the clinical role, symptom management, recognising when to seek help, how to seek help
- A national conference or series of seminars for local health care staff who might need to support management of a local child with CKD; the workshop could draw on our data and enable discussion with health care staff who are interested and able to be released from practice to attend

- Educational staff in higher education institutions who are responsible for developing curriculum for the professionals represented in our data could be provided with key findings from the study in order that the evidence can be fed into practice via new recruits
- Further research is needed that builds on the current study, working with families and MDT members to develop and evaluate a parent learning-needs assessment tool that could promote a more standardised, multidisciplinary approach to assessing parents' individual learning needs and preferences
- Further study is needed to assess the cost effectiveness of home vs hospital care and the cost to parents
- Although a small body of literature is emerging that focuses on measuring parent-child shared management of chronic conditions [16], children with kidney conditions were not represented, data collection was limited to an un-validated, postal questionnaire and the data did not explore parent-professional interactions as our study has done, thereby suggesting a need for a large mixed methods study to measure shared parent-child management in CKD care.
- More detailed research is needed that investigates the individual contribution each discipline makes, the wider impact of renal MDT support on parents' clinical role development, and a time line to help illustrate the processes by which MDT members teach and parents learn. .

1. Name of Children's Kidney Centre:

2. Where are renal transplants performed?

MDT team members - Unit Profile

3. Number of Consultants in Paediatric Nephrology   ?

- Details/ comments (NB: FOR ALL QUESTIONS)
- *Involved in teaching/ reinforcing?* (NB: FOR ALL QUESTIONS)

4. Number of Junior Doctors (i.e.: attached to Nephrology)?

5. Who performs renal surgery? (Transplants, PD catheter, central line insertion etc),

6. Number of Urology doctors part of the team

7. Number of Urology nurses part of the team

8. Number of Renal Specialist nurses

9. How is the nursing set up (between the ward and the dialysis unit)

i.e: Split or rotational

10. Number of trained Haemo dialysis nurses

11. Number of trained peritoneal dialysis nurses
12. Number of Nurses who work on Renal Ward

13. Number of Renal Ward Health Care Assistants?

14. Are there any renal paediatric nurses involved in OPD clinics?

15. Number of Dieticians

- **Are they Renal Dietician(s)**

16. Do you have a counsellor?
- **Are they a Renal Counsellor**

17. Do you have access to a Clinical Psychologist/Psychiatrist/CAMHS team?

- **Are they a Paediatric Psych**

18. Do you have a Pharmacist?
- **Are they Renal Pharmacist(s)**

19. Do you have any Playworkers?

- **Are they Renal Playworkers(s)**
20. Do you have a hospital based teacher/ teaching assistant *Involved in <u>Renal condition</u> teaching/ reinforcing?*

21. Do you have a Renal Nurse Educator?

22. Do you have a youth worker?

- **Are they a Renal youth worker**

23. Do you have a social worker?

- **Are they a Renal social worker**

24. Do you have any other staff members who are involved in patient/family teaching/ reinforcing?

25. How many families does your MDT support? (if feasible to answer/ approx)

26. Number of children on haemodialysis?

27. Number of children on peritoneal dialysis?

28. Number of children with transplants?

29. Number of children on tube feeds?

30. Number of children on Erythropoietin injections (EPO?

Discipline	Teaching only	Reinforcing only	Teaching & Reinforcing	No T 0r R
Paediatric. Nephrologist	0	25	39	0
Junior Doctors	0	12	28	7
Renal Specialist Nurses	0	0	48.2	0
Ward Nurses	0	36	284	0
HD Nurse	0	7	125	0
PD Nurse	0	25	220	0
HCA/CSW	6	5	11	17
Dietician	0	0	19	0
Counsellor/ Therapist	0	0	1	0
Clinical Psychologist	0	6.6	3	0
Pharmacist	1	2	5	3
Play Worker	1	0	15	0
Social Worker	1	3	3	2

Appendix 2: Number of staff across the 12 centres involved in teaching and reinforcing

Teaching parents study – information for focus group/individual interview participants

We want to hear your views/accounts of the following activities as they apply to your role when communicating with parents about any aspects of their child's care. *We are interested in informal or ad hoc as well as formal, subtle as well as obvious and relating to any aspect of your role that involves relaying your professional/personal knowledge and experience to parents*. Please spend a few minutes thinking about the following which may or may not shape your discussions (making notes on the sheet as personal prompts if you wish):

1. **Assessing learning needs**

2. **Creating learning opportunities**

3. **Implementing teaching strategies**

4. **Acting as interpreters and/or brokers**

5. **Assessing learning progress**

Appendix 4:Supplementary data Phase I - Initiating parents' knowledge and skill development

*Discipline	Establishing parents' condition-related knowledge and position on 'renal journey'	Determining parents' learning potential	Prioritising skills/knowledge to teach	Defining/meeting individual learning need
CP	Telling them I… having an illness is hard work, difficult & quite challenging so I'm here to add a bit extra if they'd like it - as part of the team, let them know I'd be involved with most families at some point .. normalise it		I have a model which is the child in the middle, the family, the team and the wider culture…we have life going on here and we've got history here and impact of disease here…	Might say to them 'Well how are you finding out things…are we looking after you ok..you know, are you someone who likes to know everything in a big heap?'
Dr	You realise drip feeding [information] is all you can do because the environment isn't great. need formal times, where you can create a better environment, on specific things which have objectives and backed up by informal meeting, You often see [colleagues] walk past [parents] on the ward when they're going to see someone else and there's been a sort of, reaction there [from the parents] where they've [colleague] been able to reinforce things	If a child's unwell you are not always able to have an interpreter present when you need one and that can be a problem Probably our biggest challenge is getting them [parents/children] to understand and do things, particularly in chronic conditions they're going to live with for 50 years, they really do need to know	Where there are problems with comprehension or communication, then what you do is strip out things you think are essential to the child's immediate care and try and get those done first… think later about other things, e.g. we have patients on dialysis who the nightmare might be teaching them dialysis, and you think ' teaching them to take BP will wait', even though that's a basic part of the whole process	It might just be one thing which I think is important to make the point that "it's not quite that, it's actually this" and then leave everything else which wasn't quite correct…especially if it's a chronic patient who going to be ?with us for a long time there's going to be plenty of opportunity …
Dtn	..easy to fall into trap of assuming people understand things..they want to give good impression of following everything but [maybe] haven't quite grasped things. Got to create a bit of a rapport with them	Assess how much information they are taking in. As part of the assessment] I've had a meeting with two school nurses, a community nurse, cook and a class teacher		…attempt to slow things down and make things as simple as possible
PW	…building a relationship, you're not going to get anywhere until that's happened	…might use dolls, art and craft, or just talk, drawing, whatever way of learning going to be best for them		have an agreement with parents, ' is it ok if we go to another area to discuss things [with child]?' and most are more than happy with that. Some parents might want to know what you're going to say..and we can let them know, we can discuss this …
Ph	…sometimes people come in with preconceived ideas like their auntie's on steroids for something, or granny takes aspirin	When I'm going over medicines I'm like 'you're not taking in a word I'm saying,' I can understand it because they don't have to go out that room and use that information, but the whole point about it is for them to even have it explained initially, because what I tend to do is go over it once, then again, then I say I won't speak to you again until discharge, then it will	I think it depends on how long you've got with the parent …	…in the pharmacy where you've maybe tagged on to the end of something else to explain about drugs and presume that they understand because it's what we've told everybody else and they've kind of got on with it.

*Discipline	Establishing parents' condition-related knowledge and position on 'renal journey'	Determining parents' learning potential	Prioritising skills/knowledge to teach	Defining/meeting individual learning need
		mean something to you for real, because you'll be used to them on the ward		
SW	I'd do home visits and then you get quite a different or perhaps more accurate picture of what people are like…it's good for them because they don't feel like they're burdening us (SW) too much ……give people confidence to feel it's ok to ask whatever questions they want to ask and to also not to know necessarily.	There's a lot of texting [with parents] and actually that's quite good because..organise Disability Living Allowance for families. It's actually a very good way of getting to know families… take a little time to find out whether people don't seem to be responding because they might be in shock or ..	Because there might be some sort of learning difficulty, so that's not easy to, sort of, establish first of all, it can take a little bit of time.	We're led by them, if we can we don't rush things It's even more sometimes than just knowledge, they might not feel that they're able to take on tasks that we feel would be in the child's best interests, e.g. dialysis, some parents are really resistant to taking what they see as medical treatments into their own home
T	…actually trying to experiment with the parents with different ways of telling their story that will get people to hear it, because they are trying to find their way through the system	.. they know the information they have been given but actually they really feel it is so unfair and it shouldn't be true…sometimes just saying that [to parents] is a relief because it gets them a bit acknowledging how bloody awful it is and that is it and they have to deal with it,	You can see a parents' behaviour affecting the child's behaviour and then you can adjust the parent's, if they are being too pressuring to get their child to do something and if you get them to back off a bit and give a bit more responsibility to the child,	

*Key for appendices 4,5 & 6: CP=Clinical Psychologist; Dr=Consultant Paediatric Nephrologist or Registrar; Dtn=Dietician; N= Nurse Consultant, Advanced Nurse Practitioner, Clinical Nurse Specialist, Sister, Staff Nurse; PW=Play Worker or Play Specialist; Ph=Pharmacist; SW=Social worker; T=Family Therapist or Therapist.

Appendix 5:Supplementary data Phase I - Promoting and monitoring Parents' knowledge and skill development

Discipline	Teaching in stages	Using metaphors/tools	Assessing understanding	Reviewing learning progress
CP	We talk to parents about letting the child start to organise their own medicines with supervision, telling them how we expect their role to develop. We do get some resistance, they've been in control for a long time, it's very hard to let go of the reins		…one of the ways of [assessing parents' understanding] is one of us or various people in the team will go and ask the parents, "How do you take on information? How would you like us to give it to you?	OK so what did they [Dr] say, what was it like for you, how could it have been different?
Dr	Looking at the complexity of it [information] and whether it can all be done [taught] in one go or if it needs to be given in 'chapters' We tend to do everything in little bite sized chunks really	…Nutritional Care did a series of photographs and showed them, and then had to show them pictures of what the numbers looked like because they said, "You can't count but the numbers should look like that. If you keep pressing until you get one that looks like that". So they have a sort of a like a strip of pictures. And they were just told, "This is what it's got to look like".	…don't think we take any formal assessments of families …I start talking about whatever we need to, start with …we pick up the clues and verbal feedback that we're … it's not until they're seen again when they have an opportunity to see another member of the team that you realise how much they're taking in .. frequently, you meet with both parents and that does help me to pitch…,	I say, well you might see somebody else, you'll go and see Dr A and you may suddenly think, aha, now I know what Dr B was talking about!
Dtn	We'll just go through the major hits…'okay, this, this and this, these are the things you have to avoid tonight and tomorrow, then we'll send the rest of the information by post	…you talk about what they're eating and any specific changes they have to make and then I give them the leaflet so they can read it when they get home.		…because doctors are always asking, do they understand what the medications are for all the time I guess, we do that informally all the time as part of our routine reviews that we do with them.
N	When we do our teaching 'sessions', we try and stage them over a couple of weeks so people have time for one thing to go in before you layer on another ,say right where did we get to last time? This is what we're going to be saying this time, before you say it again and at the end	…so when she goes to the local hospital now she can give that [an 'All about me book']to them and say right, read this, I'm going to go away for ten minutes and come back and then we can start again. To give parents the information we use some tools we give to the children	…important whenever you start something you go back and check, say a family had a diagnosis or treatment in clinic, quite big news and it's going to have an impact in their family life, they are going to take on care at home, where possible I'd try and go and see them at home with the SW.. pick out what was mentioned in clinic, because you find people hear one bit of news and that's it...	It's trial and error really… it's not something I consider I've been taught how to teach [parents]. Not only the ability for people to take on information, some parents do have some learning needs of their own and perhaps, as {colleague in focus group] was saying, perhaps they don't understand all the jargon and the complexities of some things, so things need to be simplified from a cognitive perspective as well. But it [talk back] works very well with the parents

Discipline	Teaching in stages	Using metaphors/tools	Assessing understanding	Reviewing learning progress
PW	had a parent saying their child has never had a blood test, didn't know what to expect, so I sat down with the child [and parents] and just went step by step. In the ward round it'll be planned when they're going home, who's going to go through things with them,	I've got my book of pictures and my dolls…parents get quite interested in them. but sometimes you take then & you're just talking to the adults…when doing transplant perhaps, about what's going to happen… everything needs to be simplified .. you think you're doing that, but we're so used to living in the hospital world..		Once you've taught the parent who couldn't read and he had a good memory so we just made sure in clinic that we always stressed, verbally, you know, and he would repeat back to us what he needed to do and also we can demonstrate on syringes how much medication we've got to give and things like that.
Ph	Depends on how long you've got with the parent, if you've got a set amount of time and you've got some info to get over to them	So you feel you're actually giving them some form of information [renal medicines book] , and a lot of times they get to know them very well therefore don't need to use the book as much, but at the beginning we find it very helpful,		
SW	…check where they feel they're at, gauging all the time where we've got them to, where we want to get them to, we might want to bring them to a level of knowledge they're not ready for, if not ready to do injections, gastric tube you might get a comm.. nurse to do it, try to find solutions rather than force them to take on tasks they're not ready to learn		One of the key things … maybe for parents that have been in the system a bit longer, is the need to recognise how expert a parent often is in their child's own care. And therefore to kind of hear the parent's perspective and where they're up to rather than just telling them what they should be doing next.	
T	Often try to move the conversation to somewhere where the parents maybe feel more competent			

	Role allocation/differentiation	Interpretation	Acting as brokers	Sharing information within the MDT
CP	when I first meet people will say 'So what's going on for you…that gets them saying what they've taken in, because I'll know probably what they've been told and a lot of what they need to know..will also give me an understanding of ok they haven't taken that bit on board or haven't understood…I'll go back to the team who will know and say 'this is what they think is happening, is that right?			Or I might not know what they've understood but I'll go back to the rest of the team who will know and say, "This is what they think is happening, is that right?"
Dr	for some things we have a check list, like, when they're going on to dialysis, that they will have to go through but, you'll be going backwards and forwards on that check list and going through things over and over. Some things are still a bit of ad hoc, but there is a list that we have in our minds that we want to make sure that parents are competent in all aspects and that actually…not just the medical condition that they're supported for but also the psychological and the whole patient	The tariff that you get for episodes of health care, you don't get a different amount of money if you're dealing with a family where they don't speak English. So it's…yeah, it can be quite difficult . Family members as interpreters... good and bad... some really positive things in it... but... sometimes they get very embroiled in the whole thing and don't have that degree of objectivity that you'd like to have in an interpreter... They're often trying to protect or to help them…	We provide a big structure of psycho social support..it really is a presence of a team. She [nurse] might get help from [name], her colleague, and she might get help from other people on the ward, other nurses on the ward, or from the pharmacist or a dietician, you know, they certainly do it as a team. The dialysis, this is a lot less about parents themselves providing the training, it tends to be, you know, more an explanation by the doctors and then, the nurses	We are very like minded in that respect. not having a full compliment in a MDT that's had a huge impact on how that team works and it does have an impact on the patients as well. So actually having the full complement makes a huge difference, it just functions much better and parents find it easier having everyone to contact. So the great thing about our team, I think, is, that we do all talk to each other, there's not this hierarchy and we all value each other's opinions and we do listen to each other.
Dtn	worked as a team, it took a long time, because when you set the boundaries, you know, we back them up and we got there eventually, some things are still a work in progress but… from my perspective parents may lose out on the ad hoc conversations. But I have a more in depth conversation when I do see them, so I think it may even out over time.	We need interpreters, we've got quite a lot of multi-cultural families ...lose the casual corridor chat	I hear what the Drs are saying and the Drs hear what I'm saying We're a close knit team	We worked at as a team, we got there, it took a long time, you know, but it was, you know, it was setting the boundaries because when you set the boundaries, you know, we back them up and we got there eventually, some things are still a work in progress.

113

	Role allocation/differentiation	Interpretation	Acting as brokers	Sharing information within the MDT
N	nurses have a very definite role to teach people how to do things, the higher end scale who are going to have a lot more clinical input we would definitely go in as two people, because I don't think as a nurse you have necessarily got the skills to think about [all the MDT members' contributions], we will encourage them to meet all the team as they go through, so everyone will get offered if they want a psychologist, it might be a one off visit with the psychologist, but we will introduce them to the social worker,	…not always best to use the family [to interpret] as they might not understand what you're saying anyhow…do actually get interpreters in,… so it's easier for us to pick up the teaching they need ,or they may have a piece of information that you're not aware of before you start teaching so, yeah, that's a real benefit. We have in house interpreters not only will they interpret exactly what you've said, but they'll tell you everything that the parents have said,	Sometimes [if a psychologist is mentioned]. people are wary maybe that they are going to tap into emotions that they don't want to express. Social workers less so…sometimes you have to explain the role of SW here. People have a vision of them from child protection but we have explained the supporting role. I think sometimes the SW is on the back of support, disability, around financial support, our social worker sorts that out, builds up very good therapeutic relationship with a lot of families.	Consultants are very good about not being pressurised into discharging someone sooner than what we would want really. We would never send someone home on a Friday on dialysis for first time Some teenage mums… have done fantastic, much better than some of the, you know, two point two, , children and parent families that you think are going to get to grips with it and just fall apart whereas somebody, you know, the teenage mums have coped amazingly so … each of us will pick up something different from the same consultation
PW	Its more about what we [play workers] can do separately, have got community play specialists, I go into houses with the nurses and work with children …while the parents get to relax while not talking in front of their children about things they may find upsetting, the methods I use for the children sometimes are very helpful for parents - are visual and simple		I go into schools to explain what the child has had done…you know, the catering staff and say this is the sort of diet this child needs. …you know, schools can plan it. The dietician can be helpful to get in touch with the school. I sat down with the child and went though it [blood sampling] …	
Ph	So it's [post clinic meeting] a really good place to share information and to make sure that we are all saying the same thing as well	We have some information in various languages especially with regards to transplantation and organ donation, it's very key to make sure you're hitting all nationalities there, but the main thing is the communication and I think it's important that families are offered the same level of information and you have to use a variety of other tools for non English speaking families		
SW	if you can find out whether they're finding it difficult to take on board the information or whether it's the…they're listening to information and thinking, I need to get back and pick the kids up from school or there's other things going on, it makes them present as if they're not taking it in but actually it's finding out what else is going on in	You can't just wander in and chat to them [if an interpreter is needed] [mother] can't read, not even the basics. But, I mean obviously she's got her own way of dealing with that…We don't have enough interpreters.	We can liaise with the [parents'] employers, with large kidney charities to help out with things, you know hospital stays…transport in and out of hospital…	We have a weekly psychosocial meeting where they [families] would be discussed at an early stage….Where there was sort of important things going on they would be brought to that meeting ..I would document it, it would be in my notes…there's a lot of, interchange ability…without the MDT [management] simply doesn't work

GP & Community nurses

Orthopaedic consultant

Transplant nurses
e.g. N9 (1)

Surgeon

Child

Dialysis nurses
e.g. N1 (13), N8 (0)

Has been referred to Clinical Psychology

Therapist
e.g. T1 (1)

Dieticians
e.g. Dtn (2), Dtn2 (3), Dtn3 (2)

Doctors
e.g. Dr1 (4), Dr6 (1), Dr9 (0)

Key:

= Renal team

= Other hospital department

= Community services
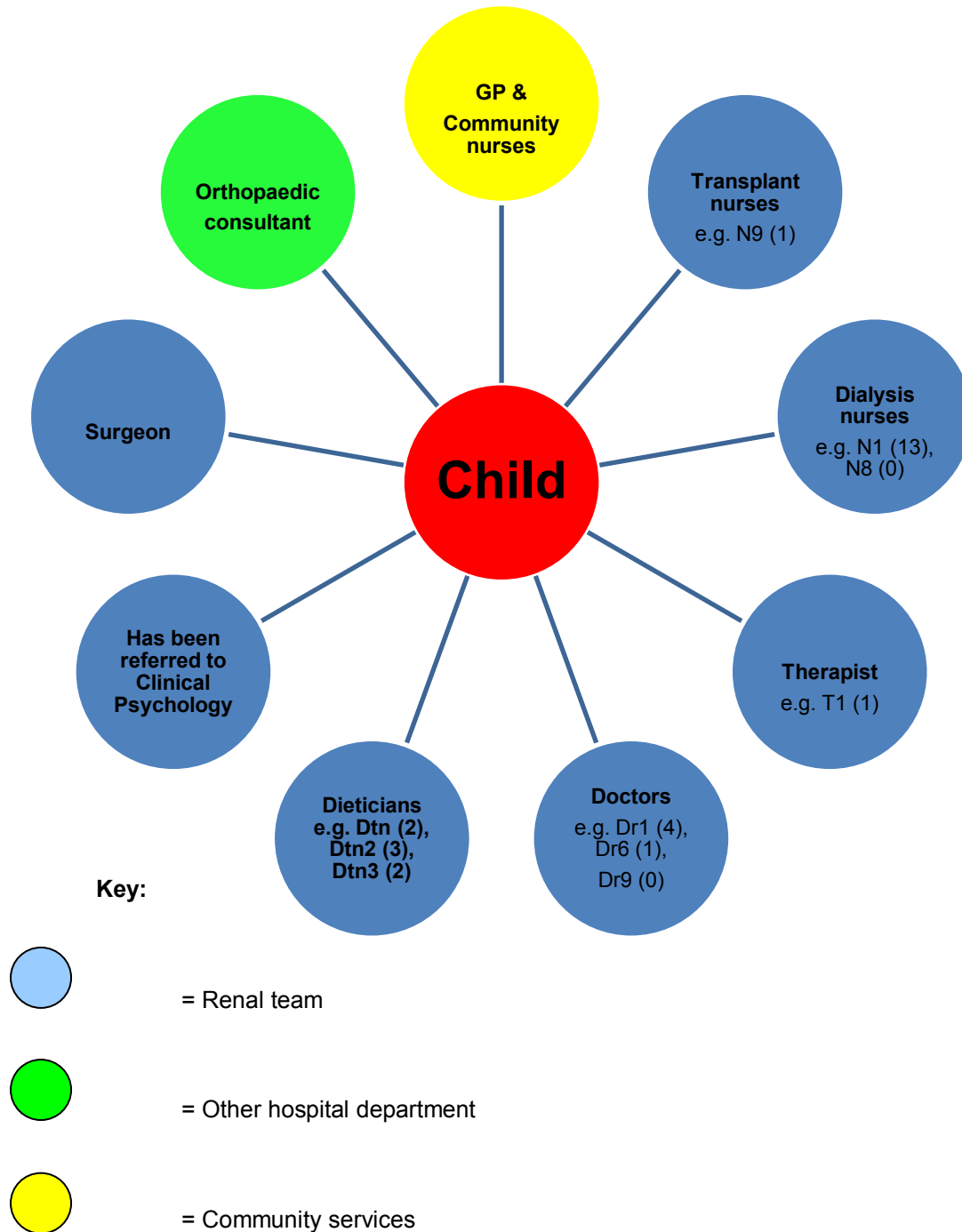
Dtn, Dr1 etc = professionals participating in the study

(number in brackets) = number of contacts the researcher had with each professional in relation to family 1

Appendix 8: Family 1 Participants who were present at each observed event

Participants / Event nos.	Child	Mother	Father	N1	N9	Dr1	Dr6	Dtn	Dtn2	Dtn3
1		X	X	X						
2		X		X						
3		X		X						
4	X	X		X						
5		X	X	X						
6	X	X	X	X						
7	X	X						X		
8	X	X	X	X						
9	X	X						X		
10	X	X		X		X			X	
11	X	X		X	X	X				X
12	X	X					X		X	
13	X	X	X	X		X			X	

Key:

= Renal team

= Other hospital department

= Community services

N2, Dr2 etc = professionals participating in the study

(number in brackets) = number of contacts the researcher had with each professional in relation to family 2

Participants Event nos.	Child	Mother	Father	N2	Dr2	T2
1			X	X		
2	X	X	X	X		
3			X	X		
4	X	X	X	X		
5	X		X	X		
6	X	X	X	X		
7	X	X	X	X		
8	X	X		X		
9		X	X	X		
10		X	X	X		
11	X	X	X			
12	X	X		X		
13	X	X		X		
14	X	X		X		
15	X	X		X		
16	X	X		X		
17	X	X		X	X	
18	X	X		X		
19	X	X			X	
20	X	X		X	X	X

Nurses
e.g. N3 (12),
N4 (4), N5 (1),
N7 (0), N10
(1)

Urology

Doctors
e.g. Dr3 (6),
Dr5 (1),
Dr7 (1)

Child

Surgeon

Play
Specialist
e.g. PW1 (1)

Social
Worker
e.g. SW1 (0)

Dietician
e.g. Dtn4 (0)

= Renal team

= Other hospital department

N3, Dr3 etc = professionals participating in the study

(number in brackets) = number of contacts the researcher had with each professional in relation to family 3

Appendix 12: Family 3 participants who were present at each observed even

Participants / Event nos.	Child	Mother	N3	N4	N5	N10	Dr3	Dr5	Dr7
1	X	X	X						
2	X	X					X		
3	X	X		X					
4	X	X	X		X				
5	X	X					X		
6	X	X	X						
7	X	X	X						
8	X	X					X	X	
9	X	X		X					
10	X	X	X						
11	X	X					X		
12	X	X		X		X			
13	X	X	X						
14	X	X	X						
15	X	X	X						
16	X	X					X		
17	X	X		X					
18	X	X	X						
19	X	X							X
20	X	X	X						

Key:

⬤ = Renal team
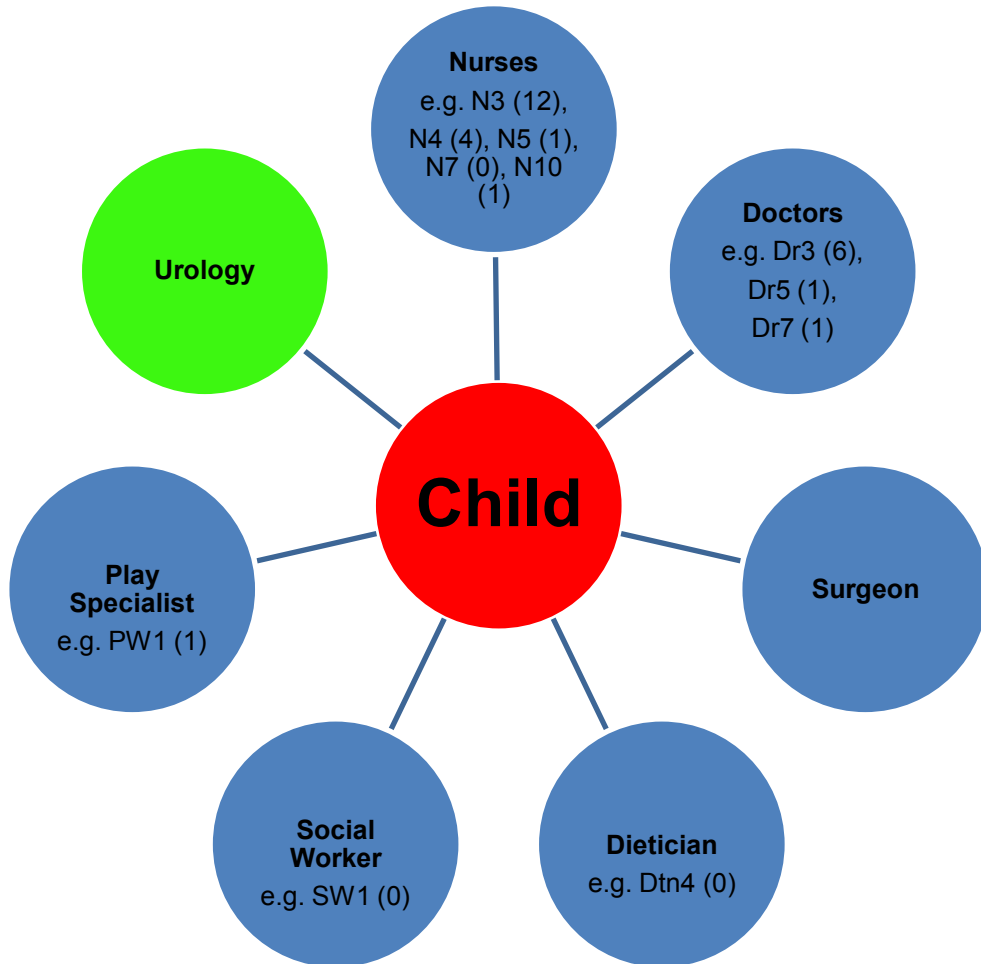
⬤ = Other hospital department

⬤ = Community services

N1, Dr6 etc = professionals participating in the study

(number in brackets) = number of contacts the researcher had with each professional in relation to family 4

Appendix 14: Family 4 participants who were present at each observed event

Participants / Event nos.	Child	Mother	Father	N1	N8	N9	Dr1	Dr6	Dr9	Dtn2	Dtn3
1	X		X	X							
2	X		X	X							
3	X	X	X		X			X			X
4	X	X	X	X				X		X	
5	X	X	X						X	X	
6	X		X			X	X				

Key:
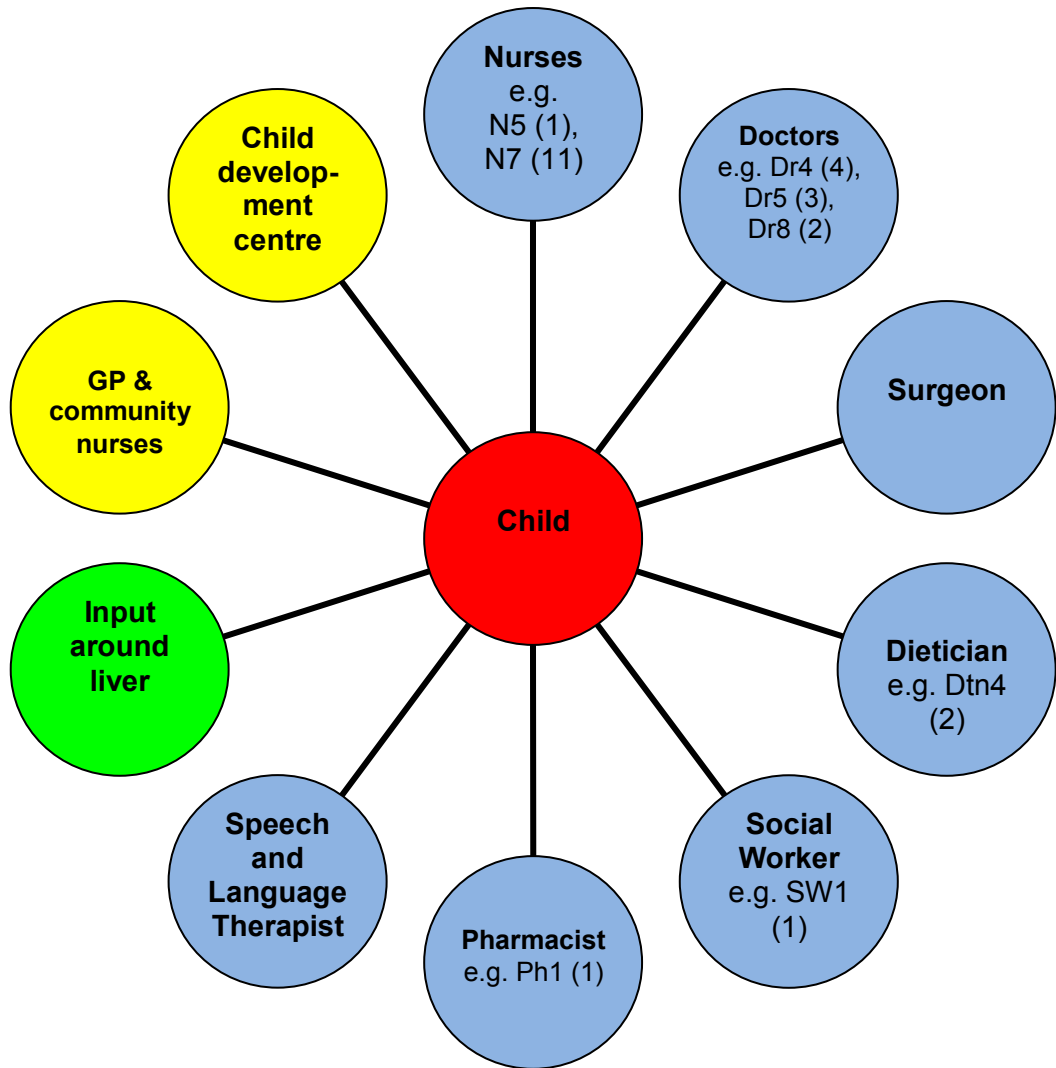
= Renal team

= Other hospital department

= Community services

N5, Dr4 etc = professionals participating in the study

(number in brackets) = number of contacts the researcher had with each professional in relation to family 5

Participants Event nos.	Child	Mother	N5	N7	Dr4	Dr5	Dr8	Dtn4
1	X	X	X					
2	X	X			X			
3	X	X				X		
4	X	X		X				
5	X	X				X		
6	X	X		X				
7	X	X		X	X			
8	X	X		X				
9	X	X				X	X	X
10	X	X		X				
11	X	X			X			
12	X	X		X				
13	X	X		X				
14	X	X		X	X			
15	X	X		X				

Key:
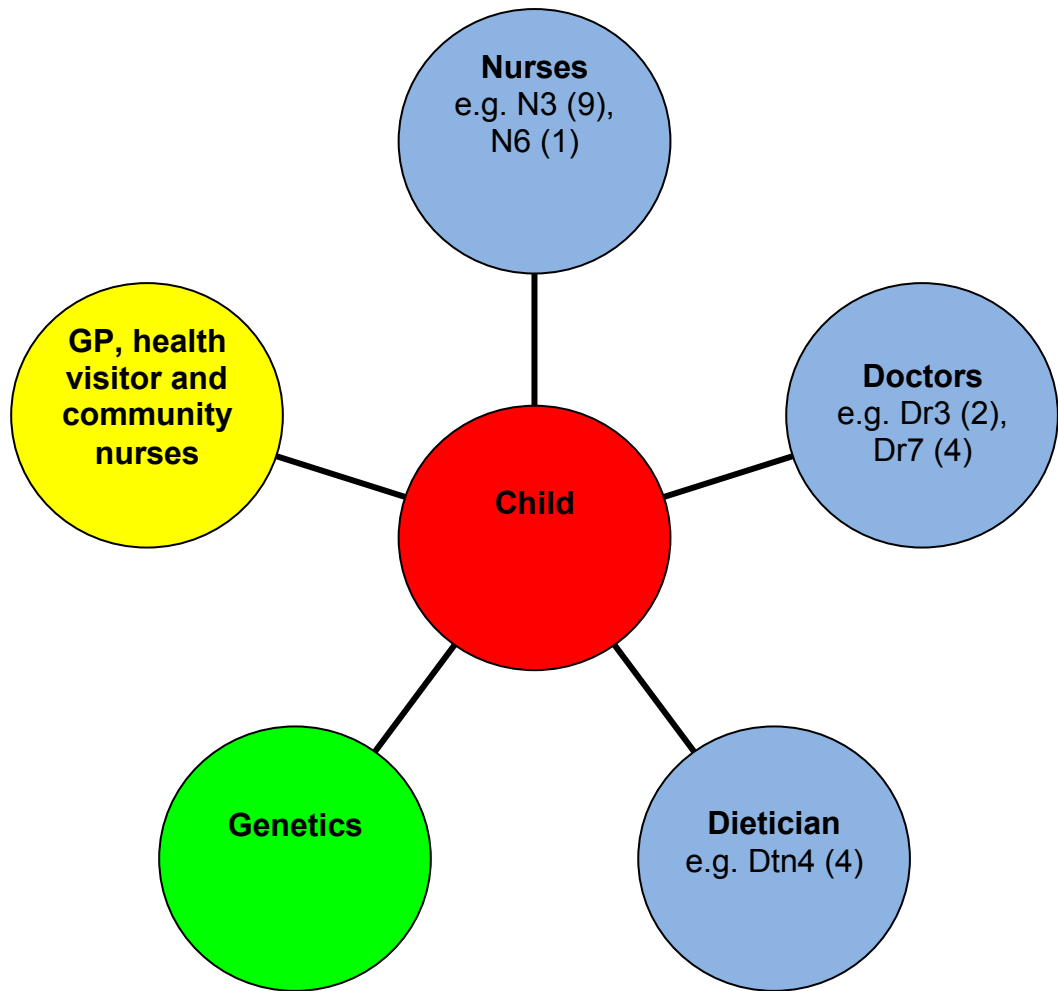
= Renal team

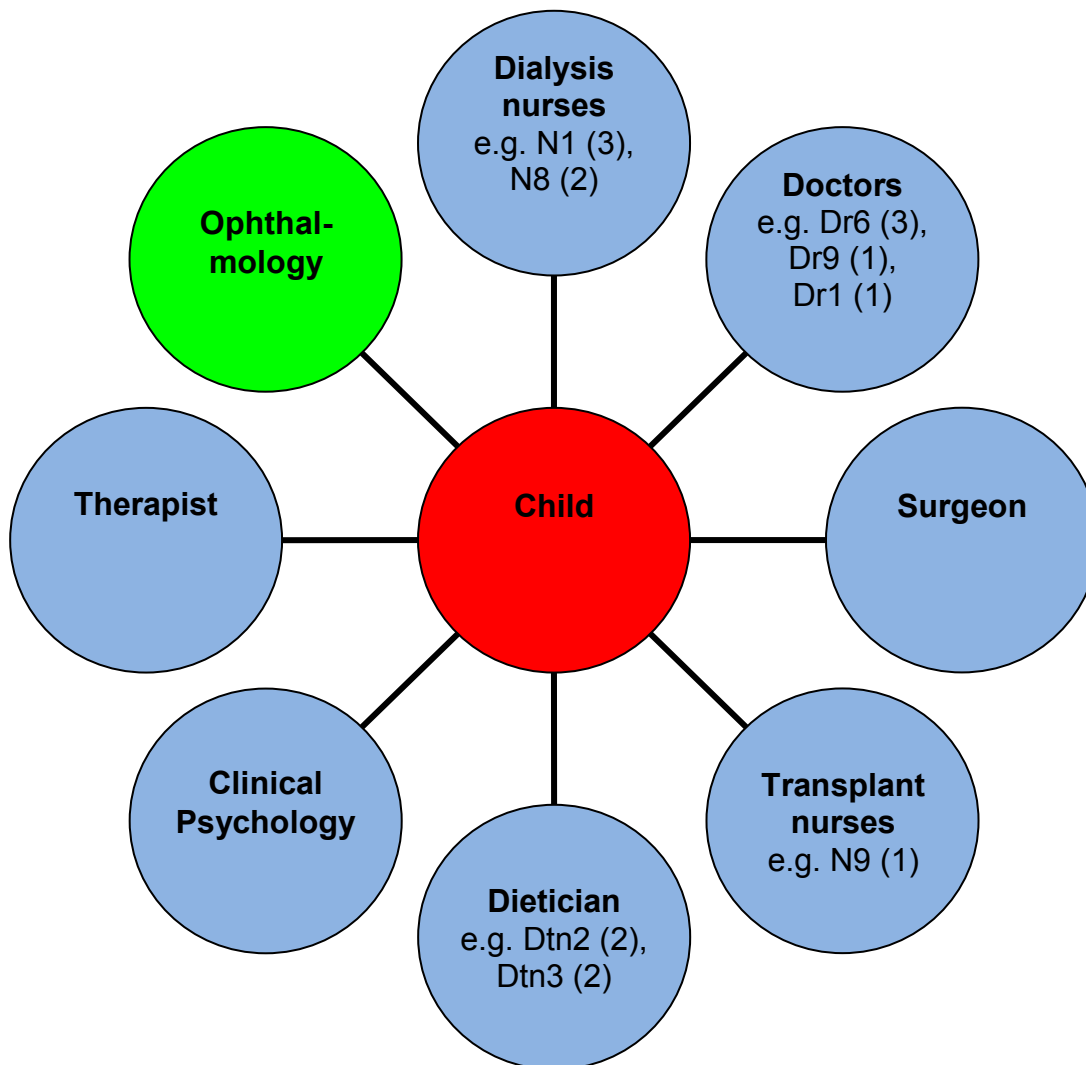= Other hospital department

= Community services

N3, Dr3 etc = professionals participating in the study

(number in brackets) = number of contacts the researcher had with each professional in relation to family 6

Appendix 18: Family 6 participants who were present at each observed event

Participants / Event nos.	Child	Mother	Father	Grand-mother	Grand-father	N3	N6	Dr3	Dr7	Dtn4
1	X	X	X	X			X			
2	X	X				X				
3	X	X							X	
4	X	X	X			X				
5	X	X	X						X	X
6	X	X	X			X				
7	X	X	X					X	X	X
8	X	X	X			X				
9	X	X		X		X				
10	X	X		X				X		X
11	X			X	X	X				
12	X			X	X	X			X	

This is the 5th and final formal teaching session with parents about home dialysis. Both parents attended 3 sessions, mother attended 1 on her own. Child not joined any. I had joined 3. Teaching from 11.55-1.40 already today. We had agreed to meet again at 3.30.

3.30: Nurse on phone. In her office, I'm waiting outside, it sounds like a difficult call with a stressed mum. She asks me if I can ask the family to wait in an adjacent room. Mum, dad, child, me, wait for 45 minutes. Mum talks about how stressful/challenging nature of nurses work e.g. long shifts, on feet all day.

4.15: Session starts. Child, mum, dad, nurse, me

In nurse's office, small, cluttered space, computer on desk, shelves/desks filled with files, teaching materials including home dialysis machine. Information posters on walls e.g. exit site.

Child, mum and dad sat on sofa, nurse on wheeled office chair, me on easy chair (we have always sat in same positions). Wheeled table in middle of room between nurse and family. Equipment on table.

Mum says child wanted to see the dummy. Child finds the dummy funny especially as it has a bottom. Nurse jokes about carrying dummy around hospital and demonstrates carrying it e.g. holding its bottom. Asks child to think of a name for the dummy that could be boy's or girl's name. We have tea.

Nurse says to child: 'This is where your mum and dad come to school'

Nurse continues teaching re: alarms, using machine and booklet. Nurse demonstrates messages on machine, there is lots of beeping sounds –child is looking at the machine.

Dad uses booklet and presses buttons on machine to bypass.

Phone rings, nurse ignores it.

Nurse explains: 'When you bypass, it's like shutting a computer down, you are asked twice, it's the same with bypass. It's a safety check, that you are asked twice. If need to do it at home, get the book out and it will talk you through it'

Nurse gives scenario e.g. child has high BP, not had a poo for days.

Nurse explains to child: 'It's only pretend. I have to make up stories so mum and dad can learn. I bet they don't talk about poo at school. I'm not a real teacher!'

Parents learn how to do manual drain. Child starts reading instructions from booklet. Mum presses buttons on machine. Dad takes over reading. Nurse is typing an email, turns to parents to say: 'I hope you can see that book is user friendly'

Discussion about power cut or if machine stops working and what parents should do

Door bell rings – nurse answers intercom as is sited in nurses' office.

(field note data continued on next page)

(Field note data continued)

Discussion about emergencies. Nurse explains: 'I always find this bit ridiculous, don't forget your common sense'. Nurse gives examples 1) leave house if there is a fire 2) scenario where dad has fallen down stairs, adapts story to stubbing toe as this dad has done this, includes child in the story.

Colleague knocks and mouths message to nurse through glass panel in door.

Phone rings –nurse ignores it.

Nurse asks parents: 'Any questions? Any random scenarios?'

Mum says: 'Might be a silly question, but we have cats. Should the cat go in the room with the machine?'

Nurse talks about importance of clean environment.

Mum: 'Do we need to change child's sheets daily?'

Nurse: 'No'

Nurse and parents joke about getting rid of the cat or the computer as the extension lead to computer [leads to plug socket in hallway] means parents bedroom door can't closely fully. [As parents plan to set up machine in this room they would need to be able to close door to keep cat out]

Phone rings – nurse answers it.

Mum expresses concerns that no doctors will be around over weekend and is worried about child's weight increase and puffy face. Nurse reassures that dialysis consultant and herself will make a plan before the end of day.

Nurse asks mum and dad to look at sheet at end of dialysis guidelines over the weekend, and to score themselves out of 10 – how confident they feel in doing different aspects of dialysis care. Asks mum and dad to try and resolve any machine alarms over the weekend.

Nurse explains: 'That's everything theoretical. You need to get practice, get your confidence and skills up to scratch. Think over the weekend, if there's something you want to cover again. Education is a continuous cycle, never ending. We are here. Much prefer you to say if you want to cover something again, we can cover it in hospital, at home, or future clinics.'

Nurse advises that if family go on holiday, dialysis fluids can be delivered worldwide. Makes plan for the evening with parents –Dad to set up the machine, mum to connect later.

Mum and dad stood up to leave room, Nurse says: 'Dialysis can be overwhelming. It's what you make of it. It will have more impact on your life, than child's. Take it in turns. Use each other for support. I can see that will happen. You have worked together. Please use me. If child is struggling at home, or you have problems at work, call us. We want to help so you can cope. You'll get into a routine very quickly. Get yourself carers allowance'

4.40: session finishes.

Participant observation is described as 'the main method of ethnography and involves taking part as a member of a community while making mental and then written, theoretically informed observations' (O'Reilly, 2009). My role was to become a member of the renal teams at both of the units, as well as maintain a role as an observer, being able to 'stand back', reflect on things and ask questions during de-briefing interviews. The aim was to be minimally obtrusive during observations of interactions between professionals and parents; for example, by choosing a place to sit slightly outside of the interaction, only limited participation (e.g. laughing in response to jokes, making eye contact, smiling) during conversations, taking discrete notes. On many occasions this could be achieved, especially as families and professionals were reported to be used to observers being present (e.g. trainee and visiting health care professionals), with some professionals commenting that in time they 'forgot' that I was present.

However, at times during the case studies my role as a participant increased in response to specific situations and/or practicalities. There were some situations for example where my role became more participatory:

- When there was limited space and seating in the room where the interaction occurred
- Occasionally professionals would speak to a family in their own language and then translate into English for my benefit
- Parents/ carers would ask me health related questions or discuss their concerns about care-giving when a professional was not present
- Professionals giving positive feedback to parents by commenting to me on how they parents were learning, when the family were present

These types of situation presented some challenges to my position within the interaction, and at these times, intuition and my own background in health care guided my response. O'Reilly (2009) explored the dilemmas posed by participant observation but emphasised the participant aspect of the role as a way to learn though 'first hand experience' and recognised that trying to act as if you were not present in a situation would have an effect. Through discussion with the CI, preparing for possible challenging situations and reflection, it is hoped that I achieved the balance of participant observation.

Topic guide for interview with parents:

Current teaching/learning:
- What knowledge and skills have you had to learn? Theory and practical skills?
- What helped you to learn?
- Has there been anything you have found difficult?
- Was there anything you found less helpful?
- Was there anything you would like to have been done differently?
- Environment?
- Tools/resources? e.g. information sheets etc
- How helpful?
- How has the teaching/learning been managed? e.g. what you learn, speed, type of learning
- Do you think the way you learn is different to partner?
- Did your child have to learn anything new?

Role of professionals:
- What professionals have been involved in helping you learn?
- How did other professionals give you support so you can do care for child? e.g. ward staff, phone calls, clinic
- How do you think professionals assess your learning e.g. decide you can do the care task on your own?

Previous experience:
- When did you last have to learn a new skill?
- Previous care giving tasks learnt?

Topic guide for interviews with professionals:

Current teaching/learning:
- Can you tell me what you have been helping the parents to learn?
- How do you feel the parents are learning?
- What did you think worked about the session that took place?
- Was there anything you would have done differently?
- Did you make any changes to how you would normally do something?
- What made you decide to do something in a certain way?
- How do you decide how much information to give?
- How do you decide what order to teach things in?
- Speed of teaching?
- How do you judge when the parents have understood/ are competent?
- Tools /resources for teaching
- Environments
- Do you adjust your training for mum/dad? If so, in what way?
- Do you do teaching with the child?
- Do you use communication with the child to help with teaching the parents? If so, in what way?
- How does age of child affect this?

Role of other professionals:
- How do you see other MDT members contribution to the parent being able to provide care?
- Role of other team members in 1) ax and monitoring 2) teaching 3) support
- When would you ask other MDT to get involved with family?

Previous experience:
- How did you learn how to give guidance/teach?
- Do you think your teaching has changed with experience?

1. Teaching and learning processes:
    1.1   Communication e.g. explanations (inc using own child and other families as examples), judging how much info to give, asking questions/getting more information (i.e. as assessment), offering feedback and reassurance, reinforcement

    1.2   Content e.g. theoretical knowledge and practical skills

    1.3   Demonstration, practice and repetition

    1.4   Competence and signing off

    1.5   Preparation e.g. going home, things which could go wrong, learning when things go wrong, being prepared for events

    1.6   Resources/tools e.g. written guidelines, visual info, metaphors, dummy, self help

    1.7   Teaching both carers/learning together, carers teaching each other, teaching child

2. Facilitators to teaching and learning:
    2.1   Attitude and behaviour e.g. flexibility, confidence, staying calm, pragmatism

    2.2   Relationships e.g. trust

    2.3   Pitching it at the right level including language/terminology

    2.4   Environment

    2.5   Expectations and previous experience of teaching & learning

    2.6   Previous experience e.g. long term conditions, child care

3. Barriers to teaching and learning:
    3.1   Ideal vs reality e.g. disturbances, letting others down, resources, environment, organisational structures, time

    3.2   Pressures to get home e.g. parents desire to go home, siblings, finances

    3.3   Differences in teaching & learning abilities and styles inc. language issues/literacy/numeracy

    3.4   Misplaced confidence including lacking confidence

    3.5   Competitiveness between carers and/or professionals

4. Ambivalence within teaching & learning encounters:
    4.1   Hospital vs home routines

    4.2   Levels of expertise (vs not knowing) e.g. diagnosis, discharge, different techniques/approaches

    4.3   Management (acceptance vs not accepting)

    4.4   Skills to learn & teach vs common sense/ second nature / logic

Appendix 24: Home dialysis training programme

Teaching	Discussed	Practised	Carers level of confidence 0-10	Assessed competent by trainer Signature and date
BP				
Weight				
Temperature				
Hand washing				
Changing the programme				
Setting up machine				
Connecting				
Disconnecting				
Recording information				
Taking a sample				
Re-priming line				
Recognising fluid overload				
Recognising dehydration				
Recognising peritonitis				
Recognising fibrin				
Catheter problems				
Action to take if break in line				
Alarms				
Manual drain				
Bypassing				
End therapy early/power cuts				

Father is learning how to home dialyse. Child is present in the teaching session.

1. Nurse explains: 'We also need to think about emergencies, or unplanned scenarios. It might sound silly, but if the house is on fire, just get out. With other scenarios, decide how much time you have and use your common sense to make the decision'.

Father: 'So the example, if there is a fire in the house, just go?'

Nurse uses teddy [which has a dialysis catheter and is connected to dialysis machine] to show how to quickly disconnect and leave.

Nurse gives an example of a gas leak, where there is more time available than in a house fire. She advises father to use alcohol gel and put the cap on the child's line. Nurse reassures: 'Don't worry about infection, if something more serious could happen. Use your common sense as a parent. Don't forget the skills you have already learnt. If [name of child] is sick, act like with your other children. If it's something serious call the ambulance. Just remember, you know what to do. Don't let the dialysis panic things. Act like with your children, use you common sense as a parent'

Nurse uses examples relevant to family e.g. grandfather slips and hurts ankle. She advises: 'Stop dialysis early, take grandfather to hospital, call me as soon as you can. Because you are the only one trained. You are the head of the family. There are others [family members] with health problems, you may have to decide on the priority. Use your common sense'

2. Nurse is talking with the child about changing the dressing on her exit site when she is at school

Child asks the nurse: 'Where do I do it? The toilets are unisex'.

Nurse: 'You could go in a cubicle. Where do you go if you are sick?'

Child: 'The office'

Nurse suggests: 'So you could go there'

3. Nurse is using the dialysis machine manual to explain about alarms when the machine is broken and system errors, which means the machine is broken. The nurse advises: 'It's like your DVD or phone playing up, switch it off, leave it for a few minutes, turn it back on and see if it will work. That old reliable trick, it's the same for the machine. Keep your fingers crossed. Walk away quietly and hope the machine will be OK. If it doesn't work, you will need to call [name of company who makes machine]. They will give you advice. They may decide to give you a new machine. So take her off, put the machine in its suitcase and wait for the new machine'

Father is learning home dialysis from a nurse:

Nurse is explaining how to manually drain and shows the father the drain bag and advises it can take 3 litres
Father asks: 'How much do I take out?'
Nurse answers: 'As much as you can'
Father checks: 'So, with the manual drain, there are no figures, it's just what comes out?'
Nurse confirms: 'Yes'

Nurse visits the family at home after a child has been discharged on home dialysis:

Mother asks the nurse: 'Ideally you want his BP [blood pressure] to be?'
Nurse answers: 'The generous range is 90-110. Ideally it would be 90-100. I'll be more concerned if he has high BP and weight in the morning. We'll talk everyday initially.'
Mother asks nurse about the size of cuff to take BP
Nurse reassures it's OK to use child size cuff and takes adult size cuff back to unit

Grandparents have bought the child to a clinic appointment with a doctor:

Grandfather asks the doctor: 'Would you recommend the PEG?'
Doctor explains: 'He [child] will cope on his own, it could be anytime between 2 and 5 [years]. If the NG tube is a problem, last time she was here [name of mother] was saying the tube needed replacing 5 times in one week, then a PEG is indicated. It's not just for the child, but for the whole family. It's easier with a PEG. But there are the risks associated with having an operation. If he was my young man, then I would probably do it. We can't say how quickly he will drink enough himself, usually by 3 or 4, he would be OK, that's from a small sample size'
Grandfather asks: 'And long term?'
Doctor reassures: 'He [child] should be OK. Most of these children do well, sometimes they are a bit smaller than other children. Some have a bit of developmental delay, but because we caught it early, he should be OK.
Grandfather says to child: 'You're not daft!'

Child and mother have a clinic appointment with a doctor:

Mother asks the doctor: 'She's [child] going through puberty. Will things [child's kidney condition] be affected when she starts her periods?'
Doctor: 'That's a good question. I can't say. It varies from person to person. We find there's usually a drop in puberty'

A nurse has a teaching session with a father and child who is starting on home dialysis:

Father gets out child's record chart from his bag, he points at the chart and asks the nurse a question: 'Why are the numbers big here?'
Nurse explains about fluid balance, amount of fluid put in will vary so the amount coming out will also vary. Explains that numbers were big as lots of fluid had been put in.

Later in the session the father returns to the record chart and asks: 'So the numbers are before and after, and the after numbers should be lower?'
Nurse: 'Yes, why would they be lower?'

Child: 'Because it pulls off the fluid'
Nurse explains process of dialysis, talks about numbers going up and down [nurse is gesturing up/down with hands as she explains]

A child and mother have a clinic appointment with a nurse. The mother is concerned about how tired the child is:

Nurse asks: 'How long does she [child] sleep for?'
Mother answers: 'I wake her up to have dinner. She also needs to catheterise and I'm not sure if she would wake up?'
Nurse: 'I don't think she would wake up. Her bladder does not respond to the stimulation of being full and so that's why she's catheterised. It means she would wet herself, or sleep with a very full bladder!'

A nurse is teaching parents how to home dialyse:

Nurse: 'Why would no fluid come out?'

Mother: 'Because he's dehydrated, he's had a wee'

Father: 'The clamp is on. It's the position he's lying in'.

Nurse: 'Yes, it's like drinking juice from a carton, when you get to the bottom you have to shake it to get it out. We'll talk about him needing to change position. Any other reasons? I can think of 2 more'.

Father: 'The machine's faulty?'

Nurse: 'Yes, but I can still think of 2 more reasons?'

Mother and father not able to answer

Nurse: 'There are 2 more reasons?'

Father: 'The tube is blocked'

Nurse: 'Yes. One more reason, remember I drew you a beautiful picture!?'

Mother: 'The tube is too high'.

A father is learning from a nurse how to dialyse his child. The child is present during the interaction:

Nurse: 'Has anyone spoken with you about what painkillers she's allowed?'

Father and child: 'No'

Nurse: 'She's not allowed Nurofen or ibuprofen as her kidneys don't work. She can take Paracetomol, but the Nurofen you can't have for the rest of your life'

Father: 'So that's Nurofen, Ibuprofen'

Nurse: 'Yes, they are not allowed. They are part of non-steroidal drugs. So she's allowed Paracetomol, but call us if Paracetomol isn't working.

Father to child: 'So that's 2, the painkillers and blood sugar if you end up in hospital'.

Nurse: 'It's perhaps good that if your father is not allowed it, to keep it out the house. Check flu preparations, some have ibuprofen in them'.

Child: 'So no Ibuprofen?'

Nurse: 'No, forever'

A child and her mother have a post-transplant clinic appointment:

 Doctor asks the mother about the child's medication: 'What are the most important ones?'

Mother names 2 medications [she answers correctly]

Doctor: 'Top stars!'

A father is being supported by a nurse to connect his child to a dialysis machine for the first time in the patient hotel:

Nurse: 'Get everything ready. It's strange being in a different room. Put your tray on the top of the machine, like on the ward. You tell me what

you're going to do'

Father is wearing gloves and touches the floor by mistake

Nurse: 'You will have to change your gloves because you touched the floor. At home, you will have to be really cautious. You could use a chair when you connect her'. The Father changes his gloves but then touches the chair.

Nurse: 'You've done the same thing, you've touched the chair.'

Father changes his gloves again. He sits in the chair to start the connection.

Child: 'Don't touch anything!'

Nurse: Are you happy you can reach everything?'

Father asks child to lift up her line

Nurse: 'And [name of child] can help by holding the corners' [of the sterile sheet under line]

Father is telling the nurse what he's doing e.g. cleaning line.

A nurse is teaching parents how to give medication to their child:

Nurse: 'You need a different syringe. A better syringe would be?'

Father and mother: '1ml'

Nurse: 'Brill'

Child and mother have a post-transplant appointment with a nurse:

Nurse: 'What's her drinking target?'

Mother: 'It's 2 ½ litres'

Nurse: 'Is she managing that?'

Mother: 'With the pump. She's drinking about 50ml'

Nurse: 'So she's getting 2 ½ through that?' [indicates the pump]

Mother: 'Hopefully she will be able to drink it in a bit, she's starting to drink a bit more'

'Medical' language:

- Nurse is talking through a booklet about a dialysis machine with some parents. Nurse explains meaning of some words e.g. "frangibles" = green seals.

-Doctor tells parents: 'I talked with [name of another doctor] about [name of child]; she suggested fluid restriction but I strongly felt he was fluid replete.'

-Nurse giving advice to parents: 'If he continues to have chronically loose stools…'

-Doctor shows parents the growth chart for their child: 'He's there, growing towards the centile, he's not achieved it. What we could say is good, is the distance between him and the line is the same, he's even drifting towards it. He's not turning corners yet. He's not at his optimal weight and height. He's desperate for calories to grow. You're doing the right things.'

-Nurse advising child and her parent: 'I also need to do some swabs closer to the date. That's to check you haven't got anything growing in your nose, your groin. We all have them. But we need to check as it will reduce the risk the infection.'

-Doctor is writing in medical file; he speaks aloud as he writes, it is unclear if he is directing this at the parents or saying aloud what he has written in the notes: 'So impression, doing well, still failure to thrive'

-Nurse explains to a parent: 'I think you'll see some real changes as her chemistry is sorting out. She'll have a lot more energy'

-The doctor and dietician are discussing a child's management during a clinic appointment with the parents and child:

    Doctor: 'These boys are hyper metabolic'

    Mother asks the nurse: 'Will her baseline change as her creatinine creeps up?'

    Nurse: 'It can do. How long has it been since her transplant?'

    Mother: 'About 6 weeks'

Nurse: 'So around nowish we should be talking about a baseline'

-The Doctor is talking with a family about their child who has a genetic condition: 'It's one of nature's problems. You will blame yourself, especially if you're the one carrying the gene, but it's not your fault. It's just when the gametes met, when the sperm met the egg, that something gets a bit lost, some of the DNA doesn't quite go right.'

-A Nurse explains to a family about their child's fluid requirements: 'It's important for him to get the fluid. He needs the fluid to get rid of things, so the fluid is to not get him dehydrated and also to get rid of the sodium and electrolytes.'

'Colloquial' language:

-Nurse is visiting a family's home to see if it would be suitable for home dialysis:

> *Mother: 'I was so worried you would say I can't have it here'*

> *The nurse reassures the Mother*

> *Mother points out the sockets in living room where the machine could be plugged in*

> *Nurse provides further reassurance: 'I think people worry, but I'm just checking there's no mould, things like that. I'm not 'Changing Rooms' [home improvement TV programme], I won't be asking you to move the mirror over there!'*

> --

-A Mother has been talking with the nurse about her child's behaviour. The Nurse reassures: 'If you take away the transplant, the dialysis, etc, she's the perfect age to be having the strops'

> *A Mother whose child will shortly be starting on home dialysis is talking with a nurse:*

> *Mother: 'Do you think her medication will differ?'*

> *Nurse: 'They might change slightly. Your kidney is working very hard now to keep you balanced. When you start on dialysis, your kidney will think 'phew, I don't have to do anymore' so it might change'.*

-A nurse is teaching parents how to use a syringe to measure their child's medication:

> *Nurse: 'That's it, you have a fiddle with it.' [means the syringe]…*

> *Later on the nurse gives further advice about how to handle the syringe: 'Don't worry, you know what to do. Tap it. If that doesn't work, knock it on its side'*

-A nurse teaching parents to use a syringe to give medication to their child, gives advice on the technique:

Nurse: 'I find if you direct it into the side of his mouth. Go slowly, don't go mental.'

-A doctor advises parents whose child needs to gain weight:

Doctor: 'We need to fatten him up'

Type of resource	Examples
Written information	• Medication sheet • Inpatient/ward drug charts • Leaflets about conditions • Step by step guidelines to setting up dialysis machine (parents encouraged by professionals to highlight text, add notes to make the guidelines personal to parents' learning needs) • Home dialysis recording chart • Information sheet with contact numbers e.g. ward • Booklet about dialysis machine • Recipe for feed • Pre- and post-transplant information
Visual information	• Photograph books showing children having procedures and treatment • Child growth chart • Posters e.g. exit site, diffusion through a tea bag • Spontaneous drawings e.g. peritoneum; fibrin in dialysis fluid; how dialysis fluid works; graphs to demonstrate effects of home dialysis vs. in centre dialysis; catheter tube • Diagrams about hand washing • Computer graphs showing child's blood results e.g. creatinine levels
Equipment	• Syringes • Medication • NG tube • Teddy bear with catheter • Catheter for dialysis • Dialysis machine • Dummy of peritoneum with exit site and catheter • Packs of dressings • 'Activity pouch' (to keep exit site dry) • Bags of dialysis fluid
Meeting others	• Visit to ward • Other child having same treatment e.g. home dialysis • Other parents whose child is having the same treatment e.g. home dialysis
Self help	• Self help Internet • Talking with family, friends and neighbours • Reading books/information etc
Metaphors and comparisons	**Parents learning home dialysis:** Nurse asks parents: 'Why would no fluid come out?' Mother: 'He's dehydrated, he's had a wee' Father: 'The clamp is on. The position he's lying in'.

Nurse: 'Yes, it's like drinking juice from a carton, when you get to the bottom you have to shake it to get it out. We'll talk about him needing to change position'

Doctor talking to parents about their child's fluid requirements:
Doctor reassures: 'More water is fine. If he wants it give it to him. When he is ill, his sodium will go up and he'll want to drink more. It's like when you eat a packet of crisps in the pub, you want to drink more. That's why they have crisps, peanuts, things like that. When he's unwell, he will produce more weak urine, and so his blood concentration will go up, his salt will go up and he'll want to drink. When he's older, he'll be able to tell you 'mum, I'm thirsty', but he can't now'

Nurse talks in an interview about teaching parents' about dialysis bags:
'When I talk about dialysis bags and the different concentrations and when you talk about the stronger dialysis bag basically pours more water out of the body, so when you've got very dilute blood and you've got a concentrated solution the body likes to be in an equal balance the water gets pulled across to dilute that sugar down till it's at an equal concentration either side of the membrane… and when I talk about it with families, depending on their capacity or whether they're looking a bit confused, I can talk about normal squash and the double concentrate that's now available and if you put the double concentrate to the peritoneum it's like the strong bag, you would need double the amount of volume of water to be pulled across to make it drinkable'

Parent asking nurse about infections resulting from dialysis:
Mother: 'How do you know if she has peritonitis?'
Nurse: 'By the colour of the fluid. It's usually very clear, but if there's an infection, you might get bits in it, like if you shredded a cotton wool ball and put it in water, it's called fibrin. That's protein from the peritoneum'

When asked what had helped her to learn, a mother explained:

> *I think just doing it, the practical stuff really, because obviously when you just sit there listening to things it doesn't really sink in does it, until you actually do it?*

> *[parents] rise to the occasion and perform, just get on with it …Mum gaining confidence…parents seen clued up, concerned but sensible…[Mum] intelligent, understands things, practically efficient, easy to deal with (Doctors_1 and _8);*
>
> *…I will show parents how to set up machine to see if they are worried during 'theory' session;…[parents] seem ready for dialysis, I have demystified the process, less scary;…family doing excellent especially as child is hard to dialyse…Dad proud of learning dialysis (Nurses_ 2 and _8);   …let families know they can contact me to ask questions, not [just] one off advice…very nice parents (Dietician_3)*

Parents reflected on tensions when they recalled the uncertainty that existed about the cause of the child's symptoms during the pre-diagnostic period. This was perceived as a barrier to eventually learning to assimilate clinical care giving skills into daily family life. This mother indicated how this uncertainty affected the potential to organise family life around the child's clinical care giving needs:

> *I tend to like to be organised and want to know where we stand and how we have to change [to accommodate clinical care within family life]; it's not just [child's] lifestyle, but ours as well…will never be the same…it's going to be, like, [child] has been born all over again, because…this time, [child's] got a condition and this will be with them for the rest of their life.*

The following field note data illustrate how for one father learning to hand wash, this was hindered by the taps:

> *Child continues reading out the instructions [on how to set up the dialysis machine].*
> *Father is hand washing. Father compares the mixer taps in the sink at the patient hotel*

When on the ward, some parents could find noise levels distracting when learning new skills. Other factors that parents said hampered their learning on the ward included occasions when equipment and supplies they needed were not available; and specialist staff being on holiday when the parents were being prepared for discharge, meaning that training could be delayed or delivered by someone with whom parents were unfamiliar.

The challenge of not having sufficient time to teach within a busy health care service was evident in this observation, where a father was learning to home dialyse:

Father asks the nurse: 'For a second person to learn [how to do home dialysis], would they need to come here?' The nurse answers: 'Yes. We have to prioritise families to go home. At the moment, we have two families wanting extra training, and they have been waiting three months.'

Father: 'What about if my mother or my wife were to watch me?'
        Nurse: 'They would still need training from me'
Father: 'What if they were to gain confidence and do it?'
        Nurse: 'No they can watch you, but they have to come to me to be trained.
        Father is smiling and says: 'I wouldn't teach everything!' Nurse laughs: 'No I won't let you!'
Father: 'We will practice this' [meaning his mother and wife will practice home dialysis with him].
Nurse: 'It makes me anxious to hear that they would hear your teaching first, before me. They can watch you, but don't teach them. English is not their first language so I wouldn't understand what they know. We could use an interpreter but it's not the same. Don't explain the whys, they can watch and read the guidelines. Don't do too much actual teaching. [Father laughs]. I can do some teaching but it will be in a few months'.
Father: 'I would like her [child's] mother to learn as sometimes I like to go to school with the other children
Later in the session, the father says to the nurse: 'It would be good if her [the child's] mum could do connection'
Nurse: 'And also [name of child]. We'll do the teaching with [name of child] and her mum together.

One mother noted that there was no discussion at the start of her training about what teaching approach she would have preferred as she learned to deliver complex aspects of care, although she believed that the nurse concerned:

…got the idea after the first one [demonstration of a skill], I needed to do more, so I started reading the instructions and that made me feel involved and it also give an idea of the list of how you do it, you know, which comes first and, I think she [nurse] saw, I don't mind doing stuff, it doesn't faze me, so maybe she got an idea from that but, I think, her teaching methods are…I think, they're already set on how she did things.

One father did not find using a 'dummy patient' to practice a skill helpful as he already had experience of a similar skill, though he acknowledged other parents could find it a useful resource:

> *Maybe for others it might be of use, but certainly for me I don't think that added anything particularly, that I can remember.*

Pitching teaching and learning at the right level:

Parents appreciated it when professionals tried to pitch their teaching at the right level for the individual; ways in which this was done included both verbal and written explanations. For instance;

- The doctor sitting with parents after the ward round and explaining treatment options using lay person's terms
- Nurses explaining about the vital observations in a straightforward way that parents could understand
- Nurses reinforcing what a doctor had said until the parent understood.

Repetition of facts was valuable; and parents were grateful if a professional demonstrated that they understood that a parent had difficulty articulating certain clinical words, or if English was not the parent's first language. For example, one father whose first language was not English explained how a nurse tailored her teaching him to perform dialysis to his specific needs:

> Father: *And, they're teaching, you know, they've [staff] been teaching for a long time, they've got experience, they're meeting, you know, English problem, how many kind of people they're meeting and they know how to, you know…*
>
> Interviewer: *Mhm. So you think they've got lots of experience teaching but also…*
>
> Father: *And if, sometimes, you know, I got a language problem, some, you know I can speak [English] a little bit, but I can't write, I got many spelling problems…so maybe, sometime, you know, I can't say full word, but then, they take, you know, they understand the main thing…*

> *…. So day one, if I can, do the theory, get them playing with BPs [blood pressure] and … the [dialysis] charts so they can start plotting their child's weight and BPs, to see the trends so that then when I come back and say 'can you see some patterns, what is happening to your child?'.*

Misplaced confidence:

Lack of confidence was a common problem amongst parents. Some parents found it 'nerve wracking' when they first took their child home after treatments, such as when NG feeding had been established. In one case study, the mother explained that the father was nervous about giving clinical care, while the father himself described it as 'daunting' when they left hospital and he had to perform NG feeds. He was worried that something would go wrong during the procedure or the child would not continue to make progress or would pull the tube out.

Another father described how he felt when he initially started to learn home dialysis:

> *Interviewer: Did you think that you'd be able to learn it?*
>
> *Father: Yes, but, I was thinking it's going to be taking a long time….but, you know, I think, three, four week got to know, this is…it used to scare me, when I come in, this is bags and all the stuff.*

A nurse commented how some of the parents managed well with clinical care giving but nevertheless lacked confidence in their own ability and that the initial obstacle to parents' learning was: *Mum's anxiety not ability.* The dietician also observed that some parents needed reassurance, as they seemed very insecure about their own skills and the child's management.

The mother of another child described how daunting it was being watched by professionals when undertaking clinical care as she was nervous, in particular about measuring blood pressure correctly, and at first thought that she would never be able to learn dialysis. A nurse, meanwhile, noted that the same parents were scared to ask professionals questions in case the professionals didn't know the answer, whereas a doctor described how lack of confidence might result in parents not asking all of their questions:

> *Often, I think they're frightened of the answers they might get, sometimes, they'll just think, 'that's a silly question, they'll think I'm daft'* (Doctor_8)

On the other hand, a few professionals expressed concerns about some parents appearing over confident around managing their child's condition, and who reported being more competent than they were. This could result in difficulties when 'correcting' a parent whilst they were learning a practical skill, or in parents not asking for advice from MDT members' when it was needed. A further concern was that over time parents would become 'complacent' when delivering care at home and that 'families can relax and pick up bad habits'. A therapist described how in pre-transplant meetings, parents could present as managing the uncertainties of transplant, but if questioned on occasions this was found to be only ' part of the picture':

> *Sometimes these meetings you struggle to get to an hour because people would just say, "Yeah, we've sorted it all out and we're going to do this; this one's going to do this, this one…", and it's all, "Yeah, we're happy, we've had the information, we know what we're doing, if it works it works, if it doesn't it doesn't; if it doesn't work we'll cross that bridge", and that's fine. But there's always the worry that that is just a smokescreen for all kinds of things, but you just have to allow that to happen really, don't you …(Therapist_1)*

The difficulty around providing feedback to parents as they learned the skills and knowledge to deliver home-based care was discussed by some MDT members. Providing feedback could present particular challenges when parents had a very different understanding of how they were managing compared to the views of the MDT. This links to sub section 4.4.5 which explores the ambivalences around professionals providing positive reinforcement and praising parents. A nurse described how an evaluation form had been developed following a situation where one family had struggled with learning clinical care but believed they had no difficulties. The purpose of the form was for parents and professionals to evaluate the teaching and learning processes separately and then meet to discuss their thoughts:

> *It would be a means, for most families, giving them reassurance and giving them a boost in their confidence to say, look, this is how well I think you're doing. I've written it down, believe in yourself, because I do, type thing. But it would also, for those few families that were overly confident or lacking in confidence that, you know, you could, at least, share some…(Nurse_1)*

As described above, misplaced confidence could act as a barrier in teaching and learning encounters; it could also contribute to tensions between people, which is explored in the following sub section

----

Professionals provided examples of having learned through experience the importance of establishing relationships in order to facilitate parent learning. Learning to teach parents from different cultures and those who spoke different languages was often a challenge but professionals described how with experience they worked out ways to manage these situations.

A dietician had learned to teach as part of her training and subsequently had worked out better ways to teach parents through experience, while a doctor believed that communication skills and empathy were innate when teaching parents. Playworkers often described using a reflective approach, one describing how they were trained to unravel parents' concerns and work through them.

As case studies progressed and families had been involved with clinical care giving over time, professionals sometimes commented in research interviews on how they thought parents were coping; these observations tended to use terminology that would be used by

an experienced heath professional when assessing a student health professional, for example:

> *[Parent] was un-phased and coped…stayed calm learnt well…mum coped amazingly, very calm… Competent calm family, end result important…quite 'black and white', asks pertinent questions, has done reading* (Nurses _ 2 and _7)
> *Mum coped, pragmatic attitude…rises to occasion and perform, just gets on with it* (Doctor_8)

These quotations suggest that professionals valued displays of 'calmness' by parents

----

Expectations and previous experience of teaching and learning:

Parents sometimes articulated in research interviews how their prior learning experience influenced the way they learned about their child's CKD management. One mother said she had not learned new skills since she was at school but needed to learn now because of her child's clinical condition. Another mother explained that she knew prior to the learning that she was someone who learned by doing rather than reading about it:

> *Interviewer: And before you started the teaching, the learning, here, did you know that you were someone who learnt by doing?*
> *Mother: Yes.*
> *Interviewer: So you had that awareness already.*
> *Mother: Yes. I knew that, if I'm allowed to get on with it, I need to read the instructions but, I like to do, I don't want to sit back and watch, I like to get hands on and work things out…*

In addition, some parents gave the impression of hearing only parts of a message relayed by a professional (e.g. information on rare side effects), and then appeared not to hear the rest of the message. This 'selective hearing' could be a barrier to parents' learning. In addition the relationship with other parents often helped to facilitate peer learning, while one mother explained how her relatives encouraged her to ask questions of professionals, sometimes doing research into the child's condition themselves before preparing the mother to have discussions with the MDT. Professionals believed it was important that parents had confidence in the professionals and were able to believe that they [professionals] *know their job.* One nurse said she would like families to approach her if they had a problem. There were occasions during teaching and learning encounters when professionals were observed to refer to the parents' specific experiences and also more generic experiences of learning as a means to offer reassurance, as illustrated by this field note data:

> *Child and mother have post-transplant clinic appointment with a doctor. The child has had a kidney transplant a few weeks previously. The doctor says: 'Have you met [name of transplant nurse]? You'll get to know us all really well, as you'll see us every day. It's all new now, it's like starting at school and doing a course. You'll be OK, you are very sensible.' The Mother replies: 'Yes, it feels like when I was learning PD [Peritoneal Dialysis]. It was difficult at first and then you get a routine'.*

One set of parents learning home dialysis:

1. Mother: 'I'm concerned about hand washing at home'

Father: 'I tried the taps at home, I think they'll be OK'.

Nurse advises parents they could use bath taps or shower hose to wash their hands.

Mother: 'I've been looking in Argos for different taps'.

Nurse reassures: 'It should be OK, you can find cheap taps on eBay'

2. The nurse leaves the room as she needs to send a fax about what needs to be delivered to family's home before child is discharged. Mother and father chat about the arrangement of the child's room at home to accommodate dialysis

3. The nurse is talking about cleaning the area and thinking about how it will work at home e.g. set up the machine in parents' room so child and his brother can play in their bedroom. The father says they are thinking about buying a trolley to put the machine on at home

4. Nurse discusses with parents what should be delivered home and when (on Friday)

5. The guidelines [on how to set up machine and connect child] are stapled together. Mother says she will separate these once they are home [as she has to touch them to turn the page and needs to keep her hands clean]

6. The phone rings, nurse answers the phone, it's the child's community nurse. Nurse feeds back on teaching so far: 'Mum and dad are learning how to care for him at home. They are doing extremely well'. She continues by discussing the support the community nurse may need to provide once the child is discharged home

7. Nurse advises the mother she will write to the family's water company to request the rate is capped as the family have a water meter at home. She will also write to electricity company to advise them the family should be prioritised if there are any works to electricity cables. Nurse checks with mother about benefits, mother advises they already claim DLA - the community nurse helped mum to complete the form.

8. Nurse advises parents that if family go on holiday, dialysis fluids can be delivered worldwide

9. Mother explains to nurse: 'When I'm connecting and disconnecting, I'm going to have to put [name of child's younger brother] in his cot'

6 References

1. DoH/DfES. Every Child Matters-National Service Framework for Children, Young People and Maternity Services. Nottingham: Department for Education and Skills, 2004.
2. Sinha MD, Webb NJA. Shared care of children with renal disease. *Current Paediatrics* 2006;16(4):254(5).
3. Lewis M, Shaw J, Reid C, Webb N, Verrier-Jones K. Demography and management of childhood established renal failure the UK. *Nephrol Dial Transpl* 2007;22:165-75.
4. Drotar D. *Promoting adherence to medical treatment in chronic childhood illness*. London: Psychology Press, 2000.
5. Swallow V, Clarke C, Campbell S, Lambert H. Nurses as family learning brokers: shared management in childhood chronic kidney disease. *Journal of Nursing and Healthcare of Chronic Illness* 2009;1:49-59.
6. Coffey J. Parenting a Child with Chronic Illness: A Metasynthesis. *Pediatric nursing* 2006;32(1):51.
7. Swallow V. An exploration of mothers' and fathers' views of their identities in chronic-kidney-disease management: parents as students? *Journal of Clinical Nursing* 2008;17(23):3177-86.
8. Knafl KA, Darney BG, Gallo AM, Angst DB. Parental perceptions of the outcome and meaning of normalization. *Research in Nursing & Health* 2010;33(2):87-98.
9. Hexem K, Bosk A, Feudtner C. The dynamic system of parental work of care for children with special health care needs: A conceptual model to guide quality improvement efforts. *BMC Pediatrics* 2011;11(1):95.
10. Aldridge M. How Do Families Adjust to Having a Child with Chronic Kidney Failure? A Systematic Review. *Nephrology Nursing Journal* 2008;35(2):157-62.
11. Sullivan-Bolyai SDCNSRN, Rosenberg R, Bayard M. Fathers' Reflections on Parenting Young Children With Type 1 Diabetes. *MCN, American Journal of Maternal Child Nursing January/February* 2006;31(1):24-31.
12. DOH. The National Service Framework for Renal Services: Working for Children and Young People. London: Department of Health, 2006.
13. Coulthard MG, Crosier J. Outcome of reaching end stage renal failure in children under 2 years of age. *Arch Dis Child* 2002;87(6):511-17.
14. Divertie V. Strategies to Promote Medication Adherence in Children With Asthma. *American Journal of Maternal Child Nursing* 2002;27(1):10-18.
15. Swallow V, Lambert H, Clarke C, Campbell S, Jacoby A. Childhood chronic-kidney-disease: A longitudinal-qualitative study of families learning to share management early in the trajectory. *Patient Education and Counseling* 2008;73:354-62.
16. Kieckhefer G, Churchill S, Trahms C, Simpson J. Measuring Parent-Child Shared Management of Chronic Illness. *Pediatric Nursing* 2009;35(2):101-27.
17. Knafl K, Gilliss C. Families and Chronic Illness: a Synthesis of Current Research. *Journal of Family Nursing.* 2002;8(3):178-98.
18. Swallow V, Lambert H, Santacroce S, Macfadyen A. Fathers and mothers developing skills in managing children's long-term medical conditions: how do their qualitative accounts compare? *Child: Care, Health & Development* 2011;37(4):512-23.
19. Swallow VM, Jacoby A. Mothers' evolving relationships with doctors and nurses during the chronic childhood illness trajectory. *Journal of Advanced Nursing* 2001;36(6):755-64.
20. Swallow V, Macfadyen A, Santacroce S, Lambert H. Fathers' contributions to the management of their child's long-term medical condition: a narrative review of the literature. *Health Expectations* 2011.
21. Macfadyen A, Swallow V, Santacroce S, Lambert H. Involving fathers in research. . *Journal for Specialists in Pediatric Nursing* 2011.

22. Swallow VM, Jacoby A. Mothers' coping in chronic childhood illness: the effect of presymptomatic diagnosis of vesicoureteric reflux. *Journal of Advanced Nursing* 2001;33(1):69-78.
23. Knafl K, Deatrick JA, Gallo A, Dixon J, Grey M, Knafl G, et al. Assessment of the Psychometric Properties of the Family Management Measure. *Journal of Pediatric Psychology* 2009:jsp034.
24. BRS. The Renal Team, A Multi-Professional Renal Workforce Plan For Adults and Children with Renal Disease: Recommendations of the National Renal Workforce Planning Group 2002: British Renal Society, 2002.
25. Menon S, Valentini RP, Kapur G, Layfield S, Mattoo TK. Effectiveness of a Multidisciplinary Clinic in Managing Children with Chronic Kidney Disease. *Clinical Journal of the American Society of Nephrology* 2009;4(7):1170-75.
26. Bayliss EA, Bhardwaja B, Ross C, Beck A, Lanese DM. Multidisciplinary Team Care May Slow the Rate of Decline in Renal Function. *Clinical Journal of the American Society of Nephrology* 2011;6(4):704-10.
27. Hovey JK. Fathers parenting chronically ill children: concerns and coping strategies. *Issues in Comprehensive Pediatric Nursing* 2005;28(2):83-95.
28. Ahmann E. Suppporting fathers' involvment in children's care. *Journal of Pediatic Nursing* 2006;32(1):88-99.
29. Hovey JK. Differences in parenting needs of fathers of children with chronic conditions related to family income. *Journal of Child Health Care* 2006;10(1):43-54.
30. O'Brien M. Shared Caring: Bringing Fathers into the Frame. London: Equal Opportunities Commission., 2005.
31. Burgess A. Fathers and Public Services. In: Stanley K, editor. *Daddy Dearest? Active Fatherhood and Public Policy.* London: IPPR, 2005.
32. Swallow V, Lambert H, Santacroce S, Macfadyen A. Fathers and mothers developing skills in managing children's long-term medical conditions: how do their qualitative accounts compare? *Child: Care Health & Development* 2011.
33. Swallow V, Macfadyen A, Lambert H, Santacroce S. Fathers' contributions to management of their children's long-term medical conditions: a narrative review of the literature. *Health Expectations* 2011.
34. Marshall C, Rossman GR. *Designing Qualitative Research*. 3rd ed. London: Sage Publications, 1999.
35. MRC. Developing and evaluating complex interventions: new guidance. London: Medical Research Council, 2008.
36. MRC. A Framework for Development and evaluation of RCTs for complex interventions to improve health. London: Medical Research Council, 2000.
37. Duffy ME. Methodological triangulation: a vehicle for merging quantitative and qualitative research methods. *Image the Journal of Nursing Scholarship* 1987;19:130-33.
38. Streubert HJ, Carpenter DR. *Qualitative Research in Nursing: advancing the Humanistic Imperative*. 2nd ed. New York: Lippincott, 1999.
39. Ritchie J, Lewis J, editors. *Qualitative Research Practice: A guide for Social Science Students and Researchers*. London: Sage Publications, 2003.
40. Green J, Thorogood N. *Qualitative methods for health research*. London: Sage, 2004.
41. Saks M, Allsop J. *Researching health: qualitative, quantitative & mixed methods*. Los Angeles: Sage, 2007.
42. Leech N, Dellinger A, Brannagan K, H. HT. Evaluating Mixed Research Studies: A Mixed Methods Approach. *Journal of Mixed Methods Research* 2010;4(1):17-31.
43. Spencer L, Ritchie J, Lewis J, Dillon L. Quality in Qualitative Evaluation: a Framework for Assessing Research Evidence. London: Government Chief Social Researcher's Office, 2003.

44. Clark J. How to peer review a qualitative manuscript. In: Godlee F, T. TJ, editors. *Peer Review in Health Sciences*. 2nd ed. London: BMJ Books, 2003:219-35.

45. Swallow VM, Allen D, Williams J, Smith T, Crosier J, Lambert H, et al. Pan-Britain, mixed-methods study of multidisciplinary teams teaching parents to manage children's long-term kidney conditions at home: study protocol. *BMC health services research* 2012;12:33.

46. Marr S, Steele K, Swallow V, Craggs S, Procter S, Newton J, et al. Mapping the range and scope of emergency nurse practitioner services in the Northern and Yorkshire Region: a telephone survey. *Emergency Medicine Journal* 2003;20(5):414-17.

47. Feveile H, Olsen O, Hogh A. A randomized trial of mailed tools versus telephone interviews: response patterns in a survey *BMC medical research methodology,* 2007;7(27).

48. Green J, Thorogood N. In-depth interviews. In: Green J, Thorogood N, editors. *Qualitative methods for health research*. London: Sage, 2004.

49. Ritchie J, Spencer L. Qualitative Data Analysis For Applied Policy Research. In: Bryman A, Burgess RG, editors. *Analyzing Qualitative Data*. London: Routledge, 1994:173-94.

50. Swallow V, Newton J, Van Lottum C. Research in brief. How to manage and display qualitative data using 'Framework' and MICROSOFT Excel. *Journal of Clinical Nursing* 2003;12(4):610-12.

51. Hammersley M, Atkinson P. *Ethnography: Principles in Practice*. 2nd ed. London: Routledge, 1995.

52. Swallow V, Newton J, Van Lottum C. How to manage and display qualitative data using 'Framework' and Microsoft (R) Excel. *Journal of Clinical Nursing* 2003;12(4):610-12.

53. Allen D, Griffiths L, Lyne P. Accommodating health and social care needs: routine resource allocation in stroke rehabilitation. *Sociology of Health & Illness* 2004;26(4):411-32.

54. O'Reilly K. *Key Concepts in Ethnography*. London: Sage Publications, 2008.

55. Hammersley M, Atkinson P. *Ethnography: Principles in Practice*. 3rd ed. London: Routledge, 2007.

56. Mays N. Qualitative research: Observational methods in health care settings. *BMJ,* 1995;311:182-84.

57. Sharman C, Cross W, Vennis D. *Observing children and young people*. London: Continuum, 2007.

58. Swallow V, Coad J, Macfadyen A. Involving children, young people and parents in knowledge generation in health and social care research. . In: Nolan M, Hanson E, Grant G, Keady J, editors. *User Participation Research in Health and Social Care*. Buckingham: OUPress, 2007:151-65.

59. Edwards A, Daniels H, Gallagher T, Leadbetter J, Warrington P. *Improving Inter-professional Collaborations: Multi-agency Working for Children's Well-being*. Abingdon: Routedge, 2009.

60. Engestrom Y, Middleton D. *Cognition and Communication at Work*. Cambridge: Cambridge University Press, 1996.

61. Lave J, Wenger E. *Situated Learning: Legitimate Peripheral Participation*. Cambridge: Cambridge University Press, 1991.

62. Lingard L, Reznick R, DeVito I, Espin S. Forming professional identities on the health care team: discursive constructions of the 'other' in the operating room. *Medical Education* 2002;36(8):728-34.

63. Wenger E. *Communities of Practice: Learning, Meaning and Identity*. Cambridge: Cambridge University Press, 1998.

64. Robinson M, Cottrell D. Health professionals in multi-disciplinary and multi-agency teams: Changing professional practice. *Journal of Interprofessional Care,* 2005;19(6):547-60.

65. Engestrom Y, editor. *Perspectives on activity theory*. New York: Cambridge University Press, 1999.

66. Engestrom Y. Expansive learning at work: Toward an activity theoretical reconceptualisation. *Journal of Education and Work,* 2001;14:133 – 56.

67. DOH. Better Information, Better Choices, Better Health: putting information at the centre of health, Department of health, London. London: Deaprtment of Health, 2004.

68. Newbould J, Taylor D, Bury M. Lay-led self-management in chronic illness: a review of the evidence. *Chronic Illness* 2006;2(4):249-61.
69. Rogers A. Advancing the expert patient? *Prim Health Care Res Dev* 2009;19(3):167-76.
70. Williams A, Noyes, J. (Joint PIs), Chandler-Oatts, J., Allen, D., Brocklehurst, P., Carter, C., Gregory, J., Lenton, S, Lewis, M., Lowes, L., Threadgold, T. Children's Health Information Matters: Researching the practice of and requirements for age appropriate health information for children and young people. *Final Report*: NIHR-SDO 2011.
71. DoH. The Expert Patient: A New Approach to Chronic Disease Management in the 21st Century. London: The Stationery Office, 2001.
72. Kirk S, Beatty S, Callery P, Milnes L, Pryjmachuk S. Evaluating self-care support for children and young people with long-term conditions: NIHR-SDO, 2010.
73. DoH. Core Principles to Support Self-Care

. London, 2008.
74. Dobbel F, Ruppar T, De-Geest S, Decorte A, Damme-Lombaerts RV-, Fine R. Adherence to the immunosuppressive regimen in pediatric kidney transplant recipients: A systematic review. *PediatrTransplantation* 2010;14:603-13.
75. Tong A, Lowe A, Sainsbury P, Craig JC. Experiences of Parents Who Have Children With Chronic Kidney Disease: A Systematic Review of Qualitative Studies. *Pediatrics* 2008;121(2):349-60.
76. Williams A, Noyes J. The Information Matters Project: health, medicines and self-care choices made by children, young people and their families: information to support decision-making. Study protocol. *Journal of Advanced Nursing* 2009;65(9):1807-16.
77. Hummelinck A, Pollock K. Parents' information needs about the treatment of their chronically ill child: A qualitative study. *Patient Education and Counseling* 2006;62(2):228-34.
78. Wysocki T, Gavin L. Psychometric Properties of a New Measure of Fathers' Involvement in the Management of Pediatric Chronic Diseases. *J. Pediatr. Psychol.* 2004;29(3):231-40.
79. Kirk. Parent or nurse? The experience of being the parent of a technology-dependent child. *Journal of Advanced Nursing* 2005;51(5):456-64.
80. Carnevale F, Macdonald M, Bluebond-Langner M, McKeever P. Using participant observation in pediatric health care settings: ethical challenges and solutions. *Journal of Child Health Care* 2008;12(18):18-32.
81. Bluebond-Langner M. *In the shadow of illness.* Chichester, UK: Princeton University Press,, 1996.
82. Carnevale FA, Alexander E, Davis M, Rennick J, Troini R. Daily Living With Distress and Enrichment: The Moral Experience of Families With Ventilator-Assisted Children at Home. *Pediatrics* 2006;117(1):e48-e60.
83. Lindsay Waters A. An ethnography of a children's renal unit: experiences of children and young people with long-term renal illness. *Journal of Clinical Nursing* 2008;17(23):3103-14.
84. Wells F, Ritchie D, McPherson AC. 'It is life threatening but I don't mind'. A qualitative study using photo elicitation interviews to explore adolescents' experiences of renal replacement therapies. *Child: Care, Health and Development* 2012:no-no.
85. NRES. Research governance framework for health and social care: Second edition. In: Service NRE, editor. 2nd ed: Department of Health, 2005.
86. MRC. Ethics Guide: Medical Research Involving Children. London: Medical Research Council, 2008.
87. Carter B, Cummings J, Cooper L. An exploration of best practice in multi-agency working and the experiences of families of children with complex health needs. What works well and what needs to be done to improve practice for the future? *Journal of Clinical Nursing* 2007;16(3):527-39.
88. Grey M, Knafl K, McCorkle R. A framework for the study of self- and family management of chronic conditions. *Nursing Outlook* 2006;54(5):278-86.

89. Schilling LS, Grey M, Knafl KA. The concept of self-management of type 1 diabetes in children and adolescents: an evolutionary concept analysis. [Review] [84 refs]. *Journal of Advanced Nursing* 2002;37(1):87-99.
90. Corlett J, Twycross A. Negotiation of parental roles within family-centred care: a review of the research. *Journal of Clinical Nursing* 2006;15(10):1308-16.
91. Fielding D, Brownbridge G. Factors related to psychosocial adjustment in children with end-stage renal failure. *Pediatric Nephrology* 1999;13(9):766-70.
92. Dean A, JWalters, Hall A. A systematic review of interventions to enhance medication adherence in children and adolescents with chronic illness. *Arch Dis Child* 2010;95:717-23.
93. Cooper C, Wheeler D, Woolfenden S, Boss T, Piper S. Specialist home-based nursing services for children with acute and chronic illnesses. *Cochrane Database Systematic Review* 2006;18(4):CD004383.
94. Goldstein S. Quality of Life in Children with CKD: Research Expanding, but More Solely Needed. *Nephrology Times* 2009;July:1517.
95. Wang K, Barnard A. Technology-dependent children and their families. *Journal of Advanced Nursing* 2004;45(1):36-45.
96. Greene S. "We're tired, not sad": benefits and burdens of mothering a child with a disability. *Social Science and Medicine* 2007;64(150-63).
97. Thorne S. Patient-Provider Communication in Chronic Illness: A Health Promotion Window of Opportunity. *Family & Community Health* 2006;29(1):4S-11S.
98. Thorne SE, Nyhlin KT, Paterson BL. Attitudes toward patient expertise in chronic illness. *International Journal of Nursing Studies* 2000;37:303-11.
99. Thorne SE, Robinson CA. Guarded alliance: health care relationships in chronic illness. *Image: Journal of Nursing Scholarship.* 1989;21(3):153-7.
100. Spiers G, Parker, G., Gridley, K., Cusworth, L., Mukherjee, S., Heaton, J., Atkin, K., Birks, Y., Lowson, K. and Wright, D. Understanding care closer to home for ill children and young people,. *Nursing Children and Young People* 2012;24(5):29-34.
101. Parker G, Spiers, G., Gridley, K., Atkin, K., Birks, Y., Lowson, K. and Light, K. Systematic review of international evidence on the effectiveness and costs of paediatric home care for children and young people who are ill, , . *Child: care, health and development* 2012;(Available online from 13 February 2012).
102. RCPCH. RCP (Royal College of Paediatrics and Child Health) Ethics Advisory Committee. *Archives of Disease in Childhood* 2000;82:177-82.
103. Sawyer S, Drew S, Yeo M, Britto M. Adolescents with a chronic condition: challenges living, challenges treating. *The Lancet* 2007;369:1481-89.
104. Bethell C, Forrest C, Stumbo S, Gombojav N, Carle A, Irwin C. Factors Promoting or Potentially Impeding School Success: Disparities and State Variations for Children with Special Health Care Needs. *Maternal & Child Health Journal* 2012;16:35-43.
105. Hayes V. Families and Children's Chronic Conditions: Knowledge Development and Methodological Considerations. *Scholarly Inquiry for Nursing Practice: An International Journal* 1997;11(4):259-90.
106. RCPCH. Improving the standard of care of children with kidney disease through paediatric nephrology networks. London: Royal College of Paediatrics and Child Health, 2011.
107. Streiner D, Norman G. *Health Measurement Scale*. Oxford: Oxford University Press, 2008.
108. Swallow V, Webb N, Hall A, Santacroce S, Smith T, Campbell M, et al. The OPIS (On-line Parent Information and Support) project - Meeting mothers' and fathers' information and support needs for home-based management of childhood kidney conditions: Research Protocol-early on-line *Journal of Advanced Nursing* 2012.