Parents' management of their child's hydrocephalus and shunt

Joanna Smith

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The candidate confirms that the work submitted is her own and that appropriate credit has been given where reference has been made to the work of others.

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Abstract

Introduction

Shunts are the main treatment for hydrocephalus. When shunts malfunction the consequences are serious and can be life threatening. Identifying shunt malfunction requires effective parent-professional collaboration: parents need to recognise and respond appropriately to the symptoms of shunt malfunction in their child; professionals need to integrate parents' information about their child's symptoms during clinical decision-making and diagnosis. This thesis explored parents' experiences of living with a child with hydrocephalus and parents' and professionals' contribution to the diagnosis of shunt malfunction in acute hospital admissions.

Methods

Two exploratory studies were undertaken using interview and observational methods to elicit data. The framework approach and conversation analysis were used to analyse and interpret data.

Findings

Parents gain considerable skills and knowledge about their child's health needs. They are able to distinguish between symptoms indicating shunt problems from other childhood illnesses. Deciding where or when to seek help is influenced by minimising disruption for the whole family and prior experiences of healthcare services. Parents' perceive that their expertise is not always valued by health professionals and not always used to make clinical decisions. Analysis of parent-professional interactions suggests health professionals' involvement of parents' in decisions about their child's care is variable. There was evidence of some collaborative practice but tensions were evident within the interactions when parents disagreed with professionals' judgments.

Conclusion

A collaborative paradigm is appropriate when engaging with expert parents living with a child with hydrocephalus. The challenge for health professionals is to integrate parents' expertise of their child's presenting symptoms within their clinical assessment when planning the child's care.

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Abbreviations

ASBAH	Association for Spina Bifida and Hydrocephalus
ASSIA	Applied Social Sciences Index and Abstracts
BNI	British Nursing Index
CA	Conversation Analysis
CASP	Critical Appraisal Skills Programme
CT	Computerised Tomography
CINAHL	Cumulative Index to Nursing and Allied Health Literature
COMRADE	Combined Outcome Measure for Risk Communication and Treatment Decisions Effectiveness
CRD	Centre for Reviews and Dissemination
DA	Discourse Analysis
DfES	Department for Education and Skills
DH	Department of Health
EMBASE	Excerpta Medica Database
FPP	First Pair Part
LGI	Leeds General Infirmary
LREC	Local Research Ethics Committee
NHS	National Health Service
IPA	Interpretative Phenomenological Analysis
OPTION	Observed Patient Involvement
PSYCINFO	Psychological Information Database
RCN	Royal College of Nursing
R&D	Research and Development
SPP	Second Pair Part
SIGLE	System for Information of Grey Literature
UK	United Kingdom
WHO	World Health Organisation

Figures and tables

Appendices

Chapter 1
Parents' management of their child's hydrocephalus and shunt: context and concepts

1. Introduction

The focus of this PhD thesis is parents' experiences and involvement in the care of their child's hydrocephalus and shunt. This chapter presents the rationale for two empirical studies: the first is a cross-sectional interview-based study exploring parents' experiences and perceptions of living with a child with hydrocephalus; the second is a mixed methods study examining parent-professional collaboration when diagnosing shunt malfunction in children. In order to provide background context to these studies, the concepts and theoretical perspectives that may explain parents' beliefs and behaviours in relation to meeting their child's needs, and the ways in which health professionals engage with parents are presented. In addition, the literature relating to hydrocephalus and its treatment, and the impact of the condition for the child and family are outlined.

Publications and presentations to emerge from this thesis to-date are presented in Figure 1.

Figure 1: Publications and presentations

Publications
Smith J, Firth J (2011) Qualitative data analysis: application of the framework approach. *Nurse Researcher* **18** (2): 52-62
Smith J, Bekker H, Cheater F (2011) Theoretical versus pragmatic design challenges in qualitative research. *Nurse Researcher* **18** (2): 39-51
Smith J, Cheater F, Chatwin J, Bekker H (2008) Parent's involvement in decisions when their child is admitted to hospital with suspected shunt malfunction: study protocol. *Journal of Advanced Nursing* 65 (10): 2198-2207
Smith J (2008) Living with a child with hydrocephalus. *Link* Summer: 224

Presentations
Smith J (2009) Parent participation in the context of diagnosing shunt malfunction in children. *Royal College of Nursing (RCN), Children and Young Peoples Field of Practice International Conference*, Liverpool Invited speaker
Smith J, Cheater F, Bekker H (2008) The challenges of interviewing parents together when exploring their experiences of living with a child with shunted hydrocephalus. *RCN International Research Conference,* Liverpool
Smith J, Cheater F, Bekker H (2008) Using the framework approach to explore parents' experiences of living with a child with hydrocephalus. *RCN International Research Conference*, Liverpool
Smith J, Cheater F, Bekker H (2008) Parents' experiences of living with a child with hydrocephalus (poster). *School of Healthcare Annual Research Conference*, Leeds Winner of the best conference poster award
Smith J, Cheater F, Bekker H (2007) Living with a child who has shunted hydrocephalus: parents' perspectives (poster). *European Health Psychology Society International Research Conference*, Maastricht
Smith J, Cheater F, Bekker H (2006) What are parents' experiences and perceptions of living with a child who has shunted hydrocephalus? (poster) *RCN International Research Conference*, York

1.1 Aims and objectives

The work presented in thesis explored parents' involvement in the care of their child's hydrocephalus and shunt and the ways in which parents' and professionals' collaborate when making a diagnosis of shunt malfunction in children. The specific objectives were to:

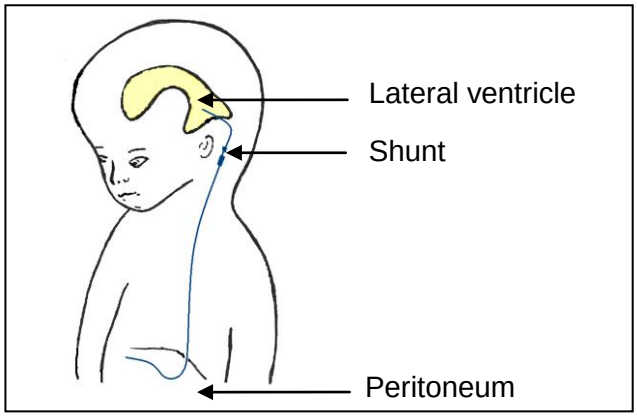
1. Compare parents' experiences of living with a child with hydrocephalus with those of other long-term conditions;
2. Explore parents' decisions when their child experiences illness symptoms and their subsequent health seeking behaviour when shunt malfunction is suspected;
3. Examine parents' and health professionals' contribution to the diagnosis of shunt malfunction in acute hospital admissions;
4. Describe parents' and health professionals' perceptions and experiences about shared-decision making processes when assessing a child with illness symptoms that may be shunt related.

1.2 Context

Hydrocephalus is a condition normally identified in early childhood where there is excessive fluid in the ventricular system within the brain. The ventricular system is a network of connected chambers which produce and contain cerebrospinal fluid. Increased cerebrospinal fluid levels cause ventricular enlargement resulting in compression and destruction of adjacent structures which affects brain growth and development (Del Bigio 1993, Fletcher et al 1996). Left untreated over half of children with hydrocephalus will not survive (Laurence and Coates 1962, Yashon et al 1965, Shurtleff et al 1973). For those children who survive they are likely to have significant physical disabilities and learning difficulties (Laurence and Coates 1962, Yashon et al 1965). An overview of hydrocephalus is presented in Section 1.3.

The main treatment for hydrocephalus is the insertion of a permanent device that diverts excessive fluid from the ventricles of the brain to another body compartment, commonly the peritoneum, known as a shunt (Figure 2). The widespread use of shunts to treat hydrocephalus has significantly improved the survival of these children: the mortality rate for children with shunted hydrocephalus is between 4 and 18% (Casey et al 1997, Fernell and Hagberg 1998, Hoppe-Hirsch et al 1998, Tuli et al 2000, Heinsbergen et al 2002, Vinchon et al 2003). Despite being the standard treatment for managing hydrocephalus shunts are prone to malfunctioning. Failure rates are in the region of 40 - 50% within the first year of placement (Piatt and Carson 1993, Drake et al 1998) and 70% of children require at least one shunt revision during their lifetime (Drake et al 1998). Identifying and treating shunt malfunction promptly is important because shunt failure can result in permanent neurological impairments or death (Kirkpatrick et al 1989, Rekate 1991, Watkins et al 1994, Iskandar et al 1998). Shunt malfunction necessitates the child to undergo surgery to revise the shunt.

Figure 2: Position of ventriculo-peritoneal shunt



If detected early, death as a result of shunt malfunction is preventable (Iskandar et al 1998). Parents living with a child with hydrocephalus are responsible for recognising and responding to possible shunt malfunction in their child. This includes seeking advice from health professionals. Likewise, health professionals have a duty of care to identify possible shunt malfunction in children with hydrocephalus. Increased clinical negligence claims because of failure to recognise shunt malfunction suggests some doctors are unable to identify the symptoms of shunt failure in children (Punt 2004). Recognising shunt malfunction is problematic because symptoms are highly variable and often unique to each child (Kirkpatrick et al 1989, Watkins et al 1994, Garton et al 2001, Barnes et al 2002). In addition, although the combination of vomiting, drowsiness and headache are highly predictive of shunt malfunction, these are the same presenting symptoms of many childhood illnesses, particularly viral infections (Watkins et al 1994, Barnes et al 2002). A key recommendation from research relating to diagnosing shunt malfunction is the need for health professionals to listen to and value parents' concerns when assessing a child for possible shunt malfunction (Watkins et al 1994, Barnes et al 2002, Punt 2004). A scoping review suggests there to be a paucity of research relating to parent-professional collaboration when establishing a diagnosis of shunt malfunction in children (Appendix I).

My interest in children with hydrocephalus and their families developed when working as a senior nurse on a children's neuroscience ward. In common with other regional children's neuroscience departments, caring for children with

hydrocephalus and their families formed a significant part of the ward's workload (Chumas et al 2001). When managing these children and their families two areas of care were of personal concern. These related to ensuring parents had the skills to recognise shunt malfunction when the child was discharged from hospital and a realisation that the child and family's lives were being disrupted because of the frequency of hospital admissions for potential shunt malfunction. Also, it was evident that parents gained considerable expertise in recognising and responding to changes in their child and had the potential to actively contribute to care decisions.

1.3 Long-term conditions in children

This section offers a definition for long-term conditions in children and outlines the impact of living with a child with a long-term condition. In addition, the Expert Patient Programme, one of the United Kingdom (UK) health strategies aimed at supporting individuals living with a long-term condition and its applicability in the child health setting will be explored (DH 2001a).

1.3.1 Long-term conditions: a definition

Defining chronic health conditions in children is complex because of their diversity, differences in disease progression and the variability of the impact on the child's growth and development. A range of terms are used to describe illnesses which are of an enduring nature and impact on the individual's life. For example the World Health Organisation (WHO) and the UK Department of Health (DH) use the terms 'chronic disease', 'chronic illness', 'chronic conditions', 'disabling conditions', 'long-standing disease' and 'long-term conditions' interchangeably to refer to conditions that are managed but not cured and affect the individual and their family in a variety of ways for the rest of their lives (DH 2001a, WHO 2002, DH 2005a, 2009).

Although used interchangeably, it is likely terminology has evolved with new ways of thinking about the relationship between health and illness (van der Lee et al 2007). For example 'chronic illness' has been defined as the presence of illness symptoms lasting more than three months, reflecting a medical model of

healthcare based on treating illness symptoms (Pless and Douglass 1971). In contrast 'chronic health conditions' refers to enduring conditions that require ongoing input from health or social services to enable the individual to fulfil their potential, reflecting a more holistic approach to healthcare (Perrin et al 1993, Stein and Silver 1999). More recently, the preference for using the term 'long-term' as opposed to 'chronic' circumvents negative associations with the latter which implies an unremitting and remorseless condition and may not represent lay perspectives.

For the purposes of this thesis 'long-term condition' will be used and refers to health conditions that are permanent and impact on the child's growth and development, necessitating ongoing health, social and/ or educational support for the child and family (Perrin et al 1993, Stein et al 1993, Stein and Silver 1999). The definition offered is appropriate for children with hydrocephalus because it is a permanent condition that may result in physical impairments such as hearing, visual and coordination problems, and learning and behavioural difficulties (Fletcher et al 1996, Fernell and Hagberg 1998, Scott et al 1998, Heinsbergen et al 2002). Children with hydrocephalus could also be classified as technology dependent because the majority of children require a permanent shunt to manage the condition. However, a shunt is an internal device and once inserted does not require ongoing maintenance unless it malfunctions.

1.3.2 Living with a child with a long-term condition

Living with a child with a long-term condition can result in challenges above usual parenting responsibilities including illness specific demands such as maintaining treatment and care regimes, social and financial constraints, and maintaining family relationships (Eiser 1990). Two distinct areas of research have evolved in relation to exploring the impact of living with a child with a long-term condition; studies that focus on identifying the factors that might account for the variations in families' responses to the child's illness and studies describing the experiences and perceptions of living with a child with a long-term condition (Knafl and Gilliss 2002). The latter is the focus of Chapter 2, which presents the findings from a structured review of studies that have explored parents' experiences of living with a child with a long-term condition. Studies exploring

differences in the responses to living with a child with a long-term condition can be clustered into two areas of research; family variables that contribute to the child's response to their condition and the identification of variables that explain the quality of family functioning (Knafl and Gilliss 2002).

Findings from empirical studies investigating the impact of living with a long-term condition for the child are equivocal; poor adjustment and psychosocial problems such as isolation, low self-worth and anxiety have been reported in some studies (Daniels et al 1987, Drotar 1997), with good adjustment reported in others (Finney and Bonner 1992, Thompson et al 1994a). Variables such as family cohesion, adjustment and conflict have been investigated as factors that have the potential to exacerbate or attenuate the impact of the condition for the child (Finney and Bonner 1992, Thompson et al 1994a, Knafl and Gillis 2002). Good family adaptation to living with a child with long-term condition is associated with better adjustment in the child (Finney and Bonner 1992, Thompson et al 1994a). Research investigating the impact for the child living with a long-term condition typically relies on proxy information gained from parents. Findings may not be representative of children and young people's perspectives.

Similarly, findings from studies investigating the impact for parents living with a child with a long-term condition are also equivocal, with good and poor adjustment reported (Thompson et al 1992, Thompson et al 1994b, Wallander and Varni 1998, Bonner et al 2006). A range of variables such as stress, family functioning and adaptation have been investigated in an attempt to understand variations in families' responses to living with a child with a long-term condition (Wallander and Varni 1998, Bonner et al 2006, Vermaes et al 2008). Fewer family stressors and effective stress-coping strategies are associated with better family functioning and adjustment to living with a child with a long-term condition (Vermaes et al 2008). Additional factors that appear to be linked to better family functioning include: having extensive social networks (Taanila et al 1999); increased financial resources (Cavallo et al 2009); a cohesive family unit and sharing of care-giving burdens (Hentinen and Kyngäs 1998); the ability to find meaning in the illness experience (Kirpalani et al 2000). However, associations

are weak making it difficult to draw firm conclusions about the significance of any single variable and the relationship between variables.

1.3.3 The expert patient

The ability of individuals to contribute to the management of their own condition has been cited as being fundamental to the future of healthcare delivery within developed countries (WHO 2002). The anticipated benefits of empowering patients to self-manage their care are improved health outcomes because patients are more likely to respond and act on illness symptoms, more effective use of medicines and treatments, greater understanding of the implications of professional advice and better ability to cope with the condition (DH 2007, Coulter et al 2008). Self-management initiatives have become embedded in the health policies of developed countries such as: the United States of America 'Chronic Disease Self Management Programme' (Lorig et al 1999); 'The Expert Patient Programme' within the UK (DH 2001a); the Australian 'Sharing Health Care' initiative (Australian Government Department of Health and Ageing 2007).

1.3.3.1 The expert adult patient

The underpinning principle of the expert patient agenda is to empower patients to use their knowledge and expertise to manage their own condition and become effective collaborators in decisions about their healthcare (DH 2001a). This empowerment is to be developed through attending a self-management programme. These programmes are based on self-efficacy theories; the prerequisite to behaviour change is dependent on improving the self-efficacy of the patient which is likely to influence health decisions and healthcare usage (Lorig and Holman 2003). Programmes focus on the common challenges confronting individuals across conditions including seeking and gaining information, managing stress, understanding service provision and working effectively with health professionals (DH 2001a, 2005b, Coulter et al 2008).

Widespread implementation of self management programmes has occurred without a critical evaluation of their effectiveness (Griffiths 2007). Two systematic reviews of lay-led self management programmes suggested there are

modest, short-term improvements in patients' confidence to manage and cope with their condition, and some improvement in symptoms but there is no evidence to support their effectiveness in terms of improved quality of life, reduced number of health professional consultations and hospital visits (Bury et al 2005, Foster et al 2007). Many self-management programmes within the UK are disease specific and delivered by voluntary organisations with minimal professional involvement, which may not provide opportunities for developing effective patient-professional collaborations (Coulter and Ellins 2006). Research suggest self-management programmes offered by voluntary organisations when compared to those delivered in partnership with health professionals and incorporated into existing service provision are less effective in relation to reducing medication usage and hospital admission rates (Coulter et al 2008).

There are several gaps in the current evidence base in relation to expert patient programmes; first the study population is based on adult patients and focussed on health outcomes (Foster et al 2007). Second, there is a paucity of qualitative approaches exploring patient experiences and perceptions of these programmes (Foster et al 2007). Qualitative methods may be more informative in terms of understanding patient expectations and the reasons for poor uptake of programmes. An evaluation of patient views about healthcare provision suggests patients want to engage effectively with health professionals and be more actively involved in the management of their long-term conditions (Richards and Coulter 2007). Yet self-management programmes have experienced recurring difficulties in recruiting participants (Coulter and Ellins 2006). The reasons for poor patient uptake include: difficulties in accessing hard to reach patients, for example, those from ethnic minority groups; lack of understanding of the purpose of the programmes; lack of receptiveness to lay-led programmes; health professionals having limited awareness of available programmes (Coulter and Ellins 2006, Pinkus 2006). Despite challenges to the delivery of self-management programmes, UK health policy is committed to advancing these programmes, with a clear mandate for primary care trusts to offer locally lay led self-management programmes to all patients living with a long-term condition (DH 2007).

1.3.3.2 The expert parent

The establishment of the expert patient agenda was criticised for not recognising and considering the specific needs of children and parents as expert patients (DfES/ DH 2004). Children and parents are likely to have similar issues to adult patients such as seeking and gaining information, managing stress and working collaboratively with health professionals. It is also likely there will be differences; for example, parents living with a child with a long-term condition have identified the need to develop the skills to ensure their child's education and development needs are met, and to deal with challenging behaviour (Hallström and Elander 2007). Teenagers and young people want more information on mental health issues, risk taking behaviours, support in relation to dealing with peer pressure and guidance when planning for the transition to adult care (Farrant and Watson 2004).

Although self-management programmes are now being implemented for young people living with a long-term condition and parents, to-date there is no empirical evidence evaluating their effectiveness. In addition, although frequently used within policy documents relating to children, the concept of 'the expert parent' has not been explored in depth (DH 2001b, DfES/DH 2004, 2005). Understanding the nature of expert parents in terms of the attributes that constitute becoming an expert, and the ways health professions engage with and incorporate expert parents' opinions into care decisions when working with children with long-term conditions may facilitate better parent-professional engagement and collaboration.

1.4 An overview of the condition of hydrocephalus

Various diseases cause hydrocephalus; approximately half of children with hydrocephalus have a congenital anatomical defect in the brain, this group includes hydrocephalus associated with spina bifida (Mori et al 1995, Fernell and Hagberg 1998). Other common causes are intraventricular haemorrhage associated with premature births and hydrocephalus following complications of meningitis (Mori et al 1995, Fernell and Hagberg 1998). National or international epidemiological data are not routinely collected relating to hydrocephalus

therefore the incidence and prevalence remains unknown. However, a review of more than 60 studies spanning 40 years reports a mean incidence rate for congenital hydrocephalus of 0.7 per 1, 000 live births (Blackburn and Fineman 1994). The prevalence rate for infantile hydrocephalus, excluding hydrocephalus associated with spina bifida, is between 0.6 and 1.6 per 1, 000 live births (Fernell et al 1986, Fernell and Hagberg 1998, Murshid et al 2000). The difference in the reported prevalence rates may be a result of improvements in neonatal care resulting in a decline in hydrocephalus associated with premature births. The cause of hydrocephalus influences treatment options and the child's prognosis in terms of mortality and functional outcomes (Mori et al 1995, Fernell and Hagberg 1998). The next section provides an overview of the management of hydrocephalus and the impact on the child and family.

1.4.1 The treatment of childhood hydrocephalus

Guidance on the most appropriate treatment for hydrocephalus does not exist; nor has a systematic review of the effectiveness of treatments been undertaken. However, there is an extensive literature base relating to the treatment of hydrocephalus which can be broadly divided into non-surgical treatments, also referred to as medical or conservative management, and surgery.

1.4.1.1 Non-surgical management of hydrocephalus

The non-surgical treatment of hydrocephalus includes: compressive head wrapping (Porter 1975); regular removal of cerebrospinal fluid (Ventriculomegaly Trial Group 1990); diuretic therapies such as acetazolamide and furosemide which slow cerebrospinal fluid production (International PHVD Drug Trial Group 1998); intraventricular fibrinolytic agents such as streptokinase and tissue plasminogen activator which break down blood clots that occur as a result of intraventricular haemorrhages in premature infants and block the flow of cerebrospinal fluid (Whitelaw et al 1996). Evidence suggests that non-surgical treatment of hydrocephalus is largely ineffective in terms of establishing effective cerebrospinal fluid circulation and preventing brain damage.

Clinical trials comparing diuretic therapies (International PHVD Drug Trial Group 1998, Kennedy et al 2001) and fibrinolytic agents (Whitelaw et al 1992, Whitelaw et al 1996) with the surgical management of hydrocephalus suggest these treatments are ineffective; the majority of children eventually require surgery. In addition, complications of non-surgical treatments include: infections and brain tissue damage due to the frequency and invasive nature of the techniques used to remove cerebrospinal fluid (Ventriculomegaly Trial Group 1990, Chumas et al 2001); adverse drugs reactions following diuretic and fibrinolytic therapies such as respiratory problems, renal and hepatic failure, and blood clotting problems (Whitelaw et al 1996, Kennedy et al 2001). Although the evidence does not support the non-surgical treatment of hydrocephalus, drug therapy may be justified in very premature infants where the risk of surgery, or not treating, is greater than those associated with pharmacological treatments (Chumas et al 2001).

1.4.1.2 Surgical management of hydrocephalus

The two main surgical procedures for the treatment of hydrocephalus are the insertion a shunt or performing an endoscopic third ventriculostomy, which aim to establish effective cerebrospinal fluid flow (Punt 2004). Endoscopic third ventriculostomy involves creating a channel between the ventricles and the spaces at the base of the brain enabling cerebrospinal fluid to drain. The advantage is that unlike shunts there is no need for a permanent implant. The main disadvantages are that the procedure is only suitable for certain causes of hydrocephalus and it is ineffective if there are problems relating to cerebrospinal fluid re-absorption (Cinalli et al 1999, Fukuhara et al 2000). In addition, many children require more than one procedure to achieve adequate cerebrospinal fluid flow and over a third of children eventually require the insertion of a shunt (Cinalli et al 1999, Fukuhara et al 2000).

Seventy percent of children with hydrocephalus are managed by the insertion of a ventricular shunt (Whitelaw et al 1996, Fernell and Hagberg 1998, Kennedy et al 2001). Since the original design in the 1950's there has been a myriad of developments in shunt systems (Punt 2004). However, all systems operate on similar principles; a catheter incorporating a one-way valve is inserted internally

and positioned to enable cerebrospinal fluid to drain from the brain to another body compartment, usually the peritoneum. Valves have threshold pressures; when the ventricular pressure is greater than the valve pressure, the valve is forced open allowing cerebrospinal fluid to flow through the system. Despite a vast array of shunt systems, only one clinical trial comparing their efficacy has been undertaken (Drake et al 1998). Findings were inconclusive with no differences in failure rates between the shunts compared (outcomes included shunt blockage, over-drainage, infections); no one design was recommended.

As highlighted in Section 1.1 shunts are prone to malfunctioning. Problems can occur because shunt components can become damaged (for example tubing can fracture or become disconnected from the valve), bacteria and debris can occlude the shunt system, and unsuitable valve pressures result in over or under drainage of cerebrospinal fluid (Piatt and Carson 1993, Drake et al 1998, Tuli et al 2004). Shunt failure causes inadequate drainage of cerebrospinal fluid with fluid accumulating in the brain and consequently a rise in intracranial pressure ensues. The effect for the child depends on the level of dependence on the shunt and the speed intracranial pressure rises. Many children are highly sensitive to increases in cerebrospinal fluid, commonly termed ‘shunt dependent’, and can deteriorate rapidly once the shunt malfunctions (Fried and Epstein 1994). Other children respond more slowly to increases in cerebrospinal fluid, and are more likely to present with subtle changes in behaviour and poor attention span rather than a sudden deterioration (Fried and Epstein 1994).

A range of factors have been investigated in relation to the possible causes of shunt malfunction. The evidence suggests:

- Shunts are more likely to fail within the first year following insertion (Drake et al 1998, Tuli et al 2000);
- Lower shunt infection rates are associated with strict adherence to infection control protocols during surgery and administering prophylactic antibiotics into the ventricles during shunt insertion (Choksey and Malik 2004);
- Lower infection and mortality rates are associated with high patient volumes and neurosurgeons working within large neurosurgical centres in relation to treating children with hydrocephalus compared with neurosurgeons with low patient volumes working in smaller centres (Cochrane and Kestle 2003, Smith et al 2004).

The two most significant risk factors in relation to shunt malfunction are age at the time of shunt insertion and the cause of the child's hydrocephalus. Shunt malfunction is more likely to occur if the child's age at the time of the shunt insertion is less than one year, with repeated revisions more likely in those children with hydrocephalus as a result of intraventricular haemorrhage or as a complication of meningitis (Piatt and Carson 1993, Lazareff et al 1998, Tuli et al 2000). The problem in relation to managing hydrocephalus in these children is one of balancing treatment complications against the potential of compromising normal brain development if hydrocephalus is left to progress (Del Bigio 1993).

1.4.2 Recognising shunt malfunction

Shunt failure, particularly for children who are shunt dependent, must be recognised and treated promptly because increased pressure in the brain can result in loss of consciousness, brain damage and death (Kirkpatrick et al 1989, Rekate 1991, Iskandar et al 1998). Research relating to recognising and responding to possible shunt malfunction in children has focused on three areas: preventing shunt related deaths; the skills of health professionals and parents in identifying shunt related illness symptoms; improving the accuracy of diagnosing shunt malfunction.

1.4.2.1 Preventing shunt related deaths

Responding to illness symptoms in their child requires parents to make a choice about where and when to seek advice. Within the UK, general practitioners are traditionally the first point of contact for individuals with health-related concerns, who decide whether referral to other services is required. Many general practitioners will have limited experience of managing children with shunted hydrocephalus (Punt 2004). Preventable deaths have occurred because illness symptoms in children with hydrocephalus have not been attributed to shunt malfunction (Iskandar et al 1998). Telephone advice and direct access to a children's neurosurgical ward is advocated as the first contact point for parents with concerns about their child's shunt (Kimmings et al 1996, Punt 2004). This type of triage can provide fast access to specialist hospital services, and for those children with a definitive diagnosis of shunt malfunction, surgery can be

arranged promptly and the shunt revised (Watkins et al 1994, Punt 2004). Uncertainty about the cause of the child's illness symptoms can be managed by a period of observation with additional investigations if required. Although direct access to regional children's neurosurgical wards is viewed as an effective model of care for the child and family, the practicalities of travel to regional centres may be difficult for some families.

A review of deaths as a direct consequence of shunt malfunction reported that some children present to neurosurgical services in a critical condition beyond medical intervention (Iskandar et al 1998). In some of these children illness symptoms had been present up to four weeks prior to death, leading to the conclusion that deaths could be prevented with improved parent education. However, data relating to parents' actions prior to the child's hospital admission and whether they had previously sought advice from health professionals was not considered; the late presentations could be a result of parents' failure to appreciate the importance of the child's symptoms and therefore seek appropriate advice, or errors in diagnosing shunt malfunction by health professionals during a prior health consultation.

1.4.2.2 The skills of health professionals and parents in identifying shunt related illness symptoms

The evidence relating to the accuracy in diagnosing shunt malfunction between doctors and parents is inconclusive. One study reported that shunt malfunction is more likely to be correctly diagnosed by parents who self-refer to neurosurgical services when compared to general practitioners and non-specialist hospital doctors (Watkins et al 1994). Whereas a second study reported that shunt malfunction is less likely to be diagnosed correctly by parents who self-refer when compared to hospital doctors (Barnes et al 2002). The findings must be considered cautiously because sample sizes were small, the grade and speciality of referring hospital doctors was unclear, and it is likely that some doctors and parents were being cautious in seeking specialist advice rather than being absolutely certain the child's illness symptoms were shunt related. Ensuring parents and primary care givers have appropriate information about the signs

and symptoms of shunt malfunction was a key recommendation from these studies (Watkins et al 1994, Barnes et al 2002).

Despite this recommendation only one study has been identified in relation to improving parents' abilities to recognise shunt-related illness symptoms in their child (Kirk et al 1992). The study was designed to test parents' knowledge pre and post an education event about hydrocephalus and shunts. Findings suggested that information provision improves parents' knowledge of hydrocephalus and shunts, but participants' prior experience of shunt malfunction did not influence either pre or post intervention test results. The authors concluded that information giving should be an ongoing process. However, the study was based on parents' ability to recall information and it is likely that a range of factors influence parents' decisions and actions when their child with hydrocephalus has illness symptoms. No research has been identified relating to parents' experiences of living with a child with shunted hydrocephalus and the process of learning to manage their child's condition.

1.4.2.3 Improving the accuracy of diagnosing shunt malfunction

As highlighted in Section 1.1, the combination of drowsiness, headache and vomiting although highly indicative of shunt malfunction are the same presenting symptoms for many childhood illnesses (Barnes et al 2002). Consequently, over half of children presenting with suspected shunt malfunction have an alternative diagnosis such as gastric, urine, throat or ear infections (Watkins et al 1994, Barnes et al 2002). The problem is not all children present with the symptoms outlined and many children have unique symptoms that indicate their shunt is malfunctioning (Watkins et al 1994, Barnes et al 2002).

Research about improving the accuracy of diagnosing shunt malfunction has focused on establishing definitive signs and symptoms, findings suggested:

- Redness of the skin over and around the shunt valve is highly indicative of shunt malfunction but is not often present (Garton et al 2001);
- Decreased conscious levels are highly predictive of shunt malfunction and is a common presenting symptoms (Garton et al 2001, Barnes et al 2002);

- Symptoms such as bulging fontanelle in infants, irritability, nausea and vomiting, and the loss of usual abilities and skills are likely to be associated with shunt malfunction (Garton et al 2001).

Difficulties in establishing shunt malfunction based on signs and symptoms have resulted in health professionals relying on the results obtained from computerised tomography (CT) scanning to diagnosis shunt malfunction. CT scanning provides the ability to visualise the brain and measure the size of the ventricles; a positive result occurs if the ventricles are enlarged when compared to previous scans. CT scanning is highly accurate with a 100% precision in relation to providing a definitive diagnosis of shunt malfunction for positive results (Watkins et al 1994). However, CT scanning is not a reliable technique for diagnosing shunt malfunction; about a third of children with no changes in the size of the ventricles will have a malfunctioning shunt (Watkins et al 1994). Despite the possibility of false negative results, CT scanning has become the main diagnostic tool for children who present with possible shunt malfunction (Garton et al 2001). Performing a CT scan has risks. Exposure to radiation may be significant for some children due to the frequency with which they undergo CT scanning. Young children may require the administration of a sedative in order to remain motionless for the duration of the scan. Sedatives can potentially cause further increases in intracranial pressure and can place the child at risk of sudden neurological deterioration (Cote et al 2000, Lawson 2000).

1.4.3 Consequences of living with a child with hydrocephalus

The outcomes for children with shunted hydrocephalus are variable with more than half of children having a combination of physical disabilities, learning difficulties and behavioural problems (Casey et al 1997, Hoppe-Hirsch et al 1998, Heinsbergen et al 2002). Living with a child with hydrocephalus has primarily been investigated in relation to the quality of life of the child with physical disabilities as result of spina bifida and hydrocephalus. Findings suggest the health related quality of life for these children is about one standard deviation lower when compared to children with other long-term physical conditions and similar to children with learning disabilities (Kirpalani et al 2000, Pit-en Cate et al 2002). Children with spina bifida have lower quality of life scores in domains related to self-care, continence and mobility and children with

hydrocephalus alone have lower scores in relation to school performance and communication difficulties (Kirpalani et al 2000, Pit-en Cate et al 2002, Bier et al 2005, Kulkarni et al 2008).

Parents' perceive that living with a child with spina bifida and hydrocephalus affects the family's quality of life because the burden of meeting the ongoing care needs for their child places strains on family relationships (Kirpalani et al 2000, Pit-en Cate et al 2002, Bier et al 2005, Vermaes et al 2005, Greenley et al 2006, Vermaes et al 2007, Kulkarni et al 2008). For children with hydrocephalus the uncertainty and potential life threatening nature of shunt malfunction is an additional concern (Query et al 1990). Findings from these studies suggest factors such as emotional stability, fewer family conflicts, and robust family resources (financial and support networks) are associated with lower parental stress and improved quality of life for the children and family. In addition, parents' personality traits and intrapersonal resources appear to be more important determinants of parental adjustment when compared to the severity of the child's physical impairments (Vermaes et al 2008). For example, extraversion in mothers is associated with lower stress levels compared to mothers who are introverts, and being amiable is associated with low stress levels in fathers (Vermaes et al 2008).

1.5 Theoretical perspectives relating to long-term conditions

Theory-based psychological models that predict health behaviours such as the 'health belief model' (Becker and Maiman 1975), 'theory of planned behaviour' (Ajzen 1985) and 'common sense model of illness representation' (Leventhal et al 1992) offer explanations about how individuals respond when confronted with a health related problem. These models have been widely used to explain factors that influence participation in health related activities such as understanding issues relating to patient adherence with treatments (Leventhal et al 1992) and exploring patients' receptiveness to self-care activities (Hampson et al 1990). The usefulness of these models to understanding illness behaviours for long-term conditions is limited. These models only partially explain health behaviours in these conditions because they do not account for the dynamic nature of the condition and the cumulative effect of different problems within an

underlying background of a long-term condition (Hale et al 2007, Hill et al 2007). In addition, the role of other family members is likely to be significant in terms of their involvement in treatments and shaping illness perceptions (Hale et al 2007).

Unlike theoretical models that aim to predict health behaviours others such as the 'illness trajectory framework' (Corbin 1998) and 'shifting perspectives model of chronic illness' (Paterson 2001) were developed specifically to understand an individuals' response to living with their long-term condition. The illness trajectory framework was developed from empirical research with terminally ill patients and proposes that patients' responses followed the course of the illness which is influenced by the cumulative effects of physical symptoms, the impact on the individuals' social world and threats to self-identity (Corbin 1998). The shifting perspectives model of chronic illness model differs from the trajectory framework in that the long-term condition is not viewed as a linear process following a predictable trajectory but as an ongoing and continuality shifting process (Paterson 2001).

The theories described above consider health related behaviours from an individual perspective. As outlined in Section 1.3.2 there are variations in the family response to living with a child with a long-term condition with both poor and good adjustment reported. Theory based models such as the 'transitional-stress coping model' (Thompson et al 1992) and 'disability-stress coping model' (Wallander and Varni 1998) offer frameworks to understand the variations in the family's response to living with a child with a long-term condition and factors that influence adaptive processes. These factors include the changing development stages of the child, family resources, stressful events such as hospitalisation of the child and work related constraints (Thompson et al 1992, Wallander and Varni 1998). The transitional-stress coping model was derived from studies exploring the psychological adjustment of children and adolescents living with cystic fibrosis (Thompson et al 1992). In contrast the disability-stress coping model emerged from studies across a range of long-term conditions in children and has greater emphasis on adjustment and re-adjustment being an ongoing process, therefore may have broader application across different long-term conditions (Wallander and Varni 1998). The 'transitional-stress coping model'

and ‘disability-stress coping model’ have some similarities with ‘family systems theory’ in that a range of factors both internal and external exert influences on family behaviours. Family systems theory differs because the focus is on understanding and explaining how each family member’s behaviour is caused by and causes changes in other family member's behaviours (Bronfrenbrenner 1979). Family systems theory is further explored in section 1.5.3.

As discussed in Section 1.4.3 the outcome for children with hydrocephalus is variable and shunts, the main treatment for hydrocephalus, are prone to malfunction which can be life threatening. We know parents are responsible for responding to illness symptoms in their child and deciding if they are shunt related. The theoretical perspectives that might be best suited to explain parents’ management of their child’s hydrocephalus and the empirical studies undertaken as part of this thesis are the ‘shifting perspectives model of chronic illness’ (Paterson 2001), ‘disability-stress coping model’ (Wallander and Varni 1998) and ‘family systems theory’ (Bronfrenbrenner 1979). These theoretical perspectives are now outlined.

1.5.1 Shifting perspectives model of chronic illness

The shifting perspectives model of chronic illness is a data driven theory developed from a synthesis of qualitative research findings that described patients’ experiences of living with a long-term condition, and aims to explain patient heath behaviours and their use of healthcare systems (Paterson 2001). The model depicts living with a long-term condition as an ongoing and continually shifting process and proposes that the experience of living with a long-term condition has two unified components; wellness and illness. Current illness symptoms and health status, in addition to personal and social demands influence whether wellness or illness dominate at any one time. Wellness situates the condition in the background and illness situates the condition in the foreground becoming the dominant focus of everyday life. The shifting perspectives model has relevance for parents living with their child with hydrocephalus because attending to illness symptoms when they occur, and deciding if they are shunt related, shifts the focus from normal parenting activities to their child’s condition.

1.5.2 Disability-stress coping model

The disability-stress coping model proposes that parental psychosocial adaptation to living with a child with a long-term condition is dependent on the relationship between stress related risk factors and stress ameliorators or resistors (Wallander and Varni 1998). Stress related risk factors include the severity of the child's illness, functional deficits and care giving burdens. Ameliorators or resistors relate to three areas: socio-ecological resources such as family functioning, family relationships and family support systems; intrapersonal resources such as cognitive and affective patterns of behaviour (parenting control norms, disposition and self perception); and stress-coping processes such as the ability to appraise prior experiences and implement coping strategies to mediate stressors. The disability-stress coping model has been used as the theoretical framework to explore the impact of living with a child with a long-term condition in a range of contexts, including studies relating to children with spina bifida (Vermaes et al 2005, Vermaes et al 2007, Vermaes et al 2008), as outlined in Section 1.4.3.

1.5.3 Family systems theory

General systems theories claim systems operate by maintaining equilibrium; systems resist disturbances and when threatened are directed to restoring balance (Constantine 1986). Systems maintain equilibrium through rules and boundaries, controls and hierarchies, and are self-regulating. In family systems theory, rules, boundaries and hierarchies form the framework within which the family operates and ensures family goals are met, enabling the family to achieve a balance between growth and stability (Bronfrenbrenner 1979). Change in one member of the family, such as ill health, impacts on all family members disrupting the system's equilibrium (Eggenberger and Nelms 2007). In common with organisational systems, families are subject to multiple and competing internal and external influences (Bronfrenbrenner 1979). Internal influences include family relationships, culture and beliefs. External influences include schools, places of work, support services, relationships with health professionals, and the wider society.

Family systems theory has been used to underpin empirical research in a range of contexts such as: parent-professional relationships (Pinkus 2006); the family experience when a family member is hospitalised with a critical illness (Eggenberger and Nelms 2007); the relationship between prenatal parenting aggression and early parent-infant relationships (Crockenberg et al 2007). Findings from these studies suggest families are inherently resilient and when faced with adversity work together to regain stability. In relation to living with a child with long-term condition the impact on the family system has not been widely studied (Wallander and Varni 1998). Family systems theory has not significantly influenced clinical practice because the theory does not fully explain the dynamics of family life, lack of consistency by health professionals in relation to embracing the family as being central to the child's care and constraints in the way healthcare systems operate (Berkey and Hanson 1991). Family systems theory has relevance for parents managing their child's hydrocephalus and shunt because internal and external family influences are likely to shape how parents respond to illness symptoms in their child.

1.6 Involving parents in their child's care

This thesis is concerned with parents' involvement in the care of their child's hydrocephalus and parent-professional collaboration when a child is admitted to hospital with suspected shunt malfunction. Current health policy advocates health services and care delivery are patient-centred, patient-professional interactions are participatory and collaborative in nature and patients ought to be offered choice and share in care decisions (DH 2001a, 2001b, DH/DfES 2004, DH 2005a, 2005b, 2007, 2009). Collaboration, when the patient is a child, involves engaging with parents. This section outlines three key interrelated concepts relating to patient involvement; patient and family-centred care, participation and collaboration and shared decision-making.

1.6.1 Patient and family-centred care

Health policies previously outlined advocate a patient-centred approach to healthcare delivery where there is a mutually beneficial partnership between patients and health professionals. Despite the attraction of a patient-centred

approach to care within the healthcare literature and current policy directives, the concept of ‘patient-centred care’ and related terms such as ‘family-centred care’ and ‘family-centred services’ are poorly defined (Mead and Bower 2000, Franck and Callery 2004). Although social and behavioural scientists have developed theoretical models that predict health behaviours and understand the individual’s response to illness, outlined in Section 1.5, the development of concepts relating to ‘patient-centeredness’ have primarily occurred in clinical practice (Mead and Bower 2000). Consequently these concepts have been developed by a range of healthcare disciplines, primarily doctors and nurses. The literature suggests professional groups conceptualise ‘patient-centeredness’ in dissimilar but overlapping ways because of differences in the purpose of patient engagement between professionals, and distinct professional values and belief systems (Mead and Bower 2000, Franck and Callery 2004).

In medicine, the term ‘patient-centred medicine’ dominates, with the literature primarily focusing on the doctor-patient consultation and the impact of patient-centred communication on health related outcomes, service utilisation and healthcare costs (Mead and Bower 2000, Mead et al 2002, Epstein et al 2004, Epstein et al 2005). ‘Family-centred care’ is particularly associated with children’s nursing, and although a nebulous concept, has through common usage become the dominant philosophy that underpins UK nursing care of the child and family (Nethercott 1993, Coyne 1996, Hutchfield 1999, Shields et al 2006, Shields et al 2008). Family-centred care is both a method of care delivery and a philosophy based on valuing the central role of the family in the child’s life and recognising the importance of working with the family in meeting their child’s health needs (Bruce et al 2002, Shields et al 2006). In comparison, the term ‘family-centred services’ appears to be preferred by professionals working with children with disabilities within education and social services, and is the advocated framework for organising services for children and their families that meet their needs (Law et al 2003, Law et al 2005).

Notwithstanding conceptual differences and lack of clarity in terminology, attributes relating to ‘patient-centeredness’ are similar across professional groups and include: valuing parents’ expertise and knowledge about their child;

forming effective partnerships with the child and family; facilitating the child and family to participate in care delivery through the process of negotiation, empowerment and shared goal setting; ensuring effective information provision to enable the child and family to collaborate in care decisions (Hutchfield 1999, Mead and Bower 2000, Law et al 2005, Shields et al 2008). Findings from empirical studies exploring parents' perspectives about their involvement in their child's care and the relationship between family-centred care and health related outcomes, service utilisation and healthcare costs are equivocal. For example, delivering care that is family-centred and addresses parent-identified concerns has been linked to improved parent and child well-being and greater satisfaction with service provision (King et al 1999, Greco and Sloper 2004, Moore et al 2009). In contrast, parents' perceive that their views are not valued and there is no active parent-professional collaboration (Corlett and Twycross 2006, Ygge et al 2006); services are not family-centred with poor coordination between health, social and education services (Ray 2002); care decisions remains in the domain of the health professional (Kirk 2001).

Despite the concepts of patient and family-centred care, and family centred services being well established with the health literature and policy directives, the evidence presented suggests implementation into everyday practice remains predominantly aspirational. This lack of widespread implementation has been attributed to:

- Poor conceptualisation of the concepts relating to 'patient-centeredness' (Mead and Bower 2000, Franck and Callery 2004);
- Health professionals' lack of understanding of and commitment to implementing these concepts (Bruce et al 2002);
- Difficulties in measuring the impact of patient-centred approaches to health improvements (Mead and Bower 2000, Shields et al 2008);
- Anxieties about role adjustments (Callery 1997).

In addition, poor parent satisfaction when engaging and collaborating with health professions has been linked with uncertainty about professionals' roles and responsibilities because of poor inter-disciplinary team work (Sloper et al 2006); parents and health professionals having differing perspectives of these concepts (Kawick 1996). In the context of children with long-term conditions a family-

centred approach to care and service delivery is particularly salient because of the enduring nature of these conditions, frequent contact with healthcare professionals and high utilisation of welfare services (DfES/DH 2004).

1.6.2 Participation and collaboration

Patients can be involved in a range of health related activities such as health consultations, treatment planning and self-care activities. Terms used to describe patient involvement are poorly defined and used interchangeably within the health literature and include ‘patient involvement’, ‘patient participation’, ‘patient collaboration’ ‘partnership-in-care’ and ‘mutual participation’ (Thompson 2007, Power and Franck 2008). Findings from a concept analysis relating to partnership-in-care and its antecedents, ‘patient involvement’ and ‘patient collaboration’ suggest patient involvement occurs when patients undertake health related self-care tasks as delegated by health professionals (Cahill 1996). In contrast, collaboration focuses on patient-professional co-operation for example the sharing of information to reach a mutually agreeable care decision. Partnership-in-care occurs when there is a reciprocal sharing of responsibility for care based on equality within the patient-professional relationship (Cahill 1996).

Changes in the profile of childhood illnesses coupled with greater understanding about the impact of separating children from their families has reduced in-patient and institutional care for children (Sheldon 1997, Alsop-Shields 2001). The care of children including those with complex needs and dependent on advanced technologies usually takes place in the home environment, with the responsibility for monitoring symptoms and responding to changes in the child’s condition primarily the role of parents (Wang and Barnard 2004, Heaton et al 2005). Changes in care delivery necessitate health professionals develop the prerequisite skills to move from a position of care prescriber to one of collaborator, working in partnership with parents.

The evidence suggests participation and collaboration are not widely practiced. Parent participation in care has been widely studied in hospitalised children, findings have identified: a coercive system of involving parents hinders the development of effective parent-professional partnerships (Coyne 1995, Corlett

and Twycross 2006); parents are disempowered with care delegated to them by health professionals resulting in anxiety when undertaking complex care tasks (Corlett and Twycross 2006, Coyne and Cowley 2007); parents' and health professionals' perspectives of collaboration and participation differ (Kawick 1996, Power and Franck 2008). For collaboration and participation to be meaningful health professionals need to understand parents' perspectives (Power and Franck 2008). Difficulties in achieving collaboration and participation are multi-faceted; health care is increasingly varied with patients' expectations, experiences, knowledge of health and heath related issues, and the degree they wish to collaborate with health professionals and participate in care being highly diverse (Collins et al 2007).

In the child health setting the evidence to-date has primarily focused on exploring parents' views about their involvement in the care of acutely ill children (Power and Franck 2008, Shields et al 2008). No studies have been identified in relation to the clinical and cost effectiveness of collaborative models of care and the processes involved in achieving effective parent-professional partnerships.

1.6.3 Shared decision-making in healthcare

There is a broad consensus amongst policy makers and professionals that health professionals should enable patients to be involved in decisions about their own health care (Entwistle 2009). Shared decision-making has particular relevance for individuals with long-term condition because the day-to day care and management of their condition becomes primarily the responsibility of the patient and their families (Von Korff et al 1997). Advancing a shared decision-making model of care has been driven by challenges to traditional views of health professionals acting in the best interest of their patients and their decisions being above question (Elwyn et al 1999). This has resulted in a shift from a paternalistic model of care, supported by Parsons' conceptualisation of the sick role, to care delivery that is collaborative in nature with mutual understanding of the patient and health professional's roles in relation to illness management (Haidet et al 2008).

Despite shared decision-making being the dominant model of patient-professional engagement (Entwistle 2009), shared decision-making is poorly defined and has not been widely adopted by health professionals (Gravel et al 2006, O'Grady et al 2010). In broad terms shared decision-making is the process whereby patients and health professionals take an active role in decisions concerning the patient's health (Briss et al 2004, Howie et al 2004). This broad conceptualisation of shared decision-making can be applied to a range of decision-making activities such as the patients' contribution to the nature of their problem (Bugge et al 2006), and the patients' involvement in decisions about care delivery and treatment monitoring (Entwistle and Watt 2006). However, there has been a tendency to consider shared decision-making primarily in terms of making treatment decisions (Entwistle 2009). In this context shared decision-making can be thought of as a process where the patient and health professional exchange treatment preferences to reach an agreement on a plan of care (Charles et al 1997). In relation to treatment decisions a shared decision-making model of care assumes a range of choices exist in relation to the care under discussion, uncertainties exist about the choices available, and there is a deliberate choice by the patient and health professional to share information and actively participate in the decision-making process (Elwyn and Charles 2009).

When the patient is a child, communication dyads are different compared to the adult patient. Shared decision-making involves health professionals' engaging with parents who are making decisions on behalf of their child. Older children and young people may be involved in decision-making processes, with or without their parents. Empirical research relating to parents making decisions on behalf of their child has been undertaken in a range of health domains including pre-natal screening and diagnosis, feeding, immunisation, long-term conditions, life support and palliative care (Jackson et al 2008). Central to shared decision-making is information exchange; eliciting information from the patient and the provision of information (Elwyn and Charles 2009). Consistent themes to emerge from a review of decision support needs of parents making health choices on behalf of their child included providing timely, consistent, up-to date, tailored information coupled with the need to talk to others in similar situations

providing opportunities to share experiences (Jackson et al 2008). In addition, parents wanted to be in control of their level of involvement in decision making. Parents' decision-making needs appear consistent irrespective of the type of decision. Making emotionally charged decisions can add to the challenges associated with shared decision-making (Jackson et al 2008). The evidence relating to parent-professional collaboration suggests parents feel decision-making processes are based primarily on the provision of information and ensuring consent for treatment rather than encouraging active participation in decisions about their child's care (Espezel and Canam 2003, Alderson et al 2006, Payot et al 2007, Stille et al 2007).

In addition to usual child health related decisions, parents living with their child with hydrocephalus may be confronted with making decisions about treatments and the withdrawal of care for critically ill infants as a result of being born premature. Parents with a prenatal diagnosis of hydrocephalus associated with spina bifida will also be confronted with decisions around continuing with the pregnancy. Making difficult decisions using complex analytical processes at a time when parents are emotionally labile and have limited opportunity to evaluate the options because their child is critically ill are unlikely to be consistent with the notion of shared decision- making. As discussed in Section 1.4.1 the treatment choices for some children with hydrocephalus are limited and treatment complications are potentially life threatening. Parents in these circumstances have no real choices. As stated above a shared decision-making model requires a range of choices to exist; this model of care delivery may be inappropriate for parents of children with hydrocephalus because of the lack of treatment options. Furthermore, shared decision-making has limitations because of assumptions that this model of care is inherently desirable and valued equally by both practitioner and parent alike.

1.7 Summary

Hydrocephalus is a long-term condition and for some children is associated with physical disabilities and learning difficulties. From the evidence presented in Section 1.4.3 living with a child with spina bifida and hydrocephalus can impact on the child and family's quality of life because of care giving burdens, restricted

opportunities as a consequence of social and financial constraints, and strains on family relationships. The findings presented were based on predominantly quantitative approaches which are valuable for measuring the factors that might account for the variations in families' responses to living with a child with spina bifida and hydrocephalus but do not consider parents' experiences and perspectives. Shunts, the main treatment for hydrocephalus, are problematic in that they are prone to malfunctioning. Shunt malfunction must be recognised and treated promptly in order to prevent neurological complications or death occurring. Detecting shunt malfunction is difficult because symptoms are variable and similar to common childhood illnesses and often unique to the child.

The responsibility for monitoring the child's condition, identifying the symptoms of shunt malfunction and responding accordingly are primarily the role of parents. The scoping review (Appendix I), conducted in preparing for this PhD, suggested there to be a paucity of research exploring parents' perceptions of living with a child with hydrocephalus and their experiences of recognising and seeking help for their child if shunt malfunction is suspected. Understanding parents' perspectives of living with a child with hydrocephalus may help explain their decisions about where and when to seek healthcare advice, and facilitate better parent-professional collaboration.

1.7.1 Thesis overview

This thesis is about parents' involvement in the management of their child's hydrocephalus and shunt. First, a structured literature review of studies describing the experiences and perceptions of living with a child with a long-term condition was undertaken and is presented in Chapter 2. It is likely parents' experiences of living with their child with hydrocephalus will be similar to parents' experiences of living with a child with other long-term conditions. Gaining insight into parents' views and experiences has the potential to foster better understanding about the impact of the child's condition on the family, which may lead to greater parent-professional collaboration in relation to managing the child's condition. The literature reviewed was used to discuss, contextualise, and verify or dispute findings that emerged from the empirical studies undertaken as part of this thesis.

Second, an empirical study designed to explore parents' experiences of living with a child with shunted hydrocephalus is reported in Chapter 3. Although it is likely parents' experiences of living with their child with hydrocephalus will be similar to parents' experiences of living with a child with other long-term conditions, there may be differences because of the constant uncertainty and potential life threatening nature of shunt malfunction. Issues emerging from clinical practice, policy drivers and a paucity of literature relating to the experiences of parents living with a child with hydrocephalus provided the impetus for undertaking this study.

Third, a second empirical study exploring parents' and health professionals' contribution to the diagnosis of shunt malfunction in children in acute hospital admissions is reported in Chapter 4. As highlighted in Section 1.5.1 current UK policy advocates a model of care delivery based on parent-professional collaboration and in the context of long-term conditions one that values patients' knowledge and expertise. However, the evidence outlined suggests parents' perceive that interactions with healthcare professionals are not collaborative in nature. Yet health professionals need to integrate parents' knowledge of their child with their clinical assessment when making a judgement about a child's illness symptoms.

The concepts and theoretical perspectives outlined in this chapter will be drawn on throughout this thesis, helping to explain study findings. Chapter 5 draws together the findings of the literature review and two empirical studies and discusses their contribution to the growing body of evidence relating to parents' experiences of living a child with a long-term condition and parent-professional collaboration. There will be a critical evaluation of these studies and the processes engaged with while undertaking this thesis. In addition to summarising the findings, key recommendations for practice, education and policy and areas for further research are presented.

Chapter 2:
Parents' experiences of living with a child with a long-term condition: a critical review of the literature

2. Introduction

This chapter presents a critical review of research that has explored parents' experiences and perceptions of living with a child with a long-term condition. The similarities and differences between parents' experiences of children living with a long-term condition and experiences of acute illness events will be highlighted. The scoping review (Appendix I), conducted in preparing for this PhD, suggested there was a paucity of research exploring parents' perceptions of living with a child with hydrocephalus and their experiences of recognising and seeking help for their child if shunt malfunction is suspected. It is likely parents' experiences of living with their child with hydrocephalus will have some similarities to parents' experiences of living with a child with other long-term conditions. There is a large literature base relating to living with a child with other long-term conditions in particular common conditions such as asthma and diabetes (Fisher 2001, Knafl and Gilliss 2002, Coffey 2006, Hallström and Elander 2007). A critical appraisal of this literature, bringing together studies that have explored parents' experiences of living with a child with a long-term condition was undertaking to provide an overview of what is already known in this field and to identify the research gaps in preparation for the empirical studies undertaken as part of this PhD, presented in Chapters 3 and 4.

2.1 Aims and objectives

This review aimed to summarise and critically evaluate the literature relating to parents' experiences and perceptions of living with a child with a long-term condition. The specific objectives were to:

1. Describe and summarise parents' accounts of living with a child with a long-term condition;
2. Identify the similarities and differences between parents' experiences of acute illness episodes in children with long-term conditions.

2.2 Review context

The purpose of a systematic review is to summarise and synthesise research findings in order to inform policy makers, professionals and patients of the best available evidence upon which healthcare decisions can be based, and to identify gaps in the evidence (Centre for Reviews and Dissemination (CRD) 2009). Reviews are broadly divided into narrative, scoping, rapid evidence assessments also referred to as rapid structured reviews, and systematic reviews (Armitage and Keeble-Ramsay 2009). Narrative and systematic reviews differ in their use of research methods. Narrative reviews tend to provide a summary of research findings in order to support an empirical study and usually report on a small selection of studies (Petticrew and Roberts 2006). Scoping reviews include a comprehensive search strategy but unlike systematic reviews do not undertake a synthesis of the evidence (CRD 2009). Scoping reviews are often used to map the literature in a broad context prior to undertaking a more comprehensive review of empirical evidence (Coad and Shaw 2008, CRD 2009).

Systematic reviews traditionally examine evidence from empirical studies about the effectiveness of a health care intervention, but recently have included factors that impact on research implementation and the patient experience (CRD 2009). Rapid structured reviews are used to summarise and synthesis research findings within the constraints of a given timetable and resources, and differ from systematic review in relation to the extensiveness of the literature search and methods used to undertake the analysis (Armitage and Keeble-Ramsay 2009, CRD 2009). However, the review needs to be as comprehensive as possible within the given constraints and undertaken in a systematic manner (CRD 2009).

2.3 Methods

This section describes the methods used to conduct the review.

2.3.1 Review design

A rapid structured review was employed to investigate parents' experiences of living with a child with a long-term condition using systematic methods. The methods used to conduct the review were informed by guidance from the CRD

methods for undertaking systematic reviews (CRD 2009). Rapid structured reviews are appropriate to identify future research priorities or, as in this review, to contextualise empirical studies prior to undertaking research in a related area (Armitage and Keeble-Ramsay 2009).

2.3.2 Sampling methods

The focus for this review was studies describing parents' experiences of living with a child with a long-tem condition. Long-term conditions, defined in Chapter 1, refer to long-standing health conditions that impact on the child's growth and development, and necessitate ongoing health, social and/ or educational support for the child and family. Although it was anticipated that included studies would primarily be qualitative because these approaches lend themselves to the exploration of parents' experiences, all study designs were included.

2.3.2.1 Inclusion and exclusion criteria

A study was included or excluded from the review based on the following criteria.

Inclusion criteria:

- Studies of parents, guardians, foster parents or carers living with a child with a long-term condition;
- Studies concerned with parents' experiences or perceptions or beliefs about living with a child with a long-term condition which could relate to the child's health, education or social care needs;
- Studies about parents' management and decisions relating to the child's long-term condition;
- Studies published in the English language.

Exclusion criteria:

- Studies about children with learning disabilities due to the heterogeneity of the cause of the disability;
- Studies with an exclusive focus on children with terminal conditions due to the nature of palliative care;
- Studies about quality of life measures alone;
- Review articles and individual case studies.

3.2.2.2 Sampling strategies

Studies were identified by searching three health and social sciences data bases, MEDLINE, CINAHL, and PSYCINFO, which routinely index qualitative studies and include a wide range of subject matter (CRD 2009). Key search terms are presented in Figure 3. Search strategies are presented in Appendix II.

Figure 3: Key search terms

Population 1	Population 2		Outcomes	Study design
Parent/s Mother/s Father/s Carer/s Guardian/s Foster carer/s	Child Children Paediatric/s Pediatric/s Daughter/s Son/s	Long-term condition/s Chronic disease Chronic illness Chronic condition/s Disabling condition/s Medically fragile children Complex needs	Experiences Perceptions Beliefs Views Attitudes Thoughts Perspectives	Qualitative Quantitative

A ten year period, January 1999 - December 2009, was chosen because studies within this period are more likely to reflect contemporary health policy, which has a greater emphasis on understanding parents' perspectives of their child's condition and actively involving them in care and care decisions.

Additional techniques were employed to reduce sampling bias and offset the imperfections associated with the indexing of qualitative studies (Wong et al 2004). First, hand searching all volumes of the Journal of Advanced Nursing and Child: Care, Health and Development from 2004 to 2009, was undertaken. These journals were selected because of their relevance to the area of describing parents' experiences. Second, grey literature, literature not indexed in bibliographic data bases, was identified by searching SIGLE, from conference proceedings and via e-mail correspondence with child health researchers. A critical issue when including studies that have not been published in the journals is the likely absence of any peer review. This clearly has implications regarding the potential quality of the findings presented but can assist in producing a balanced review because of known publication bias towards positive study findings. Third, bibliographies of key papers were reviewed to identify additional studies.

2.3.3 Materials

The development and use of a data extraction form enabled the same type of data to be extracted from each article thus reducing bias (CRD 2009) (Figure 4).

Figure 4: Data extraction form

Article identification			
Author: Title: Source: Medline CINAHL PsycInfo Hand search Other____			
Data extraction			
Location: UK Europe North America Australasia Other ____	Participants: Both parents Mothers Fathers Parents and children Other ____	Health conditions: Range Single condition _____	
Quality of study			
Theoretical foundations:			
Study design: Qualitative: Grounded theory Phenomenology Ethnography Other _____ Mixed method _____ Quantitative _____	Sample strategy: Purposeful Selective Convenience Not described Other _____ Sample size _____	Data collection: Questionnaire Interview Focus groups Observation Other_____	Analysis: Statistical Grounded theory Phenomenology Framework Content analysis Thematic analysis Other_____
Data extraction and synthesis			
Categories: Making sense of the condition Learning about the condition Monitoring the condition Mastering care regimes Interacting with professionals Service provision Grief Chronic sorrow Adaptation Normality			
Additional information			

Although data extraction forms are specific to meet the review aims, they typically include general information relating to article identification, participant characteristics, study methods and key findings (CRD 2009). These areas formed the template for the data extraction. A difficulty with the development of the data extraction form was lack of familiarity with study findings prior to undertaking the review (CRD 2009). Amendments were made to the data extraction form after piloting and following discussions with supervisors. For example interacting with health professional was added to the categories section after piloting the data extraction form.

2.3.4 Quality appraisal

There is no accepted consensus on the standards by which qualitative research should be judged (Rolfe 2006). However, a number of assessment tools are available (Popay et al 1998, CASP 1998, Spencer et al 2003a, Long and Godfrey 2004). Two commonly used structured approaches to the quality assessment of qualitative studies are the Critical Appraisal Skills Programme (CASP) appraisal tool (CASP 1998) and the quality framework (Spencer et al 2003a); a comparison of these tools and expert judgments suggested that using an appraisal tool resulted in a more structured approach when undertaken reviews (Dixon-Woods et al 2007). Although neither tool was identified as more rigorous in terms of assessing the quality of the research, the quality framework was criticised for its complexity (Dixon-Woods et al 2007). The CASP tool was used as a template to appraise the included studies and is summarised in Figure 5 (CASP 1998).

Figure 5: Summary of CASP appraisal tool (CASP 1998)

	Assessment criteria
Screening questions	1. Was there a clear statement of the research aims?
	2. Is the methodology appropriate?
Is it worth continuing?	
Detailed questions	3. Were recruitment procedures appropriate to the research aims?
	4. Were data collected in a way that addressed the research issue?
	5. Were data analyses sufficiently rigorous?
	6. Has researcher-participant relationships been adequately considered?
	7. Are the findings clear?
	8. Is sufficient data represented to justify researcher interpretations?
	9. Has the transferability to other settings been made explicit?
	10. How relevant is the research?

2.3.5 Data synthesis

Approaches to data synthesis for qualitative health reviews are based on methods of analysing qualitative data in primary research (CRD 2009). Qualitative methods applicable for synthesising qualitative studies include narrative summary, thematic analysis, grounded theory, meta-ethnography and content analysis (Dixon-Woods et al 2005). Depending on the purpose of the review, data synthesis can be integrative where the review focus is to summarise data into broad, usually well established themes or interpretative synthesis which is more concerned with the development of theory (Dixon-Woods et al 2005). Methods such as grounded theory and meta-ethnography are appropriate when undertaking interpretative synthesis, with narrative summary and thematic analysis being suited to integrative synthesis.

Integrative data synthesis based on the principles of thematic analysis underpinned the data analysis because the primary objective was to describe and summarise parents' accounts of living with a child with a long-term condition. Applying thematic analysis to health reviews involves systematically searching all selected studies to identify patterns across studies. The process results in the

development of meaningful themes without explicitly generating theory but provides a detailed description of the phenomenon being studied (Tesch 1990).

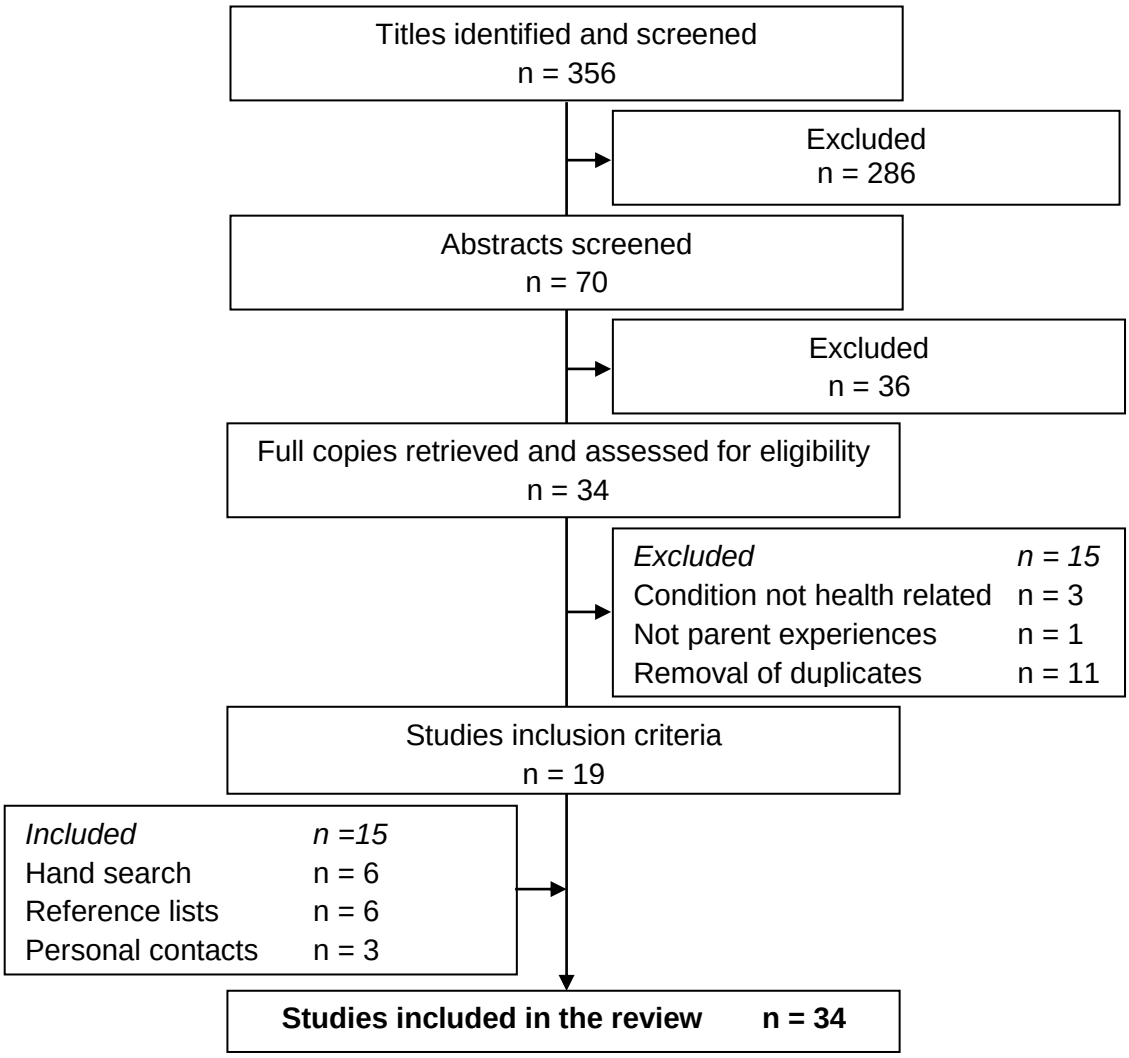
2.4 Procedures

This section describes the procedures in relation to the selection of papers, data extraction, data synthesis and the quality appraisal process.

2.4.1 Selection of papers

In order to reduce selection bias, article selection followed the stages recommended within the CRD healthcare review guidance (CRD 2009). The electronic data base searches yielded a total of 356 records. The title of each record was examined to establish if the study related to the focus of the review. Seventy titles related to the review focus; the abstract of these titles were assessed to establish if the studies met the inclusion criteria. Any uncertainties about whether to include or exclude studies were discussed at supervision meetings. Thirty-four full studies were retrieved and assessed against the inclusion criteria. Fifteen papers were excluded primarily because the child's long-term condition was a consequence of learning disabilities and not specifically health related. Six additional papers were identified from the hand search, six identified from references of included papers and three from personal correspondence, resulting in 34 studies being included in the review (Figure 6).

Figure 6: Flow chart of study selection process



2.4.2 Data abstraction

Data extraction involved identifying and documenting the information necessary to meet the review aims. Data abstraction and synthesis followed the stages of thematic analysis advocated by Braun and Clark (2006). These stages are: familiarisation of the data; generating codes; searching for themes; defining themes; reviewing and describing final themes. The principles of thematic analysis, and thematic synthesis, can be applied across a range of qualitative study approaches and different types of data (Braun and Clarke 2006, Thomas and Harden 2008). Consequently, the procedures vary to meet study or review aims (Braun and Clarke 2006). The stages of the analysis and justification for variations in the process are now outlined. First, each paper was read in order to become familiar with study settings and context, key findings and the relationship between studies.

Second, codes (units of data) were generated from the studies. Units of data related to categories, themes, concepts and metaphors used to describe study findings. Codes were summarised and recorded on the data extraction form using terms as close as possible to those reported in each study. Patterns were identified across studies enabling codes to be grouped into categories. Categories included: learning about and making sense of the child's condition; gaining the skills to meet the child's health needs; responding to changes in the child's condition; coping with emotions such as grief and loss; interacting with health professionals. These categories were incorporated into the data extraction form. The abstract nature of labels attached to some data resulted in the development of categories being an iterative process with repeated scrutiny of the narratives describing study findings to check meaning.

Third, all study findings were mapped to the categories included in the data extraction form, adding or modifying categories as new insights emerged. Fourth, themes and categories were reviewed until a coherent account emerged. Bias was reduced by ongoing reworking of themes following supervision meetings, where assumptions were challenged. An example of the stages described, using the categories labelled grief and chronic sorrow, is presented in Figure 7.

Figure 7: Developing categories and themes from coded data

Author	Codes	Categories	Theme
Monsen (1999)	Initial reactions such as disbelief and confusion were replaced by worrying about the child	• Grief	**Parent Impact**
Maltby et al (2003)	Fear and anxiety about the impact of the condition for the child was accompanied by the loss of the image of 'the healthy child'		
George et al (2006)	Grief was related to feelings of shock, anger, fear, guilt, denial and were associated with uncertainty of the impact of the condition for the family		
Johnson (2000)	Mothers lived in the present to meet the child's needs but relived the past as grieving continued	• Chronic sorrow	
George et al (2006)	Chronic grief resulted in ongoing sadness which increased as the condition progressed		
Bowes et al (2009)	Revisiting the diagnosis suggested parents' grief in relation to the child's diagnosis is ongoing		

2.4.3 Quality appraisal

Quality appraisal involved assessing each study against the predetermined criteria outlined in the CASP tool and described in Figure 5, Section 2.3.4. The CASP tool does not attached scores to each criterion and is designed to record 'yes', 'no', and 'can't tell responses'. Yes was recorded if all elements within the criteria were met, no if none and partial if some were met.

2.5 Findings

This section presents an overview of review studies, findings from the quality appraisal assessment and the themes and categories that emerged from the data synthesis.

2.5.1 Overview of review studies

A total of 34 studies were included in the review. Characteristics in relation to the geographical location of the studies, study settings, the participants and health conditions are presented in Figure 8. Study samples, analytical methods and key findings are presented in Figure 9. Twenty-seven studies were based on qualitative methods, five studies employed mixed methods and two studies employed quantitative methods (Figure 9).

Figure 8: Characteristics of the studies

Author(s)	Title	Location	Participants	Long-term health condition
Balling, McCubbin (2001)	Hospitalized children with chronic illness: parental care giving needs and valuing parental experience	USA	50 caregivers: parents and foster carers (48 women)	Conditions resulting in home enteral or parentral nutritional Children 8-21 years
Bowes et al (2009)	Chronic sorrow in parents of children with type 1 diabetes	UK	17 parents (10 mothers)	Type 1 diabetes Children 9-23 years
Callery et al (2003)	Qualitative study of young people's and parents' beliefs about childhood asthma	UK	25 dyads of young people and main carers (mainly mothers)	Asthma Children 9-6 years
Cashin et al (2008)	The lived experience of fathers who have children with asthma: a phenomenological study	Canada	8 fathers	Asthma Children aged 7-11 years
Dickinson et al (2006)	Within the web: family-practitioner relationship in the context of chronic illness	New Zealand	10 families (parents and children, number of mothers/ fathers not reported) 12 healthcare practitioners	Conditions resulting in child requiring home care interventions Children 9 months - 14 years
Fawcett et al (2005)	Parents responses to health services for children with chronic conditions and their families: a comparison between Hong Kong and Scotland	China/ UK	105 parents (details not reported)	Conditions requiring ongoing care Children under 15 years of age, range not included
George et al (2006)	Chronic grief: experiences of working parents and children with chronic illness	Australia	11 parents (8 mothers)	Condition as a result of neurological problems Children 2- 8 years
Gibson (1999)	Facilitating critical reflection in mothers of chronically ill children	Canada	12 mothers	Condition as a result of neurological problems Children 11 months to 16 years

Author(s)	Title	Location	Participants	Long-term health condition
Goble (2004)	The impact of a child's chronic illness on fathers	USA	5 fathers	Conditions requiring ongoing care Children aged 3-6 years
Green (2007)	'We're tired not sad': benefits and burdens of mothering a child with a disability	USA	110 participants (predominately mothers, numbers not reported)	Condition as a result of neurological problems Average age 5 years, range not reported
Heaton et al (2005)	Families' experiences of caring for technology dependent children at home	UK	75 participant (34 mothers, 12 fathers 13 children, 15 siblings, 1 grandparents)	Conditions resulting in technology dependent child Children 4-18 years
Hewitt-Taylor (2009)	Children who have complex health needs: parents' experiences of their child's education	UK	14 parents (12 mothers)	Conditions requiring ongoing care Children 18 months - 18 years
Hovey (2003)	The needs of fathers parenting children with chronic conditions	USA	99 fathers (48 living with child with a chronic condition, 51 fathers of well children)	Conditions included cancer, cystic fibrosis, juvenile arthritis Children's ages not reported
Hovey (2005)	Fathers parenting chronically ill children: concerns and coping strategies	USA	48 fathers	Conditions included cancer, cystic fibrosis, juvenile arthritis Children's ages not reported
Johnson (2000)	Mothers' perceptions of parenting children with disabilities	USA	10 mothers	Conditions included cerebral palsy, hydrocephalus, spina bifida Children 3-10 years
Kirk et al (2005)	Parent or nurse? The experience of being a parent of a technology dependent child	UK	33 parents (23 mothers)	Child technology dependent Children up to eighteen years
Knafl, Zoeller (2000)	Childhood chronic illness: a comparison of mothers' and fathers' experiences	USA	93 parents (50 mothers)	Conditions requiring ongoing care Children 7-14 years

Author(s)	Title	Location	Participants	Long-term health condition
Lauver (2008)	Parenting foster children with chronic illness and complex medical needs	USA	13 foster parents (10 women)	Multiple care needs such as gastric tube feeding, central line care, colostomy care, intravenous therapies Children 8 months-20 years
MacDonald, Callery (2007)	Parenting children requiring complex care: a journey through time	UK	43 participants: 26 carers (15 mothers, 4 fathers, 4 grandmothers, 3 grandfathers) 13 nurses, 4 social workers	Multiple care needs such as complex feeding and medication regimes, bowel care, catheterisation, oxygen therapy Age of children not reported
Maltby et al (2003)	The parenting competency framework: learning to be a parent of a child with asthma	USA	15 mothers	Asthma Age of children not reported
Marshall et al (2009)	Living with type 1 diabetes: perceptions of children and their parents	UK	10 families (child/mother predominantly and child/ mother/ father)	Type 1 diabetes Children 4-17 years
Miller et al (2009)	Continuity of care for children with complex chronic health condition: parents' perspectives	Canada	66 caregivers (mothers, fathers, grandparents) (45 women)	Conditions requiring ongoing care Children 5-13 years
Monsen (1999)	Mothers' experiences of living worried when parenting children with spina bifida	USA	13 mothers	Spina bifida Children 12-18 years
Mulvaney et al (2006)	Parents' perceptions of caring for a adolescents with type 2 diabetes	USA	101 caregivers (mothers, fathers, grandparents) (89 women)	Type 2 diabetes Young people 12-21 years
Notras et al (2002)	Parents' perceptions of health-care delivery to chronically ill children during school	Australia	161 parents (85 mothers)	Care needs included gastrostomy feeding, giving medications, blood sampling Children 5-14 years

Author(s)	Title	Location	Participants	Long-term health condition
Nuutila, Salanterä (2006)	Children with a long-term illness; parents' experiences of care	Finland	11 parents (10 mothers)	Conditions requiring ongoing care Children 1-9 years
Ray (2002)	Parenting and childhood chronicity: making the invisible work visible	Canada	43 parents (30 mothers)	Requiring at least one care intervention Children 15 months to 16 years
Ray (2003)	The social and political conditions that shape special-needs parenting	Canada	43 parents (30 mothers)	Requiring at least one care intervention Children 15 months to 16 years
Sallfors, Hallberg (2003)	A parental perspective on living with a and chronically ill child: a qualitative study	Sweden	22 parents (16 mothers)	Juvenile arthritis Children 7-17 years
Sanders et al (2007)	Parents' narratives about their experiences of their child's reconstructive genital surgeries for ambiguous genitalia	UK	10 parents (7 mothers)	Ambiguous genitalia Children's ages not reported
Sullivan-Bolyai et al (2006)	Fathers' reflections on parenting young children with type 1 diabetes	USA	15 fathers	Type 1 diabetes Children 2-8 years
Swallow, Jacob (2001)	Mothers' evolving relationship with doctors and nurses during the chronic illness trajectory	UK	29 mothers of children	Vesicouretic reflux Children newborns - 8 years
Waite-Jones Madill (2008)	Concealed concern: fathers' experiences of having a child with type juvenile idiopathic arthritis	UK	32 participants (8 mothers, 7 fathers, I grandmother, 8 children, 8 siblings)	Juvenile arthritis Children up to 18 years
Wennick, Hallström (2007)	Families lived experiences one year after a child was diagnosed with type 1 diabetes	Sweden	32 families (11 mothers, 10 fathers, 11 children)	Type 1 diabetes Children 9-14 years

Figure 9: Design of the studies

Author	Aim	Sample	Theory	Methods	Key findings
Balling, McC (2001)	Explore parents' participation in care when a child with a chronic illness is hospitalised	Convenience	Family systems theory	Mixed method survey. Measures: family profile inventory, parent experience scale analysed by descriptive statistics Open questions analysed by content analysis	Higher quality of care provide at home Nurses workloads limited care delivery Child not always incorporated in care Parents wanted greater involvement in care Professionals' struggled to incorporate parents' expertise into ward practices
Bowes et al (2009)	Explore parents' experiences of living with a child with type 1 diabetes	Convenience	Grief and loss Adaptation and change	Qualitative study. Interviews analysed by developing codes and categories	Parents' grief following diagnosis is ongoing Acute illness episodes, hospitalisation, change in treatments, development changes evoked a resurgence in grief Emotional support was not always available
Callery et al (2003)	Explore the beliefs of young people with asthma and their carers about managing their condition	Purposeful	None	Qualitative study. Interviews analysed using constant comparison method associated with grounded theory	Minimising the consequences of asthma is a trial and error process Accepting a tolerable levels of symptom control reflected competing demands The impact on asthma on every-day life was variable and unpredictable
Cashin et al (2008)	Explore fathers experiences of caring for a child with asthma	Convenience	None	Qualitative phenomenological study. Interviews analysed using Van Manen's approach to phenomenology	Relief in knowing the diagnosis Need to gain knowledge about the condition and treatment options Living with concerns is constant, being vigilant to illness symptoms is part of everyday life Expertise gained through knowledge

Author	Aim	Sample	Theory	Methods	Key findings
Dickin. et al (2006)	Explore parent-professional relationships in families living with a child with chronic illness	Convenience	Family-centred care	Qualitative phenomenological study. Group interviews analysed using Caelli's approach to phenomenology	Families enter a complex web of care with few choices in services and practitioners Tensions occur because of differences between professionals' working practices Moving between practitioners and services is disruptive
Fawcett et al (2005)	Explore parents' experiences of healthcare support in children with a chronic illness across two cultures	Convenience	None	Mixed methods descriptive study. Self-developed questionnaire analysed using descriptive statistics Data analysis for interviews not described	Importance of nutrition was significant in Hong Kong but not UK cultures Expectations health professional would provide support was specific to UK culture Both cultures wanted more information than provided and to participate in care decisions
George et al (2006)	Explore parents' experiences of chronic grief in children with chronic illness	Purposeful	Greif and chronic sorrow	Qualitative phenomenological study. Interviews analysed using Van Manen's approach to phenomenology	Range of emotions on receiving the diagnosis and recur at times of uncertainty Chronic grief resulted in sadness which increased as the condition progressed Satisfaction in dealing with professions was variable
Gibson (1999)	Exploration of empowerment of mothers living with their child with a chronic illness	Convenience	Empowerment	Qualitative study based on feminist inquiry. Data collection included participant observation and in-depth interviews Data analysis is unclear	Initial frustration and disbelief are replaced with accepting the situation Critical reflection enabled mothers to develop an awareness of their own strengths and resources and own values and goals Mothers developed confidence in their own abilities to care for the child

Author	Aim	Sample	Theory	Methods	Key findings
Goble (2004)	Explore fathers' experiences of caring for a child with a chronic illness	Convenience	None	Qualitative study based on phenomenology. Interviews analysed using Van Manen's approach to phenomenology	Financial impacts strained family life Fathers missed previous social activities Relationships with partners were supportive and strong but parents had no time alone Fathers filled the gap in becoming the main care giver to siblings Fathers worried about the child's future
Green (2007)	Explore the social experiences of mothering children with disabilities	Convenience	None	Mixed methods survey. Quantitative measure related to stigma and care giving burdens, range of statistical tests applied Analysis not described for qualitative interview data	Mothers lives are emotionally complex, they developed confidence but care giving was time consuming, expensive and physically exhausting Mothers valued achievements in the child Socio-cultural constraints and stigma associated with disability added to the burden of caring
Heaton et al (2005)	Explore families' experiences of caring for a technology dependent child	Purposeful	Social construction of life round multiple temporalities	Qualitative study. Interview data analysed using the framework approach	Family routines were influenced by the type of equipment and duration of treatments Considerable time committed to providing care which was often incompatible with continuing school/work and maintaining a social life
Hewitt-Taylor (2009)	Explore parents' experiences of meeting the education needs of their child with a complex health need	Convenience	None	Qualitative study. Interview data analysed using qualitative content analysis	Pre-school education is limited for children with complex needs Finding the right school is complex, added difficulties related to Statement of Special Needs procedures Effort of learning for the child was challenging and exacerbated by missing school because of acute illness episodes and attending health appointments

Author	Aim	Sample	Theory	Methods	Key findings
Hovey (2003)	Compare the needs of fathers of chronically ill children to fathers of well children	Convenience	None	Quantitative survey. Fathers' needs measured using the Hymovich Family Perceptions Inventory Analysis used descriptive statistics	Fathers of chronically ill children have more concerns than fathers of well children in relation to family health matters and the impact of caring routines on their partner than fathers of well children Similarities between the two groups related to fathers' coping with family issues and general beliefs about their lives
Hovey (2005)	Identify concerns and coping strategies of fathers of chronically ill children	Convenience	Roy's nursing models of adaptation and change	Quantitative survey. Coping and concern identified from Hymovich Family Perceptions Inventory Analysis used descriptive statistic	Fathers' perceived family had extra demands due care-giving burdens, which mainly fell to mothers Fathers were concerns about the child's health Time with their partner was limited A range of coping strategies were used such as gaining information and problem solving in relation to managing their concerns
Johns. (2000)	Explore parents' experiences of parenting children with physical disabilities	Convenience	None	Qualitative study based on grounded theory. Interview data analysed using grounded theory method of constant comparison	Mothers lived in the present to meet the child's needs but relived the past as grieving continued Mothers treated the child as normal while securing services because the child is not normal Mothers dealt simultaneously with the child's and their own issues and feelings
Kirk et al (2005)	Explore parents' experiences of caring for their technology dependent child	Theoretical	Social constructs of parenting	Qualitative study based on grounded theory. Interview data analysed using grounded theory method of constant comparison	Home is dominated by medical equipment and the frequent presence of healthcare workers Parents caring role dominated their parenting role Parents differentiated themselves from health workers because care giving was interwoven into their lives with no respite and emotionally draining

Author	Aim	Sample	Theory	Methods	Key findings
Knafl, Zoeller (2000)	Compare mothers' and fathers' views about living with a child with a chronic illness	Purposeful	None	Mixed method study. Data from family function, mood status measures were analysed using descriptive and inferential statistics Interview data analysis using grounded theory constant comparison	Parents developed a shared view of the illness, its management and impact on family life, which helped family adjustment For some parents' perspectives differed; mothers more likely to emphasise the negative effects of the child's illness on the family compared to fathers
Lauver (2008)	To understand the experiences of foster parents caring for children with complex needs	Purposeful	None	Qualitative study based on phenomenology Interviews analysed using Van Manen's approach to phenomenology	Foster parents were highly commitment to meeting the child's needs and learned about these in advance of their commitment Foster parents recognised the need for support but support provision was variable Foster parents experienced a deep sense of loss when their time as a foster parents ended but perceived the experience as life changing
Mac Donald, Callery (2007)	To describe the care trajectory of children with complex needs	Purposeful	None	Qualitative study based on ethnography. Interviews, participant observations, eco-maps and documentary review were coded, categorised and interrogated to find connections across data	Caring processes began at birth and continued throughout infancy and into adulthood Parents needs changed in relation to the child's stage of development, condition changes, family circumstances and parents age Respite care was important and the need for respite changed over time suggesting regular review with healthcare professionals was required in order to ensure resources matched parents' needs

Author	Aim	Sample	Theory	Methods	Key findings
Maltby et al (2003)	Describe and explore the daily life of mothers of children with asthma	Sampling strategies are not described	None	Qualitative study based on phenomenology. Interviews analysed using Colaizzi's stages of phenomenology	Mothers parenting competency and identity was challenged as a result of the child's condition Uncertainties about their own abilities and managing the condition existed Mothers learned to acknowledge their child's condition and adjusted to meeting their child's needs
Marsh. et al (2009)	Explore children and their parents' experiences of living with type 1 diabetes	Purposeful	None	Qualitative study based on phenomenology. Interviews analysed using Van Manen's approach to phenomenology	Families have to make sense of the condition Transition to becoming independent caused tensions between children and parents, relationships and attachments were challenged Parents' grief was ongoing because of perceived losses, disruption, changes to established routines
Miller et al (2009)	Explore parents' experiences of care across services for children with complex needs	Purposeful	None	Qualitative study. Interview data analysed by the framework approach	Effective communication was integral to achieving continuity of care Compartmentalisation of services inhibited continuity of care, parents assumed the role of co-ordinator Consistent care providers were valued by parents because of their knowledge of the child
Monsen (1999)	Explore mothers' experiences of living with a child with spina bifida	Convenience	None	Qualitative study based on phenomenology. Interviews analysed using Van Manen's approach to phenomenology	Mothers had ongoing worries about the child and family's health and worried about not coping Mothers were anxious the child would not fit in with peers and gain independence Mothers struggled with the daily complexities of care

Author	Aim	Sample	Theory	Methods	Key findings
Mulvan. et al (2006)	Explore parents' experiences of living with adolescents with type 2 diabetes	Convenience	None	Qualitative study. Focus group data was analysed using the framework approach	Role modeling had positive and negative impacts on adolescents self-management of their diabetes Parenting skills impacted on adolescents self-care Maintaining treatments was challenging Environment (clinic, home, school) influenced health behaviors, and the development stages of adolescence amplified consequences of diabetes
Notras et al (2002)	Explore parents' experience of healthcare support for children with chronic illness during school	Convenience	None	Mixed method survey. Questionnaire analysed using descriptive statistics, final themes developed using qualitative content analysis	Continue care regimes was difficult and the child's needs were not always met in school Parents' perceived teachers did not have the skills or training to meet their child's health needs Parents were not supported when they provided health care for their child during school hours
Nuutila, Salan. (2006)	Explore parent-professional relationships with families with a child with chronic illness	Purposeful	None	Qualitative study. Interview data was analysed using qualitative content analysis	Information provision was inconsistent Information was needed across the illness trajectory Professionals lack of appreciation of parents experiences, constant changes in professional challenged parent-professional relationships
Ray (2002)	To validate a model designed to describe the work relating to parenting a child with chronic illness	Purposeful	None	Qualitative study based on phenomenology. Interviews analysed using using thematic analysis	Parents needed to master technical care and monitor illness symptoms Parents compensated for the child's lack of abilities and created opportunities for the child Securing services required parents to 'work' the health, social and education systems Effort was required to support siblings and maintain family relationships

Author	Aim	Sample	Theory	Methods	Key findings
Ray (2003)	To describe the social and institutional factors that affect families living with a child with a chronic illness	Purposeful	Gidden's theory of social and structural events that shape actions	Secondary analysis of interview data (Ray 2002). Interviews were analysed using thematic analysis	Parents' perceived their role of caring for the child was influenced by professional attitudes, information provision, and available services Other influences on families caring for a child with a long-term condition included the feminisation of care and societal perceptions of disabilities
Sallfors Hallb. (2003)	Explore parents' experiences of living with their child with juvenile chronic arthritis	Theoretical	None	Qualitative study based on grounded theory. Interview data analysed using grounded theory method of constant comparison	The unpredictability of the child's symptoms resulted in anxiety, parental over protection and watchfulness Emotional challenges related to uncertainties about parenting skills and communication with professionals Ongoing adjustment as child's condition changed and new demands were balanced with every-day life
Sand. et al (2007)	Explore parents' experiences of their child's reconstructive surgery for ambiguous genitalia	Purposeful	None	Qualitative narrative study. Data obtained through in-depth interviews and analysed using a narrative framework	Parents' experiences were shaped by the conditions timeline, gender and identity issues Expectations of healthy child were challenged Parents' felt vulnerable Parents had to make a range of complex decision, which were overwhelming
Sullivan -Bolyai et al (2006)	Explore fathers' experiences of living with a child with type 1 diabetes	Purposeful	None	Qualitative study based on naturalistic inquiry. Interview data was analysed using qualitative content analysis	Fathers' experience grief on hearing the diagnosis but also focused on meeting the child's needs Fathers wanted to learn about the condition and treatments Child's condition was constantly in the background Fathers recognized mother's care responsibilities, but felt they were co-partners in the child's care

Author	Aim	Sample	Theory	Methods	Key findings
Swall. Jacob (2001)	Explore the relationship between parents and health professions when a child's has a chronic illness	Theoretical	Illness trajectory model	Qualitative study based on grounded theory. Interview data analysed using framework approach	Mothers needed to develop effective relationships with healthcare professionals which was a continual source of stress Building effective relationships was reliant on mutual respect and good communication particularly early in their child's illness
Waite-Jones, Madill (2008)	Explore fathers' experiences of caring for their child with juvenile idiopathic arthritis	Purposeful	None	Qualitative study based on grounded theory. Interview data analysed using grounded theory method of constant comparison	Fathers' described a range of losses in relation to their ability to maintain a normal family environment which was exacerbated by comparisons to fathers of healthy children The amount of care their ill child required resulted in fathers feeling that they did not spend quality time with their ill child
Wenn., Hallst. (2007)	Explore families' experiences of living with a child with type 1 diabetes	Convenience	None	Qualitative study based on phenomenology. Interviews analysed using Van Manen's approach to phenomenology	Families' perceived their lives to be ordinary but different to before the diagnosis Children did not feel their lives were particularly difficult but were frustrated in relation to being healthy but also ill, feeling independent yet supervised, confident yet insecure Parents worried about possible treatment complications

Tables 1-7 present the data extracted in relation to: the geographical location where the study was undertaken; participant characteristics; the child's health condition; underpinning theoretical perspectives; study design. The first table presents the location the studies were undertaken (Table 1).

Table 1: Geographical location of the studies (n = 34)

Location	North American	UK	Other European	Australasian	Asian
Number of studies	17	10	3	3	1

Tables 2 and 3 present the study participants and the health conditions of the children respectively. In 11 of the 19 studies where both parents participated, fathers represented less than a third of the sample (Figure 8). Participant details in relation to age, ethnicity, education, income or social class were provided in 16 of the 34 studies; parents ages ranged from 20 to 60 years and they were predominately from educated, white middle class backgrounds (Figure 8). Children's ages ranged from 1 month to 21 years (Figure 8).

Table 2: Study participants (n = 34)

Participants	Both parents	Fathers	Mothers	Range of family members	Foster parents	Family members and health professionals
Number of studies	13	6	5	7	1	2

Table 3: Health condition of the child (n = 34)

Health conditions	Range of care needs	Range of conditions	Diabetes	Asthma	Arthritis	Other[1]
Number of studies	14	7	5	3	2	3

[1]Vesicoureteric reflux, spina bifida, ambiguous genitalia

Studies represent parents with a range of experiences in relation to living with a child with a long-term condition (Table 3). Fourteen studies did not include the health condition of the children (Table 3). These studies were included because the child required long-term health interventions such as gastrostomy feeding,

intravenous medication, tracheotomy care and home ventilation. Sample sizes ranged from 5 to 161 participants (Figure 8). In 13 of the 28 qualitative studies participant numbers were less than 20 (Figure 8). However, small participant numbers is common in qualitative research because the emphasis of these methods is the quality and richness of the data collected (Robson 2002).

Table 4 presents the number of studies that used a theoretical foundation to underpin the research.

Table 4: Theoretical foundation of the studies (n = 10)

Theoretical foundation	Social constructs of life	Grief and loss	Adaptation and change	Other[2]
Number of studies	3	2	1 (+1[1])	4

[1]One study was based on concepts of grief and loss, and adaptation and change

[2]Family systems theory, family-centre care, empowerment, illness trajectory model

Tables 5 - 7 relate to the study design. Table 5 presents the number of studies in relation to the research approach adopted.

Table 5: Research approach (n = 34)

Research approach	Quant-itative survey	Mixed methods	Qualitative approaches			
			Phenomenology	Generic	Grounded theory	Other[1]
Number of studies	2	5	11	7	5	4

[1]Ethnography, feminist perspectives, narrative enquiry, naturalistic enquiry

Tables 6 and 7 present the number of studies in relation to the data collection and analytical strategies employed.

Table 6: Data collection (n = 34)

Data collection	Interview	Self-report questionnaire	Focus group	Observation
Number of studies	24 (+4[1])	7	2	1

[1]Studies used interviewing along with other data collection methods

Table 7: Methods of data analysis (studies n = 34)

Data analysis	Statis. analysis	Phenom.	Ground. theory	Frame work approach	Content analysis	Thematic analysis	Not stated[1]
Number of studies	7	9	5 (+1[2])	4	3 (+1[2])	2 (+2[2])	4 (+2[2])

[1]Procedures for coding/development of themes described (n=2); analysis unclear (n=4)
[2]Studies used more than one method of data analysis

2.5.2 Summary of the quality appraisal assessment

The CASP quality assessment criteria focuses on three key areas; rigour, credibility and relevance (CASP 1998). Rigour refers to the appropriateness of the research approach and the integrity of the methods; credibility refers to the clarity and justifications of the findings; relevance refers to the significance and the usefulness of findings. These areas are now described.

2.5.2.1 Rigour

The quality of the studies varied. A summary of the quality assessment using the CASP tool is presented in Appendix III. The research designs and methods chosen were appropriate to gain in-depth insights of parents' perceptions of living with a child with a long-term condition, with 27 of the 34 studies underpinned by qualitative methods. Sixteen of these studies were underpinned by the philosophical perspectives associated with phenomenology or grounded theory (Table 5). With the exceptions of studies undertaken by Monsen (1999), Ray (2002), Ray (2003), Dickinson et al (2006), Sanders et al (2007), Cashin et al (2008) and Marshall et al (2009), the rationale for choosing the approach adopted and its application to the study was not provided.

Although underpinning qualitative research with a theoretical framework has been cited as a means of demonstrating rigour because methodological coherence is more likely to be achieved (Morse et al 2002, Rolfe 2004), incongruence between the theoretical perspectives and methods adopted was evident. For example: two studies underpinned by grounded theory did not use

theoretical sampling strategies (Johnson 2000, Waite-Jones and Madill 2008); two studies underpinned by phenomenology (Ray 2002, Ray 2003) and one study underpinned by grounded theory (Swallow and Jacoby 2001) used generic approaches to analyse data rather than methods more commonly associated with the chosen approach. The five mixed methods studies combined quantitative and qualitative methods. However, in two of these studies details of the qualitative component were not provided (Fawcett et al 2005, Green 2007).

Data elicitation was congruent with the research methods and obtained by interview in 28 of the 34 studies (Table 6). Eight studies provided an outline of the interview topics (Monsen 1999, Johnson 2000, Callery et al 2003, Sullivan-Bolyai 2006, Cashin et al 2008, Waite-Jones and Madill 2008, Hewitt-Taylor 2009, Miller et al 2009). Seven of the 22 studies that included more than one family member provided information in relation to whether participants were interviewed together or separately (Knafl and Zoeller 2000, Callery et al 2003, Heaton et al 2005, Dickinson et al 2006, Wennick and Hallström 2007, Bowes et al 2009, Hewitt-Taylor 2009); one study provided the rationale for the decisions to interviews participants separately (Wennick and Hallström 2007). Lack of detailed description of data elicitation techniques made it difficult to assess which topics areas were explored in-depth or excluded in relation to the development of emergent themes.

Overall the procedures relating to the analysis of data were poorly described. Phenomenology was the most common choice of data analysis (Table 7). Two mixed methods studies (Fawcett et al 2005, Green 2007) and three qualitative studies did not describe the qualitative analytical methods used (Gibson 1999, MacDonald and Callery 2007, Bowes et al 2009). However, the authors of two of these studies provided a detailed description of the procedures and stages involved in data analysis (MacDonald and Callery 2007, Bowes et al 2009).

2.5.2.2 Credibility

Strategies employed to enhance the studies' credibility were poorly described. However, 16 of the 27 qualitative studies did identified the measures taken to enhance the reliability of the study findings which included: participant

verification (Johnson 2000, Maltby et al 2003, Dickinson et al 2006, Nuutila and Salanterä 2006); involving two or more researchers in data coding and analysis (Monsen 1999, Swallow and Jacoby 2001, Goble 2004, Kirk et al 2005, George et al 2006, Mulvaney et al 2006, Sullivan-Bolyai 2006, Sanders et al 2007, Waite-Jones and Madill 2008, Marshall et al 2009); external credibility check with an independent researcher (Goble 2004, Lauver 2008, Waite-Jones and Madill 2008). The use of rich extracts was used across all qualitative studies. This enabled judgements to be made about the development of themes and interpretations of the findings (Slevin 2002, Tuckett 2005). In 15 of the 27 qualitative studies extracts did not support the themes presented, the labels attached to themes lacked meaning, and findings may not have been representative of participants' accounts because extracts were not attributed to specific participants (Gibson 1999, Johnson 2000, Swallow and Jacob 2001, Ray 2002, Maltby et al 2003, Pelchat et al 2003, Heaton et al 2005, Ray 2002, Ray 2003, Sallfors and Hallberg 2003, Goble 2004, Mulvaney et al 2006, Sullivan-Bolyai 2006, Cashin et al 2008, Hewitt-Taylor 2009). The reported statistical significance of results in the quantitative studies must be interpreted cautiously because of the small sample sizes (53-110 participants) (Bailing and McCubbin et al 2001, Hovey 2003, Hovey 2005, Green 2007).

Personal biases can threaten the credibility of study finding and should be accounted for (Sandelowski 1993). Personal biases were in general not described: in five studies the authors acknowledged their own experiences of the phenomena recognising these may have influenced study findings (George et al 2006, Green 2007, Wennick and Hallström 2007, Sanders et al 2007, Waite-Jones and Madill 2008).

2.5.2.3 Relevance

Contextualising study finding is central to transferring findings to other settings (Popay et al 1998). Across studies, authors outlined the context in which the studies were undertaken and made links with the established literature when discussing their findings. Context has several facets and can be viewed from an individual level such as beliefs and cultures and in broader terms such as political and economic factors (Holloway and Wheeler 2002). Seventeen of the

34 studies were undertaken in North American (Table 1) and although this does not negate the findings, the way health systems operate in these countries may have impacted on parents' experiences. Parents' accounts were more likely to include concerns relating to meeting the healthcare costs of living with a child with a long-term condition (Hovey 2003, Ray 2003, Goble 2004). The cultural and social diversity of parents living with a child with a long-term condition are not represented. Findings predominantly represent mothers' perceptions of living with a child with a long-term condition. This has implications for practice; for example one study suggested the 'parenting competency framework' developed from mothers' accounts may enhance the provision of information and support interventions for parents with a living with a child with a long-term condition, yet the framework may not meet fathers needs (Maltby et al 2003).

2.5.3 Synthesised findings

Despite the variability in the quality of the studies there were similarities across findings. The categories identified during the synthesis of study findings were grouped into three overarching themes: 'illness management', 'parental impact' and 'social context'. Some categories were associated with parents' initial response to the child's diagnosis; others evolved over time. The themes and associated categories, presented in Figure 10, will now be described.

Figure 10: Parents' experiences of living with their child with a long-term condition: immediate concerns and ongoing challenges

Theme	Immediate concerns	Ongoing challenges
Illness management	Learning about the condition Monitoring symptoms and responding to changes in the child's condition Interacting with professionals	Mastering technical aspects of care Working in partnership with health professionals Co-ordinating services for the child
Parental impact	Making sense of the condition Grief and loss	Chronic sorrow Adapting and coping Physical and emotional overburden
Social context	Managing disruption	Maintaining normality Seeking social support systems Maintaining relationships

2.5.3.1 Illness management

Six categories were identified from study findings in relation to managing the child's condition. First, parents wanted to learn about their child's condition once they had received the diagnosis. Perceptions that information was an important aspect of taking control of their child's well-being was evident across studies (Bailing and McCubbin 2001, Maltby et al 2003, Ray 2003, George et al 2006, Nuutila and Salanterä 2006, Sanders et al 2007, Cashin et al 2008). Parents wanted information about: the disease and treatments (Bailing and McCubbin 2001, Cashin et al 2008); accessing services and support networks (Ray 2003, George et al 2006); strategies that would help them cope (Nuutila and Salanterä 2006). Parents' described difficulties in obtaining information and many were dissatisfied with the information provided by health professionals (Swallow and Jacoby 2001, Fawcett et al 2005, George et al 2006, Nuutila and Salanterä 2006, Sanders et al 2007). Barriers to effective information provision included: the overuse of medical jargon (Swallow and Jacoby 2001); insufficient, inaccurate and unclear information (George et al 2006, Nuutila and Salanterä 2006, Sanders et al 2007); information being given quickly with little opportunity for discussion (George et al 2006, Nuutila and Salanterä 2006); inappropriate timing of information (Maltby et al 2003). Information needs continued throughout the child's illness trajectory and at significant developmental milestones such as adolescence (Nuutila and Salanterä 2006).

Second, gaining control of their child's condition involved taking responsibility for, and developing the skills to monitor and respond to changes in the child (Ray 2002, Sullivan-Bolyai et al 2006, Cashin et al 2008). Differences in responding to the child's illness were reported: the unpredictability of the condition resulted in some parents being constantly vigilant to changes in their child (Sallfors and Hallberg 2003, Cashin et al 2008 Sullivan-Bolyai et al 2006); for others monitoring their child's condition became part of every-day life (Ray 2002, Wennick and Hallström 2007). Constant vigilance was heightened for parents of children with complex medical needs who relied on technology 24 hours a day to maintain functions of daily living (Heaton et al 2005, Kirk et al 2005).

Third, studies consistently identified that parents wanted to develop effective relationships with health professionals but communicating with professionals was stressful (Swallow and Jacob 2001, Ray 2002, Dickinson et al 2006). Parents' satisfaction with their relationships with health professionals was variable. Parents were more satisfied with their child's care when care was co-ordinated by a specific individual such as a named key worker or there was continuity in the professionals providing care for the child (Ray 2002, Dickinson et al 2006, Miller et al 2009). Relationships built on mutual respect and trust endured over time and provided a consistent support mechanism once developed (Swallow and Jacoby 2001). Relationships were poor when parents' felt undervalued for example being labelled as non-compliant if decisions about their child's care did not conform to professionals' perspectives (Balling and McCubbin 2001, Dickinson et al 2006, Nuutila and Salanterä 2006, Miller et al 2009).

Fourth, parents' roles changed to one of care-giver as a result of providing nursing and medical care to their child. For some parents this formed a significant part of parenting their child above usual parenting tasks (Monsen 1999, Ray 2002, Sallfors and Hallberg 2003, Heaton et al 2005, Kirk et al 2005, Wennick and Hallström 2007, Cashin et al 2008). There were variations in the type of care commitments across studies, which appeared to be condition specific for example: parents of children with rheumatoid arthritis provided physical care to their child because of pain and reduced mobility (Sallfors and Hallberg 2003, Waite-Jones and Madhill 2008); parents of children with diabetes focussed on encouraging their child to maintain treatment and dietary regimes (Sallfors and Hallberg 2003, Wennick and Hallström 2007, Bowes et al 2009, Marshall et al 2009); parents of children dependent on technology described becoming competent in using medical equipment in order to care for their child (Heaton et al 2005, Kirk et al 2005). Regardless of the child's specific condition, care commitments were emotionally laden with caring roles often dominating parenting roles (Ray 2002, Kirk et al 2005, Sullivan-Bolyai et al 2006).

Fifth, findings across studies identified that parents developed considerable expertise in managing their child's condition and want to work collaboratively and share responsibility for their child's care with health professionals (Bailing and

McCubbin 2001). They expected care to be negotiated (Dickinson et al 2006) and be involved with care decisions (Fawcett et al 2005) but did not want sole responsibility for care decisions (Bailing and McCubbin 2001). However, variations in parent-professional collaboration were reported across studies: some parents' perceived that their expertise and contribution to care was not valued and they were not involved in care decisions (Bailing and McCubbin 2001, Ray 2003, Maltby et al 2003, George et al 2006, Nuutila and Salanterä 2006); whereas other parents' perceived that they were included in care decisions (Ray 2003, Fawcett et al 2005, Sullivan-Bolyai et al 2006). It was also reported that some parents adopted a passive role in relation to care decisions because of a lack of confidence and the perceived paternalistic approach of some health professionals (Fawcett et al 2005).

Sixth, studies reported failures in health care systems to meet the child and family's needs. Regardless of the child's condition, parents wanted well organised services with effective communication and collaboration across services, shorter waiting times and clear care plans (Ray 2002, Dickinson et al 2006, Lauver 2008, Miller et al 2009). Some studies reported difficulties with obtaining equipment appropriate to the child's needs and lack of appropriate training to use equipment (Ray 2002) and lack of information about available services (Ray 2003, Dickinson et al 2006, MacDonald and Callery 2007, Lauver 2008). Despite policy directives advocating the need for improved interagency working and placing the child's needs at the centre of service delivery (DfES/DH 2004), parents' described services as being uncoordinated and bureaucratic fitting the child into existing systems rather than services being organised around the child's needs (Notras et al 2002, Ray 2002, Hewitt-Taylor 2009, Miller et al 2009). There was also poor cohesion across health, education and social services (Ray 2003, Hewitt-Taylor 2009). Studies reported that parents' responded to the failure of welfare systems to meet their child needs by undertaking the role of care co-ordinator (Monsen 1999, Ray 2003, Dickinson et al 2006, Green 2007, Hewitt-Taylor 2009, Miller et al 2009). Developing this role was more likely to be representative of parents living with a child with complex care needs (Ray 2003, Dickinson et al 2006, Green 2007).

2.5.3.2 Parental impact

Five categories emerged in relation to the impact of living with a child with a long-term condition for parents. The first category was concerned with making sense of the child's condition. Although making sense of their child's illness was an initial response to the child's illness, parents revisited the meaning of the illness throughout the illness trajectory, particularly when there were changes in the child's condition (Sallfors and Hallberg 2003, Bowes et al 2009). Studies described competing demands in relation to: trying to understand the condition and deal with their own feelings while simultaneously being responsible for the child's emotional well-being (Johnson 2000, Sanders et al 2007); reconciling conflicts between treatment demands and meeting the social needs of the child (Callery et al 2003); meeting the child's health needs and the family's needs (Hovey 2005); treating the child as normal while securing services that would maximise the child's heath and development (Johnson 2000, Hewitt-Taylor 2009, Bowes et al 2009). At times these competing demands were overwhelming and parents were unsure where to seek support (Ray 2002, Dickinson et al 2006).

Second, studies identified the emotional impact of living with a child with a long-term condition. Grief was experienced in response to receiving the child's diagnosis with parents describing a range of feelings such as confusion, disbelief, anxiety, turmoil and a loss of identity (Gibson 1999, Johnson 2001, Swallow and Jacob 2001, Maltby 2003, Cashin et al 2008, Waite-Jones and Madill 2008, Sanders et al 2007, Bowes et al 2009, Marshall et al 2009). Relief because of worries about the gravity of the child's symptoms was also experienced, particularly when the duration of illness symptoms had been lengthy prior to diagnosis (Nuutila and Salanterä 2006, Cashin et al 2008). These initial emotions dissipated over time (Cashin et al 2008, Marshall et al 2009). For some parents a more enduring grief commonly referred to as 'chronic sorrow' evolved (Johnson 2001, Swallow and Jacob 2001, Cashin et al 2008, Bowes et al 2009, Marshall et al 2009).

Third, ongoing grief impacted on parents' ability to cope with their child's condition (Johnson 2001, Swallow and Jacob 2001, Cashin et al 2008, Bowes et al 2009, Marshall et al 2009). Chronic sorrow appeared to have two dimensions;

enduring grief because of the consequences of the condition for the child and limited opportunities for parents to meet their own needs (Marshall et al 2009, Bowes et al 2009); a resurgence of grief at times of adversity such as changes in the child's condition (Wennick and Hallström 2007, Bowes et al 2009). Chronic sorrow resulted in an inability to retain and assimilate information (Cashin et al 2008), continually searching for the reason their child has a long-term condition (Johnson 2001, Bowes et al 2009) and feelings of self blame (Johnson 2001, Swallow and Jacob 2001, Cashin et al 2008, Bowes et al 2009). Parents managed their grief by focussing on their child's achievements (Johnson 2001, Green 2007), taking opportunities to strengthen their relationship with their child when performing care (Ray 2002, Waite-Jones and Madhill 2008) and being flexible in relation to care and treatment regimes (Ray 2002, Callery et al 2003).

Fourth, adaptation and coping was identified as a salient feature of living with a child with a long-term condition. Parents' adjustment appeared to be a dynamic process because of ongoing changes in their child's condition and stage of development balanced with varying family needs (Sallfors and Hallberg 2003, MacDonald and Callery 2007, Marshall et al 2009). Over time most parents adapted and coped to living with a child with a long-term condition (Gibson 1999, Knafl and Zoeller 2000, Maltby 2003, Wennick and Hallström 2007), but for some this was difficult, particularly parents of children with significant developmental and neurological disabilities (Johnson 2000, George et al 2006). Parents employed a range of strategies to adjust to living with a child with a long-term condition, including: information gathering (Sallfors and Hallberg 2003, Hovey 2005, Nuutila and Salanterä 2006); establishing social networks which provided emotional and practical support (Sallfors and Hallberg 2003, Waite-Jones and Madill 2008); developing problem-solving skills such as appraising prior experiences when making care decisions (Gibson 1999, Hovey 2005); being stoical to manage emotional distress (Waite-Jones and Madill 2008).

The fifth category related to the impact of the child's condition on parents quality of life. Parents were physically and emotionally overburdened which manifested as chronic fatigue (Monsen 1999, Heaton et al 2005, Green 2007), frustration (Gibson 1999, Ray 2002) and feeling emotionally challenged (Ray 2002, Heaton

et al 2005, Sullivan-Bolyai et al 2006). Overburden was more likely to occur in parents of children with complex needs because maintaining daily living activities required continuous care provision (Monsen 1999, Heaton et al 2005, Kirk et al 2005). In these situations parents' described meeting their child's needs as being interwoven with their entire lives. Studies identified that living with a child with a long-term condition placed limitations on parents' career aspirations (Heaton et al 2005, Green 2007) and social opportunities (Ray 2002, Goble 2004, Fawcett et al 2005). Mothers' experienced the greatest disruption because they were more likely to assume the role of main carer (Sallfors and Hallberg 2003, Hovey 2005, Green 2007). Fathers' perceived that their role as family provider and protector was challenged because of money pressures and claiming financial benefits (Hovey 2003, Goble 2004), loss of control because of relying on others to support the family (Waite-Jones and Madill 2008) and concerns about the family's health and well-being (Knafl and Zoeller 2000, Hovey 2005, Waite-Jones and Madill 2008). In contrast, living with a child with a long-term condition provided opportunities for personal development such as improved communication (Swallows and Jacoby 2001, Green 2007) and organisational skills (Ray 2002, Green 2007).

2.5.3.3 Social context

Four categories emerged in relation to the social context of living a child with a long-term condition. First, studies described family life being disrupted because of the unpredictability of the child' condition such as the frequency of acute hospital admissions (Callery et al 2003, Sallfors and Hallberg 2003) and having to accompany the child for therapies and clinic appointments (Ray 2002, Sallfors and Hallberg 2003, Heaton et al 2005, Kirk et al 2005, Cashin et al 2008). These disruptions impacted on the time available for the family to spend together. In order to manage these disruptions, parents functioned as two sub-units; one parent responding to the needs of the child with a long-term condition, the other meeting siblings' needs (Ray 2002, Waite-Jones and Madill 2008). Although working as two sub-units hindered attempts at maintaining normality (Ray 2002), there were positive aspects to this disruption (Sullivan-Bolyai et al 2006). For example partner relationships strengthened because of having to effectively

communicate about sharing parenting tasks on a daily basis (Heaton et al 2005, Fawcett et al 2005, Sullivan-Bolyai et al 2006).

Second, most studies reported a range of challenges in relation to achieving normality. These challenges included: maintaining ongoing treatment regimes (Mulvaney et al 2006, Wennick and Hallström 2007); lack of flexibility of health, social and educational systems to meet the family's needs (Notras et al 2002, Ray 2002, Hallström and Elander 2007, Hewitt-Taylor 2009, Miller et al 2009); socially constructed barriers that prevented their child participating in usual childhood activities such as play, schooling and making friends (Ray 2003, Green 2007, Sanders et al 2007). Regardless of the child's diagnosis parents strove to create a normal family environment, which was more likely to be achieved if parents had a positive view of living with their child with a long-term condition (Gibson 1999, Cashin et al 2008) and were proactive in managing their child's condition (Cashin et al 2008). In addition, a sense of normality was created by incorporating caring routines into every-day family life and the family working as a unit (Knafl and Zoeller 2000, Ray 2002, Heaton et al 2005).

The third category related to developing effective social support networks. Establishing social support networks were important aspects of coping with the child's condition (Ray 2002, Lauver 2008). Information about the availability of support groups and specialist networks happened by chance rather than being provided as an integral part of care delivery (Ray 2002). In relation to their child, parents' experienced difficulties in securing appropriate pre-school educational placements and social outlets for their child, particularly a child with communication and learning difficulties (Ray 2002, Hewitt-Taylor 2009). Parents of children with complex needs perceived their child had difficulties developing true friendships but tolerance from other children was an acceptable alternative (Ray 2002). Parents' perceived that health professionals lacked the skills to provide support in relation to meeting their own and child's wider social needs (Fawcett et al 2005, Bowes et al 2009). Despite parents valuing support networks, the opportunity to be part of a support group was variable and parents' involvement self-management programmes was not evident in the review studies.

The fourth category related to maintaining family relationships. Studies described family relationships were strained, regardless of the child's condition, and parents' perceived that living with a child with a long-term condition placed them at risk of marital breakdowns (Ray 2002, Goble 2004, Hovey 2005). The main barrier to maintaining family cohesion was the time needed to meet care-giving commitments resulting in partners having limited opportunities to spend time alone (Goble 2004, Hovey 2005, Green 2007). Different approaches to managing the child's condition also created family tensions (Ray 2002, Knafl and Zoeller 2000). In contrast, some studies reported relationships were strengthened this being attributed to a mutual commitment to meeting their child's needs and recognition of the care burdens placed on the child's main carer (Ray 2002, Goble 2004). Although, there was limited exploration within the review studies relating to maintaining relationships with wider family and friends, social outlets were identified as buffers to the challenges of living with a child with a long-term condition and maintain a sense of normality (Ray 2002, Waite-Jones and Madill 2008). Reactions from family and friends ranged from unconditional support and ongoing friendship to a gradual withdrawal of support and offers of friendship (Ray 2002). These responses were rationalised by parents in terms of the degree family and friends felt comfortable with their child's condition (Ray 2002, Ray 2003, Green 2007, Sanders et al 2007).

2.6 Discussion

This section considers the findings in relation to the review objectives.

2.6.1 Parents' experiences of living with a child with a long-term condition

This review aimed to describe parents' experiences of living with a child with a long-term condition, which are now explored in relation to the following questions:

1. What were the salient features of living with a child with a long-term condition?
2. What was the impact of living with a child with a long-term condition?
3. How did parents integrate the child's needs into every-day family life:
4. How effective are support systems?

First, a significant feature of living with a child with a long-term condition, regardless of the diagnosis, related to managing the child's condition. Review findings suggested that to take control of the child's condition parents need: knowledge of the condition and treatments (Nuutila and Salanterä 2006, Cashin et al 2008); to learn from illness episodes and use these experiences to identify and respond to subsequent illness symptoms in their child (Ray 2002, Callery et al 2003); to develop effective relationships with health professionals (Bailing and McCubbin 2001, Fawcett et al 2005). The review found parents were not always supported in their quest for information and forming relationships with healthcare professionals was stressful. Although parents became experts in managing their child's condition, the emotional 'burden' associated with providing care for their child, particularly managing life threatening complications, and having ultimate responsibility for their child's health were at times overwhelming (Kirk et al 2005, Sullivan-Bolyai et al 2006). This resulted in uncertainties in relation to recognising and responding to changes in their child's condition.

Second, the review findings suggest the impact of the child's condition is temporally related; dealing with immediate concerns following the child's diagnosis and responding to the more enduring challenge of integrating the child's needs into family life. Parents' experienced a range of emotions following the child's diagnosis associated with grief, but these emotions dissipated as parents accepted the reality of the situation and focussed on meeting the child's needs (Swallow and Jacob 2001, Bowes et al 2009). For some parents a more enduring grief developed which impacted on their ability to make sense of, and accept, their child's condition (Johnson 2001, Cashin et al 2008, Bowes et al 2009). Parents have multiple functions that may include parenting, employment and societal roles (Major 2003). Living with a child with a long-term condition impacted on these roles. Mothers' experienced the greatest role change because they were more likely to assume the role of main carer, which impacted on their career aspirations (Heaton et al 2005, Green 2007). Caring roles dominated parenting roles because of the physical and emotional drain of providing ongoing care to the child, and the intimate and complex nature of care regimes (Kirk et al 2005, Sullivan-Bolyai et al 2006). Care-giving burdens and a

lack of effective support systems resulted in parents potentially becoming isolated with few social outlets (Heaton et al 2005).

Third, integrating the child's needs into every-day family life was a way of managing disruption and creating a normal family environment. Responding and adjusting to the child's condition is a dynamic and continually shifting process. As discussed in Chapter 1, Section 3, parents' ability to respond and adjust to living with a child with a long-term condition is influenced by a range of factors including family functioning and cohesion, coping strategies, support systems, financial and intrapersonal factors. Review findings were similar in that creating a normal family environment was more likely to be achieved if the family shared responsibility for caring routines, partners valued each other's contribution to family life, and parents were able to develop effective support networks (Ray 2002, Goble 2004, Cashin et al 2008, Heaton et al 2005).

Fourth, the review identified the quality of parent-professional interactions was variable. Professionals rely on parents to provide healthcare interventions to the child and recognise changes in the child's condition. The parent-professional dyad appears problematic in that parents' perceive that their expertise and contribution to care is not valued (Bailing and McCubbin 2001, Nuutila and Salanterä 2006). Collaboration in relation to care decisions was not evident in review studies. Service provision lacked coordination and was not responsive to meeting the child's needs (Ray 2002, Dickinson et al 2006). Home-care programmes for children with long-term conditions have shifted the responsibility of the child's care to parents without a reciprocal shift in resources or considering the best way to support parents in their role as the primary care giver (Ray 2003). Whist parents recognised their commitment to their children, with or without a long-term condition, they perceived that it was expected they would take on the additional responsibility of meeting their child's health, development and physical needs in addition to everyday parenting (Sallfors and Hallberg 2003, Heaton et al 2005, Kirk et al 2005, Cashin et al 2008). The amount of nursing and medical care required was significant for some children, yet there appeared to be a lack of support for parents in relation to the role as caregiver.

2.6.2 Similarities and differences between parents' experiences of acute illness episodes in children with long-term conditions

The second review objective was to consider the similarities and differences between parents' experiences of an acute illness with long-term conditions. When a child becomes ill and parents are uncertain about the cause or seriousness of the illness symptoms, it is likely they will seek advice from health professionals (Neill 2000). Evidence suggests that parents' needs are similar to those of parents of children with long-term conditions; they want information about the condition and to be involved in care decisions (Kai 1996, Neill 2000). Parents are often not involved in care decisions, which results in a disparity between parents and professionals expectations of parent-professional encounters (Kai 1996). In addition, and similar to parents of children with long-term conditions, parents want their expertise to be recognised (Neill 2000). For parents of children with acute illness episodes this expertise relates to parental competence, whereas parents living with children with long-term conditions want their expertise and experiences in relation to managing their child's condition to be valued.

When a child is ill, it is likely parents will need to organise care for other dependents, particularly if the child requires hospitalisation, secure time away from work and make adjustments to their usual routines in order to meet any additional needs the child's illness places on the family (Callery 1997). For most childhood illness this disruption is transient. However, findings of the review suggest it is the unremitting nature of these adjustments that are challenging for parents living with a child with a long-term condition. The frequency of acute illness episodes and hospitalisation are greater for a child with a long-term condition compared to children who do not have a long-term condition and therefore disruptions are recurrent (Newacheck et al 1998). Frequently requesting time away from work to care their child can be an added source of stress for parents. In addition to the disruption of acute illness episodes, the review identified that living with a child with a long-term condition can impact on usual family routines because of ongoing care giving burdens (Ray 2002, Sallfors and Hallberg 2003, Heaton et al 2005).

The final area where both similarities and differences exist between parents' experiences of an acute illness in children and long-term conditions related to in-patient care. Parents want to be involved in care decisions regardless of the child's condition (Power and Franck 2008). There are situations when parents' perceived that it was beneficial for health professionals to assume responsibility for their child's care, particularly in emergencies. Parents of children with long-term conditions through experience and the frequency of hospital admissions realised that in reality few choices exist in relation to managing their child's acute health needs (Ray 2002). Across the literature parents' accounts suggested health professional attitudes and willingness to collaborate with them was variable and inconsistent. Parents of hospitalised children expected to participate in the direct care of their child but did not want to undertake complex care unless that care was required on discharge (Corlett and Twycross 2006, Coyne and Cowley 2007). Parents of children with a long-term condition have no choice in mastering complex care and treatments because they are an integral part of their child's life (Ray 2002, Heaton et al 2005, Cashin et al 2008).

2.7 Review limitations

The review has several limitations. First, all relevant studies may not have been captured. Undertaking a systematic review, where a wider range of data bases would be searched, may have generated additional studies. Second, techniques associated with integrative data synthesis such as meta-ethnography may have resulted in a greater theoretical depth to the analysis (Dixon-Woods et al 2005). An interpretive approach to data synthesis enabled key themes to be identified across studies in order to describe in detail parents' experiences of living with a child with a long-term condition.

The third limitation relates to the heterogeneity of study approaches. A third of the studies considered one aspect of the parents' experience such as grief, loss, stress and coping which may not have captured the intricately interwoven facets that contribute to parents' experiences of living with a child with a long-term condition. About half of the studies adopted a disease specific approach such as asthma and diabetes, providing valuable insights into the experiences, perceptions and challenges facing these parents. This may lead to

improvements in specific areas of care delivery and service provision (Stein and Jessop 1984, Eiser 1990). In contrast, studies that are not disease specific can explore shared experiences, irrespective of the child's diagnosis. Findings from these studies may assist health commissioners when considering the best use of resources to meet a range of needs. While there will be similarities, it cannot be assumed the experiences of parents whose child has a specific condition will be the same for parents of children with a different condition (Stein and Jessop 1984, Eiser 1990). Although similarities existed across studies, parents' accounts of disease specific challenges may not have been captured.

2.8 Gaps in the literature

There has been an increase in studies solely about fathers' perspectives of living with a child with a long-term condition, as identified in the studies included in the review presented in this chapter. However, where both parents were included fathers remained under-represented. Consequently, the review primarily reflects mothers' experiences of living with a child with a long-term condition. Participants' accounts may not be representative of the minority ethnic groups that exist within the UK. There needs to be a continued drive to include fathers and other family members' in future studies about living with a child with a long-term condition.

The review findings suggest that parents' perceive that healthcare delivery and services do not always meet their child's needs and support parents in their role as the child's carer: emotional and social support, information provision and skills acquisition training appear to be inadequate for some parents. There appears to be a gap between parents' requirements and care provision. Although the studies described parents' experiences, additional research mapping parents' expectations against current care provision may help identify future priorities in relation to service provision for children with long-term conditions.

The review findings suggest that parents develop considerable expertise in managing their child's long-term condition. Parents' perceive that this expertise is not always valued and they are not included in decisions about their child's care. Despite a substantial body of evidence about parents' perceptions of their

involvement in the care of children in hospital, and parents' desires for effective parent-professional collaboration, collaborative practice remains inconsistent (Power and Franck 2008, Shields et al 2008). Further research is needed to explore the differences between parent and health professional expectations about parent-professional collaboration in the context of parents caring for children with a long-term condition. As the complexity of care delivered in the home environment continues to increase, understanding how parents' develop the expertise to manage their child's condition may ensure parents receive the appropriate support to develop their role as the expert parent. To-date concepts relating to the expert parent are poorly described. Exploring how health professionals' engage with and incorporate expert parents' opinions into care decisions when working with children with long-term conditions may foster improved parent-professional collaboration.

It is likely that parents of children with hydrocephalus have similar experiences to parents of children with different long-term conditions. However parents' experiences and perceptions may be different. These differences may relate to the unpredictability and life threatening nature of shunt malfunction. Undertaking an empirical study exploring parents' experiences and perspectives of living with a child with hydrocephalus would identify these similarities and differences.

Chapter 3:
Parents' experiences of living with a child with hydrocephalus

3. Introduction

This chapter presents a study designed to explore parents' experiences of living with a child with hydrocephalus. As previously discussed in Chapter 1, Section 1.4.3, hydrocephalus is a long-term condition and a shunt is the main mode of treatment. Shunts are problematic as they frequently malfunction which can be life threatening. The evidence presented highlighted that detecting shunt malfunction is not straightforward because symptoms are unpredictable, variable and often unique to the individual child (Kirkpatrick et al 1989, Watkins et al 1994, Garton et al 2001, Barnes et al 2002). These studies recommend that health professionals' listen to and value parents' concerns when assessing a child for possible shunt malfunction. Health professionals' often perceive p2arents as being inaccurate in their assessment of their child's condition (Iskandar et al 1998, Barnes et al 2002).

As highlighted in Chapter 2, parents living with a child with a long-term condition other than hydrocephalus want to be knowledgeable about their child's condition, be able to monitor and respond effectively to changes in the condition and form positive relationships with health professionals. It is likely parents of children with hydrocephalus have similar expectations and experiences to parents living with a child with other long-term conditions. However, there may be differences because of the diverse ways in which hydrocephalus presents and the uncertainty and potential life threatening nature of shunt malfunction. Understanding parents' experiences of living with a child with hydrocephalus and how they recognise and respond to suspected shunt malfunction has the potential to foster greater understanding between parents and health professionals and improve parent-professional collaboration when determining whether illness symptoms are shunt related. The aim, design, methods, data analysis and findings of a study designed to explore parents' experiences of living with a child with shunted hydrocephalus are now presented.

3.1 Aims and objectives

This study aimed to understand parents' experiences and perceptions of living with a child with shunted hydrocephalus. The specific objectives were to:

1. Examine parents' understanding of hydrocephalus and its treatment;
2. Investigate how parents learn about shunt management and associated complications;
3. Explore parents' decisions when their child experiences illness symptoms and their subsequent health seeking behaviour when shunt malfunction is suspected.

3.2 Study setting

The two main support networks for parents living with a child with hydrocephalus within the regions of Yorkshire and Humberside are a National Health Service (NHS) acute hospital trust and a voluntary organisation, the Association for Spina Bifida and Hydrocephalus (ASBAH). Children with hydrocephalus in Yorkshire and Humberside have their acute care managed primarily by the regional neurosciences services based at Leeds General Infirmary (LGI). Data about the number of children admitted for potential shunt complications are routinely collected from the neurosciences in-patient ward. Data for the calendar year when this study was undertaken are presented in Table 8. In addition, children with hydrocephalus and their families are offered support from the Northern England Branch of ASBAH. In January 2006 there were 730 children registered with the Northern England Branch of ASBAH.

Table 8: Admissions for potential shunt complications in 2005 (children's neurosciences shunt register, LGI)

Children admitted for suspected shunt malfunction	Total number of admissions for suspected shunt malfunction[1]	Children who required a shunt revision	Total number of shunt revisions[2]
66	116	31	46

[1] Some children had more than one admission
[2] Some children had more than one shunt revision

3.3 Methods

This section outlines and justifies the study design, and the sampling, data collection and analytical strategies employed.

3.3.1 Study design

The design was a cross-sectional interview-based survey employing qualitative methods. This design was appropriate as the purpose of the study was to explore the breadth and depth of parents' experiences and perceptions of living with a child with hydrocephalus. Qualitative methods are particularly suitable when research questions would be difficult to answer by the manipulation of variables such as making sense of complex situations and when little is known about a topic (Barbour 2000, Flemming 2007). The application of qualitative methods enables phenomena to be explained and ultimately fosters a deep understanding of phenomena such as patients' experiences of health and illness (Morse and Richards 2002).

Designing an enquiry based study investigating how individuals make sense of and response to illness experiences is challenging because of the range of qualitative methods available. Choices are complex because there is no definitive way of classifying qualitative methods (Patton 2002). In addition, it has been suggested that over immersion in the epistemology of qualitative methods has to some extent undermined their application and potential to answer questions that could enhance practice (Rolfe 1998, Sandelowski 2000, Cheater 2003). Qualitative methods can be divided into three broad groups:

- Socio-linguistic methods that explore the use and meaning of language such as discourse analysis (Potter and Wetherell 1987) and conversation analysis (Schegloff 2007);
- Methods that describe and interpret participants' views in order to understand the unique meaning and significance of phenomenon through the 'lived experience' such as phenomenology (Carpenter 2007);
- Methods that develop theory, typified by grounded theory (Glaser and Strauss 1967).

These methods are well established and rooted in the philosophies of social sciences disciplines such as anthropology, sociology and psychology. The

increased value of qualitative inquiry within health and social sciences disciplines has resulted in refinement and further development of methods associated with qualitative research (Patton 2002, Ritchie 2003). It has been postulated that as qualitative inquiry evolves and its application increases, the methods of undertaking qualitative research should stand alone without having to be underpinned by a particular philosophical perspective (Patton 2002, Ritchie 2003). Generic or descriptive designs are qualitative approaches not underpinned by a specific theoretical framework (Sandelowski 2000, Holloway and Tordes 2003, Cooper and Endacott 2007).

The merits of undertaking qualitative research with or without a specific theoretical framework continue to polarise qualitative researchers (Baker et al 1992, Paley 1997, Sandelowski 2000, Maggs-Rapport 2001, Reeves et al 2008). Advocates argue that the absence of a theoretical framework results in methodological incongruity which threatens the credibility of study findings (Rolfe 2006, Reeves et al 2008). Opponents suggest the rigorous application of theoretical frameworks leads to the development of abstract concepts removed from the original data resulting in poor representation or misinterpretation of participants' accounts (Sandelowski 2000, Ritchie 2003).

It is claimed that generic approaches are not a research methodology but a method of undertaking analysis (Braun and Clark 2006). Yet, the process of grouping data into themes (thematic analysis) is a core skill of qualitative researchers and the bedrock of theoretical approaches such as grounded theory and phenomenology (Holloway and Tordes 2003). Thematic analysis is the most widely used analytical method in qualitative research (Braun and Clark 2006). Perhaps thematic analysis, in common with other generic approaches, should be considered a methodology in its own right. The debates about the relative merits of theoretical and generic research approaches added to the challenges of choosing a design appropriate to meeting the study objectives. Appreciating the ontological and epistemological perspectives of ethnography, grounded theory and phenomenology, and their application to this study assisted in making an informed choice about the study design (Figure 11).

Figure 11: Application of three approaches to qualitative research

Approach	Key features	Application
Ethnography Based in anthropology Appropriate for describing and understanding a social or cultural group, or system	Explores the meaning individuals place on the beliefs and values of a group Interactions and events examined by emersion into the system	Parents and their child with hydrocephalus can be viewed as a social group, a possible research question using an ethnographical lens is: *Do parents living with a child with hydrocephalus have similar social opportunities to parents living with a child without hydrocephalus?* An ethnographical approach might not address specific study objectives such as how parents learn about and respond to shunt malfunction
Grounded theory Based in a variety of disciplines, but primarily sociology Appropriate for developing theory	Explores social processes Principle aim is developing theory rather than describing participant accounts Data collection is varied but commonly obtained by interview	Grounded theory could be used to explore parents' experiences of living with a child with hydrocephalus, a possible research question adopting a grounded theory approach is: *How do parents make decisions about their child's health needs when their child has hydrocephalus?* A grounded theory approach could explore parents' decisions when the child is ill but might not address the broader aim of describing parents' experiences in-depth. Theory generation was not an explicit study aim. A range of theories exist (Chapter 1) that help explain the impact and response to living with a long-term condition
Phenomenology Based in a variety of disciplines, but primarily psychology Appropriate for understanding the 'lived experience' of participants	Exploration of phenomena to understand the unique significance to those experiencing it Data primarily obtained by interview but a range of data collection methods are used	A phenomenological approach could be used to gain an understanding of the unique meaning and significance for parents living with a child with hydrocephalus, a possible research question using a phenomenological lens is: *What is the lived experience of parents who live with a child with hydrocephalus?* The broad study aims could be achieved because implicit within phenomenology is uncovering meaning by describing participants' experiences. Interviews are often unstructured with the topics discussed driven by participants. The specific study objectives might not have been met using a wholly unstructured approach

A cross-sectional interview-based survey design, underpinned by generic qualitative methods, was chosen because these approaches are more likely to remain true to participants' accounts and ensure the researchers' own

interpretations are transparent (Sandelowski 2000). The study design was based on the interrelated concepts of interpretivism and reflexivity balanced with pragmatism and transparency advocated by Morse and Richards (2002), and Snape and Spencer (2003) which can be achieved by:

- Employing methods appropriate to answer the question, rather than fitting questions to a particular theoretical framework;
- Applying analytical strategies to find meaning and understand complex issues;
- Valuing and accurately representing participants' accounts;
- Clearly delineating between researcher interpretations and individual participant's descriptions while recognising deeper insights can be gained from synthesising and comparing participants' accounts;
- Reflecting on and acknowledging personal values and beliefs that may influence or bias the study;
- Being open to scrutiny in order to demonstrate transparency.

3.3.2 Ethical approval

Recruiting participants from NHS settings requires adherence to the principles of the NHS research governance framework (DH 2005c) and approval from a recognised research ethics committee. Favourable local research ethics committee review (LREC reference AB/44233/1C/442+33/60145/1) and site specific approval from the local research and development department (R&D reference RD/10553/1) enabled the study to proceed. Although the research governance framework does not apply to participants outside the NHS the same ethical considerations were relevant and maintained across both study settings. The national and local ASBAH teams were provided with the study information; their support enabled potential participants to be identified and approached from the local ASBAH register.

3.3.3 Sample selection

Recruiting participants with the required experiences is central to achieving study aims (Morse and Field 1996, Coyne 1997). Purposeful, selective and theoretical sampling are the most common research sampling strategies (Coyne 1997). However, these terms have different meanings in the literature and are often

used interchangeably (Coyne 1997). Schatzman and Strauss (1973) describe selective sampling as ongoing recruitment as the study evolves; whereas Glaser's (1978) and Sandelowski's (1995) differentiation between selective and theoretical sampling is based on the former having predetermined sampling criteria and the latter having a flexible sampling criteria that develops as the study progresses. Morse (1991) suggests both purposeful and theoretical sampling involve the selection of participants with broad topic knowledge but in theoretical sampling there is subsequent modification of the sampling criteria as the study evolves enables participant recruitment to be refined.

The differences between the strategies outlined appears to relate to whether sampling criteria are predetermined prior to data collection or adapted in response to preliminary data analysis. A purposeful sampling strategy was adopted and in relation to this study refers to the selection of participants using predetermined criteria. The inclusion criterion was broad and included parents of children with shunted hydrocephalus. However, factors likely to impact on parents' experiences and adjustment to living with a child with hydrocephalus were identified in advance, and parents were sampled to reflect:

- The range of conditions that may result in hydrocephalus because this influences the presence of associated conditions;
- Frequency of shunt complications because of the disruption to family life;
- The age of the child.

In addition, characteristics such as the family structure including other siblings, distance from regional support networks, socio-economic background and ethnicity may influence parents' perceptions and experiences. These factors were considered during data analysis and discussed in relation to the findings.

Parents were sampled from the ASBAH and neurosciences in-patient ward shunt registers. Two sampling sources were used because the larger ASBAH register was considered more likely to recruit parents with a range of experiences. In contrast to parents recruited from the in-patient setting, relying solely on the ASBAH register to recruit parents may not have captured parents with recent

experience of their child requiring hospital admission for potential shunt malfunction. The sampling procedures are outlined in Section 3.5.1.

Qualitative research aims to collect information rich data. Sample sizes are often small in comparison to quantitative research and a balance needs to be achieved between obtaining data of sufficient depth and breadth and the resources available (Patton 2002). In addition, it is not always possible, nor desirable, to predict precise sample sizes at the start of a qualitative study. This is not problematic because data collection and preliminary analysis occur simultaneously which guide the final sample size ensuring the study aims are met. For the purpose of this study it was anticipated that data saturation would be achieved at around 20 interviews. However, it was recognised that there needed to be flexibility and decrease or increase the number of interviews depending on whether new issues emerged during the interviews.

3.3.4 Data collection methods

A semi-structured interview method was adopted to elicit data. Interviewing was an appropriate data collection method because the research interview is well established (Holstein and Gubrium 2003a) and enables meaningful engagement with participants allowing them to share their experiences, thoughts, attitudes and beliefs (Lambert and Loiselle 2008). The interview is a social encounter orientated towards symbolic interactionism, where meaning is constructed through participant-researcher interactions, in order to generate new knowledge (Holstein and Gubrium 2003b, Speziale 2003). Consequently, interviewing is an active process and the resultant data are shaped by the interviewer and participant. The strengths and limitations of interviewing as a data collection method are summarised in Figure 12.

Figure 12: Strengths and limitations of interviewing

Strengths	Limitations
High response to questions (Edwards and Talbot 1999, Polit and Beck 2004)	Requires experience and skills to construct questions that facilitate responses in relation to the study focus (Holstein and Gubrium 2003b, Lambert and Loiselle 2008)
Potential to collect rich data and illuminate insights that are difficult to obtain by other approaches (Robson 2002)	Collecting and analysing data is resource intense, can generate much irrelevant data (Edwards and Talbot 1999, Robson 2002)
Uncertainty and ambiguity can be clarified, avoiding misinterpretations (Robson 2002)	Lack of standardisation of questions may affect consistency of data generated (Robson 2002)
Flexible with opportunity to modify the line of enquiry (Robson 2002)	Personal influences relating to data construction and interpretation can result in biases in the findings (Robinson and Thorne 1988)
Non-verbal cues provides additional information (Edwards and Talbot 1999)	Incorporating observational data into the findings often lacks clarity (Duggleby 2005)
Therapeutic benefits for participants recalling events and experiences (Edwards and Talbot 1999)	Participants may find the process distressing because of the intrusive nature of questions (Edwards and Talbot 1999, Price 2002)

Viewed as a continuum, the semi-structured interview would be roughly equidistant between the structured and unstructured interview. During data elicitation researcher bias is less likely in semi-structured compared to unstructured interviews because the use of an interview schedule ensures similar questions are asked across participants (Fontana and Frey 2000, Dearnley 2005). The measures taken to reduce potential biases when formulating questions are discussed in relation to developing the interview schedule (Section 3.3.4). Unlike structured interviews, semi-structured interviews aim to ensure a balance is achieved between consistency and flexibility when asking questions in particular when responding to and exploring participant cues (Fontana and Frey 2000, McCann and Clark 2005). However, the use of an interview schedule may not facilitate participants to tell their story (McCann and Clark 2005).

A semi-structured interview approach was adopted to enable meaningful engagement with parents while ensuring the interview remained focused on meeting the study objectives (Wimpenny and Gass 2000, Price 2002). In addition, having a structure to guide the interview offered security to the novice researcher (Price 2002). The success of interviewing as a data collection method depends on the researcher having the skills to enable participants to share their stories and experiences, and participants having the skills to express their responses in a way that represents their realities (Holstein and Gubrium 2003b, Patton 2002, Lambert and Loiselle 2008). Developing the skills to engage meaningfully with parents was essential to maximise data generation and was central to the rigour of the study. The procedures in relation to undertaking the interviews and the pilot of the interviews, which included a critical evaluation of the interview technique, are described in Section 3.5.2.

3.3.4.1 Participant units: single versus couple interviews

Interviews were undertaken per household, sometimes one parent, sometimes two parents in response to real-world contexts and recognising parents shared responsibility for decisions about the child's care. Data derived from single versus couple interviews may differ. Individual interviews and group interviews or focus groups are commonly used to elicit information from participants but have ontological differences: the interview aims to gain deep insights about the topic from the individual perspective (Holstein and Gubrium 2003b); in contrast the emphasis in focus groups is participant interactions (Morgan 1997, Duggleby 2005). Collecting interactional data is important in focus groups in order to illuminate the negotiation of group language, values and beliefs about the topic being explored (Kitzinger 1994, 1995).

Interviewing couples together interweaves elements of the individual interview and the focus group; the structure is similar to semi-structured and unstructured interviewing but the couple's interactions are also likely to be significant. In focus groups it is unlikely that members will have personal connections and intimate knowledge of other participants which contrasts with couple interviews where the participants' relationship has greater potential to influence the direction of the interview. Consequently, decisions about interviewing couples together were

carefully considered. Consideration needs to be given to the sensitivity of the topics being discussed: for example research about family members' perceptions of a family event, such as family violence, the potential for lack of disclosure of pertinent information and creating tension between interview participants may mean individual interviews, not joint interviews, are the method of choice (Larossa et al 1981). Interactions between parents, discussion and resolutions when different perceptions are presented are likely to enhance the quality of data collected and may mean couple interviews, as in this study which focussed on understanding parents' management of their child's long-term condition, are the method of choice (Larossa et al 1981).

Until recently, there had been assumptions mothers could represent the views of all family members (Åstedt-Kurki et al 2001). Although, it is likely the family will have shared views which may be represented by mothers' accounts, other family members will have unique perspectives (Eggenberger and Nelms 2007, Wennick and Hallström 2007). In the review studies (Chapter 2, Section 2.5.1) both parents participated in over half of the studies included but fathers represented less than a third of the sample. In the studies that included both parents methodological issues such as whether couples were interviewed together and procedures relating to managing and analysing data from joint interviews were poorly described. When the research focus relates to understanding parents' experiences of living with a child with a long-term condition, as in this study, it is preferable to represent both mothers and fathers views. Undertaking couple interviews was influenced by the following factors:

- A commitment to representing parents' shared and individual perspectives and the way in which couples construct meaning of their child's illness (Eggenberger and Nelms 2007);
- The potential to increase the uptake of fathers, who have traditionally not participated in studies about family life, and may feel more comfortable with a joint rather than individual interview (Alan 1980);
- Pragmatic reasons such as the practicalities of organising more than one interview particularly for those families who lived in remote locations and a desire to minimise disruption for the family (Hertz 1995).

There is a wealth of guidance about conducting individual interviews (Fontana and Frey 2000, Price 2002, Holstein and Gubrium 2003a, b) and group interviews or focus groups (Morgan 1997, Duggleby 2005, Lehoux 2006). In contrast, there is limited literature or guidance relating to interviewing couples (Hertz 1995, Eggenberger and Nelms 2007). The challenges when designing and undertaking the study in relation to couples as participant units are presented in subsequent sections; recruiting participants (Section 3.5.1), conducting the interview (Section 3.5.2) and managing the data (Section 3.5.3).

3.3.4.2 Focus group

One focus group was undertaken in order to externally validate the study findings. The group consisted of four participants, two parents who had participated in the interviews and two ASBAH advisors. The aim of the focus group was to ascertain whether the findings provided an accurate account of living with a child with hydrocephalus. Participants were provided with a summary of the concepts and themes that emerged from the study and the conceptual framework, which were used as the focus of the discussion. Participants were invited to consider and discuss the following questions:

1. Do you think the key areas described as uncertainty, developing expertise and normality capture what it is like to live with a child with hydrocephalus? (Prompts- what would you take out? Is there anything you would change?)
2. Do you think learning through experience, adapting across the trajectory of the condition and making decisions represents how you go about meeting your child's needs?

The focus group was audio-recorded and transcribed verbatim. The data elicited were included in the analysis.

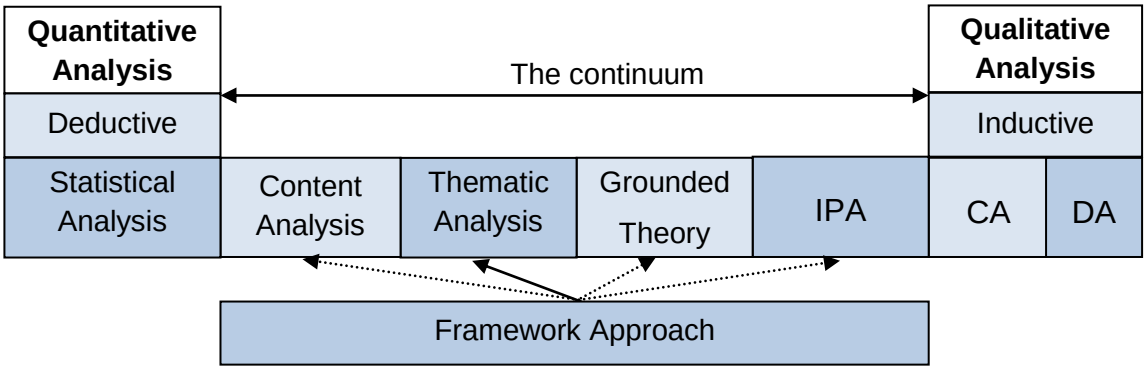
3.3.5 Data analysis

This study employed the framework approach to underpin data analysis (Spencer et al 2003b). This approach was appropriate for the following reasons: first, the approach was designed for the analysis of cross-sectional descriptive data enabling different aspects of the topic of interest to be captured (Snape and Spencer 2003). Second, a particular strength of the framework approach relates to the transparency between participants' descriptions and researchers'

interpretations of participants' experiences (Spencer et al 2003b). Third, for the novice researcher moving from data management to developing the analysis sufficiently to meet the study aims is daunting. The interconnected stages within the framework approach explicitly describe the processes that guide the systematic analysis of data from initial descriptions to explanatory accounts.

Although qualitative data analysis is inductive and focuses on meaning, analytical strategies are diverse with different purposes and ontological and epistemological underpinnings (Morse and Richards 2002). One way to understand qualitative data analysis is to consider the processes involved, which include: quasi-statistical approaches such as content analysis; the use of frameworks or matrices such as thematic analysis; and interpretative approaches such as interpretative phenomenological analysis (IPA) and grounded theory; socio-linguistic approaches such as discourse analysis (DA) and conversation analysis (CA) (Crabtree and Miller 1992, Patton 2002). If data analysis is represented as a continuum, deductive approaches would be situated at the opposite end of the continuum to wholly interpretive approaches (Figure 13).

Figure 13: Approaches to data analysis (Smith et al 2011)



Qualitative data are often obtained through participant interviews. The subsequent analysis is based on a common set of principles: transcribing the interviews; immersion in the data to gain detailed insights of participants' accounts; developing a data coding system; linking codes or units of data together to form overarching categories and themes which may lead to the development of theory (Morse and Richards 2002). Analytical frameworks such as the framework approach (Spencer et al 2003b) and thematic networks (Attride-Stirling 2001) are gaining popularity because they systematically and

explicitly apply the principles of undertaking qualitative analysis to a series of interconnected stages that guide the process (Pope et al 2000, Patton 2002). These methods can provide rich insights into complex phenomena, be applied across a range of theoretical and epistemological approaches, and expand on or test existing theory (Spencer et al 2003b, Braun and Clark 2006). Thematic analysis has been criticised for lacking depth, fragmenting data, being subjective and lacking transparency in relation to the development of themes, which can result in difficulties when judging the rigour of the findings (Attride-Stirling 2001).

The framework approach appears to have a greater emphasis on making the process of data analysis transparent and illustrating the linkage between the stages of the analysis (Pope et al 2000, Snape and Spencer 2003, Braun and Clark 2006). Central to the analytical processes within the framework approach are a series of interconnected stages that enables the researcher to move back and forth across the data until a coherent account emerges (Snape and Spencer 2003). This results in the constant refinement of themes which may lead to the development of a conceptual framework. The application of the framework approach to this study is described in Section 3.5.3.

3.4 Materials

This section describes the development of study materials (invitation letter, information leaflet, consent form, interview schedule), and the use of the qualitative data software package NVivo®. Examples of participant materials are included in Appendix IV.

3.4.1 Invitation letters

Parents were invited to participate in the study in writing from the consultant neurologist, for the hospital sample, and the ASBAH advisor for the ASBAH sample, negating the need to obtain Section 60 support. Researchers not employed by NHS organisations are required to apply to the appropriate patient information advisory group to access patient identifiable information in order to comply with Section 60 of the 2001 Health and Social Care Act (DH 2003). Invites were posted to the usual contact for correspondence and explicitly stated

both parents were being invited to participate. The invite included a participant response form, to be completed and returned in the prepaid envelope by parents willing to participate. This form requested details of how and when parents could be contacted. On receipt of this form, parents were contact by telephone to arrange a mutually convenient time and place to undertake the interview.

3.4.2 Study information leaflets and consent forms

A study information leaflet was developed and included with the invitations. Care was taken to ensure information about the study was in sufficient detail and in an appropriate format to enable parents to make an informed choice about participating (Länsimies-Antikainen et al 2007). The NHS research governance framework (DH 2005c) guidance on developing information sheets informed the content and style of the information leaflet. The risks and benefits of participating in the study were outlined and are discussed in Section 3.9. Contacts were provided for all research team members and the university research grants manager, who was independent to the study and the nominated contact in the event participants had concerns about the study. Ensuring the leaflet's content was clear, free from ambiguity and written at a level suitable for a range of reading abilities included: assessment of the grammar and content by the regional ASBAH team; calculating the readability using the Gunning Fog index (www.sharedlearning.org.uk/fog). The Fog index score was 9.8, within the range appropriate for the UK populations' average reading level (Long 2007).

Obtaining informed consent is a requirement to fulfilling health care ethics committee and research governance requirements (DH 2005c). Receipt of response forms implied participants had consented to take part in the study. However, documentary evidence is good practice and usually a requirement of local ethics committees (Long 2007). A consent form was developed based on examples of good practice available from the national research and development information support services web site (www.rdinfo.org.uk). Parents were asked to sign the consent form prior to commencing the interview, which served two purposes; an opportunity to ascertain whether parents had understood the study information (DH 2001c), and ensured consent was obtained in a timely manner (Long 2007). Following research governance framework guidance (DH 2005c),

the signed form was retained by the researcher and a copy given to the participant. Permission was sought to audio-record the interviews. This ensured data were accurately recorded and allowed parents to be listened to without having to simultaneously take extensive notes (McCann and Clark 2005).

3.4.3 Interview schedule

A schedule was used as a template for undertaking the interviews (Figure 14). The purpose of the schedule was to maximise information elicitation central to the study objectives. Interview topics were developed around three areas; parents understanding of hydrocephalus and treatment options, parents' experiences of learning about shunts and their complications and parents' decisions about seeking help for the child when they suspected the shunt was malfunctioning. The development of the interview schedule was influenced by the literature relating to hydrocephalus and parents' experiences of living with a child with other long-term condition, presented in Chapters 1 and 2 respectively. In addition, research supervisors, the ASBAH advisor and clinicians who provided advice about the study evaluated the content of the schedule in order to reduce researcher bias.

The ordering of questions was based on the laddered technique where the researcher moves from descriptive to more emotive topics as the interview progresses (Price 2002). The purpose of this technique is to establish a rapport with participants relatively quickly, which can assist them to tell their stories and share difficult experiences. Prior to commencing the interviews time was allowed for general introductions and confirming participants understood the purpose of the interview. Field notes made during the initial telephone contact were used to assist in establishing rapport, for example inquiring about a family activity. The interview concluded with collecting information relating to participants ages, education, occupation, number of children in the family, ethnic background, thanking parents for their time and willingness to share their experiences and explaining the subsequent stages of the study.

Figure 14: Interview schedule

Guiding questions
Describing experiences Would you describe your family? How did you find out your child had hydrocephalus? What were you told about hydrocephalus when your child was first diagnosed? What were you told about the treatment of your child's hydrocephalus? Can you explain how shunts were explained to you? Were you given an opportunity to discuss shunts with anyone else? What do you remember as being helpful when you were getting all this information? What do you remember as being unhelpful when you were getting this information?
Knowledge of hydrocephalus Before your child was diagnosed with hydrocephalus had you heard of the condition? Can you explain why your child has hydrocephalus? Would you describe what you know about the treatments for hydrocephalus? How did you explain your child's hydrocephalus to family or friends? What have you told/ will you tell your child about hydrocephalus?
Making-decisions about illness symptoms Will you describe when your child was last ill? (What sort of symptoms did your child have?) Did you worry that the illness may be related to the shunt? (Why was that?) (What did you do? What advice were you given? How did you feel?) If your child is ill, how do you know if it is a problem with the shunt or not? (What particular symptoms are you looking for?) Can you remember an occasion when your child was ill and you thought it was a shunt problem but it wasn't? (What did you do? What happened? How did you feel?)
Feelings about impact of hydrocephalus for the child and family Will you describe how you felt at the time your child was diagnosed with hydrocephalus? How do you feel hydrocephalus has affected, if at all, aspects of your child's life? How do you feel your child's hydrocephalus has affected the rest of the family? What worries, if any, do you have about your child having a shunt? How do you feel about your child having a shunt? Have you heard of any occasions when other parents thought everything was OK but their child had a problem with the shunt? Can you think of any reasons this happen? Thinking about everyday life, do you make any extra considerations because your child has a shunt? (If so in what ways?) Do you have any thoughts or worries about your child caring for themselves in the future?
Concluding questions Suppose a group of healthcare staff were trying to decide the best way to support parents' who have a child with a shunt, what would you recommend? Do you have anything you wish to add?

Building up the depth of questions

3.4.4 Qualitative software programme

The qualitative software programme NVivo® version 2 was used to assist data management. Although qualitative data software packages are not a pre-requisite for undertaking qualitative analysis their use has become widely accepted because they have sophisticated code and retrieve functions which speeds up the process of managing large data sets (Lewand-Hunt et al 1997, McLafferty and Farley 2006). Caution was exercised when using NVivo® because extensive coding and categorising can result in data becoming unmanageable with the analysis becoming a reductionalist rather than interpretive processes (Morrison 1998, McLafferty and Farley 2006). The use of data analysis software packages can only assist the analytical processes because decisions about the development of codes, categories and themes and their interpretation depends on the creativity and critical thought processes of the researcher (Patton 2002). The challenges in using NVivo® are described in the data analysis section (Section 3.5.3).

3.5 Procedures

The following section outlines the procedures relating to the recruitment of participants, undertaking the interviews and data analysis.

3.5.1 Recruitment procedures

The senior nurse responsible for maintaining the in-patient shunt register and the local ASBAH advisor identified families who met the inclusion criteria (Section 3.3.3). Twenty five parents were invited to participate from the ward shunt register and 20 from the ASBAH register. Invitations were posted in groups of 10-15, with a six week interval between posting each batch of invites. Sampling was modified for each group of invites depending on whether respondents reflected the range of factors outlined in the sample criteria. For example five families responded from the first ten invites; parents were from a White-British background, their child was over five years of age, the cause of hydrocephalus was intraventricular haemorrhage and all children had undergone shunt surgery within the previous year. The sample in the second group of invites primarily consisted of parents of child under five years of age, intraventricular

haemorrhage was not the reason for the child's hydrocephalus and the child's admission to hospital did not require a shunt revision.

The characteristics of families who declined to take part in the study differed in comparison to those who participated. Parents who did not participate were more likely to be from an ethnic-minority community and parents of children less than one year compared to parents who participated (Table 9).

Table 9: Non-respondent versus respondent characteristics

	Non-respondent (n = 29)	Respondent (n =16)
Ethic group		
White British	15	16
Asian or Asian British	10	0
Not known	4	0
Child characteristics		
Gender male : female	10: 19	9:7
Age (years)	Av. 6.6**:** range 1-15	Av. 6.6**:** range 2-13
Less than 5	14	8
6-10	8	5
11-15	7	3
Reason for hydrocephalus	(n= 17)[1]	(n= 15) [1]
Intraventricular haemorrhage	13	7
Spina bifida	2	5
Aqueduct stenosis	0	2
Other	2	1

[1]The reason for hydrocephalus was only available from the in-patent shunt register because this data is not routinely recorded on the ASBAH register

One of the challenges of recruiting participants to the study related to actively encouraging both parents to participate. Typically mothers completed the response form and indicated that their partner would participate but work patterns restricted their availability. This was overcome by offering interviews during evenings, weekends and statutory holidays with a choice of venue including the parents' home, the university or the in-patient ward, where private rooms could be secured. The majority of interviews were undertaken in parents' homes. One mother chose the in-patient ward as the location for the interview. Simultaneously recruiting parent's while undertaking preliminary data analysis influenced when to cease data collection. Data saturation in the broadest sense

refers to the researcher recognising participants are not offering any additional information and the data are of sufficient depth to meet the study aims (Tuckett 2004). Judgements about when data saturation had been reached followed agreement with research supervisors that recurring patterns within the data were clearly apparent.

3.5.1.1 Participant characteristics

Sixteen families were recruited to the study. One family had recently relocated to the South of England and were excluded because it was impractical to arrange a face-to face interview. Twenty-five parents participated in the study in total, comprising of ten couples and five mothers. Parents' characteristics and the characteristics of the child in relation to the cause of hydrocephalus and shunt history are presented in Table 10.

Table 10: Participant characteristics

Parents' characteristics	**Total (n = 25)**	**Ward (n =12)**	**ASBAH (n =13)**
Age (years)	Av. 38.3: range 21-52	Av. 37.8: range 21-51	Av. 38.5: range 29-52
21-30	2	1	1
31-40	12	6	6
41-50	9	4	5
Above 50	2	1	1
Highest Qualification			
A levels or above	13	8	5
GCSE	10	4	6
None	2	0	2
Socio-economic classification[1]			
1	0	0	0
2 - 4	13	6	7
5 - 7	6	5	1
8	6	1	5
Ethic group: White British	25	12	13
Number of children	Av. 2 : range 1-5	Av. 2: range 1-3	Av. 2: range 1-5
1	6	2	4
2	7	5	2
3 or above	2	1	1

[1]UK National Statistics Socio-economic Classification

Child characteristics	Total (n = 25)	Ward (n =12)	ASBAH (n =13)
Gender male: female	8:7	3: 4	5:3
Age (years)	Av. 6.7: range 2-13	Av. 7: range 3-11	Av. 6.6: range 2-13
Under 5	7	3	4
6-10	5	4	1
11-15	3	1	2
Age at diagnosis			
Prenatal	5	2	3
Neonate (less than1 month)	7	4	3
1-4 months	3	2	1
Reason for hydrocephalus			
Intraventricular haemorrhage	7	4	3
Spina bifida	5	2	3
Aqueduct stenosis	2	1	1
Post meningitis	1	1	0
Associated conditions[2]			
Epilepsy	5	3	2
Cerebral palsy	2	0	2
Hearing impairments	2	2	0
Other	2	1	1
None	5	2	3
Shunt revisions	Av. 1.7: range 0-4	Av. 2: range 0-4	Av. 1.4: range 0-3
0	3	1	2
1	4	2	2
2	3	2	1
3 +	5	3	2
Type of school/nursery			
Mainstream	9	5	4
Mainstream + support	5	2	3
Special school	1	1	0

[2]One child had both cerebral palsy and epilepsy

Participants were recruited from a mix of rural, semi-rural and inner city areas. Parents' ages ranged between 21 and 52 years, with an average age of 38 years. All parents were from a White-British ethnic background and half were educated to A-level or above. Social class was identified using the UK National Statistics Socio-economic Classification, which replaced the Registrar General's Social Class Classification for the 2001 population census, and classifies individuals based on occupation. Classification ranges from group 1 (higher management) to 8 (long-term unemployed). More sensitive measures of assessing socio-economic status based on occupation, education and income

are available but were not used because information relating to participants' income was not obtained (Deonandan et al 2000). Socio-economic classification ranged from social group 2 (lower managerial and professional occupations) to group 8 (unemployed).

The number of children within the family ranged from one to four, and the ages of the children with hydrocephalus ranged from 2 to 13 years. All the children had been diagnosed as having hydrocephalus in infancy or during the prenatal period. The main causes of hydrocephalus were intraventricular haemorrhage as a result of being born premature and hydrocephalus associated with spina bifida. With one exception, all of the children had been admitted to hospital for potential shunt malfunction; the number of admissions ranged from one to many. The majority of children had required surgery to revise the shunt. Some children had required more than one shunt revision, of which five children had undergone three or more revisions. Many of the children had conditions associated with hydrocephalus such as epilepsy and cerebral palsy. The majority of the children attended mainstream school with some children requiring additional support from a non-teaching assistant.

In summary the final sample reflected a range of characteristics and thus the potential for diverse experiences that might impact on parents' perceptions of living with a child with hydrocephalus. A range of causes of hydrocephalus and associated conditions were represented, and the frequency of shunt complications varied. Although participants were diverse in relation to social class and age they did not represent the diversity of ethnic-minority communities within the UK.

3.5.2 Pilot interviews

Two pilot interviews were undertaken; a mother and a couple. The pilot was conducted to test and refine, where necessary, the interview schedule. The pilot also enabled the development of the skills required to elicit meaningful information from parents by undertaking a critical reflection of the parent-interviewer interactions. In addition to drawing on experiences of engaging with

families in acute health care settings, a range of probing techniques were used to enhance the quality of the data elicited, including: allowing silences and thought time; repeating key points and seeking clarification when there were uncertainties about parents' responses; offering encouragement by acknowledging participants experiences; using probing questions to explore issues further (Russell 2000). Observation and non-verbal cues can aid in contextualising the data and capture the dynamics of the interaction (Duggleby 2005). Brief notes were taken during the interview to record non-verbal observations.

The pilot interviews were transcribed verbatim and reviewed by both research supervisors. The first interview with a mother obtained a considerable volume of relevant data suggesting the questions were appropriate to meet the study objectives. Over adherence to the schedule resulted in lost opportunities to explore topics in greater depth because of not responding to the mothers' cues. Minor changes were made to the prompts within the interview schedule to assist in responding to parents' cues. Both parents participated in the second pilot interview; in this interview a focussed conversation approach was adopted. The dialogue that developed between both parents enabled the interview to progress more naturally. At times the mother dominated the conversation. Strategies were identified to facilitate both parents to share their experiences such as allowing silences and thought time, re-directing the conversation back to the other parent for further exploration and making notes on the schedule when one parent changed the direction of the conversation as a reminder to seek the other parents' perspective.

Pilot interviews can be used to refine data collection methods but attempts to undertake detailed analysis are meaningless because of insufficient data (Morse et al 2002). The pilot interviews were incorporated into the main study because parents' descriptions were a valuable contribution to understanding living with a child with hydrocephalus. The value of the pilot interviews related to reflecting on the techniques required to elicit meaningful information from participants. Consequently an approach was adopted where there was ongoing reflection and development of interview techniques. As the number of interviews increased,

there was less rigid adherence to the schedule with greater focus on listening and responding to parents' cues.

3.5.3 Data analysis

The unit of analysis was the interview, either couples or one parent depending on whether both parents participated. The interconnected stages of the framework approach guided the data analysis from the development of descriptive accounts to explanatory interpretations (Spencer et al 2003b). Although the approach enabled data to be explored systematically, the analytical processes were iterative and involved forward and backward movement across the stages of data management, descriptive accounts and explanatory accounts (Figure 15). This iterative process was essential to the creativity of the analysis, development of ideas, clarifying meaning and reworking concepts as new insights emerged from the data. The framework approach was applied across all parent interviews and the data obtained from the focus group. The stages of the analysis are now described.

Figure 15: Overview of the framework approach (adapted from Spencer et al 2003b)

Stage	Components
Data management	1. Transcribe the interview data verbatim 2. Become familiar with the data through reading and re-reading the transcribed interviews 3. Indentify and organise data into initial themes and categories 4. Develop a coding index from initial themes and categories 5. Assign data to the themes and categories
Descriptive accounts	1. Summarise and synthesise the coded data and refine initial themes and categories 2. Identify key dimension of the synthesised data: detect associations between themes until the 'whole picture' emerges 3. Develop more abstract concepts (core concepts)
Explanatory accounts	1. Develop associations/ patterns within the core concepts 2. Reflect back on the original data as a whole and analytical stages to ensure parents' accounts are accurately reflected and reduce the possibility of misinterpretation 3. Interpret and find meaning to explain the concepts and themes 4. Seek wider application of the concepts and themes

Continuum

3.5.3.1 Data management

Data management involved transcribing the interviews and developing a system for sorting data into meaningful units. Qualitative researchers usually work with text rather than audio data. Audio-recordings can be transcribed in entirety or focus on selected sections of the interview. In the latter a coding frame is developed in advance usually in situations where the research is highly focussed or the data is voluminous and for pragmatic reasons it may not be possible to transcribe the entire interview (Richards 2005). This approach can result in sections of data being fragmented from the original which can result in data being misinterpreted. All interviews were transcribed verbatim and in entirety because little is known about parents' experiences of living with a child with hydrocephalus. This also maintained the natural dialogue that occurred in the couple interviews.

Working with the data transcriptions began with attaching labels to the data. In common with other approaches to qualitative data analysis, terms such as codes, categories, themes, and concepts are used interchangeably within the framework approach. The meanings of these terms in this study are:

1. **Codes:** labels or tags given to a unit of data. A unit of data refers to key words, phrases or sentences. Codes are the building blocks of data analysis and provided a brief summary of parents' accounts using their own words (in-vivo codes);
2. **Categories:** folders that contain codes about the same topic, category labels remained close to parents' words;
3. **Themes:** categories that have been linked into broad groups, in a similar way that codes are grouped into categories;
4. **Concepts:** ideas that link themes together. Concepts formed the framework that represented the whole story and reflected parents' perceptions of living with a child who has hydrocephalus.

Four interview transcripts were used to develop the codes and initial categories. The interviews were chosen because they represented a range of experiences: in three families the children had many hospital admissions for potential shunt malfunction, some of these admissions required shunt revision; and in one family, used as comparison case, the child was a young person who had never

encountered complications with the shunt. In addition, there were variations in relation to the cause of hydrocephalus and associated conditions, parents' ages and number of siblings within the family. Codes were developed by summarising each line, phrase or paragraph from the transcript using parents' own words. The process initially involved using printed versions of the transcripts with key phrases highlighted and comments written in the margins to record preliminary thoughts. Initial categories were developed by making links between codes where similar topics were being described. A coding matrix was used to record and track changes. An example of the coding matrix highlighting the processes involved in identifying codes and initial categories is presented in Figure 16.

Figure 16: Example of the coding matrix

Family 11	In-vivo codes	Description	Initial categories
'if she wasn't getting any better and she wasn't keeping any food down and **looking more** and more **ill, we would start to think about the shunt.** We have kind of ruled out in our mind it's not just a simple thing, like a tummy bug. **You know if your child is being sick whether they are poorly or not'.** *Dad*	**'Looking more ill… think about the shunt'**	Deciding if illness symptoms are shunt related	Recognising the illness is shunt related
	'know …your child'	Know something is wrong	Recognising when the child is ill
'I think it is the out of hours that we find difficult, **if we are unsure** if we go out of hours service **we know that we will be admitted. So we tend to wait a bit longer'**. *Mum*	**'if we are unsure'**	Unsure about illness symptoms	Uncertain about illness symptoms
	'know will be admitted'	Experience services	Views about services
	'wait a bit'	Deciding what to do	Deciding when to seek advice
'it tends to be **us kind of knowing** really that it's not the shunt but always having that tiny **bit of doubt** that what if it is if she does get worse then we have to **do something about it quite quickly'**. *Dad*	**'us kind of knowing'**	Know something is wrong	Recognising when child is ill
	'bit of doubt'	Unsure about illness symptoms	Uncertain about illness symptoms
	'do something quickly'	Need to act quickly-why	Responding to possible shunt malfunction

Each code initially formed a potential category but as coding progressed and the number of initial categories developed, similar categorise were refined into broader categories. Similar categories were eventually brought together to form initial themes. These categories and themes formed the coding index that was used as a means of organising the whole data set. The coding index was constantly refined throughout the process of data analysis as new insights emerged. The coding index is presented in Figure 17.

Figure 17: The coding index

Initial themes	Initial categories
1. Getting a diagnosis	Establishing a diagnosis
	Interactions with health professionals at the time of diagnosis
	Parents feelings at the time of diagnosis
	Experiences at diagnosis
2. Making sense of hydrocephalus	Beliefs about hydrocephalus prior to the child's diagnosis
	Experiences of hydrocephalus prior to the child's diagnosis
	Beliefs about cause of the child's hydrocephalus
	Beliefs about hydrocephalus following the child's diagnosis
	Feelings about the child having hydrocephalus
	Beliefs about treatment options
	Beliefs about the complications of treatment
	Feelings about treatments
	Experiences of treatments and treatment complications
	Expectations about the impact of hydrocephalus for the child
	Expectations relating to family activities
	Experiences of impact of living with a child with hydrocephalus
3. Uncertainty	Reason for illness symptoms
	Impact of the condition on the family
	The child becoming independent
	The child's development
	Embarking on family activities
4. Parents' concerns	Anxiety about the child becoming ill
	Risks relating to surgery
	Anxiety about recognising shunt malfunction
	Anxiety about the child's future
	Worrying about the child when in the care of others
	Worry about others being able to recognise shunt malfunction

5. Responding to the child's needs	Recognising when the child is ill
	Experiences of shunt complications
	Beliefs about the signs of shunt malfunction
	Recognising when the child's illness is due to shunt malfunction
	Taking precautions to protect the child because of the shunt
	Making allowances for the child because of hydrocephalus
	Explaining hydrocephalus to the child
6. Making decisions	Making choices about treatment options
	Beliefs about involvement in healthcare decisions
	Deciding if illness is due to shunt problem or not
	Deciding when to access healthcare services
	Lifestyle choices
	Family activities
	Feelings about making decisions
7. Support systems (health, education and voluntary services)	Information needs
	Sources of information
	Assessing information
	Support needs
	Obtaining support
	Beliefs about health professionals' ability to recognise shunt malfunction
	Experiences of health professionals recognising shunt malfunction
	Beliefs about health systems meeting the child and family's needs
	Experiences of health systems meeting the child and family's needs
	Beliefs about health professionals' knowledge of hydrocephalus
	Beliefs about engaging with professionals
	Experiences of engaging with professionals
	Beliefs about teachers' awareness of the hydrocephalus
	Beliefs education systems meeting the child and family's needs
	Experiences education system meeting the child and family's needs
	Beliefs about voluntary support agencies
	Experiences of voluntary support agencies
8. Impact of living with a child with hydrocephalus	Effects of hydrocephalus for the child
	Effects of additional conditions for the child
	Impact on family activities/ lifestyle
	Impact on parent relationships
	Impact on siblings
	Impact on extended family relationships
9. Maintaining normality	Others response to the child
	Beliefs about bringing up a child with hydrocephalus
	Making adjustments to normal family activities
	Comparing the child to peers
	Wanting the child to be accepted
	Wanting the child to develop friendships
	Wanting the child to become independent
	Wanting the child to be treated the same as other children

Data management is often viewed as a lower order activity but the decisions made when developing codes and categories impact on and influence later explanatory accounts (Morse and Richards 2002, Spencer et al 2003b). Reading, reflecting on and recording thoughts through memos and annotations is central to the development of initial codes and categories. The development of an effective coding index can only occur by knowing the data (Spencer et al 2003b). Familiarisation with the data occurred at different levels and was an ongoing process: audio recordings were listened to as soon as possible after the interview in order to expand on field notes and record preliminary thoughts. Data were transcribed within three weeks and read in conjunction with listening to the recordings to check the accuracy of the transcription and add to field notes. The four interview transcripts used to develop the coding index were reviewed by both research supervisors. This was an important part of the ongoing measures taken to reduce biases by exploring and debating different interpretations within the data. The study objectives were regularly referred to during the development of the coding index in order to remain focussed on meeting the study aims.

Once the initial coding index was developed NVivo® was used to store and organise codes, categories and themes. This enabled data to be retrieved and reviewed easily. However, using NVivo® was not without challenges; the ability to sort and store data quickly resulted in an initial coding frenzy which initially hindered data management and the depth of the analysis (Holloway and Wheeler 2002). Over coding was managed by ongoing review of the coding index, and regular discussions and reviews of interview transcripts with supervisors, resulting in a balance being achieved between depth and volume.

Although the unit of analysis was the interview, the use of NVivo® enabled data sets to be created which allowed data to be searched across interviews in relation to defined variables. Three data sets were created: mother/father; children with hydrocephalus/ children with hydrocephalus and associated conditions; urban/rural living. Creating the mother/father data set was problematic because the mother and father responses from joint interviews had to be uploaded into NVivo® as separate text files. Although this enabled data to be searched for either mothers' or fathers' responses or both across categories,

the data became fragmented. This was managed by constantly referring back to the original transcript because only considering one partners part of the conversation often made little sense. The segmentation of data and detachment from the original context is a recognised problem with the use of qualitative software packages (Spencer et al 2003b). In this study the number of couple interviews was relatively small, moving back and forth between the joint interview and parents' separate responses was essential to ensure the analysis remained grounded in the data, but this may not be realistic in studies with larger data sets. Data management concluded when all interview transcripts were sorted and stored into the categories outlined in the coding index.

3.5.3.2 Descriptive accounts

Descriptive accounts involved summarising and synthesising the coded data. A crucial element within qualitative analysis is the critical thinking that occurs in relation to how participants' descriptions were coded, links between codes and categories and between categories and themes (Spencer et al 2003b). Remaining true to participants' descriptions is a fundamental principle within the framework approach and central when developing more abstract concepts. For the novice researcher the movement from in-vivo codes and initial categories and themes to more abstract concepts seemed incompatible and contradictory. Two linked processes were undertaken to reconcile these tensions. First, data was synthesised by refining the initial themes and categories until the whole picture emerged whilst remaining grounded in parents' description. This was achieved by constantly referring back to the original transcripts and checking the meaning across interviews using NVivo ® search functions.

Second, abstract concepts were developed through the identification of key dimensions of the synthesised data, and making associations between themes and concepts. The development of the themes and categories from which the core concepts emerged are summarised in Figure 18. In addition, participants of the focus group confirmed concepts and themes were an accurate reflection of living with a child with hydrocephalus, although minor changes were made to the wording of themes following parents' contributions.

Figure 18: Developing core concepts and themes (numbering mapped to coding index)

Initial themes	Refined categories	Links between categories	Final themes	Core concepts
1: Getting a diagnosis	1.1 Events leading to diagnosis 1.2 Reactions to diagnosis 1.3 Interactions with health professionals	1.1 Making sense of hydrocephalus (2) 1.2 Uncertainty (3.1) 1.3 Deciding about treatment options (7.1)	• **Making sense of hydrocephalus and treatments**	**DEVELOPING EXPERTISE**
2: Making sense of hydrocephalus	2.1 Prior knowledge and experience of hydrocephalus 2.2 Understanding hydrocephalus and treatment options 2.3 Initial expectations about the effect of hydrocephalus for the child and family	2.1 and 2.3 link to experiences at diagnosis (1) 2.2 Making sense of the shunt (6.3) 2.3 Uncertainty about the effects (3.1) and impact of hydrocephalus (5)	• **Understanding support organisations**	
6: Responding to the child's needs	6.1 Knowing something is wrong 6.2 Responding to changes in their child 6.3 Making sense of the shunt 6.4 Experience of shunt complications 6.5 Responding to the child's needs	6.2 Uncertainty (3.2) and making decisions (7) 6.5 Making decisions (7)	• **Differentiating between childhood illness and shunt malfunction**	
7: Making decisions	7.1 Types of decisions in relation to living with a child with hydrocephalus 7.2 Factors that influence decisions	<u>Making decisions threads throughout but particularly related to responding to the child's needs</u>		

4: Parents' concerns	4.1 Shunt related concerns 4.2 Concerns about the child's future	4.1 Responding to changes in child (6.2)	• **Reactions to the child's diagnosis** • **Concerns about the shunt** • **Receptiveness of professionals to interacting with the family** • **The child's future**	**UNCERTAINTY**
9: Support systems	9.1 Support needs 9.2 Barriers and facilitators relating to support systems 9.3 Perceptions of service provision in meeting the needs of the child and family	9.1 Information needs threads throughout links to making sense of hydrocephalus (2) 9.1 Parents' interactions with healthcare professionals link to at the time of diagnosis (1.3)		
3: Uncertainty	3.1. The uncertain effects of the hydrocephalus for the child 3.2 Shunts malfunction	<u>Uncertainty threaded throughout all initial themes</u>		
5: Impact of living with a child with hydrocephalus	5.1 Impact of hydrocephalus for the child 5.2 Impact of living with a child with hydrocephalus for the family	5.1 Linked to concerns (4) and normality (8)	• **Barriers and facilitators to normal family life** • **Valuing normal life** • **Balancing normality with watchfulness**	**A NORMAL LIFE**
8: Normality	8.1 Achieving and maintaining normality 8.2 Factors that contribute to achieving normality for the child and family	<u>Achieving and maintaining normality threaded throughout all initial themes</u>		

3.5.3.3 Explanatory accounts

Explanatory accounts began with reflecting on the original data as a whole and the analytical stages in order to ensure parents' accounts were accurately represented and reduce misinterpretation. This stage may result in the development of typologies which categorises participants into discrete groups (Spencer et al 2003b). Findings were contextualized by exploring the relationship between the final concepts and the established literature and theoretical perspectives relating to living with a child with a long-term condition, presented in the discussion of the findings (Section 3.7).

3.5.4 Presenting the findings

The style in which qualitative research findings are presented is more flexible compared to quantitative research because of the uniqueness of each study (Richards 2005). The variability in the way research findings are presented, the complexity of the language used and a preoccupation with the epistemological foundations of qualitative studies has created barriers to understanding and utilising findings to inform practice (Rolfe 1998, Sandelowski 2000, Ramprogus 2002). Conventional ways of presenting qualitative findings include interweaving findings and interpretations with the established literature or presenting the findings and discussion separately. The latter approach was adopted in an attempt to: present the findings in a way that will make sense to the reader; demonstrate transparency between parents' accounts and researcher interpretations; ensure the depth and richness of the parents' accounts were captured (Morse and Richards 2002, White et al 2003).

Direct extracts from the original data contextualise study findings and enable judgements to be made about their credibility (Holloway and Wheeler 2002). Participant quotes have been used judiciously in order to illustrate themes and bring the data to life. Illustrating the findings with participants' own words can be problematic because the choice of extract and participant pseudonym influences the way participants' stories are represented and interpreted by the reader. Findings from qualitative cross sectional studies must represent the diversity of participants' experiences (Spencer et al 2003b); a range of examples have been

included that represent similar and different perspectives. Pseudonyms protect individual identities but the choice of pseudonym infers certain traits or characteristics about that individual (Dearnley 2005). Pseudonyms were therefore not used. Remembering parents' names facilitated the nuances within the interview to be recalled which adding meaning when interpreting parents accounts. A balance between not attaching a pseudonym nor using terms such as participant or respondent which can appear impersonal was achieved by referring to parents as mum or dad and assigning participant units with a case number, for example *Family 6 dad.* The child's age was included in order to contextualise parents' accounts.

3.6 Study findings

This section presents the study findings and the conceptual framework developed from the findings. The three concepts 'uncertainty', 'developing expertise' and 'a normal life' and the themes that formed these concepts will now be described. Explanations of the findings will be offered in Section 3.7.

3.6.1 Uncertainty

Uncertainty emerged as a dominant feature of parents' accounts of living with a child with hydrocephalus. Parents' described a range of uncertainties which related to the meaning and potential impact of hydrocephalus for the child and family, recognising shunt malfunction, the child's future and interacting with health professionals. Although these uncertainties were grouped into four themes; 'reactions to the diagnosis', 'concerns about the shunt', 'the child's future' and 'the receptiveness of professionals to interacting with the family', uncertainty was a constant part of parents' daily lives. In addition to uncertainty emerging as a core concept, parents' uncertainties were multi-faceted and interlinked with the core concepts 'developing expertise' and 'a normal life'.

3.6.1.1 Reactions to the child's diagnosis

The diagnosis of hydrocephalus resulted in a range of reactions. The most common reaction was shock, often heightened by uncertainties relating to the

child's survival and the possibility of brain damage. Fear of treatment complications was an added concern for parents whose professional roles had included working with children with hydrocephalus. For parents of infants diagnosed with spina bifida during routine antenatal screening the possibility of hydrocephalus added to parents anxieties about their unborn child. Emotions at the time of diagnosis contrasted to those anticipated on the arrival of a new baby. In addition, relief was also a common emotion particularly in situations when parents knew something was wrong with their child but perceived this was a result of their inability to meet their child's needs. The following extracts illustrate parents' reactions to their child's diagnosis:

> 'But I think, well I remember feeling, like to me I felt the whole world had collapsed It was quite scary really wasn't it, because we didn't know how it was going to affect him'. *Family 12 mum, child 4 years*

> 'I was horrified. Absolutely horrified. Because I thought, I remember one little boy in particular, I nursed…he had had a shunt put in and it had failed and every attempt to make it work had failed'. *Family 14 mum, child 12 years*

> 'I found that then he had spina bifida… the hydrocephalus and they just kept monitoring it until he was born and they would just have to see how severe it was. They can't tell until he was born… so at first I'm really in a state, I wasn't really sure because you know they kept saying, the doctors, that he might have brain damage'. *Family 1 mum, child 3 years*

> 'It's just such a big thing to take in, that there's something wrong with this little baby. But then again, deep down I think we were happy, well not happy, but we thought yeh we weren't doing it wrong and it wasn't our fault'. *Family 3 mum, child 5 years*

Although at the time of the initial diagnosis parents' described feelings of 'shock', 'numbness' and that their 'whole world had collapsed', parents' recalled their initial uncertainties related to doubting their ability to cope with a child with a long-term condition and the impact living with a child with hydrocephalus would have on family life. Uncertainties about the ability to cope with their child's condition added to parents' concerns about meeting, and having responsibility for their child's immediate care needs. In contrast coping with a child with

hydrocephalus was less important for parents having to deal with the uncertainty of their child's immediate survival. Initial perceptions of coping with living with a child hydrocephalus included:

> 'I did worry how I would cope'. *Family 11 dad, child 5 years*

> 'We were thinking that we wouldn't be able to do things that other families would be able to do weren't we. Like in the beginning, like go on holiday, on an aeroplane and what if something happened you know'. *Family 12 mum, child 4 years*
> 'Hydrocephalus was just another thing not that important in the overall scheme of everything else (child) had to do just to survive, there was so much going on, everything was difficult at the time….everything was crisis management, we just hoped he would survive it didn't matter how'. *Family 2 dad, child 8 years*

> 'Devastated obviously, frightened… my overwhelming fear at the time was cot death and if something happened… and I thought that if I went home and something happens to her they will say well hang on a minute she found out there was something very wrong with the baby'. *Family 7 mum, child aged 10 years*

In summary, experiences and events leading up to the child being diagnosed with hydrocephalus varied. However, the reactions and uncertainties about the potential impact of living with a child with hydrocephalus and ability to cope were similar across parent accounts. The diagnosis of hydrocephalus in premature infants was overshadowed by the uncertainty of the child's immediate survival.

3.6.1.2 Concerns about the shunt

A prominent feature of daily life related to the uncertain and unpredictable nature of shunt complications which was heightened immediately following a period of shunt related problems. The unpredictable nature of shunt malfunction was an ongoing concern and cause of uncertainty for parents. These concerns and uncertainties related to the potential life threatening nature of shunt malfunction and the risks associated with surgery such as the child not surviving the operation. The following extracts summarise parents' emotions and uncertainty relating to shunt malfunction:

> ‘To me it is stressful because it is twenty-four hours a day, you know in another couple of hours things could change and we could be over in (city). It’s stressful and you know it could all go wrong again …at the end of the day he could die from a blocked shunt’. *Family 2 mum, child 8 years*

> ‘You are thinking is he going to be alright when he comes out (of surgery) or is he going to come out or whatever. You really are thinking is he going to be coming back. You just totally don’t know’. *Family 12 dad, child aged 4 years*

Although the unpredictability, life threatening nature and need to recognise shunt malfunction appeared to be parents’ main concerns, parents’ uncertainties relating to shunts had multiple layers. Some parents’ described the uncertainty of not knowing if planned shunt revisions would be required in response to their child’s growth. For other parents’ uncertainties related to not knowing if their child’s shunt would be permanent, in particular whether the shunt would be required throughout adulthood. Other parents’ described uncertainties relating to whether the shunt was functioning correctly, as opposed to malfunctioning. The following extract summarise these uncertainties:

> ‘We had been quietly worried about this (routine shunt revision) for three years or so thinking any time now he was going to have the whole thing out again. I suppose that it was a huge relief once we knew that he hadn’t got to have a new shunt’. *Family 10 dad, child aged 6 years*

> ‘We don’t know if it’s (the shunt) over draining or under draining…I think the problem at the moment is that they quite honestly don’t know what causing it, and that’s quite hard’. *Family 4 mum, child aged 10 years*

Ways of coping with shunt malfunction included being constantly vigilant for illness symptoms that might indicate a problem with the shunt, seeking advice from healthcare professionals and trying not to dwell on potential shunt malfunction. For example:

> ‘So you think about if the shunt blocks, you worry and constantly ring the hospital and constantly taking him to the doctors and check him out. So that really is what it is, is how it is’. *Family 1 mum, child 3 years*

> ‘I remember when she was 4 months and she was in and out, that’s when I really think about it, it was really strong and you’re observing her all the time. But as the years have gone by, I don’t really think about it as much, if the shunt’s working or not’. *Family 11 dad, child 5 years*

In summary, parents’ described a range of uncertainties and concerns about shunts. However, the unpredictable but likelihood that their child’s shunt would malfunction was a constant source of uncertainty for parents. Parents’ concerns and uncertainties about shunt malfunction were similar for parents of children who had required a shunt revision and parents whose child had not required a shunt revision.

3.6.1.3 The child’s future

Uncertainties about their child’s future included: living independently; developing friendships and forming relationships; managing their own health needs; participating in every day social activities. Although parents’ described a range of uncertainties about their child’s long-term future and ability to live independently, these concerns appeared to be heightened for parents whose children had complex needs, particularly children with physical disabilities. Mobility and continence related issues were identified as the main barriers to social integration and the perceptions these issues would become more evident during the transition to adulthood. The range of views about their child’s future are summarised in the following extracts:

> ‘I think it will get worse, I think that impact on his social life will become more so. So my own concern is that he lives an independent life and is happy’.
> *Family 15 dad, child 5 years*

> ‘The elimination side of things but she is going to have a rough time with other children as she gets older. I think, well anticipate that she will have difficulties as children get older they get a bit mean and will comment. I imagine she will face obstacles with other children like bullying’. *Family 5 mum, child 6 years*

Parents’ described uncertainties in relation to their child’s ability to develop the skills to recognise shunt problems and manage associated health issues in the future. Balancing the need to support the child to become independent with

overprotection because of health related concerns was more evident in mothers' accounts. Fathers' recognised their partners concerns but were more pragmatic in their approach to their child becoming independent and engaging in social activities. For children with complex needs, who were unlikely to become independent, parents were uncertain who would care for their child in the long-term. Ways of coping with the uncertainties relating to their child's future included focusing on the present, not dwelling on the future and ensuring their child has the skills to make their own decision. The following extracts summarise parents' uncertainties about their child's future:

> '(Partner) is a bit scared when he first starts going out with his mates around town and stuff. You might have a scenario where there's a fight, or somebody bangs his head or and stuff. At the end of the day you can't not let him go out can you, he will be old enough to do what he wants'. *Family 12 dad, child 4 years*

> 'Well when she's living by herself, now when she gets older and epilepsy side, if she was to collapse in the street, that's a bit of a thing for me…..That's when I'm thinking about in the future'. *Family 3 mum, child 5 years*

> 'What is going to happen in the future when he finishes school? He will probably always be going to have to live with us and what is going to happen to him'. *Family 8 mum, child 11 years*

> 'I deal with the here and now. And hope that the skills that we teach him now will equip him for when he is older and he can make his own judgements. That's really the best we could offer I think'. *Family 14 mum, child 12 years*

In summary, parents' described a range of uncertainties relating to their child's future but gaining independence was a particular concern, particularly parents whose child had complex needs. Mothers' expressed more concerns than fathers about the child's ability to recognise shunt problems. However, it may be that fathers' hide their concerns better. Parents of children with complex needs were unsure who would meet their child's needs in the long-term.

3.6.1.4 Receptiveness of professionals to interacting with the family

A key feature of living with a child with hydrocephalus related to parents' wanting to develop effective relationships with professionals (health professionals and teachers) and ASBAH advisors. Parents' accounts suggest the ability to develop effective relationships with professionals was variable. The variability in the receptiveness of professionals to interacting with the child and family resulted in many uncertainties for parents. Parents' described uncertainties about the best way to interact with health professionals and contribute to care decisions. These uncertainties influenced the subsequent strategies parents developed when interacting with professionals.

Involvement in care decisions at the time of diagnosis was variable: some parents' described not being included in treatment decisions or having to initiate discussions about treatment options with health professionals. In contrast, others described being offered treatment options and being involved in care decisions. Where parents collaborated with health professionals in relation to planning treatments, choosing the insertion of a shunt was influenced by: weighing up the risk of shunts with other treatment options; considering the length of time treatments had been established and their success rates; listening to the experiences of other parents of children with hydrocephalus; considering if alternative treatments to shunts could be attempted when the child was older and able to make their own choices. However, the urgency in treating the child because of the life threatening nature of the condition resulted in parents often having no real choices in relation to their child's treatment. In these situations parents' described trusting health professionals' judgements. The following extracts illustrate parents' perceptions of their involvement in treatment decisions:

> 'I don't think we had a choice, well I don't mean choice, I think that there is no choice, she was so ill in the beginning that she had to have it. And that were it really'.
> *Family 4 mum, child 10 years*

> ‘Well we sat down with the doctors didn’t we? I think, well, we asked the doctors and they just said it is your choice they were just given the stats on what was more…’ *Family 12 dad (mum interrupts)*
> ‘One was the shunt and the second option was a third ventriculostomy, but you thought well that is a bit of risk so obviously we went for the safer option. It was done on a percentage really wasn’t it?… A mum (on the ward) was saying to me her little boy had the third ventriculostomy and it hadn’t worked so she was taking him back in and going for the shunt option. So emm- just sort of chatting to other people as well and other parents you pick up information don’t you’. *Family 12 mum, child 4 years*

Ongoing support was provided by health professionals, ASBAH advisors, teachers and other parents who also live with a child with hydrocephalus. When seeking support from professionals (health professionals and teachers), parent-professional interactions ranged from being supportive to parents not feeling their knowledge and experiences in managing their child’s condition were valued. Variability in the receptiveness of professionals to listen to and value parents’ experiences resulted in uncertainties when engaging with professionals. Uncertainties about interacting with professionals were heightened following a change in circumstances such as relocating into another area or the child progressing through the education system. There was a perception that health professionals were not always willing to engage in meaningful discussion with parents and they made judgements about the information shared with parents. Parents’ perceived that healthcare systems were not conducive to engaging in meaningful discussion with health professionals. There were concerns about some professionals (health professionals and teachers) not having the knowledge and skills to meet their needs. The following extracts summarise parents’ accounts of interactions with professionals:

> ‘When there's a problem and we just take him to the ward no matter what. You can just call the ward at any time, and the nurses are very good you are never make you feel like oh it’s you again. They just say bring him in and we'll check him out…we must believe parents they know best’. *Family 2 dad, child 8 years*

> ‘When they are in clinic they need to get through other patients and they can’t spend too much time but we sort of saying well how does it compare to the last scans he had last year. He didn’t really want to talk about it’. *Family 15 mum (dad interrupts)*

‘No he didn’t seem interested. What we want to know is not about hydrocephalus, we want to know about (child’s) hydrocephalus, so to do that we need to have a look at scans and someone to sit down and spend just half an hour with us that’s all… I am sure if someone explained it we could really understand them and get some knowledge. It’s not as though we’re stupid’. *Family 15 dad, child 5 years*

‘I think the label uncertainty is really appropriate and really sums up what it is like. But it is not just about doctors and teachers experience or I suppose knowledge is it. I remember having a lot of uncertainty when (child) went up to seniors, he was used to the school in the village and teachers and children know him and are tolerant of him. I was concerned about the response he would get in a large school and would the teachers understand his needs when they have so many other children. But they have been marvellous and it’s not just about their knowledge but how they respond to having a child like (child) in the school’. *Family 8 dad, child 11 years (focus group)*

Ways of managing uncertainty in relation to the receptiveness of professionals included providing professionals with information about their child’s condition and developing coping strategies such as accepting the way professionals interact with parents and rationalising the need to seek support is permissible. Parents’ described having to be an advocate for their child when interacting with professionals for example emphasising changes in their child which are likely to indicate a problem with the shunt or suggesting ways their child’s learning needs could be met. Examples of managing uncertainty when engaging with professionals included:

‘His teacher that he has now we did some leaflets for her and she has read them because she was asking me questions. Obviously you have to go through that every year but if they are willing to just take time out themselves you feel more secure.’ *Family 12 dad, child 4 years*

‘We were treated as if we were really young at some points and I was quite disappointed about that. As if we were children ourselves, we did feel as if we were being spoken down to a few times. Emm but that is something that you have to brush to one side’. *Family 6 mum, child 3 years*

‘I know there is something wrong. She said we will see how he goes… I said look he needs to be looked at. I said I have been patient, I know what you see is not what

> the books tell you but please do something. So they said they would scan… he is under pressure it's blocked. And I said I know that, I have been saying this all day mum'. *Family 14 mum, child 12 years*

In summary, parents' accounts revealed a range of uncertainties in relation to living with a child with hydrocephalus from reactions to their child's initial diagnosis to thinking about their child's future. Parents' uncertainties were interconnected and had multiple layers for example the unpredictability of shunt malfunction compounded parents' uncertainties about differentiating between illness symptoms that were likely to be as a result of general childhood illness and those associated with shunt malfunction. Although parents were uncertain about their child's future they did not appear to dwell on the future and concentrated on the immediate needs of their child and family. For some families meeting their child's immediate needs appeared to focus on the ever present uncertainty that their child's shunt may malfunction, necessitating parents to seek advice from healthcare professionals. Uncertainties relating to the nature of shunt malfunction, the responsiveness of professionals when seeking advice and whether the family live in close proximity of the regional centre appeared to influenced parents' decisions in relation to where and how they develop effective support systems. The concept of uncertainty is intertwined with the core concept labelled 'developing expertise', described next, particularly the theme labelled differentiating between general childhood illnesses and shunt malfunction.

3.6.2 Developing expertise

Parents are responsible for recognising changes in their child that might indicate a problem with the shunt, and responding accordingly. Experience of managing the child's condition enabled some parents to develop the role of 'expert parent'. Developing expertise involved learning about hydrocephalus, developing the skills to recognise shunt malfunction and making decisions about when and where to seek advice. Developing expertise was associated with three themes; 'making sense of hydrocephalus and treatments', 'differentiating between childhood illnesses and shunt malfunction' and 'understanding support organisations'. These themes are now described.

3.6.2.1 Making sense of hydrocephalus and treatments

Making sense of hydrocephalus involved: understanding why their child developed hydrocephalus; the potential impact of the condition on the child's growth and development; becoming knowledgeable about hydrocephalus, treatments and associated problems. Initially making sense of hydrocephalus was bound to the emotions parents' experienced on first learning of their child's diagnosis. The diagnosis was difficult to comprehend for mothers who had been proactive in relation to maximising the chances of a healthy pregnancy and minimising the risk of the baby being born with a neural tube defect. For parents who had never heard of the condition grappling with the label of hydrocephalus compounded their bewilderment. Not knowing the cause of their child's hydrocephalus appeared to be an unresolved issue for some parents. Making sense of hydrocephalus also included understanding the potential impact of the condition on their child's growth and development. The following extracts relate to parents making sense of hydrocephalus:

> 'When the word hydrocephalus was said to us it was like a Greek Island. You know, well what is it?… What does it mean?… And I said why, what's happened?' *Family 3 mum, child 5 years*

> 'I mean we, I think (child's) condition has actually been caused through shear negligence through the labour basically and mismanagement…that caused the hydrocephalus'. *Family 6 dad, child 3 years*
> 'I wrote a diary whilst I was in hospital but I don't feel comfortable anybody reading it at any point, not yet anyway. I think they mentioned intraventricular haemorrhage at the time'. *Family 6 mum, child 3 years*

> 'I had taken folic acid for three months before I conceived and most of the way through the pregnancy. I was so shocked to hear that she had hydrocephalus because I thought I had done everything they said you should do to avoid the risk of that being an issue'. *Family 7 mum, child 10 years*

Prior knowledge of hydrocephalus varied from having never heard of the condition to having previous contact with individuals with hydrocephalus, either informally or as part of professional roles. The need to learn about hydrocephalus and its treatments was irrespective of parents' prior knowledge or

experience of the condition. Becoming knowledgeable about hydrocephalus served several purposes: as a means of counterbalancing the shock experienced when their child was first diagnosed; to participate in care decisions; to develop the skills to respond to their child's needs; to engage effectively with health professionals; be an advocate for their child. The need to learn about hydrocephalus is summarised in the following accounts:

> 'It was fluid on the brain….I knew roughly what it was about but I didn't know the details, no. So we needed to find out really'. *Family 15 dad, child 5 years*

> 'You have all these questions and doubts, you think anything to do with your brain sounds oh horrific. The hospital were good and gave us booklets and things. Then we just started looking on the internet. You want to be able to try because at the end of the day when you are the main carers you want to try (to meet your child's needs) and think is it that or is it that (shunt problem). You want to be able to decide if it's the shunt'. *Family 12 mum, child 4 years*

Information about hydrocephalus and its treatment was obtained from health professionals, ASBAH advisors, other parents living with a child with hydrocephalus, family, friends and internet web sites. The quality of information provided particularly health professionals was variable. Sometimes information provision was appropriate to meet parents needs, delivered clearly and in a way that demonstrated empathy. In contrast, other accounts described information provision as inadequate with the amount of information overwhelming and an over-use of complex terminology. In addition, parents' perceived that health professionals made assumptions about their information needs and restricted the information provided. The existence of professional hierarchies within the healthcare teams was perceived as a barrier to information sharing. The way information was shared with parents, particularly at the time of diagnosis, had a lasting impact on parents. The information provided by ASBAH was described as invaluable, particularly planned educational events where there was to opportunities to network with other parents and experts working with children with hydrocephalus.

The following extracts provide examples of parents' perceptions of information provision:

> 'I mean he (GP) worded things so superbly he said she, the water drains into the head, it flows into the head but it is not coming away. You know he gave us a lot of confidence it was all explained quite simply and it does stay with you, those first few explanations do actually stay with you'. *Family 7 mum, child 10 years*

> 'Yes they know the medical side but they don't know what is really like, they don't really provide any information'. *Family 2 mum, child 8 years*

> 'We have found out a lot ourselves on the internet, we have got our own research capability, if you like, if we haven't fully understood something from the healthcare professions, then we have been able to look this up further. But I can imagine that if people didn't have access to the internet, or those capabilities, I could see them not getting the information'. *Family 11 dad, child 5 years*

> 'The only thing that we get is from ASBAH. If not part of it (ASBAH) you are left to go on your own little merry way'. *Family 12 mum, child 4 years*

Knowledge of the treatments for hydrocephalus varied, some parents' described shunts as the only treatment option, whereas other parents' described a range of treatment options included those in the early stages of development. Despite variations in treatment knowledge, shunts were perceived as synonymous with hydrocephalus. Detailed knowledge of shunt systems, their development and how they operated appeared to contribute to parents' ability to make sense of their child's condition. When describing treatments medical terms were adopted suggesting a socialisation process occurs as parents become experts in managing their child's care and develop the skills to effectively engage with health professionals. The importance of shunts in managing their child's condition emerged as a dominant feature of living with a child with hydrocephalus. Shunts were described in terms of significantly improving the outcome for children with hydrocephalus, and more specifically being essential to their child's survival. Although the majority of parents' described shunts positively, the need to be vigilant in watching for signs of shunt complications

consistently emerged. The following extracts are examples of parents trying to making sense of the treatments for hydrocephalus:

> 'Hydrocephalus and the shunt to me are one and the same thing, one is the disease and other is the piece of kit to treat it. I think it's the same thing to me'.
> *Family 15 dad, child 5 years*

> 'I obviously know the shunts the main thing and, is it third ventriculostomy …which wasn't thought to be appropriate in (child) case. They're doing some research into medical medication or something and that side but at the moment, shunt is the main treatment'. *Family 5 mum, child 6 years*

> 'You know it was a surgeon who was discussing the problem with an engineer and the engineer came up with the idea of a shunt that could be a type of plumbing to move fluid from the brain to other parts of the body. It was marvellous and there was no way at the time to treat the children'. *Family 2 dad, child 8 years*

> 'I would say apart from the fact that it saved his life, fantastic. I mean the downside is having to be careful and watch out and all the rest of it but the benefits outway'.
> *Family 15 dad, child 5 years*

In summary, making sense of the child's condition involved becoming knowledgeable about hydrocephalus in order for parents to cope with their initial reaction to their child diagnosis, develop the skills to respond to their child's needs and contribute to care decisions. It is likely that developing the knowledge and skills needed to meet their child's needs is the start of the process of parents developing the expertise to manage their child's condition.

3.6.2.2 Differentiating between childhood illnesses and shunt malfunction

As highlighted in Chapter 1, the signs of shunt malfunction are similar to those of common childhood illnesses. The ability to recognise shunt malfunction developed through gaining knowledge about hydrocephalus and its treatment, and experiences of illness episodes in their child including those which were shunt related. The majority of the children had required at least one revision of the shunt, with three or more revisions not uncommon. Consequently some

parents developed considerable expertise in recognising changes in their child that might suggest shunt malfunction and described a range of situations where they were able to differentiate between general childhood illnesses and shunt malfunction. Across accounts the life threatening nature of shunt malfunction resulted in concerns that illness symptoms might be shunt related were always in the background. Concerns about shunt malfunction were highlighted in the comparison case, where the child's shunt had been in place for over 12 years, and despite never encountering a shunt related illness parents' described being alert to the possibility that illness symptom might indicate a problem with the shunt. The following examples relate to parents' accounts of identifying illness symptoms in their child:

> 'It does stick in my mind about his hydrocephalus even though, touch wood, he has had no problems, if he gets a headache it's the first thing I think about if his shunt's okay'. *Family 13 mum, child 13 years*

> 'Whenever (child) is ill, we would always think is it the shunt. It's always the first thing, which really it should be, the first thing you think of is, is it the shunt'. *Family 11 dad, child 5 years*

> 'I remember one time when he actually got pneumonia didn't he… we knew something was wrong, we thought he had got a bad cold… he was obviously very listless, I think it (shunt problem) did cross my mind'. *Family 15 mum, child 5 years*

> 'Once she had this flu bug that has been going round…..the high temperature, blinding headache and felt sick. Which for her is normal shunt problems but I just know there are subtle differences. And also her sister had had it the previous week which reassures me and is my benchmark'. *Family 7 mum, child 10 years*

It relation to identifying shunt malfunction it emerged that a continuum exits; parents are either certain that changes in their child are shunt related or not and in other situations there are uncertainties about illness symptoms being shunt related. Although parents could provide examples of knowing illness symptoms were shunt related or not, and where uncertainties existed, they found it difficult to express exactly how they knew illness symptoms in their child were definitely related to shunt malfunction. Explanations included just knowing the subtle

differences between general childhood illnesses and shunt problems, recognising changes in their child's usual habits and behaviours that were likely to be indicative of a shunt problem and instinct. Parents appeared to be referring to the concept of tacit knowledge when describing just knowing changes in their child were shunt related. This tacit knowledge was particularly heightened for parents of children with complex needs, where complications of associated conditions often resulted in similar illness symptoms to those of shunt malfunction. Examples of parents' accounts of differentiating between general childhood illnesses and shunt malfunction in their child included:

> 'We didn't really have any problems with the hydrocephalus, until (child) was three. Although we had always had problem with food and vomiting, this was different. (Child) had headache, he was crying but it was different to his normal cry, his vomiting was not after feeds as usual, but in the morning and before feeds…... He just wasn't right. You think how will you know, but it's your child and you know it is different, a different type of headache'. *Family 2 mum, child 8 years*

> 'Instinct. Because of her colour, there is just something about her eyes or she will start to use maybe the wrong word, or a bit sluggish in the morning and it just rings bells really'. *Family 7 mum, child 10 years*

> 'It sounds ridiculous but not himself. I think because we know him so well and in terms of health so well we can spot when something's are not quite with him right straight away. We know straight away'. *Family 15 mum, child 5 years*

A range of emotions were described in relation to making decisions about the cause of their child's illness symptoms. These emotions included: anxieties about making the right decision; being fearful of not detecting shunt malfunction; being overwhelming by having to make shunt related decisions on behalf of their child; feeling guilty for accessing the regional centre if concerns were not proven to be shunt related; being over cautious about responding to illness symptoms in their child; being judged by health professionals and other parents because of the frequency they accessed health services; frustration if no definite cause for the illness symptoms could be found. In contrast, accepting there would be times when accessing health services would be precautionary was perceived to be acceptable because of the uncertain nature of shunt related illness

symptoms. Concerns about the consequence of shunt complications included brain damage because of repeated shunt revisions, the effects of radiation because of the number of CT scans their child required and the impact of repeated hospital admissions on the child and family. The following extracts illustrate parents' feelings relating to making decisions about their child's shunt:

> 'Sometimes you feel like judge, jury and doctor and everything don't you'. *Family 12 mum, child 4 years*

> 'That the shunt blocks and I don't notice - that's my biggest worry'. *Family 1 mum, child 3 years*

> 'We will take him to the (regional centre) and it won't turn out to be anything serious, it's bound to happen. But we are cool with that, I'm fine with that. It's better than the thought of missing it'. *Family 15 dad, child 5 years*

> 'Some parents are like, are you taking her to the doctors again, she has only got a cold they haven't got a clue.' *Family 6 mum, child 3 years*

In summary, parents developed considerable expertise in relation to recognising shunt malfunction in their child gained through becoming knowledgeable about hydrocephalus and its treatment, and experiences of shunt malfunction. Making decisions about the cause of illness symptoms and the possibility of not detecting shunt related illness symptoms were at times overwhelming.

3.6.2.3 Understanding support organisations

Parents relied on support from health services to meet their child's acute and long-term health needs, education services to meet their child's education needs and networks such as ASBAH to provide information and emotional support. Support needs change over time and in response to their child's health needs and ongoing development. At times meeting their child's needs was dominated by acute illness and the possibility of shunt malfunction. Once illness symptoms were identified as shunt related parents had to decide when and where to seek advice and support. Although parents were aware they could directly access the regional children's neurosciences ward, they also described accessing primary

and secondary healthcare service in the first instance if they had shunt related concerns. A range of factors influenced parents' decisions in relation to where to seek advice including: the degree of certainty their child's symptoms were suggestive of shunt malfunction or more likely to be general health concerns; previous experiences; health professionals' familiarity with the child and family; the experience and knowledge health professionals had in relation to children with hydrocephalus; practical issues such as anxieties about driving a sick child to a city a considerable distance way. Although having direct access to the regional children's neurosciences ward was valued by parents and described as an essential safety net, parents living in rural areas were more likely to consult their general practitioner as the first point of contact. The following extracts summarise parents' accounts of accessing health services:

> 'My GP's good. I rushed her round to the doctors and the doctors are very good and see her straight away and if I am struggling and I think, like that and I think it is her shunt I usually go straight round there'. *Family 9 mum, child 2 years*

> 'I would bring her here (neurosciences ward). It's been difficult this time because we have come quite a lot of times, I could have gone home to doctors, but I think you just know, you get a feeling, so you have a safety net here, I just ring, we have direct access'. *Family 4 mum, child 10 years*

> 'I don't really go to the GP'S because the GPs just send me to the hospital, because they say they're not that clued up on him - so they would rather I go straight to the hospital (regional centre)'. *Family 1 mum, child 3 years*

In addition to deciding where to seek advice, parents had to decide when to seek advice. Seeking advice varied from a few hours from the onset of shunt related illness symptoms to two weeks. Parents' decisions were influence by: the recommendations within the ASBAH alert cards, which recommend seeking advice if acute illness symptoms persist for four hours or more; advice from health professionals; previous experience of shunt malfunction; previous experience of hospital admissions. For example:

> 'They (doctors) say if it has been going on for a fortnight you know then bring him in. You sort of learn that you have to give it time and see if it changes'.
> *Family 10 dad, child 6 years*

> ‘Some of these warning cards it says up to four hours - you know get medical advice’. *Family 3 mum, child 5 years*

> ‘We spend quite a lot of the time waiting in (local hospital) for someone to make a decision, which we can do that at home really, can’t we. We know that if we go to out of hour’s service we know that we will be admitted. So we tend to wait a bit longer that’s in cases where we are unsure. If we were absolutely definite, we go straight to (regional centre’). *Family 12 dad, child 4 years*

Parents were able to identify the services and support available when their child had acute illness symptoms. In contrast, identifying services relating to other aspects of their child’s needs was variable and for some parents fraught with difficulties. Support in relation to meeting the child’s educational and developmental needs was important, yet parents’ perceived that no individual took overall responsibility for their child’s wellbeing and there was lack of co-ordination between services. Parents of children with complex needs found it difficult to identify and navigate their way round services that might help them meet their child’s wider health and educational needs. Irrespective of the differences in parents’ understanding of support service, the majority of parents indicated they would value having a key worker with detailed understanding of the needs of children with hydrocephalus. Some parents’ felt this role was in-part met by the ASBAH advisors, but their limited availability, a perception that they did not work in collaboration with acute health services and lack of local advisors was identified as a barrier to ASBAH advisors fulfilling a key worker role. The following extracts are examples of the perceived gaps in service provision:

> ‘I don’t know where to go for instance I think that we could do with a disabled badge but how do you go about doing things like that. And it’s that element there, that element that looking further a field that you don’t know that’s where you slip up, you know. I sometimes wonder if you do need a bit more knowledge but where to get that knowledge and that help.’ *Family 10 mum, child 6 years*

> ‘(ASBAH advisor) was really really supportive and made me feel like he weren’t the only one. I felt there was plenty of support and there was loads of people that lived with it and that made me feel a whole lot better’. *Family 1 mum, child 3 years*

> ‘There has been no one who has taken ownership of his hydrocephalus or who has been able to answer questions about his longer term issues, implications if there are any…. the neurosurgeons in (regional centre) don’t want to know, are not interested we’ll put the shunt in and we’ll fix it if it is broke but in terms of long-term prospects issues they’re not bothered really.’ *Family 15 dad, child 5 years*

> ‘With the number of consultants she sees, appointments and all her educational appointments… a nurse specialist that could have that relationship together and pull that care together, I mean (child) has eight consultants who do not work alongside each other’. *Family 11 mum, child 5 years*

In summary, parents’ described a range of factors that influence where and when they accessed health professionals and had knowledge of support systems available to meet their child’s acute health needs. In contrast, parents’ described a lack of coordination and uncertainly about services in relation to meeting their child’s ongoing needs.

3.6.3 A normal life

The final core concept related to living a normal life. The unpredictable nature of shunt malfunction was disruptive and had the potential to dominate family life. Decisions about family activities were at times influenced by the needs of the child with hydrocephalus. Parents were watchful for the symptoms of shunt malfunction but this was balanced with creating a normal environment for their child and integrating their child with hydrocephalus needs into every day family life. A normal life was associated with three themes; ‘barriers and facilitators to normal family life’, ‘valuing normal life’ and ‘balancing normality with watchfulness’. These themes will now be described.

3.6.3.1 Barriers and facilitators to normal life

When summing up their experiences of living with a child with hydrocephalus, it emerged that any specific considerations parents made because of their child’s hydrocephalus and associated conditions became integrated into every-day life. The concept of normality was often described as meaningless because parents’ believed all families were unique, with their own issues and concerns. Parents’

described a range of barriers in relation to undertaking family activities and perceived lifestyle choices were influenced by the needs of their child with hydrocephalus. These included: disruption because of the frequency the child required hospitalisation and the number and timing of planned out-patient appointments; having to be available to responds to concerns about health related issues while the child was at school; providing care for their child during school hours; lack of social opportunities for themselves and their child. There were constraints when undertaking family activities because of the unpredictable nature of shunt malfunction and the amount of planning required to ensure their child's needs were met. For example when holidaying abroad it was difficult to obtain travel insurance for their child with hydrocephalus. Mothers' accounts suggested meeting their child's needs was not compatible with full-time employment. The following extracts summarise parents' perceptions of undertaking family activities and influences on lifestyle choices:

> 'When we moved, we looked again to be near the hospital, I know it sounds stupid but you feel you've got a safety net we, we are near there because you know it's the best place for (child)' *Family* 3 *mum, child 5 years*

> 'We can't do anything, can't plan. Like tomorrow, I mean they're off school and like today we have a hospital appointment, we'll do something but we can't plan, so it affects family life. I couldn't work full time. Part-time is not by choice because of all (child) appointments and obviously if they ring you up from school I have to come out of work'. *Family 4 mum, child 10 years*

> 'I got a phone call when I was at work, from a teacher at school saying that she had felt a lump on the back of her head but she hasn't banged it and if it is just the shunt and I said well that it's always there. So I had to drive home from work to feel it and confirm to them that is just how the shunt should be even though we had told them previously and shown them where it was in the past so they are on edge about it'. *Family 11 Dad, Child aged 5 years*

Comparing their child's development with the child's peers' reinforced normality but also highlighted differences in the child's abilities. Differences in their child's development were more evident as their child became older and some parents' perceived that their child was beginning to become aware of these differences.

A range of perspectives were described about the impact of the child's condition when engaging in activities with peers; some parents' perceived that their child would not participate in the same activities as their peers because of physical disabilities. In contrast, other parents' accounts suggested that limitations in their child's physical abilities were not a barrier to their child engaging in the same activities as their peer. Some parents of children with complex needs perceived they were fortunate when they compared their child to children with other disabilities. The following extracts summarise parents' accounts of differences between their child and the child's peers:

> 'It makes her different to everybody else and she wants to be the same….now she is getting to the stage where she is thinking about more and she is looking at other people and seeing what they have got and what they can do and she is comparing herself.' *Family 7 mum, child 10 years*

> 'We have brought him up to believe that although he has a disability, he is not disabled and to me disability can be a state of mind as much as the problem not just a state of the body. We try to encourage him to do things… he has been abseiling, pot holing, rock climbing he's done all the things that his friends have done'. *Family 14 mum, child 12 years*

> 'You just think how lucky you really are. You always think it is the worst thing in the world but there are a lot of people worse off than you. I think you do realise how lucky you are.' *Family 9 dad, child 2 years*

3.6.3.2 Valuing normal life

Valuing normal life was evident in the way family life was described; love for their child and their child's contribution to family life; embracing their child's abilities; recognised their child as a child first and foremost with unique strengths and skills; enjoying family activities. Valuing normal life was evident because of the efforts parents made to engage in usual family activities such as seeking information about local hospitals before embarking on holidays. Travelling without insurance for their child with hydrocephalus was typical. Examples of valuing family life included:

‘They offered me a termination and stuff, and I said no no it was meant to be… I'm glad you know I went through with it. He is great pleasure. He loves mummy’. *Family 1 mum, child 3 years*

‘You know people think hydrocephalus, might think is all bad news. But it’s not, there’s a lot of reward, for example a child who has so much against them doing so well’. *Family 2 dad, child 8 years*‘

‘Be confident really give them all the confidence that you possibly can and not to make it out that is a negative bad thing or that it is going to stop them from doing things or all that. Just be positive and do things that you want to do that you would do even if they didn’t have hydrocephalus or a shunt put in. Don’t let it stop you from doing anything’. *Family 12 mum, child 4 years*

‘See your child as a child first and foremost and look at all the positive things, and be aware that the shunt may or may not have problems but try and not let it take over your life. It will always be there in the back of your mind, but look on the positive’. *Family 2 mum, child 8 years*

‘You have just got to get on and do the things you want to do. So we do things but we haven’t got any travel insurance’. *Family 8 Mum, child 11 years*

Parents’ described living with a child with hydrocephalus as having similar challenges to bringing up a child without hydrocephalus, and highlighted that all children have unique needs. Parenting roles included ensure opportunities were available for their child to reach their full potential whether they had hydrocephalus or not. The following extracts highlight parents’ views about parenting a child with hydrocephalus:

‘It’s difficult not to be frightened but it (hydrocephalus) becomes part of every-day life, it’s not the first thing on your mind. But day to day we just live like normal, and they are like any brother and sister and fight and you can’t stop that and try and live as normal a life as we can’. *Family 5 mum, child 6 years*

‘Worrying, continually but you do about all of your children… you worry that they will get in with the wrong crowd and not make good of themselves. But I do worry extra about (child)’. *Family 7 mum, child 10 years*

'(Brother's) needs are very different. It's what can we do that actually meets everybody's needs best. (Child) loves to swim and that's fine and we always take that into account. Maybe you have that with all kids'. *Family 8 mum, child 11 years*

3.6.3.3 Balancing normality with watchfulness

In addition to being a significant feature of the concept labelled 'uncertainty' (Section 3.6.1.2), shunt related concerns were also associated with the concept of living a normal life. Parents balanced striving for normality with being constantly vigilant in relation to detecting shunt malfunction. Being watchful for illness symptoms and ongoing concerns about shunt malfunction influenced parenting practices including: being overprotective and not disciplining their child because of having a diagnosis of hydrocephalus; restricting physical activities, particular if there was a risk of head injury; taking extra precautions when planning family activities. Parents tried to balance protecting their child with allowing them to participate and experience life. For example:

'You have to be a lot more cautious and think a lot more about things, about what you are doing and where you go …. it is a big deal but it's not that big… it is just the way it is'. *Family 11 dad (mum interrupts)*
'So I think you are right (partner), we try very hard to let her experience life as any other four or five year old. I don't think we minimalise it, I think we respond appropriately but we try not to let it limit (child's) life or ours, or our lives'.
Family 11 mum, child 5 years

'I'm too soft, let him get away with a lot more because he is poorly, I think I can't shout at him. But you can really, it's just the way you think but you should treat him as normal just because there's something wrong with him. If he was healthy I would be a lot more strict'. *Family 1 mum, child 3 years*

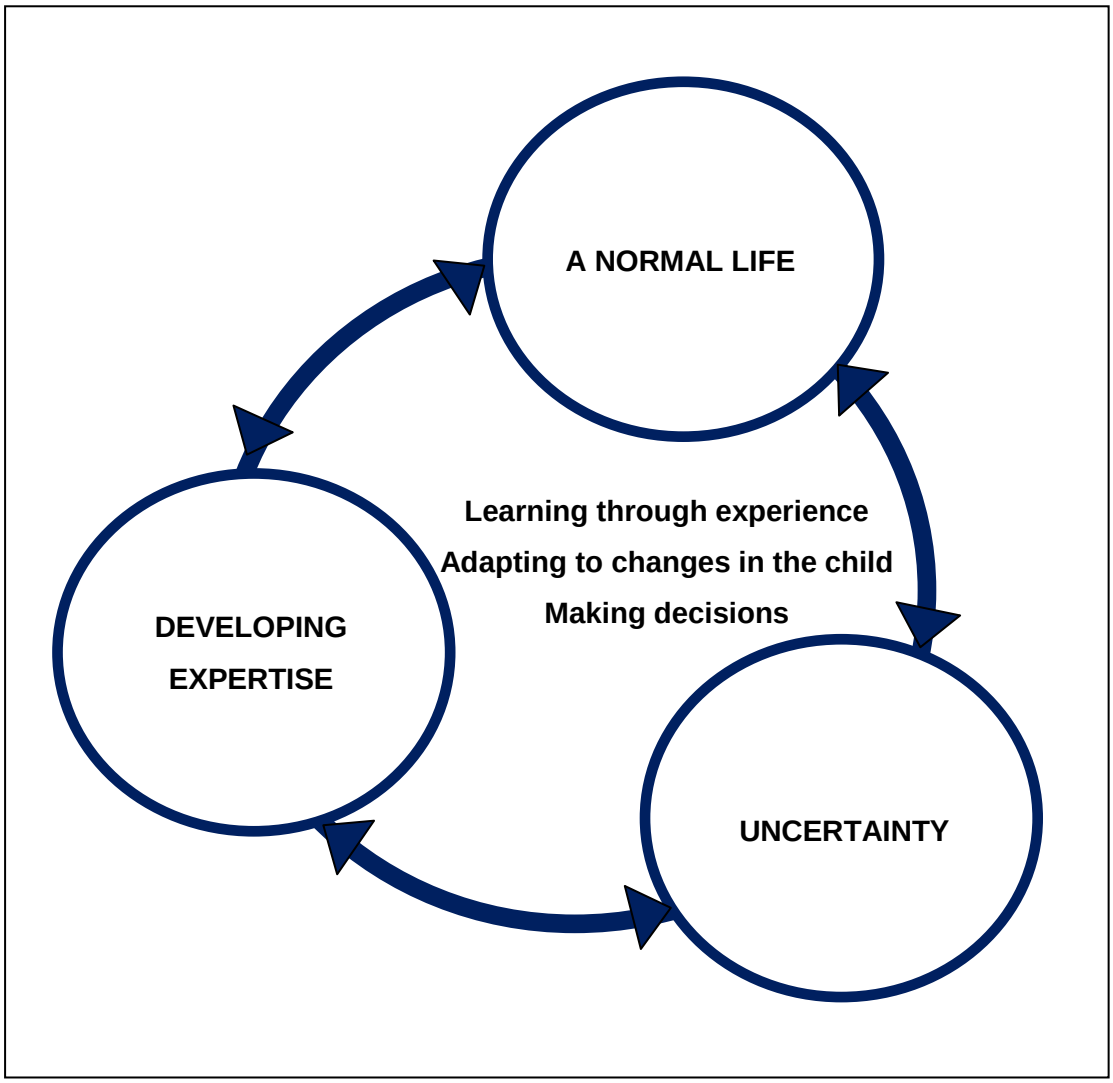
'We are a little bit over protective about his head. I don't think that is a bad thing but it does impact in terms of what we do, we are more protective of him than we would normally be. When he is having a play fight with (sister), sometimes we let them get on but other times we say watch his head. But whether we are just over cautious sometimes, but they have got to play together they are brother and sister and they have got to enjoy that aspect'. *Family 15 dad, child 5 years*

In summary, the concept of normality had little meaning to many parents, who perceived they had similar challenges to other families. However, the uncertainties and life threatening nature of shunt malfunction appeared to influences lifestyle choices such as employment, where to live and when planning family activities. Parents tried to balance the constant vigilance in identifying signs of shunt malfunction with living a normal family life.

3.6.4 The conceptual framework

The conceptual framework presented in Figure 19 attempts to represent (with the acknowledged limitations of a 2-dimensional diagram) a dynamic model of living with a child with hydrocephalus. The model reflects parents' accounts of living with a child with hydrocephalus and represents the way they assimilated and integrated their experiences and knowledge as they gained expertise in managing their child's condition and responded to the evolving needs of their child. The three concepts 'uncertainty', 'developing expertise' and 'a normal life' interlink and are bound together by the dominance of shunt related concerns that were evident throughout parents' accounts. At times responding to possible shunt malfunction dominated family life. Decisions about meeting the child health needs were balanced with meeting the wider family needs. The threads that link the core concepts, 'learning through experience', 'adapting to changes in the child' and 'making decisions', represent how parents responded to, and integrated the needs of their child with hydrocephalus into family life.

Figure 19: Conceptual framework: dynamic model of living with a child with hydrocephalus



In order to illustrate the relationship between the core concepts, one family's journey is presented (Figure 20). This example focuses on the way parents developed expertise in relation to recognising illness symptoms that may indicate shunt malfunction and how decisions were made about when and where to seek health care advice.

Figure 20: Developing the expertise to recognising shunt malfunction: a journey

Family 11, child aged 5 years

Mum 'Initially she had so much surgery, it was a roller coaster, it was difficult. So in the start we probably rang (the ward) an awful lot if we were unsure… well nothing was ever trivialised, we were never made to feel that we were over-reactive parents. It was just a safety net really…them being there'.
*Links the theme 'receptiveness of professionals to interacting with the child and family' (**uncertainty**) with the theme 'concerns about the shunt' (**developing expertise**).*

Dad 'Because the shunt blocked and has been revised, each time we have gained more information. If we haven't fully understood something when we have been able to look this up further. So our understanding of (child's) condition is quite detailed, so that's been really helpful'.
*Links the theme 'making sense of hydrocephalus and its treatments' (**developing expertise**) with '**learning through experience'**.*

Dad 'We are more aware now that if it was a problem with the shunt then she will become progressively more and more ill. It isn't just a case of that she is ill and stays the same it would be degenerative for want of a better word. So that is probably quite a big step for us but we are always aware'.
*Links the theme 'differentiating between childhood illness and shunt malfunction' (**uncertainty)** with '**learning through experience'**.*

Mum 'Now (child's) older and can communicate with us we can actually ask her. We were probably over cautious because up to the age of two every time she was sick, or her cry change we though oh gosh we went (to the ward)'.
*Links the themes 'differentiating between childhood illness and shunt malfunction' (**uncertainty)** to '**adapting to changes in the child'.***

Mum 'I think it's the out of hours that we find difficult, if we are unsure. Well we'll say we won't take her (to local hospital) because they tend to keep her in. You can't expect all doctors to have that sort of expertise. So we know that if we go out of hours we will be admitted. So we tend to wait a bit longer'.

Dad 'In all those situations it tends to be us kind of knowing really that it's not the shunt but always having that tiny bit of doubt that what if it is. We always then think if it is (the shunt) she's going to get worse and then we have to do something about it quite quickly'.
*Links the themes 'differentiating between childhood illness and shunt malfunction' and 'receptiveness of professionals to interacting with the family' **(uncertainty)** to **making decisions.***

Mum 'I think we respond appropriately we try not to let it limit (child's) life or ours, or our lives...we try not to wrap her up in cotton wool. We try very hard to let her experience life as any other four or five year old. We probably find out as much information as we can, you reach a point where you just start getting on with it and perhaps don't worry quite as much'.
*Links the themes 'valuing normal life' and 'balancing normality with watchfulness' (**living a normal life)** with **learning through experiences.***

Core Concept: Developing expertise

3.7 Discussion

The discussion is presented in two parts; first the core concepts are explained. Second, there will be an exploration of the ways in which parents assimilate their knowledge and experiences as they gain the expertise to become effective managers of their child's condition.

3.7.1 Explaining the core concepts; developing expertise, living with uncertainty and a normal life

This section summarises the similarities and differences between the findings of the study presented in this chapter and the key themes identified in the literature review (Chapter 2). Although specific typologies did not emerge from the analysis, links to typologies associated with the concept of uncertainty were evident. These links are presented were appropriate.

3.7.1.1 Uncertainty

Uncertainty occurs when there is doubt about the best course of action in a given situation (Morse et al 2000, Penrod 2001, Penrod 2007). Illness-events result in a multiplicity of uncertainties emerging which commonly relate to: the diagnosis and its meaning; treatment choices and their effectiveness; the long-term consequences of the condition and future life choices; the impact on relationships (Penrod 2001, Shaha et al 2008). These uncertainties mirrored the findings reported in the study presented in this chapter. Uncertainty was a prevailing feature throughout parents' descriptions of their lives and was associated with the meaning of the diagnosis, the unpredictability of shunt malfunction, concerns about the child's future and interacting with health professionals. Uncertainty can provoke a range of reactions and responses including anxiety, a sense of loss, insecurity, alterations to an individual's usual locus of control and the ability to make decisions (Penrod 2002, Shaha et al 2008). Uncertainty at the time of diagnosis was identified in the review findings (Chapter 2) and evoked emotions such as anxiety, confusion, doubt, blame, and guilt (Gibson 1999, Ray 2002, Marshall et al 2009). The findings of the study presented in this chapter identified similar reactions to the diagnosis but there

was also fear and shock because of uncertainty about their child having brain damage because of hydrocephalus.

Uncertainty has been identified as a significant psychological stressor for individuals with long-term conditions (Mishel 1997). Consequently the last decade has witnessed a range of theories emerging that attempt to explain the relationship between uncertainty and the meaning of illness events (Wright et al 2009). The uncertainty in illness theory suggests that uncertainty following an illness diagnosis causes a shift in an individuals' usual functioning which can be reconciled through the process of recognising, appraising and managing the cause of the uncertainty (Mishel 1988, 1990). An alternative conceptualisation of uncertainty suggests responding to uncertainty is based on the individuals' perception of their level of confidence and control in relation to making decisions in a given context (Penrod 2007). Resolution is influenced by the risks associated with available choices and past experiences of similar situations (Penrod 2007). Drawn from empirical research, four typologies were identified that influenced the degree in which the individual was able to resolve the uncertainty (Penrod 2001, Penrod 2007). These were 'overwhelming uncertainty' which occurs when there is low control and low confidence; 'role uncertainty' with high control and low confidence; 'pervasive uncertainty' with low control and high confidence; 'minimal uncertainty' with high control and high confidence.

Findings from the study presented in this chapter could in part be explained by the theories presented above. However there were differences, these differences in part may be a result of the range, nature and inter-connectedness of the uncertainties described by parents. Uncertainties had many layers and changed as parents adapted to the needs of their child and changes in their child's condition. Resolving uncertainty according to the model developed by Penrod (2001, 2007) is dependent on managing the interconnected concepts of control and confidence. However, in the context of living with a child with a long-term condition lack of treatment choices and the unpredictability of treatments complications are often outside parents' control (Maltby et al 2003, Dickinson et al 2006). In these circumstances shifting from a position of low to high control may not be feasible. Findings reported in this chapter suggest parents

constantly observe their child for illness symptoms because of the unpredictable nature of shunt malfunction. This lack of control may explain the reason uncertainties in relation to detecting shunt malfunction in their child dominated parents' accounts of living with a child with hydrocephalus. Parents ultimately deferred decisions about the shunt to health professional because shunt malfunction can be life threatening. For some parents lack of control combined with low confidence positioned them in the typology described as overwhelming uncertainty (Penrod 2007).

Removing or reducing uncertainty involves using strategies to gain control and develop confidence in managing the situation causing the uncertainty (Mishel 1988, Penrod 2002). Parents who participated in the study presented in this chapter described becoming knowledgeable about their child's condition and integrating their child's needs into usual family routines. This enabled them to gain control of the situation and manage their uncertainties in relation to the meaning and potential impact of hydrocephalus for the child and family and interacting with health professionals. However, parents acknowledged having no control over the shunt. Parents' accounts suggested that through experience they developed confidence in their ability to recognise and respond to possible shunt malfunction. As parents' confidence increased they wanted greater involvement in care decisions when seeking advice from health professionals. Lack of control but increased confidence positioned parents in the typology described as pervasive uncertainty (Penrod 2007). Although uncertainty in relation to shunt malfunction remained, managing uncertainty was consistent with the uncertainty in illness theory in that parents acknowledged the factors that contributed to their uncertainties and concerns and were able to appraise their actions and identify possible future actions (Mishel 1988, 1990).

Although the concept of uncertainty did not emerge as a substantive theme within the literature review of parents' experiences of living with a child with a long-term condition, attributes of uncertainty were embedded throughout review findings (Chapter 2). Lack of control was identified in relation to: receiving the diagnosis (Sanders et al (2007); progression of the child's condition (Ray 2002); securing appropriate services to meet the child's needs (Ray 2002). Lack of

confidence was associated with: engaging with health professionals (Balling and McCubbin 2001, Maltby et al 2003, Sallfors and Hallberg 2003, Dickinson et al 2006); recognising illness symptoms and managing the child's condition (Maltby et al 2003, Nuutila and Salanterä 2006). Building effective relationships with health professionals was identified as difficult for parents because of lack of continuity in the professionals providing care for the child and the paternalistic approach to engaging with parents adopted by some professionals (Ray 2003, Dickinson et al 2006, Miller et al 2009). These findings were consistent with the findings from the study presented in this chapter, in particular parents' accounts of their uncertainties in relation to the meaning and potential impact of hydrocephalus for the child and family at the time of diagnosis, recognising shunt malfunction and interacting with health professionals.

3.7.1.2 Developing expertise

Developing the expertise to manage the child's condition was a key theme within the findings of the literature review (Chapter 2) (Gibson 1999, Callery et al 2003, Hallström and Elander 2007, Lauver 2008). Gaining expertise was perceived as a way to optimise the child's heath and development, and to minimise the physical, psychological and social impact of the condition on the child. Illness management included developing the skills to monitor and responding to changes in the child's condition (Ray 2002, Sullivan-Bolyai et al 2006, Cashin et al 2008) and forming effective relationships with health professionals (Ray 2002, Swallow and Jacob 2001, Dickinson et al 2006). Findings from the study presented in this chapter had similarities to those identified in the literature review. A significant part of managing their child's hydrocephalus was associated with recognising shunt malfunction and responding accordingly. Through integrating their knowledge and experiences of their child's condition parents developed considerable competence and expertise in relation to differentiating between general childhood illnesses and shunt malfunction, which often relied on their ability to recognise and respond to subtle changes in their child. The process of learning through experience, in other words how parents become an expert, is discussed in Chapter 5, Section 5.2.

Acquiring information was a key strategy in relation to becoming knowledgeable about their child's condition (Bailing and McCubbin 2001, Ray 2003, Maltby et al 2003, Dickinson et al 2006, Nuutila and Salanterä 2006, Lauver 2008, Cashin et al 2008). Knowledge was perceived as necessary in order to provide care to their child, manage treatment complications and collaborate with health professionals. However, parents information needs are not always met (Ray 2002, Starke and Möller 2002, Hummerlinck and Pollock 2006). In contrast, although parents have an overwhelming desire for information, the way information is used is variable; for example, parents may disregard or modify information that does not sit with their own beliefs (Fisher 2001, Dickinson et al 2006). This has the potential to cause tensions between parents and health professionals (Dickinson et al 2006).

Effective information sharing can be achieved by providing information clearly, free from medical terminology, in a timely manner and considers individual preferences in relation to the amount and depth of information required (Starke and Möller 2002, Mitchell and Sloper 2002, Hummerlinck and Pollock 2006). In keeping with findings from the literature, parents in this study presented in this chapter obtained information from a variety of sources including health professionals, support groups, family, friends, other parents and the world-wide web (Gravelle 1997, Fisher 2001). However, health professionals were the primary source of information and parents expected them to provide information about their child's condition and treatments. In relation to health professionals, parents' accounts in the study presented in this chapter suggest their satisfaction with information provision was variable. In contrast, parents were highly satisfied with the information provided by ASBAH advisors. Parents' perceived that health professionals over used medical terms and provided vast quantities of information in succession with limited opportunity for discussion. In addition, parents found it difficult to assimilate information immediately after the diagnosis because of concerns about their child's immediate needs and trying to cope with their emotions relating to the diagnosis and the possible impact of the condition on the child and family.

Parents' desire to collaborate effectively with health professionals was identified as a key finding in the literature review (Chapter 2) (Bailing and McCubbin 2001, Swallow and Jacob 2001, Ray 2002, Dickinson et al 2006). Health policy has endorsed a model of service and care delivery based on patient-centeredness and patient-professional interactions that are participatory and collaborative in nature (DH 2001a, DH/DfES 2004, DH 2005a, 2005b, 2007, 2009). In keeping with findings from the literature, parents in the study presented in this chapter perceived collaborative practice and the value health professionals placed on their expertise to be variable. Developing effective relationships with health professionals has been identified as stressful for parents (Swallow and Jacob 2001, Ray 2002, Dickinson et al 2006). Parents in this and other studies perceive that health professionals, in particular those working outside specialist areas, do not always have the expertise to manage their child's condition (Ray 2002, Ray 2003). However, parents in the study presented in this chapter recognised it was not feasible for professions to be experts in all conditions but they did expect professionals to be receptive to their child's needs and be willing to collaborate with them as the expert in their child's care.

3.7.1.3 A normal life

Normalisation is the process by which an individual, or in the case of children the child and family, respond to and manage their condition or disability in order to maintain usual or expected social activities (Knafl and Deatrick 1986, Morse et al 2000). Within the UK, the concept of normalisation appears to have developed in response to policy shifts, where greater emphasis has been placed on the integration of marginalised groups into wider society, such as people with mental health needs, special educational needs and learning disabilities (DfES 2001, DfES 2004, DfES 2005). There is an assumption normalisation is a desired outcome for parents living with a child with a long-term condition and that parents and professionals share the same socio-cultural values, beliefs and goals (Rohm and Bradley 2005).

Attributes of normalisation derived from research findings exploring normalisation and its meaning to families living with a child with a long-term condition have been identified as: acknowledging the existence of the condition and potential

threat to family life (Deatrick et al 1999); making comparisons with a reference group for example families who do not live with a child with a long-term condition (Morse et al 2000); engaging in parenting behaviours that are consistent with the reference group (Deatrick et al 1999, Morse et al 2000); emphasising similarities rather than differences with the reference group (Deatrick et al 1999, Morse et al 2000); developing strategies that re-enforce identification with the reference group (Deatrick et al 1999, Morse et al 2000). Parents in the study presented in this chapter did not readily identify with the term 'normalisation' as described in the literature (Fisher 2001, Knafl and Gilliss 2002, Ray 2002, Coffey 2006, Wennick and Hallström 2007). Parents preferred to focus on the uniqueness and individuality of their family. Unlike the attributes associated with normalisation (Deatrick et al 1999, Morse et al 2000), parents' accounts in the study presented in this chapter recognised both the similarities and differences between their child and the child's peers.

Acknowledging the existence of the long-term condition has been identified as a key stage in the process of normalisation (Deatrick et al 1999) and has been associated with the ability to cope and adjust to the child's condition (Knafl and Gillis 2002, Sallfors and Hallberg 2003, Maltby et al 2003). Parents may also deny the existence of their child's condition as a coping strategy when faced with adversity, particularly at the time of diagnosis or the child has few illness symptoms (Gravelle 1996, Johnson 2000). For parents in the study presented in this chapter, the unpredictability and life threatening nature of shunt malfunction, and the frequency of hospital admissions resulted in hydrocephalus being a constant presence, which for some parents dominated family life. In order to effectively manage their child' health needs parents had to accept the condition and be vigilant for the signs of shunt malfunction. The shifting perspectives model of chronic illness, described in Chapter 1, proposed that ongoing illness symptoms situates the condition in the foreground and become the dominate focus of everyday life (Paterson 2001). Findings from the literature review (Chapter 2), highlighted that living with a technology dependent child, where the family environment is dominated by the presence of medical equipment, resulted in the child's condition remained in foreground of everyday life (Heaton et al 2005, Kirk et al 2005, Rehm and Bradley 2005).

The process of normalisation is hindered when living with a child with a long-term condition because of ongoing disruptions to family life as a result of providing direct care and accompanying the child for treatments and clinic appointments (Hentinen and Kyngäs 1998, Ray 2002, Fisher 2001). Over time the majority of parents embed their child's needs into the routines of daily live (Gibson 1999, Knafl and Zoeller 2000, Maltby 2003, Wennick and Hallström 2007). For other parents incorporating their child's needs into usual family routines required a considerable amount of effort and any additional adversities threatened family coping skills (Johnson 2000, George et al 2006). Findings in the study presented in this chapter identified that being constantly alert for shunt related illness symptoms was a potential barrier to living a normal life; parents recognised this issue describing the need to balance being watchful with creating a normal environment for their child and family.

3.7.2 Interpreting the conceptual framework: a dynamic model of living with a child with hydrocephalus

The conceptual framework presented in Section 3.6.4 and depicted in Figure 19 represents a dynamic model of living with a child with hydrocephalus. This section will explore the connections between the concepts; these connections are the means by which parents assimilate knowledge and experiences in order to become effective managers of their child's condition.

3.7.2.1 Learning through experience

In common with findings from the literature (Ray 2002, Sullivan-Bolyai et al 2006, Cashin et al 2008), parents in the study presented in this chapter acknowledged their responsibility for monitoring their child's condition. Parents developed considerable experience in managing their child's condition. For some parents this included being able to distinguish between the symptoms of shunt malfunction and those indicative of common childhood illness. Developing expertise in relation to recognising and responding to illness symptoms and managing the child's condition appeared to involve the process of integrating knowledge of hydrocephalus and its treatment, their child's usual behaviours and prior experiences of illness episodes in the child. Developing expertise will be

explored further in Chapter 5, Sections 5.2 which draws together the findings from the two empirical studies undertaken as part of this thesis.

Findings from the literature review (Chapter 2) highlighted that parents' perceived that their experiences and contribution to care decisions are not always valued by health professionals (Balling and McCubbin 2001, Ray 2002, Dickinson et al 2006, Nuutila and Salanterä 2006, Miller et al 2009). Although the accounts of parents' presented in this chapter suggested they valued professionals' contribution to their child's care, this was not reciprocated. In common with the literature review, parents' perceived that their expertise and detailed knowledge of the specific symptoms that might indicate their child's shunt was malfunctioning were not always valued.

3.7.2.2 Adapting to changes in the child

Findings from the study presented in this chapter suggest parents' perceive that they have similar concerns, anxieties and challenges to parents of children who do not live with a child with a long-term condition. However, at times family life was dominated by the needs of their child with hydrocephalus. Parents' also described making adjustments to ensure all family members' needs were met. As a concept adaptation is poorly defined (Rentinck et al 2006) but in the context of living with a child with a long-term condition can be considered as the ability to adjust established routines in order to incorporate their child needs into family life (Cooper 1999). In common with findings from the literature, parents' accounts in the study presented in this chapter suggest that after a period of adjustment the child's needs become integrated into every-day life (Hentinen and Kyngäs 1998, Fisher 2001, Ray 2002).

Current research both supports and refutes whether the ability to adapt and accommodate a child's needs into the family system is linked to specific disease classifications or the severity and duration of the illness (Newacheck and Halfon 1998, Cohen 1999, Manuel et al 2003, Cavallo et al 2009). From the findings presented in this chapter it seems likely that common patterns in adapting to their child's condition are found across a range of illnesses rather than a disease by disease basis. Findings indicated that parents of children with hydrocephalus

and associated conditions had extended care-giving roles compared with parents of children with hydrocephalus alone. However, accommodating the child's needs into every day family life was evident across parents' accounts and not related to the complexity of the child's needs. As outlined in Chapter 1, section 1.4.3 the effects of hydrocephalus for the child are variable can impact on the child's development. Associated problems such as learning difficulties and the acquisition of social skills may not become apparent until the child is older. Consequently, the process of adaptation was ongoing as parents responded to changes in the child's developmental stage.

There are a range of theoretical models which explain the way family's respond to living with a child with a long-term condition. Of the theoretical models described in Chapter 1, Section 1.5.1, the shifting perspectives model of chronic illness is the model that best fits parents' perceptions of living with a child with shunted hydrocephalus (Paterson 2001). Living with a child with a long-term condition is often perceived as a linear process where the child's illness follows a predictable trajectory and therefore parents responses and adaptation progress in a similar time-line (Gravelle 1996). In contrast, the shifting perspectives model of chronic illness views living with a long-term condition as a continually shifting process with the individual's life having two domains, one where wellness dominates and the second where illness dominates (Paterson 2001).

Findings from the study presented in this chapter suggested that for the majority of the time wellness domain dominated; parents' perceived that they were like any other family, engaging with and undertaking usually family activities, with the child's condition ever present but in the background. However, a change in their child's condition, for example following shunt related illness episodes and the disruption associated with hospital admissions, resulted in a shift in domain with illness moving to the foreground. At these times the child's condition dominated and became the focus of family life and the uncertainty of shunt malfunction became a daily reality. As a consequence family activities were influenced by the needs of the child with hydrocephalus. When illness was in the foreground, parents' concerns about the impact of hydrocephalus for their child resurfaced. Returning to the domain where wellness was in the foreground occurred once

the acute illness episode resolved. In situations when the child's illness symptoms persisted, the illness domain dominated and parents' perceived that the condition impacted on the child and family's quality of life.

3.7.2.3 Making decisions

Parents make a range of health related decisions relating to their child's health (Chapter 1, Section 5.3). In the study presented in this chapter, parents' identified having to make decisions about: prenatal screening and continuing with the pregnancy; treatment choices including the withdrawal of care as a result of the infant being born premature; decisions relating to treatment complications. In common with findings from the literature, the range of emotions experienced at the time of diagnosis made it difficult for parents to assimilate information and contribute meaningfully to decisions about their child's immediate care (Gibson 1999, Johnson 2001, Swallow and Jacob 2001, Maltby 2003, Cashin et al 2008, Bowes et al 2009). In addition, findings from the study presented in this chapter identified that parents' perceived that their contribution to care decisions was limited because for the majority of the children the insertion of a shunt was the only treatment available.

One of the common sources of patient dissatisfaction is a lack of involvement in decisions about their care (Grol et al 2000, Richards and Coulter 2007). The concept of shared decision-making, where the patient is actively involved in the evaluation of possible treatment options and shares in decisions about the care package that best meets their needs, is based on a range of treatment options being available (Coulter et al 2008). In the context of the study presented in this chapter, when the shunt malfunctions the only reasonable course of action is surgical revision of the shunt. Parents' acknowledged there were no alternative treatment choices following a definitive diagnosis of shunt malfunction. However, they wanted to collaborate with health professionals when establishing the diagnosis. Parents also wanted health professionals to recognise their knowledge, skills and experience with regard to knowing their child. Parents' accounts suggested that health professionals' willingness to collaborate about their child's diagnosis and care was variable. In the context of a lack of treatment choices and the life threatening nature of shunt malfunction it is likely

that shared decision-making is not the appropriate paradigm. A model of collaboration is more appropriate, where parent-professional engagement centres on involving parents in decisions about the likely cause of illness symptoms.

3.8 Issues of rigour

Demonstrating rigour in qualitative research is challenging because there are no accepted standards by which qualitative research is judged (Rolfe 2006). It is not possible to apply quantitative tests and measures to establish the validity, reliability and generalisability of study findings (Tobin and Begley 2004). In the context of qualitative research: validity refers to the precision in which the findings accurately reflect the data (Morse and Field 1996, Lewis and Ritchie 2003); reliability refers to the consistency of the analytical procedures (Long and Johnson 2000, Cho and Trent 2006); generalisability refers to the transferability of the findings to other settings (Lewis and Ritchie 2003). The credibility of the study is also dependent on the researcher accounting for personal and research method biases that may have influenced the findings (Sandelowski 1986, Cho and Trent 2006, Bradbury-Jones 2007). These are considered in Chapter 5, Section 5.4. This section describes the measures employed to ensure findings were valid and reliable, and the transferability of study findings.

3.8.1 Validity

The validity of this study related to accurately representing and interpreting parents' accounts of living with a child with hydrocephalus. Validity can be achieved through: acknowledging biases in sampling and data collection techniques (Morse et al 2002); checking the accuracy of the data collected; ensuring labels attached to data are meaningful (Lewis and Ritchie 2003); demonstrating clarity in terms of thought processes during data analysis and subsequent interpretations (Mays and Pope1995); ensuring different accounts are represented (Lewis and Ritchie 2003).

Validity was achieved by:

- Recruiting participants with diverse experiences in relation to living with a child with hydrocephalus. However, the final sample had limitations in that all participants were from a White-British ethnic background;
- Interviewing couples together. This had the potential to improve the accuracy of responses because one parents' accounts stimulated recall in another and clarified areas of uncertainty (Allan 1980);
- Establishing a comparison case; one couple had not experienced shunt related illness episodes in their child, a teenager with a shunt since infancy. Considering the alternative view enhanced understanding of living with a child with hydrocephalus (Morse et al 2002, Tobin and Begley 2004);
- Ongoing critical reflection of interview techniques to ensure the data elicited was of sufficient depth and relevance (Holstein and Gubrium 2003b);
- Audio-recording the interviews. This enabled the interviews to be transcribed verbatim, the accuracy of transcriptions was checked by comparing transcriptions with the audio recordings (Tuckett 2005);
- Clearly describing the methods and undertaking a comprehensive analysis of the data (Snape and Spencer 2003);
- Attaching meaningful labels to the initial categories and themes in order to remain close to participants' accounts (Snape and Spencer 2003);
- Representing the range of parents' perspectives and actively seeing out similarities and differences across participants' accounts, prior to developing the final themes and concepts (Tuckett 2005);
- Using rich and thick verbatim descriptions of parents' accounts within the findings. This enables the reader to evaluate if participant accounts reflect emergent themes (Slevin 2000, Tuckett 2005);
- Presenting the findings and discussion separately ensured participants' accounts were not concealed within final interpretations. This enables the reader to assess the integrity of interpretations (Mays and Pope 1995).

Researcher bias in relation to data construction (influence) and data interpretation (immersion) threaten the validity of qualitative study findings (Robinson and Thorne 1988). Engaging with other researchers was not only essential to reduce research bias but enhanced personal development, and is discussed in Chapter 5, Section 5.4.1. Supervisors have a key role in relation to ensuring a study's credibility by challenging decisions and assumptions (Holloway and Wheeler 2002).

Research supervisors were involved in the development of the coding index, emergent themes and final concepts:

- The four interview transcripts used to develop the coding index were reviewed independently by both supervisors. A consensus was reached about the meaning and inclusion of initial categories;
- A further random sample of five transcripts was reviewed by both supervisors during the analytical stages, which assisted with the ongoing refinement of categories and themes, and the development of the conceptual framework.

Validity can be increased through the technique of respondent validation or member checking (Long and Johnson 2000, Tuckett 2005). Respondent validation includes inviting participants to comment on: the interview transcript to check accuracy and provide opportunity to add additional comments (Cho and Trent 2006); whether the final themes and concepts created adequately reflect the phenomena being investigated (Long and Johnson 2000). In relation to this study participants were offered the opportunity to review the interview transcripts. Although the majority of parents responded positively to reviewing their interview transcripts, only three parents returned their transcripts. Parents' annotations of the transcript primarily related to transcription errors. Parents' evaluation of the study findings is presented in the following section relating to reliability.

3.8.2 Reliability

Reliability is concerned with the consistency of the analytical procedures (Long and Johnson 2000, Cho and Trent 2006). Strategies used to enhance the validity of findings, such as audio-recording interviews and respondent validation, are also applicable to reliability. Two strategies particularly associated with demonstrating the reliability of qualitative research findings used in this study were auditing the decision trail and data triangulation (Long and Johnson 2000).

Managing the voluminous and often unstructured nature of the data required meticulously record keeping, demonstrating a clear decision trail and ensuring interpretations of data were consistent and transparent (Sandelowski 1993, Mays and Pope 1995, Slevin 2000). Reflecting on research journal entries, which recorded meetings, seminar feedback, interview field notes, decisions when generating codes and categories, and links to related literature was an essential

part of the iterative processes when developing final themes and the conceptual framework. Auditability does not, in itself, confirm reliability, which is dependent on the quality of the decisions made and whether other researchers would make comparable conclusions following similar decisions (Sandelowski 1993, Slevin 2000). The decisions in relation to the analytical stages have been described in-depth in Section 3.5.3.

The purpose of data triangulation is primarily to confirm the reliability of the study findings (Sandelowski 1995, Tobin and Begley 2004). One focus group described in Section 3.3.4.2 was undertaken as a complementary data collection strategy, with the explicit aim of verifying the study findings (Sandelowski 1995, Shih 1998). Parents' judged the findings as an accurate representation of living with a child with hydrocephalus. Parents highlighted' the appropriateness of the inter-linking threads that connected the concepts in the framework as an effective way of describing the complexity of their lives. However, parents' perceived that three of the labels were not meaningful and made alternative suggestions: 'professionals experiences of managing a child with hydrocephalus' became 'receptiveness of professionals to interacting with the family'; 'adaptation across the trajectory of the condition' became 'adapting to changes in the child'; and 'striving for normality' became 'a normal life'.

3.8.3 Transferability of the findings

Transferability has three interlinked elements: representational, inferential and theoretical transferability (Lewis and Ritchie 2003). The first is concerned with representing the participant group and whether a different group of parents would result in similar findings (Lewis and Ritchie 2003). Recruiting from two settings and including rich extracts representing a range of parents' experiences, with confirmation of the findings by focus group members suggests that findings are likely to reflect the participant group (Slevin 2000, Tuckett 2005). Second, inferential transferability relates to the application of finding to others contexts (Lewis and Ritchie 2003). Parents' accounts of living with a child with hydrocephalus have similarities to parents' experiences of living with a child with a long-term condition other then hydrocephalus which were identified in the literature review (Chapter 2). Links have been made throughout the discussion

to this literature (Section 3.6). It is likely findings from this study are also applicable to parents living with a child with other long-term conditions.

Third, theoretical transferability relates to the wider implications of the study findings which could include influencing policy, contributing to existing theories and developing research methods (Lewis and Ritchie 2003). Links have been made to concept of uncertainty (Section 3.7.2.1) and the shifting perspectives model of chronic illness (Section 3.7.1.3). Theoretical links to the concept of becoming an expert are discussed in Chapter 5, Section 5.2.

3.9 Ethical issues

The development of study information leaflets and consent forms has been described in Section 3.4.2. This section will outline the ethical issues ensuring consent was an informed choice, participants were treated respectfully and sensitively and information remained confidential.

3.9.1 Maintaining participants' rights

Study information leaflets clearly stated that parents could choose whether to participate or not in the study. However, relying on third parties to contact parents potentially influenced their decisions about participating. Some parents may not have responded to the invite because of concerns about discussing their experiences whilst their child required ongoing healthcare. Other parents may have perceived participating would benefit the child's future care, or felt obligated to participate because they were invited by the consultant neurologist or ASBAH advisor. The study information leaflets clearly stated participating would not directly benefit their child's care which was reinforced prior to commencing the interview. On balance using third parties to contact parents was preferable to the alternative of accessing case notes or electronic records to obtain addresses for correspondence, which may contain other sensitive patient data.

As described in Section 3.4.2, consent was implied when parents returned the participant response form and was confirmed prior to commencement of the interview when written consent was also obtained. Consent was obtained from

both parents where couples were interviewed together. Parents were informed of their right to stop the interview at any time without explanation and they could choose not to answer any questions if they wished. Details of who to contact if parents had concerns about the study were provided in the information leaflets. Parents who did not respond to the initial invite were not sent follow-up invitations to prevent them feeling coerced into taking part.

3.9.2 Treating participants respectfully and sensitively

The potential consequences of participating in this study were inconvenience, inviting a stranger into the home and emotional distress because of the potentially intrusive nature of questions (Smith 1992, McCann and Clark 2005). Inconvenience was minimised by offering a choice of interview venues and times such as evenings and weekends. Correspondence used official hospital, ASBAH or university insignia. Formal identification was presenting prior to entering parents' homes.

Recognising and responding to emotional distress because of the potentially intrusive nature of questions was considering in advance of the study, and systems were in place to refer parents to the senior ward sister, ASBAH advisor or consultant neurologist if required. There are opposing views about the researchers function in the interview setting; researchers can remain distant from participants or embrace the concept that the interview is a collaboration and view offering support as part of the process (Robinson and Thorne 1988, Wilde 1992, Morse and Field 1996, Carolan 2003). Although questions did not appear intrusive, some parents reacted emotionally when revisiting the time of diagnosis and describing concerns about their child's future. Not responding to these emotions could have created a barrier to establishing rapport with parents, while responding can result in becoming overly immersed in parents' experiences (McCann and Clark 2005, Peel et al 2006). Based on personal and professional moral frameworks, offering parents support by listening and empathising, while remaining impartial, appeared appropriate.

Treating parents respectfully included ensuring shared and individual perspectives were represented when parents were interviewed together

(Eggenberger and Nelms 2007) and valuing parents' accounts (Smith 1992, Kvale 2006). The relationship between the researcher and participant is integral to the success of the quality of data obtaining during the interview (Kvale 2006). The balance of power within this relationship lies with the researcher, which can result in participants providing information they perceive is appropriate rather than a true reflection of their experiences (Wilde 1992, Kvale 2006). Being an 'insider' and having something in common with participants can reduce potential power imbalances (Slevin 2000); parents' receptiveness suggested that being a children's nurse was associated with being an insider.

Eliciting information from more than one parent within the same interview had the potential for one parent to dominate the interview (Duggelby 2005). In the context of this study the possible interactions were mother/father, mother/interviewer and father/interviewer dyads with the potential for one dyad to dominate. Potential power dynamics within the interview can result in the interviewer creating an alliance with one parent by confirming or rejecting differing views between parents (Duggelby 2005). Section 3.5.2 outlined the strategies used to reduce possible tensions within the interviews. These strategies appeared successful, with the exception of the couple in the pilot interview, the transcripts of couple interviews suggested parents' contributions were equally and examples of shared and differing perceptive have been presented in the findings (Section 3.3.6).

Valuing parents' accounts and willingness to share their experiences was achieved by disseminating study findings (Johnson 2007). A range of strategies have been undertaken to disseminate study findings: parents were sent a summary of the key findings; dissemination to the wider hydrocephalus and spina bifida community was achieved by publishing key findings in the ASBAH's newslink; dissemination of key findings to health professionals, to-date, has primarily been through conference presentations (Chapter 1, Figure1).

3.9.3 Maintaining confidentiality

Maintaining confidentiality related to three areas: ensuring parents personal details remained confidential; maintaining parent anonymity; storage of data. Parents were allocated a unique identifier, which was used on all data relating to parents. Only I held information about parents' identities. Parents frequently referred to each other, the child, professionals and services by name within the interview, these were removed during the transcription of the audio-recordings.

Maintaining parents' anonymity included using pseudonyms. Although using pseudonyms is essential in ensuring anonymity, their use can create tensions for the researcher as discussed in Section 3.5.4. Additional concerns in maintaining parent anonymity related to the possibility that ASBAH advisor would be able to recognise individual parents because of her intimate knowledge of the participant group. As an advisor to the study she was aware of the ethical principles outlined within the study protocol and the need to maintain confidentiality. The ASBAH advisor was aware that some parents had participated. Some parents had informed her that the interview had taken place and others sought advice about taking part in the study prior to returning the participation reply form. Two families, with their agreement, were referred to the ASBAH advisor because they had sought specific advice that required addressing outside the interview.

The local ethics committee recommendations in relation to the storage of data were followed. This included storing all data relating to the interviews on a password protected computer and destroying audio-recordings within three months following transcription. Only members of the research team had access to the original transcripts, which did not identify parents by name. In addition, interview transcripts will be destroying three years after completion of this thesis.

3.10 Study strengths and limitations

The strengths of this study relate to the rigorous application of methods that captured and described parents' experiences of living with a child with hydrocephalus. In contrast to the findings of the literature review fathers were well represented (Chapter 2). Data elicitation techniques generated rich data. The application of the framework approach and the measures undertaken to enhance the credibility of the study ensured the findings were an accurate representation of parents' accounts. The findings add to the growing literature relating to parents experience of living with a child with a long-term condition.

There are however several limitations to this study. Participants did not reflect the diverse minority-ethnic communities within UK society. The number of parents who consented to participate in the study was comparatively low (36%). However, postal recruitment is associated with response rates in the region of 30% (Harrison and Cock 2004). Poor response to the study invitations may have reflected the recruitment strategies: attempts to recruit participants from minority-ethnic communities has been identified as particularly challenging and may have contributed to the number of parents who did not respond (Hussain-Gambles 2004, Godden et al 2010); sending follow-up invitations for parents who did not respond to the initial invite may have enhanced recruitment but may have been overly intrusive. Although personal biases are presented in Chapter 5, Section 5.4.1, it is likely personal experiences may have influenced the study findings.

3.11 Chapter summary

This exploratory study of parents' experiences of living with a child with hydrocephalus resulted in the development of a conceptual framework that grouped the emergent themes into three core concepts; 'uncertainty', 'developing expertise' and 'living a normal life'. Living with a child with hydrocephalus is a life-long dynamic experience as represented by the conceptual framework. This dynamic model of living with a child with hydrocephalus reflects both the evolving needs of the child throughout their development and the way parents' assimilate their experiences and knowledge as they develop the expertise to manage their child's condition. Parents are constantly adapting, changing and learning;

integrating knowledge and experiences enables them to making sense of their child's conditions and incorporate the child's needs into every day family life.

Findings from the study presented in this chapter were similar to findings identified from the literature review of parents' experiences of living with a child with a long-term condition other than hydrocephalus (Chapter 2). Similarities included: the reactions and emotions on receiving the child's diagnosis; taking responsibility for and developing the skills to monitor and respond to changes in the child's condition; interactions with health professionals' not always meeting parents' expectations; perceptions that health professionals do not always value parents' contribution to care decisions. In contrast, the unpredictable and life threatening nature of shunt malfunction, and the similarity to the symptoms of common childhood illnesses resulted in uncertainty being part of daily life.

Parents develop considerable expertise in recognising and responding to illness symptoms in their child. For some parents this including differentiating between illness symptoms that were indicative of common childhood illness and those that were more likely to be due to a problem with the shunt. The concept of the expert parent will be revisited in Chapter 5, Section 5.2, which draws together the findings from the two empirical studies undertaken as part of this thesis. Although parents developed considerable expertise in managing their child's condition they did not feel health professionals always listened to their concerns and valued their experiences. Parent-professional collaboration was variable.

Chapter 4:
Parent-professional interactions in acute care encounters

4. Introduction

This chapter presents a study designed to explore parent-professional interactions when making a diagnosis of shunt malfunction in children. Current policy advocates health professionals actively engage with and involve parents in their child's care (DfES/ DH 2004, DH 2007). Chapters 2 and 3 highlighted that parents reported not always being involved in decisions about their child's care and perceive their expertise is not valued. Parent-professional communication appears to be primarily focussed on information giving, ensuring consent for treatment and establishing good rapport rather than encouraging parents to contribute towards care decisions (Able-Boone et al 1989, Espezel and Canam 2003, Payot et al 2007).

Evidence presented in Chapter 1 highlighted that detecting shunt malfunction is not straightforward because symptoms are unpredictable, variable and often unique to the individual child (Kirkpatrick et al 1989, Watkins et al 1994, Garton et al 2001, Barnes et al 2002). These studies recommend health professionals' listen to and value parents' concerns when assessing a child for possible shunt malfunction. Parents' accounts of living with a child with hydrocephalus, presented in chapter 3, suggest parents develop considerable expertise in managing their child's condition. Parents become highly attuned to the unique signs of shunt malfunction in their child and are able to differentiate between the symptoms of shunt malfunction and other childhood illnesses. Study findings also indicated that parents want to contribute towards decisions about their child's care but this input does not appear to be a priority for health professionals. No study has explored or evaluated the significance that healthcare professionals place on parents' concerns in the context of diagnosing shunt malfunction in children. A detailed examination of the interactions between parents and health professionals may identify approaches that support or hinder parents' contribution to the child's care when they seek healthcare advice in the context of suspected shunt malfunction.

4.1 Aims and objectives

This study explored parent and health professionals' contribution to the diagnosis of shunt malfunction in acute hospital admissions. The specific objectives were to:

1. Describe parents' engagement with health professionals when they suspect their child's shunt is malfunctioning;
2. Describe health professionals' responses to information from parents when making judgments about shunt malfunction in children;
3. Identify whether or not the judgments of parents and professionals are similar in respect of diagnosing shunt malfunction;
4. Identify parent-professional collaboration and shared decision-making at each stage of the care pathway;
5. Describe parents' perceptions and experiences of their encounters with professionals when they suspect their child has a shunt malfunction;
6. Describe health professionals' perceptions and experiences of their encounters with parents when making decisions about the care of a child with suspected shunt malfunction.

4.2 Study setting

Children with hydrocephalus in West Yorkshire, North Yorkshire and Humberside have their acute care managed primarily by the regional neurosciences services based at the Leeds General Infirmary (LGI). Data about the number of children admitted for potential shunt complications are routinely collected from the neurosciences in-patient ward. Data relating to children admitted during the study period is presented in Table 11. A range of healthcare professionals are involved in the care of children with hydrocephalus and their families. When a child is admitted with acute problems because of suspected shunt malfunction the child's care involves nurses and doctors. In this study the nurses were qualified children's nurses and included ward sisters and staff nurses, and for the purpose of this study are referred to as senior and junior nurses respectively. Doctors included foundation year 1 and 2 doctors, traditionally referred to as house officers and speciality registrars working in paediatric and neurosurgery specialities; for the purpose of this study they are referred to as junior doctors and senior doctors respectively.

Table 11: Admissions for potential shunt complications (children's neurosciences shunt register September 2008- August 2009)

Children admitted for suspected shunt malfunction	Total number of admissions for suspected shunt malfunction[1]	Children who required a shunt revision	Total number of shunt revisions[2]
62	117	26	38

[1]Some children had more than one admission
[2]Some children had more than one shunt revision

4.3 Methods

This section outlines and justifies the study design, sampling, data collection and analytical strategies employed.

4.3.1 Study design

This was primarily a qualitative study using a range of methods. A qualitative approach was indicated for two reasons; first the study focused on an area where there is no or limited evidence. A scoping review revealed no published research that explored parent-professional interactions in this clinical area (Appendix I). Second, exploring the interactions that occur between parents and health professionals, when assessing a child for possible shunt malfunction, required an approach that incorporated a micro-interactional element alongside broader qualitative methods.

A range of research methods have been undertaken to investigate and explore patient participation in healthcare consultations. Quantitative methods have focused on measuring: the quality of the consultation (Howie et al 2004); the extent to which patients are involved in care decisions (Elwyn et al 2005); patients' outcomes such as satisfaction when communicating with professionals and confidence with the decisions made (Edwards et al 2003); the level of agreement between patients and professionals in relation to shared perspectives of the illness experience (Haidet et al 2008). Quantitative approaches provide ways of measuring the extent to which tasks associated with patient collaboration are being used in clinical practice but do not consider the nature of

patient-professional interactions and the way interactions are structured and interpreted by participants (Collins et al 2007).

In contrast, qualitative methods are used to explore complex situations, explain behaviours and gain a deep understanding of the patient experience (Morse and Richards 2002). A range of qualitative methods have been applied to explore the facets of patient-professional interactions and collaboration (Collins et al 2007). Broad qualitative methods, such as interview based studies, do not explore the micro-interactional element of talk-in-interaction (Bugge and Jones 2007). In contrast, observation studies are particularly suited to exploring patient-professional collaboration because they can focus on the ongoing sequential development of participants' talk-in-interaction (Chatwin 2004). Conversation analysis (CA) is useful for studying patient collaboration because the methods enable naturally occurring interactions to be analysed objectively and in-depth in order to identify the sequences and structures that govern how activities in talk are organised (Bugge and Jones 2007, Chatwin 2009).

CA is particularly concerned with the actions (for example greetings, requests, invitations) the speaker is attempting to accomplish and how these actions are formulated, and interpreted by others (Drew 2005). CA is based on three fundamental assumptions: interactions exhibit organised patterns and recurrent structural features; each speakers utterances contribute to the ongoing development of the sequence through a process of turn-taking and can only be understood in context, in particular how the action in the immediate turn informs the actions in the next turn; every detail in the interaction such as the timing of utterances (for example interruptions, pauses, overlapping talk) and the nuances of sound production (for example word emphasis, intonation of speech) has relevance (Heritage 1984).

CA has broad application and has been used extensively in many institutional settings with a strong representation in the healthcare arena (for example Collins et al 2005, Plug and Reuber 2007, Chatwin 2009). CA has limitations in that it does not deal with the unobservable elements of the interaction, such as omissions, and participants' feelings and thoughts (Bugge and Jones 2007,

Collins et al 2007). Other research methods such as interviews and questionnaires are better suited to the exploration of participants' experiences, their perceptions of patient-professional collaboration and the tasks associated with shared decision-making (Bugge and Jones 2007). It was appropriate to use a range of methods to explore the breadth and depth of parent-professional interactions when a child is admitted to hospital with suspected shunt malfunction and to capture different aspects of parent-professional collaboration. The methods comprised of:

- An observational element where CA was applied to recorded interactions between parents and health professionals when a child was being assessed for possible shunt malfunction;
- Follow-up semi-structured interviews with participants who participated in the recorded interactions in order to elicit their perceptions of the interaction;
- Questionnaire about parents' involvement in care decisions exploring variations between observed and perceived shared-decision making tasks;
- Analysis of audit data, collected as part of usual care, in order to explore the relationship between participants' perceptions of the child's illness symptoms at the time of assessment and admission outcomes.

4.3.2 Ethical approval

Recruiting participants from NHS settings requires adherence to the principles of the NHS research governance framework (DH 2005c) and approval from a recognised research ethics committee. Favourable local research ethics committee review (LREC reference 08/H1313/18) and site specific approval from the local research and development department was successfully obtained (R&D reference 08/H1313/18).

4.3.3 Sample selection

Participants were invited to take part in the study from the children's neurosciences ward at the LGI. Children with hydrocephalus can access the ward directly through a process of self-referral. Participants were purposefully selected. The sample criteria were broad and included all parents of children admitted to the ward because they were concerned about their child's shunt and all health professionals involved in the initial assessment of the child.

Characteristics such as social and educational backgrounds may influence parents' experiences. For health professionals, their role, grade and length of time caring for children with hydrocephalus may influence their experiences in relation to assessing a child for potential shunt malfunction. Participant characteristics were elicited during data collection and were considered during the analysis and when presenting study findings. The sampling procedures are outlined in Section 4.5.1.

In qualitative research, predicting exact samples sizes is not always possible and is usually determined by the emergent themes and data saturation (Higginbottom 2004, Coyne 1997). For the purpose of this study it was estimated that a sample of 15 parents and 15 health professionals would ensure coverage of a range of encounters between professionals and parents. Due to the large amount of detailed interactional data that these encounters were likely to generate, this number was considered appropriate, and is in line with other CA based studies of this scope and depth (Chatwin 2004). However, the need to be flexible and increase or decrease the number of participants, if required, was recognised.

4.3.4 Data collection strategies

Data were collected from a range of sources. First, interactions between parents and health professionals regarding the assessment of the child in order to establish a diagnosis of shunt malfunction, as part of usual care, were audio-recorded. Recorded interactions included those between parents-junior nurses, parents-senior nurses, parents-junior doctors and parent-senior doctors.

Second, post diagnosis follow-up interviews were undertaken with parents and health professionals who participated in the recorded interactions. Interviewing is a well established data collection method and has been described in Chapter 3, Section 3.3.4. Semi-structured telephone interviews were undertaken to explore participants' views about the interaction and beliefs about parental involvement in their child's care. A semi-structured interview approach was chosen to: reduce research bias by using an interview schedule (Dearnley 2005); enable meaningful engagement with participants while ensuring the interview remained focused on meeting study objectives (Wimpenny and Gass 2000, Price

2002); achieve a balance between consistency and flexibility with regards to responding to and exploring participant cues (Fontana and Frey 2000, McCann and Clark 2005). The development of the interview schedule is described in Section 4.4.2. Telephone interviewing has been used successfully to investigate patient satisfaction with healthcare interventions and service provision (Wilson et al 1998). Telephone interviews were appropriate because the questions were highly focussed and it was anticipated the interviews were likely to be of shorter duration compared to face-to-face interviews and fit into the busy lives of parents and health professionals (Wilson et al 1998).

Third, parents and professionals who participated in the interviews also completed a participant satisfaction questionnaire. The questionnaire was based on a Likert-type scale with participants indicating their agreement to statements about engaging with parents and the tasks associated with shared-decision making during the consultation. The development and design of the questionnaire is outlined in Section 4.4.3. Fourth, information was extracted from data routinely collected by the children's neurosciences services when a child is admitted for potential shunt complications which included presenting symptoms, medical history in relation to shunt complications, management plans and admission outcomes. Data relating to the outcome the child's admission were used to identify whether the judgements of parents and professionals were similar in respect of diagnosing shunt malfunction.

4.3.5 Data analysis

The range of methods, their theoretical underpinning, specific purpose and suitability for the analysis of qualitative data have been outlined in Chapter 3, Section 3.3.5. The study reported in this chapter employed a range of analytical methods. First, the principles of CA were applied to the data relating to the recorded interactions between parents and healthcare professionals. A key element of the study was the exploration of ongoing, naturalistic parent-professional interactions. CA is a well established socio-linguistic approach for analysing naturally occurring behaviour, where a detailed analysis of the structure and sequential organisation of talk can reveal the mutually and inextricably linked actions that occur within interactions (Psathas 1995). The

analysis explored the patterns, structures and practices of talk-in-interaction through the application of the four basic CA concepts; turns at talk and turn-taking, turn design, social actions and sequence organisation (Drew 2005). Drawing on data from the study presented in this chapter an overview of the analytical procedures associated with CA are presented in Section 4.5.3.1 (page178). CA was an appropriate analytical method to explore, at a micro-level, the dynamics of parent-professional interactions in relation to parents' descriptions of their child's symptoms and how parents' and professionals' collaborate when planning the child's care.

CA is a comparatively new discipline with ongoing research focussing on describing the patterns of ordinary talk-in-interaction (Hutchby and Wooffitt 2008). In these instances large collections of data are analysed and arranged into collections which focus on discrete actions such as greetings, requests, agreements and closure of sequences. Understanding the characteristics of ordinary talk is essential to contextualise and make comparisons where talk is likely to be more formal and asymmetrical such as patient-professional interactions (Heritage 1984). 'Pure' CA research is essential in establishing an authoritative body of evidence relating to the practices and principles of ordinary conversation but has been criticised for lacking meaningful application to real word contexts, and not considering institution and social roles that impact on the interaction (Psathas 1995, Hutchby and Wooffitt 2008). The principles can be applied to smaller studies or even individual cases where a detailed examination of an interaction can provide illuminating insights into healthcare practice (Chatwin 2004). An applied, pragmatic, approach to CA is likely to be more useful where the researcher is not from a pure CA background or CA is being used in combination with other methods (Chatwin 2004), as in this study.

Second, the principles of the framework approach, based on thematic analysis, were employed to underpin the analysis of data obtained from the individual interviews (Spencer et al 2003a). The framework approach was appropriate as this approach can be used across research designs and to complement other methods of analysis (Ritchie 2003). The stages of the analysis contribute to ensuring transparency between participants' descriptions and researchers'

interpretations of participants' experiences (Spencer et al 2003a). The latter was particularly salient in this study, where there was potential to lose sight of participants' accounts when drawing together findings from different elements of the study. Third, data obtained from the questionnaires and clinical audit were quantitative in nature. Analysis of the extrapolated data consisted of descriptive statistics, primarily percentages and frequencies.

4.4 Materials

This section describes the development of study materials (information leaflets consent forms, interview schedule and questionnaire) and the data software utilised. Examples of participant materials are included in Appendix IV.

4.4.1 Study information leaflets and consent forms

Separate study information leaflets were developed for parents, children and health professionals. Developing the information leaflet followed the processes outlined in Chapter 3, Section 3.4.2. Ensuring the content of the leaflets was clear, free from ambiguity and written at a level suitable for a range of reading abilities included: assessment of the leaflet's grammar and content by the regional ASBAH team; and calculating the leaflets readability using the Gunning Fog index. Gunning Fog index scores between 6 and 10 are deemed easy reading (Long 2007); the scores were 6.68, 10.75 and 11.75 for the child, parent and health professional leaflets respectively. Health professionals were provided with information sheets in advance of recruitment as part of their induction programmes and in opportunistic meetings during routine weekly ward visits. Posters about the study were displayed on staff and parent notice boards.

Obtaining consent is a requirement to fulfilling health care ethics committee and research governance requirements (DH 2005c). Developing the content and style of the consent forms followed the processes outlined in Chapter 3, Section 3.4.2. Participants were asked to sign the consent form prior to the child's assessment. The form included a section relating to the willingness of participants to take part in the follow-up interview. To ensure consent was obtaining in a timely manner, consent to participate in the interview was re-

confirmed verbally prior to commencing the interview. Permission was sought to audio-record the parent-professional interactions and the telephone interviews.

4.4.2 Interview schedule

An interview schedule was developed and used as a template for undertaking the interviews in order to maximise information elicitation central to the study objectives. Interview topics were developed around three areas: parents' concerns about their child's illness symptoms; making decisions about illness symptoms; perceptions of parental involvement in care. The interview schedule (Figure 21) was influenced by the literature relating to hydrocephalus and parents' experiences of living with a child with hydrocephalus, presented in Chapters 1 and 3 respectively.

Figure 21: Interview schedule

Guiding questions – parents
Describing parents' concerns Thinking back to the time just before your child's admission to hospital, what made you think there was something wrong with your child? What did you do and who did you contact when you realised there was something wrong? (Who did you seek advice from when you thought something was wrong with your child? Did you talk to anyone else other than the health professional?)
Making decisions about illness symptoms Will you describe how you (or the referring doctor) decided your child should go to hospital? (What influenced these decisions?) On this occasion how likely did you feel that your child had a shunt problem?
Feelings about being involved in your child's care How well did you feel the doctors and nurses listened to your concerns? (How did this compare with previous experiences? Could you express your concerns?) How did the doctors and nurses take into account your views about your child's symptoms? (How did this compare to previous experiences?) How were you involved in decisions about your child's care during this latest hospital admission? (Is this different from previous experiences?) How much do you want to be involved with doctors and nurses when they are deciding if your child's shunt is working? (Would anything make your involvement easier?) Can you think of a situation where you would not want to be asked by doctors and nurses for your views?

Building up the depth of questions

Guiding questions - health professionals
Describing parents' concerns What do you think prompted parents to seek advice about their child? What did you feel were parents' main concerns?
Making-decisions about illness symptoms During your assessment what were your concerns about the child's symptoms? Do you feel your concerns were different or similar to parents' concerns? (Why?) How likely did you feel that the child's shunt was malfunctioning? (What was this based on? What made you think this was not a 'normal' childhood illness?) When undertaking your assessment, how did you use parents' knowledge of their child/ experience of shunt malfunction when making a diagnosis?
Feelings about involving parents in care How did you feel you involved parents during your assessment of the child? (What do you think the advantages and disadvantages to involving parents when you are deciding if their child's shunt is functioning or not?) How important do you feel it is for parents to contribute to care decisions in emergencies, such as suspected shunt malfunction? (Can you think of a situation where you feel it is not appropriate to include parents in care decisions?) What do you think enables parents to contribute to care decisions about their child?

Building up the depth of questions ↓

In order to reduce researcher bias the development of the schedule included regular assessment by research supervisors, the ASBAH advisor and clinicians who provided advice about the study. The ordering of questions, in terms of the level of intrusiveness, was based on the technique described in Chapter 3, Section 3.3.4.

4.4.3 Participant satisfaction questionnaire

The purpose of the participant satisfaction questionnaire was to determine similarities and differences between parents' and health professionals' perceptions of parent involvement in decision-making when diagnosing shunt malfunction in children. As highlighted in Chapter 1, Section 1.6.3 shared decision-making occurs when the patient and health professional exchange treatment preferences to reach an agreement on a plan of care (Charles et al 1997). Two reviews evaluating shared decision-making tools identified that the majority of tools measured broad concepts such patient satisfaction, patient preferences, information giving and communication styles rather than shared decision-making (Elwyn et al 2001, Dy 2007). In addition, it has been suggested that decision-making tasks may differ across clinical settings requiring the development of a specific tool relevant to the setting (Dy 2007).

Items within the questionnaire were designed around the broad concepts of shared-decision making. Items were developed from the OPTION (observed patient involvement) (Elwyn et al 2003) and COMRADE (combined outcome measure for risk communication and treatment decision-making effectiveness) (Edwards et al 2003) tools. The OPTION shared-decision making tool consists of 12-items relating to the extent to which clinicians involve patients in decisions about their care (Elwyn et al 2003, Elwyn et al 2005). The COMRADE tool explores patient involvement in relation to; the effectiveness of health professionals' description of treatment options which must account for patients' preferences, checking patient understanding, and exploring patient concerns and expectations (Edwards et al 2003). The tool consists of 10-items relating to the patient's satisfaction with the interaction and 10-items relating to the patient's confidence in the decisions made during the consultation.

The OPTION (Elwyn et al 2005) and COMRADE (Edwards et al 2003) tools are designed for use in clinical situations where treatment choices exist. Their application was limited in this study because no 'real' treatment options existed. In addition: the COMRADE tool evaluates patients' perspectives of the consultation but does not consider professionals' perspectives; items in the OPTION tool are scored if they are observed during the interaction and does not consider participant perspectives and therefore the unspoken element within consultations. The OPTION and COMRADE items relating to the preferred way of presenting information, delaying treatment decisions and choosing treatment options were not appropriate in the context of this study because shunt malfunction is managed as a medical emergency requiring prompt diagnosis and treatment. The questionnaire contained 10 items that were scored using a 5-point Likert-type scale with the following response choices; 'strongly agree', 'agree', 'neither agree or disagree', 'disagree', 'strongly disagree'. Health professional and parent versions of the questionnaire, along with the relationship to the OPTION and COMRADE tools, are presented in Figure 22.

Figure 22: Participant satisfaction questionnaire

	Parent questions	S/A	A	N	D	S/D
1	Doctors listened to your concerns[1]					
	Nurses listened to your concerns[1]					
2	Doctors suggested possible causes for the child's symptoms[2]					
	Nurses suggested possible causes for the child's symptoms[2]					
3	Doctors explored your views when assessing your child[1]					
	Nurses explored your views when assessing your child[1]					
4	Doctors explored possible treatment options for this admission (including taking no action)[1,2]					
	Nurses explored possible treatment options for this admission (including taking no action)[1,2]					
5	Doctors explained the advantages and disadvantages of the possible treatment options for this admission (including taking no action) [1,2]					
	Nurses explained the advantages and disadvantages of the possible treatment options for this admission (including taking no action)[1,2]					
6	Doctors checked your understanding of the treatment options for this admission (including taking no action)[2]					
	Nurses checked your understanding of the treatment options for this admission (including taking no action)[2]					
7	Doctors provided opportunity for you to ask questions[1,2]					
	Nurses provided opportunity for you to ask questions[1,2]					
8	Doctors asked how much you wanted to be involved in decisions about your child's care[2]					
	Nurses asked how much you wanted to be involved in decisions about your child's care[2]					
9	Doctors involved you in decisions about your child's care[1]					
	Nurses involved you in decisions about your child's care[1]					
10	You were satisfied with the doctors assessment of your child[1]					
	You were satisfied with the nurses assessment of your child[1]					

SA-strongly agree, A-agree, N-neither agree/disagree, D-disagree, SD-strongly disagree
Questions related to items within the COMRADE[1] and OPTION[2] tool

Health professional questions		S/A	A	N	D	S/D
1	Listening to parents' concerns was central to deciding if their child's shunt was functioning[1]					
2	It was important to discuss with parents possible causes for the child's symptoms[1]					
3	It was important to discuss with parents their views when you were assessing the child[2]					
4	It was important to discuss with parents possible treatment options for this admission (including taking no action)[1, 2]					
5	It was important to discuss with parents the advantages and disadvantages of the possible treatment options in relation to this admission (including taking no action)[1,2]					
6	It was important to discuss with parents their understanding of the treatment options in relation to this admission (including taking no action)[2]					
7	It was important to provide parents with an opportunity to ask questions[1,2]					
8	It was important to discuss with parents how much they wanted to be involved in decisions about the child's care[2]					
9	It was important to make decisions about the child's care with their parents[1]					
10	You were satisfied with the level you involved parents when assessment and planning care for their child[1]					

SA-strongly agree, A-agree, N-neither agree/disagree, D-disagree, SD-strongly disagree
Questions related to items within the COMRADE[1] and OPTION[2] tool

4.4.4 Technology and data software programmes

The hand-held EdirolR-09HR® digital recorder was chosen to record the interactions because: the recorder is compact with a built-in microphone and speakers, convenient for portable use, unobtrusive and simple to operate; has a high-sensitivity stereo condenser achieving high-resolution and low-noise recordings; data could be stored on a memory card. Ease of use was important because recordings were dependent on the ability of nurses to use the recorder. Training and regular updates in using the recorder were undertaken with the nurses; no technical problems were reported during the study. Having two memory cards enabled data to be removed from the ward as soon as was practicable, which assisted in the secure storage of data and ensured the recorder was available at all times across the data collection period.

Audacity® software was used to store and play recordings of the interactions and was chosen for pragmatic reasons. The package and support from experienced users was available within the School of Healthcare. Audacity® enabled sound waves to be displayed graphically, providing information about the quality of speech. The digital data could be manipulated for example to improve the sound quality and reduce background noise, and tags can be inserted to label relevant sections of data. These functions enhanced the quality of the transcriptions. The use of a wide screen lap top enabled the digital recording and transcribed word document to be displayed simultaneously on screen during the analysis of interactions. The qualitative software programme, NVivo® version 8, was used to manage the interview data.

4.5 Procedures

This section outlines the procedures relating to the recruitment of participants, data collection and data analysis.

4.5.1 Recruitment and consent

Participants were recruited from the children's neurological ward, LGI. As CA is based on the analysis of naturally occurring interactions it was not necessary to be present during the recording of the parent-professional encounters. Participant recruitment was undertaken by the senior nurses on the ward because of the unpredictable nature of shunt malfunction, with children admitted any time during the 24 hour period. All four senior nurses working on the ward agreed to take responsibility for recruiting participants. Individual briefings with the nurses were undertaken to ensure they had a clear understanding of the study aims and recruitment procedures. Effective communication with the nurses was maintained by building on well established links developed during liaison visits as part of the nurse lecturer role.

Parents of children admitted to the ward between September 2008 and August 2009 because of concerns relating to the shunt and health professionals involved in the child's care were invited to participate in the study. Where the child was accompanied by their mother and father, both were invited to participate. Two stages were involved in recruiting participants. First, the senior nurse on duty at

the time of the child's admission provided parents with study information and gained informed consent from those willing to participate. Consent was obtained from children who were likely to participate in the interactions. In the unusual situation where the child was identified as requiring immediate emergency care, the nurses used their clinical judgement in relation to approaching parents to participate in the study. Second, once a parent had been recruited the senior nurse provided the health professionals involved in the child's initial assessment with the study information, ascertained their wiliness to participate and then gained consent from those willing to participate.

Parents and health professionals were asked to indicate on the consent form if they were willing to participate in the follow-up interview. The ward was contacted daily to ascertain if any interactions had been recorded, and as soon as practicable the audio-recorder memory cards changed, participant information packs were replenished and consent forms retrieved. Participants were contacted by telephone to arrange the follow-up interview. The recruitment strategies described resulted in 40 participants taking part in the study across 14 admissions: 26 family members (13 mothers, 6 fathers, 7 children) and 14 health professionals (2 senior nurses, 2 junior nurses, 4 senior doctors, 6 junior doctors). The following data were collected:

- Twenty-one audio-recorded interactions: combinations were parent (mother or father or both) and nurse or doctor, seven interactions included the child;
- Thirty-one follow up-interviews: 12 mothers, 1 father, 2 senior nurses, 2 junior nurses, 4 senior doctors, 5 junior doctors (some health professionals participated in more than one interview);
- Forty-four questionnaires: 12 mothers, 1 father, 2 senior nurses, 2 junior nurses, 4 senior doctors, 5 junior doctors (parents completed separate questionnaires for nurses and doctors, some health professionals completed more than one questionnaire);
- Ward outcome data and child characteristics were collected for all 14 admissions.

4.5.1.1 Participant characteristics

Participant characteristics were only available for parents and health professionals who participated in the follow up-interviews. Child characteristics collected as part of the routine shunt audit were available for all admissions. Table 12 presents a summary of participant and child characteristics.

Table 12: Participant characteristics

Parents characteristics	**(n = 13)**
Gender male: female	1:12
Age (years)	Average 38.5: range 21-56
21-30	3
31-40	6
Above 40	4
Highest Qualification	
A levels or above	4
GCSE	4
None	5
Socio-economic classification	
2	3
5 - 7	4
8	6
Ethic group	(n=14[1])
White British : Asian	13 :1
Child characteristics	**(n=14)**
Gender male: female	9: 5
Age (years)	Average 8.6 : range 1-15
Under 5	5
6-10	2
11-15	7
Reason for hydrocephalus	
Intraventricular haemorrhage	6
Idiopathic	2
Spina bifida	2
Other[2]	3
Shunt revisions	Average 2 : range 0-12[3]
0	4
1	3
2	3
3 +	4

[1] One parent participated in the interaction but not the interview, ethnic group was obtained from the ward shunt register [2]Chiara malformation, arachnoid cyst, tumour [3]One child had undergone over 50 operations primarily related to the shunt

Health professional characteristics		(n=13)
Gender male: female		6:7
Age (years)		Average 33.6 : range 27-56
21-30		4
31-40		8
Above 50		1
Years since qualified		Average 8.8 : range 3-17
Less than 5		4
6-10		6
Above 10		3
Role and grade		
Senior nurses	Band 7	1
	Band 6	1
Junior nurses	Band 5	2
Senior doctors	Specialist Registrars	4
Junior doctors	Specialist trainee (yr 2)	2
	Specialist trainee (yr 3)	3
Ethnic group		
White (British and Irish)		10
Asian (Indian and Pakistani)		3

Social class was identified using the UK National Statistics Socio-economic Classification, as described in Chapter 3, Section 3.5.1.1. In summary the final sample for parents reflected a range of experiences. The frequency of shunt complications varied. Although parents were diverse in relation to social class and age they did not represent the diversity of minority-ethnic communities in the UK. Health professionals were diverse in relation to age, grade, role, ethnic background and length of time since initial qualification.

4.5.2 Pilot of data collection methods

A pilot study was undertaken over a three month period to test, and where necessary refine, the recruitment procedures and data collection methods. First, the recruitment strategies were tested in order to ensure the senior nurses were familiar with the procedures previously outlined. Five participants (two mothers, one father, one junior doctor, one senior nurse) were recruited for two child admissions. The junior doctor participated in both admissions. No problems were reported for the first admission. In the second admission the junior doctor refused to sign a consent form stating he had already consented to participating

in the study. It was decided that in similar situations as long as the doctor consented verbally and previous written consent had been obtained this would be acceptable. The junior nurse involved in the child's assessment for the second admission did not wish to participate in the study. Additional briefings were undertaken with the nurses to provide reassurance about confidentiality and discuss their concerns about participating. No other modifications were made to the recruitment procedures. No technical problems were reported with recording the parent-professional interactions.

Second, the interview schedule was tested. The pilot interviews were transcribed verbatim, and reviewed by the research supervisors. The schedule appeared appropriate across participant groups because the data were highly focussed and relevant to meeting the study aims, which suggested the questions were relevant. However, the senior nurses asked for several questions to be clarified. On reflection the terminology was biased towards medical language. This resulted in minor changes to two questions with the health professional interview schedule for example 'during this consultation what were your main concerns about the child's symptoms' was changed to 'during your assessment what were your main concerns about the child's symptoms'.

Third, the participant satisfaction questionnaire was tested. The questionnaire was administered towards the end of the telephone interviews. The senior nurse suggested, particularly for parents, that receiving a copy of the questionnaire in advance of the telephone interview would have assisted in formulating responses and could add clarity when explaining the scoring system. In response to these comments, a copy of the questionnaire was posted to participants along with a confirmation of the day and time of the follow-up interview. No modifications were made to the wording of the questionnaires. Detailed analysis of the pilot data were not undertaken because of insufficient data (Morse et al 2002). The pilot data were incorporated into the main study.

4.5.3 Data analysis

This section will describe the analytical methods; CA applied to the parent-professional interactions, the framework approach applied to the individual interviews and the quantitative analysis of questionnaire and clinical audit data. The unit of analysis was the child's 'admission' which included episodes of care relating to the child's initial assessment and the admission outcomes (Figure 23).

Figure 23: Data collected for each unit of analysis

Admission	Interactions			Interviews (included questionnaire)				Audit
1	Mum, dad SN[1]	Mum, dad JD[1]		Mum	SN[1]	JD[1]		✓
2		Mum, JD[1]		Mum		JD[1]		✓
3		Mum, JD[1]		Mum		JD[1]		✓
4		Mum, child JD[2]		Mum		JD[2]		✓
5	Mum, child JN[1]		Mum, child SD[1]	Mum	JN[1]		SD[1]	✓
6	Mum, dad JN[2]	Mum, dad JDr[3]	Mum, dad SD[2]	Mum	JN[2]	JD[3]	SD[2]	✓
7	Dad, child SN[2]			Dad	SN[2]			✓
8	Mum, child SN[1]	Mum, child JD[4]		Mum	SN[1]			✓
9		Mum, dad child, JD[4]		Mum		JD[4]		✓
10		Mum, child JD[5]		Mum		JD[5]		✓
11			Mum, child SD[3]				SD[3]	✓
12	Mum, JN[1]			Mum	JN[1]			✓
13	Mum, dad child, SN[1]	Mum, dad child, JD[4]	Mum, dad child, SD[4]	Mum	SN[1]		SD[4]	✓
14		Mum, dad child, JD[6]		Mum				✓

JN (Junior nurse) SN (Senior nurse) JDr (Junior doctor) SN (Senior doctor)

Data analysis was a two stage process. First, the different types of data (observational, interview, questionnaire and ward audit data) were analysed

separately using the methods described below. Second, the preliminary findings from the analyses of the observational, questionnaire and audit data were incorporating into the final stages of the framework approach during the analysis of the interview data. One of the strengths of the framework approach relates to the stages not being linear but act as scaffold that guides the analysis (Smith and Firth 2011). This enabled back and forth movement across both the interview data and the other data sets, resulting in the integration of the findings from the separate analyse and refinement of the final themes until a coherent account emerged.

4.5.3.1 Analysis of parent-professional interactions

The data corpus consisted of 21 recorded interactions of health care consultations relating to the assessment of children with suspected shunt malfunction. Interactions included one or both parents and their child if they also participated in the consultation and a health professional. Analysis of the interactions involved four stages: transcription of the audio-recorded interactions; locating discrete cases of interest within the data of relevance to the focus of the study; applying CA methods to explore and describe these cases in-depth; returning to the original corpus to refine the descriptions until a coherent account emerged (Hutchby and Wooffitt 1998).

All interactions were transcribed verbatim and in totality. The audio-recordings together with the transcriptions were reviewed in order to become familiar with the data. Possible areas of analytical interest in relation to the study aims were identified (Collins 2005). This involved reviewing in depth the three interactions recoded during the pilot study (mother-father-senior nurse, mother-father-junior doctor, mother-junior doctor interactions) in order to locate discrete events and patterns within the interaction which included: sequences relating to every day talk such as greetings and closings, and sequences specifically relating to patient-professional collaboration such as the presenting symptoms, diagnosis delivery and treatment recommendations (Stivers 2006). Two areas of analytical interest were identified; turns at talk relating to establishing the likely cause of the child's illness symptoms and those involving parents when planning care and

treatments. Ongoing review of the data identified a third area of interest, namely turns of talk associated with building rapport with parents.

In order to describe and compare patterns of communication in the context of parent-professional collaboration, CA methodology was applied to all cases identified as relevant to the study focus (Drew et al 2001). Detailed transcription of the selected extracts was undertaken using a well recognised CA notation system (Jefferson 2004). Punctuation symbols such as full stops, commas and question marks are used to denote characteristics of ongoing speech in CA and not as conventional grammar functions. The notations used in this study are presented in Figure 24. The recordings were transcribed in sufficient depth to capture the relative timings of speech delivery and aspects of the characteristics of speech delivery to explore the facets of talk-in-interaction relative to the study. However, it is acknowledged that the level of transcription was not as detailed as that required for 'pure' CA studies.

Figure 24: Transcription notation system for CA

Relative timing of utterances	
(0.5)	Numbers in brackets indicate timings in whole and tenths of a second
(.)	A full stop in brackets indicates a micro pause of less than two tenths of a second
=	No discernible interval between turns
[ ]	Square brackets are used to denote overlapping speech
Characteristics of speech delivery	
.	Full stops are used to indicate a falling intonation
here	Underline is used to emphasis words relative to surrounding talk
↑ **or** ↓	Indicates speech spoken with a high or low pitch relative to surrounding talk
°here°	Degree signs indicate speech that is quiet or soft relative to surrounding talk
>this<	Talk speeded up or compressed relative to surrounding talk
<this>	Talk slower or elongated relative to surrounding talk
.hhh	Indicates an in breath (number of h's indicate length)
hhh.	Indicates an out breath (number of h's indicate length)

Detailed transcription is an essential part of CA and enables the characteristic patterns of talk to be identified such as the timing of utterances (for example interruptions, pauses, overlapping talk) and the nuances of sound production (for example word emphasis, intonation of speech) (Chatwin 2004). Once the detailed transcription of data had been completed, the analytical processes associated with CA (turn-taking, turn design, social actions and sequence organisation) were applied in order to describe the patterns and norms of ordered conversation (Drew 2005).

Fundamental to conversation is the notion of turn taking, in that one speakers turn is followed by another speakers turn. Although there is an infinite variation in the length and actions the turns are trying to accomplish each turn consists of recognised components known as a turn construction unit (TCU): a TCU has three components and must be phonetically correct, grammatically correct and have a complete action (Schegloff 2007). Turn design is the building block of interaction and central to CA (Drew et al 2001). Turn design is concerned with how speakers select amongst the various options available the content of their turn and the actions they wish the turn to accomplish (Drew 2005). It is through the sequential development of turns that interaction occurs. Tracking the similarities and differences in turn design and consequences in relation to the sequential development of talk enabled the characteristics of parent-professional interactions to be explored in the selected cases.

A brief illustration of the application of CA is outlined by considering the extract in Figure 25. The interaction occurred between a mother and junior nurse during the child's assessment for potential shunt malfunction recorded as part of this study.

Figure 25: Application of CA

Extract 1: presenting symptoms (mum_6 - junior $nurse_2$ interaction)

1	$JNurse_2$	right (.) I'm (name) I'll be looking after him	
2		when (.) while he's here (0.5)	
3		emm (.) <he came in last week for a> (.) was	
4		it↑ last week=	
5	Mum_6	yeh	
6	$JNurse_2$	for a shunt [revision↑	
7	Mum_6	[yeh last (.) Friday	
8	$JNurse_2$	and how's he been since then↑ (0.7)	FPP (request)
9	Mum_6	he's been alright↑ in himself↑ (0.3) but (.)	SPP (respond)
10		he's↓ just vomiting (.) emm (.) °he just doesn't	
11		seem to be keeping anything down↓°	
12	$JNurse_2$	how much is he vomiting (0.3)	FPP (request)
13	Mum_6	do you mean compared to usual↑	Insertion
14	$JNurse_2$	yes	Insertion
15	Mum_6	a lot (.) a lot more↑ than usual	SPP (respond)

The concepts of turn-taking, turn design, social actions and sequence organisation will be outlined by considering in detail lines 8-7 in the above extract. Line 8 consists of one TCU, 'how's he been since then', and was phonetically and grammatically correct and has a complete action in the form of a request. In the most basic form turns at talk consist of two turns by different speakers, which are ordered relative to one another (Schegloff 2007). The turns are differentiated into 'first pair parts' (FPP) and 'second pair parts' (SPP). Actions associated with the FPP are typically requests, invitations or announcements and initiate the exchange. Actions associated with the SPP are in response to and are related to the FPP such as rejections, agreements or disagreements with the FPP. For example the nurse's turn in line 8 (FPP) the action the nurse is trying to accomplish is a request for information; the mother's turn in line 9 (SPP) responds to the request in the FPP. In this example of a request-response sequence the FPP and SPP are adjacently placed. The delay in the mother's response (0.7) suggests a potential problem with the request.

The construction of turns in relation to soliciting the patients' presenting problems has been extensively studied (Robinson 2006); evidence that the mother interprets 'how's he been since then' as soliciting a follow-up information request

is apparent in her response 'he's been alright' (line 9). The mother's turn consists of three TCU 'he's been alright↑ in himself', 'he's↓ just vomiting' and 'he just doesn't seem to be keeping anything down↓'. The pauses at the end of each TCU suggest possible turn completion which could have initiated a new speakers' turn. In the absence of the nurse taking the opportunity to respond at the completion of each TCU, the mother continues with her turn. The action changes from a general response about her sons' progress (line 9) to outlining the current problem (line 10-11). In contrast, the SPP in line 15 is not adjacent to the FPP in line 12, a request for further information about the presenting symptom. The action in the inserted turns, lines 13-14, is a request by the mother to clarify the information being solicited before she formulates her response. Even within this short extract, it is evident that each turn is built on and influences the sequential development of the interaction.

Refining the descriptions until a coherent account emerged involved: re-reading the whole transcripts and re-listening to the interactions for the selected extracts to which CA was applied; comparing cases to establish if findings made sense and related to the context of the clinical setting (Hutchby and Wooffitt 1998). The final stage resulted in continual refining of the descriptions of the cases of interest; these cases and their structural properties are presented, with supporting examples, in Section 4.6.

4.5.3.2 Analysis of interview data

The framework approach was used to analyse participant interviews. The framework approach and associated procedures have been described in-depth in Chapter 3, Section 3.5.3. In summary, the stages of the framework approach are: data management (identifying units of data or codes from the transcribed interview data and grouping the codes into broader categories and themes); descriptive accounts (mapping the range and diversity of data to initial categories and constantly refining categories and themes until the 'whole picture' emerges); explanatory accounts (interpretation of the final themes and associations). The application of these stages in relation to this study is now described.

All interviews were transcribed verbatim and in totality. Familiarisation of the data began by reading and re-reading the interview transcripts. Transcripts of the five pilot interviews (two parents, one nurse and one doctor, who participated in tow interviews) were used to generate preliminary codes and categories. Codes were developed by summarising lines, phrases or paragraphs within the transcripts while remaining true to participants own words; a coding matrix was developed to record and track changes. An example of the coding matrix is presented in Figure 26.

Figure 26: Example of the coding matrix

	In-vivo codes	**Description**	**Initial categories**
Admission1 *Mum* Well at first they thought it was an ear infection. I had to **keep saying this was nothing like when he had an ear infection**, they said they would keep an eye on him overnight. So at first **they did not really listen**.	**kept saying this was nothing like when he had ear infection**	Disagreement with HP's judgements	Disagreement about cause of illness symptoms
	they did not really listen	Not being listened to	Not listening to parents
Admission1 *Junior doctor 1* Parents' views are important but **do not have same clinical knowledge so their concerns may be different** to medics. **Parents thought it might indicate a problem with the shunt. I thought it was likely to be an ear infection.**	**not same clinical knowledge so concerns may be different**	Different knowledge	Role differences
	parents thought problem was with shunt I thought an ear infection	Disagreement between HP's/ parents reason for symptoms	Disagreement about the cause of illness symptoms
Admission1 *Senior nurse 1* I **appreciated that his behaviour was different**, and as with many children with learning disabilities, it is subtle differences that can make a difference and **parents are really the ones who know these subtle differences**.	**appreciated behaviour was different**	Know something is wrong	Recognising illness symptoms
	parents are really the ones who know subtle differences	Acknowledge parents knowledge of child	Valuing expertise

HP: health professional

Codes of similar topics formed initial categories. Categories were refined and brought together to form initial broad themes. These refined categories and themes formed the coding index that was used as a means of sorting and organising the whole data set. The coding index was constantly refined throughout the process of coding the whole data set as new insights emerged. The coding index is presented in Figure 27. Once the initial coding index was developed NVivo® was used to store and organise codes, categories and themes. This enabled data to be retrieved, reviewed and refined easily.

Figure 27: The coding index

Initial themes	Initial categories
Reaching a diagnosis	Eliciting parents' concerns
	Recognising illness symptoms
	Certainty about illness symptoms
	Uncertainty about illness symptoms
	Differentiating between other illnesses and shunt problems
	Agreement about the cause of illness symptoms
	Disagreement about the cause of illness symptoms
Involvement: listening	Listening to parents
	Not listening to parents
Involvement: provision of information	Information sharing
	Inadequate information provision
Involvement: deciding the plan of care	Parents included when planning care
	Parents excluded when planning care
	Inconsistencies when planning care
Beliefs about involving parents in care decisions	Perceptions of parents involvement in care decisions
	Valuing expertise/ knowledge of parents when planning care
	Expertise/ knowledge not valued when planning care
Healthcare professional practices	Role differences
	Healthcare professional experience
	Identifying level of care
	Providing support
	Building rapport with parents

The final stage of the analysis involved making association across data sets. For example analysis of the observational data identified collaboration could occur when 'eliciting parents' concerns' and 'planning care': these were included as categories during the process of refining categories. The final themes from which the core concepts emerged are outlined in Figure 28.

Figure 28: The development of core concepts and themes (numbering mapped to coding index)

Initial themes	Refined categories	Links between categories	Final themes	Core concepts
1: Reaching a diagnosis	1.1 Eliciting parents' concerns	Valuing / not valuing parents (5.2 and 5.3)	• **Eliciting and valuing parents' concerns**	**ESTABLISHING A DIAGNOSIS OF SHUNT MALFUNCTION**
	1.2 Recognising illness symptoms	Categories overlap, all relate to: establishing a diagnosis and the value placed on parents contribution to establishing the diagnosis (5.2 and 5.3)		
	1.3 Certainty about illness symptoms			
	1.4 Uncertainty about illness symptoms		• **Incorporating parents knowledge and experience with the clinical assessment**	
	1.5 Agreement about the cause of illness symptoms			
	1.6 Disagreement about the cause of illness symptoms	Role differences (6.1)		
	1.7 Differentiating between symptoms of other illness and shunt problems	Healthcare professional's experience (6.2)	• **Establishing a cause for illness symptoms**	

2: Involvement: listening	2.1 Listening to parents 2.2 Not listening to parents	Beliefs about involvement (5.1) Beliefs about involvement (5.1)	• **Involving parents in care planning**	**COLLABORATION: PERCEPTIONS AND PRACTICES**
3: Involvement: provision of information	3.1 Information sharing 3.2 Inadequate information provision	Beliefs about involvement (5.1) Beliefs about involvement (5.1)		
4: Involvement: deciding the plan of care	4.1 Parents included when planning care 4.2 Parents excluded when planning care 4.4 Inconsistencies when planning care	Beliefs about involvement (5.1) Beliefs about involvement (5.1)	• **Barriers and levers to effective parent-professional collaboration**	
5: Beliefs about involving parents in care decisions	5.1 Perceptions of parents involvement in care decisions 5.2 Valuing expertise/ knowledge of parents when planning care 5.3 Expertise/ knowledge not valued when planning care	Beliefs about involvement (5.1) Parents included when planning care (4.1) Parents excluded when planning care (4.2)		
6: Healthcare professional practices	6.1 Role differences 6.2 Healthcare professional experience 6.3 Identifying level of care required 6.4 Providing support 6.5 Building rapport with parents	Establishing a diagnosis (1.8) Establishing a diagnosis (1.8) Parents included when planning care (4.1) Parents excluded when planning care (4.2)	• **Perceptions of parent-professional collaboration**	

Explanatory accounts began by reflecting on the original data as a whole, and the analytical stages, in order to ensure the experiences and perceptions of participants were accurately represented and to minimise the possibility of misinterpretation. The final stages involved making sense of the concepts and themes in terms of participants' beliefs and experiences. This was achieved by exploring the relationship between the core concepts, interactional data and quantitative data and making links to the established literature relating to patient involvement, presented in Sections 4.6 and 4.7 respectively.

4.5.3.3 Analysis of quantitative data

The quantitative data obtained from the questionnaires and clinical audit were analysed using simple descriptive statistics, primarily in the form of percentages and frequencies. Analysis of quantitative data enabled comparison to be made between perceived shared-decision and the process of facilitating parent-professional engagement.

4.5.4 Presentation of findings

Different ways of presenting qualitative research findings were outlined in Chapter 3, Section 3.5.4. Challenges in presenting the findings of the study reported in this chapter related to demonstrating the unique contribution of findings from the parent-professional interactions, interviews and qualitative data while simultaneously presenting a cohesive account of parent-professional collaboration in the context of diagnosing shunt malfunction. These challenges were reconciled by presenting the findings in two sections. First, a summary of the findings from each of the data collection methods are reported. Second, the findings are drawn together to describe in-depth patient-professional collaboration in the context of diagnosing shunt malfunction with consideration given to the similarities and differences across findings. Direct extracts have been used to: provide evidence of the observed patterns of speech within the interactional data; illustrate themes and bring the data to life; contextualise study findings and enable judgements to be made about their credibility. Section 4.7, presents a separate discussion of the findings with links to the established literature and relevant theoretical perspectives.

4.6 Study findings

4.6.1 Overview of study findings

A summary of the findings from the parent-professional interactions, follow-up interviews, participant satisfaction questionnaire and clinical audit are presented.

4.6.1.1 Parent-professional interactions

The topic sequences within doctor-patient consultations topics are well established and relate to greetings, the presenting complaint, examination, making a diagnosis, treatment planning and closings sequences (Robinson 2003). These well established sequences were not always evident in the parent-junior doctor interactions in the data corpus relating to the study presented in this chapter. In over half of the parent-junior doctor consultations a possible reason for the child's presenting symptom was not offered. Information specific to the context of the consultation was elicited in relation to the child's past medical history and developmental progress and was typically appended to the presenting complaint sequence. Interactions involving nurses and senior doctors were different in structure compared to those of junior doctors; for nurses and senior doctors sequence topics primarily focused on assessment and care planning. Within the data corpus there was evidence of health professionals' involving parents in the child's care for example establishing parents' concerns and when ascertaining whether illness symptoms were likely to be shunt related or not. The areas of analytical interest relevant to this study were: establishing the likely cause of the child's illness symptoms; planning care and treatments; and building rapport with parents. These turns at talk are now summarised.

Twenty-three cases of interest were identified relating to establishing the likely cause of the child's illness symptoms. Analysing these cases identified four types of turn designs: health professionals invited parents to offer a possible cause for the child's illness symptoms, parents initiated the offer of a possible cause for the child's illness symptoms, and parents either accepted or rejected health professionals' judgements about the likely cause of the child's illness symptoms. Parents were more likely to offer a possible cause for the child's illness symptoms if invited to by health professionals (Table 13). The frequency

in which parents accepted or rejected health professionals' judgements about the reason for the child's illness symptoms were equal.

Table 13: Establishing a cause for illness symptoms (n = 23)

Turn design	Parent invited to offer a diagnosis	Parent initiated the offer of a diagnosis	Parent accepted professional judgements	Parent rejected professional judgements
Frequency	30% (n=7)	18% (n=4)	26% (n= 6)	26% (n= 6)
Example	Doctor: so what are you your thoughts as to what's going on Mum: well I don't really know but the shunts is a concern	Mum: he could have chicken pox he has spots on his legs Doctor: it's worth taking a look	Doctor: he looks like he has a virus, we'll do a scan just in case Mum: ok yes I think he's virally	Doctor: does anyone have coughs, colds tummy bugs Mum: if I thought she had a virus I wouldn't have brought her in

Eleven cases of interest were identified in relation to involving parents when planning care and treatments. In addition, there was evidence across the data corpus of parents interacting with health professionals about the best way to undertake care interventions such as taking blood samples from their child. These data were not analysed. Analysing the cases of interest identified two types of turn designs: parents either accepted or rejected care plans. Parents were more likely to accept than reject care plans offered by health professionals (Table 14).

Table 14: Interactions about planning care (n = 11)

Turn design	Accepted care plans	Rejected care plans
Frequency	82% (n=9)	18% (n= 2)
Example	Doctor: the concern is the shunt isn't inside the tummy but I don't think it's that, we'll keep him overnight, if he's still headachy in the morning then we'll repeat his scan Mum: that's fine	Doctor: we'll have to do a CT scan Mum: with it hurting at the back I thought about the cyst changing at the back of his head, would he need an MRI to see that

Rapport and empathy are beneficial to developing effective patient-professional communication (Chatwin et al 2007). Actions that facilitate rapport building include; the way professionals position themselves during introductions, the use of humour by patients and professionals, professionals sharing their knowledge of the patients' presenting problem, emphasising the value of the patients' story and solving the patients' health-related problems (Ruusuvuori 2005ab, 2007). These were evident across this data corpus, particularly in opening sequences when professionals used their knowledge of the child's presenting problem or previous admissions as a means of eliciting parents' concerns. In the context of establishing a diagnosis of shunt malfunction two areas of analytical interest were explored; acknowledging parents as experts and empathising with parents about the difficulties in identifying shunt malfunction in children (Table 15).

Table 15: Generating rapport and empathising with parents (n = 7)

Turn design and actions	Acknowledging parents expertise	Empathising about identifying shunt malfunction
Frequency	43% (n= 3)	57% (n= 4)
Example	Doctor: everything is normal but because she has a shunt and you think there may be problems with it I think we should do a CT scan, I have discussed this with the registrar and he was quite happy with that Mum: OK	Mum: like I said he doesn't really suffer from headaches Nurse: so that's another thing if it's not routine, some children can get headaches but he doesn't normally get headaches, sometimes it can be shunt related or sometimes it can be they've got a temperature, a bit virally, a bit of a bug and in some cases we just never know

4.6.1.2 Participant interviews

Two core concepts characterised participants' experiences and perceptions of collaboration when diagnosing shunt malfunction in children. The first concept related to the challenges when establishing a diagnosis of shunt malfunction in children. The second concept related to parents' and professionals' perceptions of collaboration, and the practices of health professionals that enabled or hindered collaboration. These concepts and related themes are presented in Figure 29, and will be described in Section 4.6.2.

Figure 29: Parent-professional collaboration when diagnosing shunt malfunction

Concept	Themes
Establishing a diagnosis of shunt malfunction	• Eliciting and valuing parents' concerns • Incorporating parents' knowledge with the clinical assessment • Establishing a cause for illness symptoms
Collaboration: perceptions and practices	• Involving parents in care planning • Barriers and levers to effective parent-professional collaboration • Perceptions of parent-professional collaboration

4.6.1.3 Questionnaire and outcome data

The frequency of responses expressed as a percentage for each statement within the questionnaire for both parents and health professionals are presented in Table 16.

Table 16: Comparison of parents' and professionals' satisfaction with the consultation
(n=26 parent responses, n=18 professional responses)

Question	Score (%)	S/A	A	N	D	S/D
1. Listening/ being listened to	Parent	65	23	12	0	0
	HP	44	40	6	0	0
2. Causes for the child's symptoms suggested	Parent	35	27	23	11	4
	HP	61	39	0	0	0
3. Parents views included in the assessment	Parent	54	31	4	11	0
	HP	61	33	6	0	0
4. Treatment options discussed	Parent	35	35	15	15	0
	HP	50	39	11	0	0
5. Advantages/ disadvantages of treatment discussed	Parent	42	15	12	31	0
	HP	45	33	22	0	0
6. Parents understanding of treatment options ascertained	Parent	50	27	4	19	0
	HP	50	22	28	0	0
7. Parents had opportunity to ask questions	Parent	73	19	0	8	0
	HP	83	17	0	0	0
8. Ascertain level parents wanted to be involved in care decisions	Parent	27	46	23	9	0
	HP	33	44	17	6	0
9. Decisions about care were made with parents	Parent	65	15	8	8	4
	HP	50	39	11	0	0
10. Satisfaction with the level of involvement in care	Parent	61	23	8	0	8
	HP	61	39	0	0	0

SA-strongly agree A-agree N-neither agree or disagree D-disagree SD -strongly disagree
HP = healthcare professionals

Across all questions, 55% of the scores for both groups related to 'strongly agree' or 'agree' responses. With the health professionals there was no 'strong disagreement' in response to any of the statements and 'disagreement' with only one statement relating to ascertaining the level parents wanted to participate in care decisions. In contrast, parents used the full range of response categories with 'strong disagreement' or 'disagreement' indicated in 9 of the 10 statements.

Table 17 presents the data extracted from the clinical audit in relation to the child's presenting symptoms and admission outcomes. Interview data relating to participants' initial judgments about the likelihood of the shunt being blocked is also included. The most common presenting symptom was headache occurring in 10 (70%) children and was associated with vomiting in four children and irritability in two children. Three children had a blocked shunt identified from CT scan results. Parents' and health professionals' initial judgments in relation to the likelihood of the shunt being blocked and an actual diagnosis of a blocked shunt were variable. Three health professionals, two doctors and one nurse, on initial impression felt the child's shunt was not likely to be blocked, yet the CT scan results were suggested of a blocked shunt which was confirmed during surgery to revise the shunt.

Table 17: Diagnosing shunt malfunction: presenting symptoms, admission outcomes and participant judgments (audit data)

Presenting symptoms (n= 14)[1]					
Headache	Nausea/ vomiting	Swelling/redness over shunt site	Irritable	Pyrexia	Drowsy
10	7	4	2	1	1
Diagnosis (n= 14)					
Shunt blocked (surgery required)		Possible shunt over draining (no treatment)		Infection	No diagnosis
3		3		4	4
Participant initial judgments (n =31)					
		Certain shunt blocked (Definite shunt blocked)		Uncertain shunt blocked (Definite shunt blocked)	
Parents (n = 13)		9 (3)		4 (0)	
Doctors (n = 11)		3 (1)		8 (2)	
Nurses (n = 7)		3 (2)		4 (1)	

[1] Most children had more than one symptom

Health professionals' experiences in relation to working in the speciality of children's neurology were variable (Table 18). Although the nurses and senior doctors had considerable experience in assessing children for shunt malfunction, all professionals reported uncertainty when diagnosing shunt malfunction.

Table 18: Professionals' perceptions of their accuracy in diagnosing shunt malfunction

	Years qualified	**Years working in child neuro-logy**	**Perception of accuracy in diagnosing shunt malfunction**				
			Number of shunts assessed per year	Correctly diagnosed blocked shunt (%)	Incorrectly diagnosed blocked shunt (%)	Correctly diagnosed **not** blocked shunt (%)	Incorrectly diagnosed **not** blocked shunt (%)
SNurse 1	17	10	30	60	20	10	10
SNurse 2	17	17	20	45	5	40	10
JNurse 1[1]	15	13	50	20	10	60	10
JNurse 2[1]	5	5	20	25	25	40	10
SDoctor 1	9	5	60	35	15	35	15
SDoctor 2	10	6	8	50	10	40	0
SDoctor 3	8	0.4	4	0	0	100	0
SDoctor 4	8	2	20	50	0	30	20
JDoctor 1	3	0.3	15	13.3	60	13.3	13.3
JDoctor 2	3	0.4	25	40	40	8	12
JDoctor 3	8	0.4	1	100	0	0	0
JDoctor 4	7	0.2	4	25	0	75	0
JDoctor 5	5	0.2	4	25	25	50	0

[1]Although the term junior nurse was used to refer to band 5 staff nurse, they had considerable post qualification experience

4.6.2 Similarities and differences across data findings

This section brings together the findings from the observational, interview and quantitative data in order to present a cohesive account of parents' involvement in their child's care in the context of diagnosing shunt malfunction. Similarities and differences across data findings will be highlighted. Although an explanation of the findings is presented with the discussion, Section 4.7, preliminary explanations of the structural proprieties of the CA illustrative cases are included.

4.6.2.1 Establishing a diagnosis of shunt malfunction

A significant aspect of managing hydrocephalus in children relates to recognising illness symptoms indicative of shunt malfunction, which may be unique to the individual child, and establishing a definitive diagnosis. Three themes emerged from the data in relation to establishing a diagnosis of shunt malfunction: 'eliciting and valuing parents' concerns'; 'incorporating parents' knowledge and experience within the clinical assessment'; 'establishing a cause for illness symptoms'. These themes are now described.

4.6.2.1a Eliciting and valuing parents' concerns

Eliciting and valuing parents' concerns were perceived as an essential part of establishing a diagnosis of shunt malfunction in children by health professionals. Across parent and professional accounts there was recognition that parents' knowledge of their child and experiences in managing their child's condition were central to the assessment processes. Health professionals' consistently highlighted the need to listen and take account of parents' concerns. In contrast, parents' perceptions about the value health professionals' placed on their concerns were variable, evident from the questionnaire findings and the interview accounts. Some parents did not feel their views were included in the assessment process (Question 3, Table 16). The following extracts summarise participants' accounts relating to eliciting and valuing parents' concerns:

> 'One nurse said to me you know your daughter best and how she is in herself. So they do listen to you. Well they did to me and my concerns. I mentioned it (the shunt) and they said they'd get it checked straight away and they did'. *Admission 10, mum*

> 'Parents' know the child far better than you do and they know when their children aren't well. Mum is probably as experienced as anyone in terms of shunt problems for (child's name) and the symptoms that he shows…Shunts are very difficult so we are obliged to treat everything seriously, especially if parents have concerns…his symptoms aren't always the text book symptoms'. *Admission 1, junior doctor*$_1$

> 'I am not sure if they (doctors and nurses) believed me at first, I had to keep saying this was not usual. Although they listened they didn't really seem to believe me'. *Admission 1, mum*

The structure of the parent-professional interactions relating to establishing the likely cause of the child's illness symptoms provided evidence to support parents' perceptions that their concerns and experiences were not always valued. The properties of the three illustrative cases (Figures 30, 31 and 32), identified in the interactional data corpus, highlight differences in the way parents' concerns were elicited and valued. The extract below provides evidence of effective parent-doctor collaboration during the process of eliciting parents' concerns.

Figure 30: Eliciting parents' views about the cause of illness symptoms

Extract 2: cause of illness symptoms (mum-dad-junior doctor interaction: extract at 6m 5s of the interaction, total interaction 29 minutes)

1	JDr_1	fine (.) ok (.) so (.) h. ok↑ and so what↑ are you <u>your thoughts</u> as to
2		what's what what's going on with this
3	Mum_1	[.h °well° h. well don't <u>really</u> know↑
4	Dad_1	[°what's causing it° =
5	JDr_1	°probems°(unclear)
6	Mum_1	I just I mean we were <u>obviously</u> concerned about the shunt cos we
7		know about that and we know that that's there =
8	Dad_1	from [what we got told from when the shunt got done they says <u>don't</u>
9	Mum_1	[emm
10	Dad_1	be surprised↑ if he gets to have it replaced within the first six months
11	Mum_1	well [the that was that was ages ago but emm
12	Dad_1	[but were always wondering aren't we but were always [wondering
13	Mum_1	[that was
14		our↑ only concern=I mean the only <u>thing</u> that stopped us ringing
15		<u>straight</u> away when it=he started having them is because they're <u>not</u>
16		<u>constant</u> and it just seems strange that all of a sudden he can go back
17		to normal↑ but (.) today he just seemed in so much pain and it were
18		we were just <u>concerned</u> and it does seem to be related to his head
19		and his eyes↑
20	JDr_1	he puts his hands to his head
21	Mum_1	yeh=
22	Dad_1	he's always [(gripping) screwing his eyes [up
23	Mum_1	[yeh [yeh so that was our only
24		concern really
25	Dad_1	there has been a few times where he's looked like is eyes have been
26		really [stingless clawing at his eyes n sort of like
27	Mum_1	[yeh
28	Dad_1	hitting himself on head
29		(child in background)
30	JDr_1	°ok° (child in background) (0.3) ok any vomiting at all

The doctor's turn in line 1 has two actions. The first TCU, 'fine ok so ok', has minimal pauses between utterances and an in-breath (line 1). This combination of elements serves to indicate that the encounter is moving on to a new sequence (Schegloff 2007). In the second TCU (lines 1 and 2) the doctor invites parents (you corrected to your) to offer a reason for their child's illness symptoms, with 'your thoughts' emphasized. Multiparty conversations can be problematic; not all parties are assured an opportunity to be next speaker and a bias can emerge which favours the prior speaker (Sacks et al 1974). In the above example (line1) there is ambiguity from the doctor in selecting the next speaker. It has been shown that where this type of ambiguity occurs in next speaker selection, determining who will speak next is often managed through a process of interactional negotiation (Stivers 2001). This is evident in the present example where when both parents respond simultaneously (lines 3 and 4) they then proceed to engage in a negotiation routine as they orientate themselves to take turns at responding (lines 6 and 8).

The mother's turn (line 3) begins with an in-breat'h and quiet speech as she constructs her response. This perhaps indicates that she views the prior turn as an invitation (Sacks et al 1974). The father's initial response (line 4) is quiet and although he receives the invitation, he does not respond to it. The doctor's turn in line 5 is unclear but is followed immediately by the mother taking a turn where she offers a possible reason for her concerns (line 6); 'obviously concerned about the shunt', with an emphasis on 'obviously'. The sequence progresses in lines 6-20 to a dialogue between parents which builds on and clarifies the information they initially provided. During this exchange there is no interruption from the doctor. His next turn (line 20) is essentially a clarification and acts as a continuation prompt, evident in lines 20-29 where parents continue the narrative relating to their concerns. The sequence concludes with a receipt of parents' accounts by the doctor (line 30) and a transition to a new sequence within the same turn, indicated by 'ok' and a new topic proffer in the form of an invitation.

Although focussing on treatment decision-making, patient-professional collaboration can be thought of as a 'bilateral' or 'unilateral' process (Collins et al 2005). In the former collaboration occurs as a process of negotiation and is

enacted during patient-professional interactions, whereas in the later the health professional operates autonomously and in the main independent of their interactions with the patient. The extract presented in Figure 30 has evidence of interactional features consistent with a bilateral approach to parent-professional collaboration such as the doctor's invitation to parents to express their views of the likely cause of their child's symptoms and allowing them to tell their story (Collins et al 2005). The following extract (Figure 31) is an interaction between a doctor and mother, and involves the same junior doctor as in the previous example (Figure 30). The evidence presented is consistent with a more unilateral approach to parent-professional collaboration.

Figure 31: Tensions when dealing with the expert parent

Extract 3: cause of illness symptoms (mum-junior doctor: extract at 8m 30s of the interaction, total interaction 38 minutes)

1	JDr_1	°fine fine° (.) ok so (.) so your concern=you (.) you think there is
2		something wrong with the shunt (.) °do you.° (.)
3	Mum_2	or he's not tolerating the pressure=
4	JDr_1	so you want↑ (0.3) so (.) so ok↑ (.) so it might be (0.5) might be low
5		pressure because (.) he cause (.)
6	Mum_2	< I don't know what pressure valve they put in you see I know it's
7		different>=
8	JDr_1	different but err (.) but err (.) before↑ this (0.3) we hh. we= they said
9		[it was
10	Mum_2	[they said it was [over draining
11	MedSt	[over draining (unclear)
12	JDr_1	[over draining ok >so they've probably put a slightly
13		higher pressure↑ one in< =
14	Mum_2	right
15	JDr_1	>but then if the ventricles have shrunk down< then that sounds like (.)
16		they've drained quite well. (.)
17	Mum_2	mmm but have they drained too much.
18	JDr_1	yeh hhh(.) but should suggest it might be a low pressure headache
19	Mum_2	°mmm°
20	SHO_1	they they usually resolve in time I think=>my understanding is< (.) that
21		low pressure headaches °sort° of because as you get you just have to
22		readjust to them (.) sort of readjust [to the pressure
23	Mum_2	[mmm
24	JDr_1	but err (.) [but
25	Mum_2	[but it's like where it moves around you know that's °you
26		know really° (.)
27	JDr_1	ok=

28	Mum_2	but I'm not sure (.)
29	JDr_1	fine but otherwise he's been eating and drinking ok↑

The above sequence was appended to history taking relating to the child's presenting symptoms, past-medical history and developmental progress. As in extract 2 (Figure 30), the opening sequence, starting at line 1, serves two purposes. The combination of 'fine fine ok so' indicates that the encounter is moving on to a new sequence (Schegloff 2007). In contrast to extract 2 where the second action in the turn (line 1, Figure 30) is designed as an open invitation to parents to offer a reason for their child's illness symptoms, the second action in the turn in line 1, extract 3 (Figure 31) makes an assessment of the mother's likely concerns prior to seeking the mother's view (line 3). The turn design is shaped to produce a preferred response (Schegloff 2007); the mother could have agreed with the doctor's assessment but she offers a related but alternative 'dispreferred' response (line 3). Although the purpose of the doctors' turns in the openings of the two sequences aim to solicit parents' perceptions about the likely cause of their child's presenting symptoms the design of the turns have contrasting sequential consequences.

The doctor's offer in relation to the reason for the mother seeking medical advice appears problematic; he corrects his offer from 'your concern' to 'you think', there is a pause before completing his turn and falling intonation at the end of the turn (line 2) suggesting he does not necessary concur. In her turn (line 3) the mother responds to the initial invitation and expands the opportunity to participate by offering an alternative explanation for her concerns. The doctors' next turn (line 4) follows a pause and starts with an utterance 'so you want' with rising intonation on 'want' which is corrected to 'so so it might be'. This is followed by an offer of an alternative cause for the child's illness symptoms (line 5). The sequences progresses (lines 4-25) with an expansion of the initial invitation (line 1); the mother offering a reason for the child's illness symptoms and the doctor responding.

Explanation-response sequences in medical encounters have been described in depth (Gill 1998, Gill and Maynard 2006). Typically doctors may leave elements of patients' explanations unacknowledged as they focus on the tasks of the

medical consultation. However, as in this extract, doctors may also disregard patients' explanations and insert their own explanatory responses (Gill and Maynard 2006). Conflicts between the viewpoints of the doctor and patient can result in tensions developing which influence the sequential structuring of the interaction. As the above sequence progresses the mother receipts the doctor's offer of an explanation for the child's symptoms with minimal responses 'right' (line 14) and 'mmm' (lines 19 and 23). Doctors' responses when soliciting patients' presenting concerns are crucial in establishing or rejecting the legitimacy of the presented problem (Robinson2006). In the extract presented, the doctor receipts the mother's concern with 'ok'. This acknowledges, but does not address her prior turn (line 27), indicating a rejection, or at least a down-grading, of the legitimacy of problem she presents. The mother's response to the initial invitation (line 1) occurs in line 28 with 'I'm not sure'. The sequence concludes with a receipt of mother's account by the doctor (indicated by 'fine' in line 29), and the turn continues without pause to a new sequence and topic proffer in the form of an invitation.

The evidence provided in the above discussion suggests 'trouble' within the interaction. First, the doctor's assessment of the mother's reason for seeking medical advice was problematic. This is evident in a number of the doctor's turns which include numerous pauses, changes in pitch, and 'hitches and perturbations' (lines 4 and 8) (Schegloff 1979). Similarly, at lines 27 and 28, it is evident that although he acknowledges the mother's concerns he does not address them (lines 27 and 28) (Schegloff 2007). In contrast, the mother's turns were even in tone, measured and controlled. During the follow-up interview the doctor recognised mum as having considerable experience in relation to identifying the signs of shunt malfunction in her child; the child had undergone approximately 50 shunt related operations. This interaction has features that indicate a more unilateral approach to parent-professional participation such as the presentation of the mother's concerns was based on the doctor's opinion (Collins et al 2005). Significantly, during the follow up interview the mother perceived that her views were not valued:

> 'They don't seem to take on board what your saying, that's my feeling'. *Admission 2, mum*

Extract 4 (Figure 32) is a lengthy sequence between a mother and nurse. It has similarities to the extract just described, in that the nurse also offers the mother a reason for her concerns but in this example the subsequent turn designs develop differently.

Figure 32: Listening to parents' stories

Extract 4: cause of illness symptoms (mum-child-senior nurse: extract from the start of the interaction, total interaction 12 minutes)

1	$SNurse_1$	right (.) hhh. [emm (.)
2	Mum_8	[hhh. (cough)
3	$SNurse_1$	I've <u>just</u> come to have a chat with you emm (.) because you've brought
4		(child's name) to hospital emm cause you think he's got a problem
5		with his shunt is that ok [is that right↑
6	Mum_8	[yes
7	$SNurse_1$	[ok
8	Mum_8	[yes that fine yeh
9	$SNurse_1$	so can you just tell me I've read emm because you've been to A and E
10		over at at (local hospital) <and I've read that> but if you can just tell
11		me in your own words emm what concerns brought made you to take
12		him to to A and E
13	Mum_8	right erm (.) right I been he woke up (.) right I went into his bedroom to
14		wake him up this morning.
15	$SNurse_1$	yes
16	Mum_8	and he said to me emm mum (.) me neck hurts I says oh does↑ it and
17		he says yeh he says its <u>swollen</u> I says right then sit up love so I can
18		have a look at you so I'll just open [your
19	$SNurse_1$	[mmm
20	Mum_8	blinds and curtains so I can have a look at it in natural light and he sat
21		straight up and I could see (.) that it was more <u>swollen</u>
22	$SNurse_1$	right=
23	Mum_8	at the right hand side by his shunt than (.) the other side (.) so I says
24		oh↑ love it is and I says how's it feel he says it hurts and he says I
25		don't feel so good I've got headache**.**I say aright ok↑ explained cause
26		<this morning of all mornings> I had to be somewhere else at half past
27		seven
28	$SNurse_1$	°h.°
29	Mum_8	and I called in at the our doctors at half past seven to make an
30		appointment↑ for him
31	$SNurse_1$	Yeh
32	Mum_8	there were <u>no</u> appointments available (.) erm (.) before I left the house
33		for to make that appointment (child's name) I said to (child's name) oh
34		get up↑ have a wash brush your teeth anyway
35	$SNurse_1$	yeh=
36	Mum_8	cause you still have to get ready emm (.) I found out when I got back

37		home that he'd (.) when he'd actually got out of bed and went to go to
38		the toilet he said he felt like he was going to pass out he felt ↑ dizzy=
39	$SNurse_1$	right=
40	Mum_8	he'd a bit of double vision and said it lasted about ten minutes I said
41		right ok↑ then °love° but he started to cry
42	$SNurse_1$	mmm
43	Mum_8	h. you know and it's not something he normally does=
44	$SNurse_1$	no=
45	Mum_8	started to cry and says it really hurts and he's in pain (.) I says °right
46		love° well I can't↑ get you an appointment with the doctors but I'll take
47		you on to casualty to see what they say there
48	$SNurse_1$	mmm
49	Mum_8	emm (.) after a long discussion with the triage nurse as to whether or
50		not (local hospital) could take or (other local hospital) (local hospital)
52		said they'd assess him (.) emm he got assessed and then the
52		consultant came in and he↑ had a look at him and then just suggested
53		it would be better for↓ (child's name) to come over to you where h. (.)
54		when I h. (.) this is going to sound silly
55	$SNurse_1$	°no it's ok°=
56	Mum_8	(child's name) used to always lay down=he last had his last shunt in
57		(.) six years ago
58	$SNurse_1$	yeh
59	Mum_8	h. and he (.) his symptoms were never (.) all↑ <your meant to get
60		headaches vomiting double vision>=
61	$SNurse_1$	yeh
62	Mum_8	he never had them all at the same [time
63	$SNurse_1$	[no
64	Mum_8	<one time he would be sick or one time he was running round the
65		ward>
66	$SNurse_1$	yeh
67	Mum_8	and his shunt he'd got the shunt hh. failure↓ you know Yeh
68		so he's never had consistent (.) diagnosis [whatever it is
69	$SNurse_1$	[yeh or the typical=
70		symptoms=
71	Mum_8	typical symptoms= that's it=
72	$SNurse_1$	yeh
73	Mum_8	typical symptoms↑ .hh (.) so with that at <the back of my mind> I'm
74		more cautious of what's going on
75	$SNurse_1$	mmm
76	Mum_8	but I said to (child's name) it looks like it could be (.) you know a leak.
77		with it bulging there↑=
78	$SNurse_1$	yeh yeh↑
79	Mum_8	and but he has got a headache and his eyes (.) you you I think you
80		can tell a lot from a [shunt with the [eyes
81	$SNurse_1$	[mmm [mmm
82	Mum_8	now h. (child's name) does have nystagmus which doesn't help
83	$SNurse_1$	yeh
84	Mum_8	so (.) when he turns his head to the left his eyes will be you know
85		[I can't do it

86	$SNurse_1$	[yeh
87	Mum_8	will be over [there looking at you
88	$SNurse_1$	[ah ah
89	Mum_8	and he <u>can't</u> do it
90	$SNurse_1$	right
91	Mum_8	he's saying to do that it (.) it it's <u>really</u> painful in't it (child's name)↑
92	$SNurse_1$	yeh
93	Mum_8	right and same the other way and but yet hh. because <he has
94		nystagmus> when he looks forward
95	$SNurse_1$	mmm
96	Mum_8	he's not going to get good vision of you anyway=.
97	$SNurse_1$	right ok
98	Mum_8	emm (.) I don't think he's had double vision again. (.) since (.) we took
99		went to A and E but I know walking from the car up here he said he
100		felt dizzy↓
101	$SNurse_1$	ok right=
102	Mum_8	emm so↑ it's↑ just↑ a combination**.** of a lot of <u>things</u> really the
103		headache the eyes and the swelling**.**=
104	$SNurse_1$	right [^{o}ok^{o}
105	Mum_8	[that just made me think that it might be <u>starting</u> to build up
106	$SNurse_1$	yeh=
107	Mum_8	or has he got a leak or
108	$SNurse_1$	yeh=
109	Mum_8	or I don't know**.**
110	$SNurse_1$	I think↑ you've↑ done the <u>right</u> thing obviously you like you say you've
111		got some concerns and the best [thing is to get it checked out↑ and
112	Mum_8	[yeh
113	$SNurse_1$	like you say he's not normally a young man that complains about
114		things

The above example does not begin with a social greeting as would be expected in both ordinary conversations and health consultations (Robinson 1998). Interactions prior to the formal consultation can provide opportunity for rapport building and have sub-textual functions such as the likelihood that the consultation will be collaborative or not (Chatwin et al 2007). Informal talk had taken placed prior to the recording of the interaction during the process of establishing the mother's willingness to participate in the study. The opening sequence, extract 4 (Figure 32) has multiple TCU's. The sequence begins with the nurse seeking permission to proceed with the assessment 'I've just come to have a chat with you' (line 3) and offers the mother a reason for seeking advice 'cause you think he's got a problem with his shunt' (line 4). The final TCU in the nurse's turn concludes with 'is that ok, is that right' (line 5), with a rise pitch at the

end. This is potentially problematic because there are two possible actions within this TCU; seeking agreement for the assessment to continue and establishing the reason for seeking advice. This projects two possible outcomes; the mother responds to the first action to proceed twice with a 'yes' (line 6) repeated with 'yes that's fine' (line 8). However, the first 'yes' is in overlap with the end of the prior turn and is likely to be a response to confirming she feels the child has a shunt problem and 'yes that's fine' is likely to be in response to the nurse's request to undertake the assessment. The nurse responds in lines 9-12 by inviting the mother to outline her concerns. In addition to seeking agreement for the assessment to continue and establishing the reason for seeking advice, the nurse also conveys to the mother that she has knowledge about the reason she has sought medical advice (Robinson 2006). This action is followed up in line 10 with 'if you can just tell me in your own words what concerns brought you made you take him to A and E' and serves to reinforce that the mother's narrative is central to the consultation (Chatwin et al 2007).

The sequence progresses (lines 13-103) with an exchange of turns that are designed to enable the mother's telling of her story evident by the nurse encouraging the mother to develop her narrative with continuation prompts such as 'mmm', 'right' and 'yeh'. It is evident that the mother has been able to say all that she wanted when she offers a short summary of her accounts (lines 107-112) (Jefferson 1978). This summarising, or returning to a topic already broached in a sequence can indicate completion of a 'telling', and as in this case, acts as cue to the nurse that the narrative is complete. It is also evident that the nurse has facilitated this free development of the narrative because the mother's response to her primary enquiry turn 'what concerns made you to take him to A and E' (line 11) does not occur until line 104 with; 'so it's a combination of things'; 'starting to build up' (107); 'possible leak' (line 109). The sequence concludes with an offer of reassurance from the nurse that the mother's actions were appropriate; 'you've done right' (line 112), with a rise in intonation after 'you've' and emphasis on 'right'.

In the opening sequences of extracts three and four (Figures 31 and 32), lines 2 and 3 respectively, both the doctor and nurse make an assessment of the

mothers' likely concerns prior to inviting the mothers to express their views. However, the sequential development of the interactions and as a consequence the nature of the parent-professional collaboration differed. First, it is worth noting that the sequences are at different points within the consultation. Although like the doctor, the nurse makes an assessment of the mother's likely concerns, the sequence is at the start of the mother-nurse interaction and her turn is designed to convey her knowledge of the child's condition (Robinson 2006). In contrast the sequence in the mother-doctor interaction occurs after an eight minute history taking sequence. The mother-doctor interaction adopts a biomedical approach often observed in medical consultations (Gill and Maynard 2006). Although initiated by the mother 'he's not tolerating the pressure', (line 3, extract 3) the use of medical terminology is mirrored by the doctor and the mother. The analysis suggests potential difficulties during the encounter; the mother's expert knowledge of her child's condition and the doctor's interpretation of the child's illness symptoms conflicted. This is confirmed in both the doctor's and mother's accounts of the encounter which are included in the examples from the interview data on page 210 and page 214 respectively. The nurse interaction allowed the mother to share her concerns with minimal interruption. This extended narrative serves to maintain the focus of the interaction within the mother's domain (Clark and Mishler 1992). The mother-nurse interaction is consistent with a bilateral approach to parent-professional participation compared to the more unilateral approach adopted by the doctor (Collins et al 2005).

4.6.2.1b Incorporating parents' knowledge with the clinical assessment

Diagnosing shunt malfunction was perceived as problematic because children do not necessarily present with the classic symptoms associated with increased pressure in the brain, and many children have unique symptoms that indicate their shunt is malfunctioning. Detailed knowledge of the child's development, usual behaviours and previous symptom associated with shunt malfunction were perceived by parents and health professionals as essential to establish a diagnosis. Across parents' and health professionals' accounts there was recognition that parents' knowledge of their child and experience in managing their child's condition were central to the assessment processes. Parents' and health professionals' described ways in which parents' knowledge and

experiences were incorporated with clinical judgements when deciding whether illness symptoms were shunt related or not, for example:

> ‘We’ve got objective measures of how we would assess a shunt and I think (parents) can tell us things that are very subjective, very highly specific to individuals, to the child really, so they can give you quite a clue that if they say something’s not right you have to know that there’s something potentially not right and so you must go about excluding everything’. *Admission 5, senior doctor*$_1$

> ‘Parents’ know their children the best and what we might consider normal for one child is completely out of this child’s normal behaviour for them, so we’d miss clues, we’d misdiagnose if we didn’t involve parents. So I was trying to find out in the past what had happened, how this time compared to previous times that she was worried about shunt problems. Mum was thinking it could either be the shunt or it could be a urine infection because (child) also has problems with urine infections, she wasn’t sure which one it could be and obviously a shunt infection is probably more serious than a urine infection. I think she thought it was getting more like a UTI from her previous presentations of shunt problems but she just wanted it to be checked out really. I was taking my lead more from mum than trying to say what I thought but I think we probably had about the same idea’. *Admission 10, junior doctor*$_5$

> ‘So if mum was saying that she thought it was a viral thing then that might mean we’ll not do a full CT scan and that sort of things like that which for him is good because he’s not getting X-rays. *Admission 8, senior nurse*$_1$

> ‘The neurosurgeon didn’t know (child’s name) so he didn’t know what she’d normally be like with her shunt and her scans weren’t showing that her ventricles in particular were more enlarged than normal and there was nothing obvious on shunt series so all he really had to go on was the fact that we were telling him that she was very symptomatic and that because of the length of time that it had being going on we couldn’t see any other reason for her being as she was’. *Admission 14, mum*

4.6.2.1c Establishing a cause for illness symptoms

Uncertainty about the cause of illness symptoms was evident across parents’ and health professionals’ accounts. Review of the in-patent discharge data and participants’ perceptions of their accuracy in diagnosing shunt malfunction suggested establishing a diagnosis of shunt malfunction based on clinical

symptoms is difficult (Tables 17 and18). Difficulties related to differentiating between symptoms that might be shunt related and those of common childhood illnesses, particularly viral infections. Parents and health professionals were able to provide the rationale in relation to their initial impressions of the cause of illness symptoms. However, the relationship between participants' initial impressions and the admission outcome, in terms of the symptoms being shunt related, were variable. The examples below relate to the same admission; the outcome data reported the child's shunt was revised:

> 'This is not how he usually is and I just knew this wasn't him. He wasn't right he started holding and shaking his head, and having one of these episodes and they were also concerned this is so unlike him and his behaviour is out of character that it had to be his shunt. I just though what else could it be'. *Admission 1, mum*

> 'Children at that age pull their ears with an ear infection, so I didn't entirely dismiss the shunt but it did go down on my list of possibilities because clearly he has signs of an ear infection with frank pus, and it was a nasty ear infection…. So I thought the ear infection was causing all the problems'. *Admission 1 junior doctor$_1$*

> 'These were new symptoms, shaking his head, and they were not like usual when (child's name) gets a cold or earache and could be due to the shunt'. *Admission 1, senior nurse$_1$*

In contrast, the following accounts are examples when parents' and health professionals' believed symptoms were likely to be due to shunt malfunction; outcome data reported the children as having a viral infection:

> 'I thought probably about 80% a problem with his tubing but that's high because he's had his tubing snapped from there before. So with it already snapping from there it was an option that the same thing could have happened again'. *Admission 8, mum*

> 'At first I did think it was blocked I just thought his symptoms were more classical he looked like he was having headaches, he would be one that I thought shunt until proven otherwise'. *Admission 3, junior doctor$_1$*

In summary, the nature of shunt malfunction and unpredictability of symptoms resulted in uncertainty when establishing a diagnosis of shunt malfunction based on clinical symptoms. Health professionals' described valuing parents' concerns,

while parents' perceived that their views are not always valued. Analysis of the parent-professional interactions provides evidence of collaborative process when parents' concerns were elicited. However, there was also evidence of tensions within the parent-professional interactions, particular when junior doctors were interacting with parents with considerable experience of managing their child's condition.

4.6.2.2 Collaboration: perceptions and practices

Involving parents across the care pathway was highlighted as the desired model of care delivery for parents and professionals alike. Three themes emerged from the data that were associated with collaborative practice: 'involving parents in planning care'; 'barriers and levers to effective parent-professional collaboration'; 'perceptions of parent-professional collaboration. These themes are now described.

4.6.2.2a Involving parents in care planning

Findings from the participant satisfaction questionnaire suggest that the majority of parents and health professionals were satisfied with the overall level of parents were involvement in their child's care (Table 16). Responses to statements relating to ascertaining the level parents wanted to be involved in care decisions and decisions being made with parents were more variable. This reflects parents' and health professionals' accounts within the interview data, which described parents' involvement in care planning in terms of informing parents of their child's progress at each stage of the pathway rather than active involvement with care decisions. In addition, parents did not want sole responsibility for decision about their child's care. Parents and health professionals struggled with the concept of parent-professional collaboration in relation to treatment decisions in this clinical context because no 'real' choices existed. Examples of participants' accounts relating to involving parents in care planning included:

> 'I think it's kind of keeping them informed of what procedures there are and then just obviously giving them lots of reassurance and support it depends on how ill the child is'. *Admission 13, senior nurse*$_1$

'They informed us of everything that had gone on, emm I don't know how to answer that (involvement in care decisions) because they do obviously go through everything with you on each procedure, so you are involved all the time. There's only one decision to be made really and obviously at the end of the day we just want him to be right and want his shunt working. So if they're 99.9% sure that it, I mean we looked at the scans and he showed us and everything, we could see for ourselves it was disconnected. I would not like to think we would have the final decision, but I would also like to think that everything has been discussed… you like to think doctors know what they're doing and it's their job at the end of the day isn't it'. *Admission 13, mum*

'I think we probably informed the parents of what was going on in terms of what tests were being arranged and what investigations were being arranged which is probably an indirect way of involving them in his care. *Admission 13, senior doctor*$_4$

Parents were much more likely to accept rather than reject the plan of care offered by health professionals (Table 14). Although parents were less likely to reject care plans offered by health professionals, the design and properties of the parent-professional interactions when accepting or rejecting care were different (Figures 33 and 34). Evidence in the way these interactions were structured suggests that when rejecting care plans, interactions with parents becomes problematic and is now explained by referring to the following illustrative cases.

Figure 33: Accepting care plans

Extract 5: planning care (mum-child-senior doctor: extract at 3.35s of the interaction, total interaction 5 minutes)

1	SDr$_1$	ok↑ =
2	Mum$_6$	°yeh right° (unclear)
3	SDr$_1$	emm (.) the scan of your head↑ yeh-I mean (.) you have a slightly
4		unusual hydrocephalus condition↓ (.) °essentially yeh called° >benign
5		intracranial hypertension< (.) emm your scan (.) does not show dilation
6		up the ventricles but in your condition↑ I don't tend↑ to <expect↑ to see
7		[that >
8	Mum$_6$	[°right° (unclear)
9	SDr$_1$	err if anything the ventricles are actually smaller compared to the that
10		ct the special ct we used in your last operation (0.3) emm and the the
11		shunt has not broken↓ >you know that its [a plastic tube and they<
12	Child$_6$	[yeh

13	SDr_1	> can break the whole way down so we've done a whole series of x-
14		rays the [whole way down↓<
15	$Child_6$	[yeh
16	SDr_1	emm (0.4) I don't think we need to rush to do anything urgently
17		tonight↑
18	$Child_6$	ok= yeh↑ I mea-I think (.) from what I can gather↑ and tell me↓ if you
19	SDr_1	agree with hhh. (.) this has been gradually getting [worse↑
20		[yeh
21	$Child_6$	there hasn't been a dramatic bang [today↑ [or anything↓
22	SDr_1	[no=
23	$Child_6$	[no
24	Mum_6	emm (0.3) so I- I don't think we will rush to theatre to do anything
25	SDr_1	evening↑
26		°ok°=
27	$Child_6$	yeh↑ although I think we are going to have to scratch our heads
28	SDr_1	together here↑ to think about what we do need to do↑
29		yep=
30	$Child_6$	ok and what we probably will do is get the ophthalmologist to see you
31	SDr_1	tomorrow↑ morning
32		ok=
33	$Child_6$	so I think you should stay with us (.) yeh=
34	SDr_1	yep= (muffled)
35	$Child_6$	stay in tonight and let's have a think
36	SDr_1	yep [that's fine↑
37	$Child_6$	[ok
38	Mum_6	because you're not just simple↓ hhh… (laughter)
39	SDr_1	ok↑ (0.5) I don't know the solution to your problem just [yet↑
40		[no that's↑ fine
41	$Child_6$	(laughing?)
42		er (.) I think we need to do some more tests =ok °>probably better just
43	SDr_1	staying with us<° till we hit this nail on the head proper again
44		[yes
45		[°yes°
46	Mum_6	[that fine not a problem↓
47	$Child_5$	ok↑
48	SDr_1	[yep
49	Mum_6	[yep (.) am I allowed to eat↑
50	$Child_6$	Yes
51	SDr_1	

In the above extract the senior doctor has just completed his examination of the child and is moving on to a new sequence indicated by 'ok' with rising intonation in line 1. The doctor offers his views in lines 3-7 of the child's assessment. When children and parents have an equal opportunity to contribute to diagnosis and treatment stages of the consultation, it is more likely that these activities are accomplished through parent-doctor interactions (Tates et al 2002). Children are

more likely to participate if specifically invited to do so by the health professional (Stivers 2001). In the above example, although he does not use the child's first name, the doctor positions the child as the next speaker by the use of the second person pronoun 'you' (Stivers 2001, Clement et al 2008), for example 'your head' (line 3), 'you have a slightly unusual hydrocephalus' (line 3), 'your scan' (line 5), 'your condition' (lines 6). However, it is the mother (in overlap and muffled) who responds (line 8). The doctor continues to select the child as the next speaker, using second person, 'your last operation' (line 10) in his turn. The dialogue in the remainder of the sequence is primarily between the child and the doctor, with minimal contribution from the mother and her contribution is often in overlap with the child (for example line 24, 38).

In line 16 an initial plan of care is offered which on completion of the doctor's turn is immediately accepted by the child in line 18. Once accepted the doctor moves on to providing more details in relation to establishing the cause of the child's illness symptoms (lines 28, 31, 34, 43). Although a diagnosis is not established, both the child and mother, orient themselves to accepting the plan of care, evident by immediately responding to the doctor's turns, with 'ok', 'yep', and 'that's fine' (for example lines 30, 33, 38, 47). These features are typical in medical encounters when there is acceptance of treatment decisions (Stivers 2006).

In contrast the following example, extract 6 (Figure 34), there is active resistance to the care plan offered. The extract is part of the same interaction presented in Figure 31 (extract 3), this sequence relates to care planning. The interaction has similar features to extract 3 in that the doctor's turns are punctuated with pauses, changes in pitch and hitches when delivering a possible diagnosis (lines 3-5) and when suggesting a plan of action (line11-22). In contrast the mother's turns are even in tone, measured and controlled (lines 18 and 24). The doctor's plan of investigations is not accepted by the mother, this 'dispreferred' response appears to result in the subsequent sequences being problematic (lines 3-6, and 14).

Figure 34: Rejecting care plans

Extract 6: planning care (mum-junior doctor: extract at 3m 36s of the interaction, total interaction 38 minutes)

1	JDr_1	right (child's name)=
2	Mum_2	oh [yer feet are cold↑(child's name)
3	JDr_1	[emm ok there's <u>nothing</u> to find again↑ no (.) no (.) obvious signs or
4		anything it's just the symptoms your complaining of (.) emm (.5) you
5		you look (.3) look your <u>normal</u> well self to me↑ (.) in your (.) in terms of
6		your emm (.5) °how he is↓°
7	Mum_2	oh yeh↑ he always <u>does</u> yeh
8	JDr_1	but emm I °'ll take what your saying so I'll have a chat to the emm° (.)
9		the registrars =
10	Mum_2	yeh he's always <u>well</u> in himself =
11	JDr_1	and I think it's probably going to be (.) the usual the usual emm (.) sort
12		of investigations I think
13	Mum_2	°not pressure↓ monitoring°
14	JDr_1	>no-n-no↑ (.5) no↑ (.5) we'll not get there first (.) < we'll have to do the
15		[<u>CT scan</u> first
16	Mum_2	[CT scan (.) yeh↑
17	JDr_1	so (.) no (.) so I think probably =
18	Mum_2	with↑ it with him saying its hurting here rather than the nape of his neck
19		I thought about is the <u>cyst</u> changing↑ at the back of his head=
20	SHO_1	°well↓° =
21	Mum_2	since surgery↑
22	JDr_1	°I don't know I don't know to be honest° =
23	Mum_2	would he need an MRI↑ to see that [or
24	JDr_1	[well I think at this stage
25		we need to get a CT scan
26	Mum_2	°right°=
27	JDr_1	and have a look
28		(background noise/ continues clinical examination of child)
29	JDr_1	emm (.3) I've a feeling °they're ° going to want the emm (.3) err get a
30		CT scan done a shunt series and take it from there ok (.) <u>bloods</u> (.)
31		°they might want bloods doing° ok
32		(mum does not respond interaction continues with child's clinical
33		examinations)

The doctor initiates the plan of care in line 11. The mother responds immediately on completion of the doctor's turn, quietly and emphasises, evident by a fall in intonation, that she would resist pressure monitoring. The mother builds a case for the investigations which she believes are appropriate in lines 18, 19 and 23. The doctor resists the mother's suggestions and moves to close the sequence, 'well at this stage we'll need to get a CT' in line 24. This turn is delivered at an

even pace without the pauses and changes in intonation evident in his prior turns (line 3-6 and 14). The mother in her pre-closing turn receipts that she understands this sequence is closing with a quiet right in line 26. The quiet responses coupled with the non-response (line 28) suggest the mother does not necessarily concur with the care plan. Doctors are orientated towards patients accepting treatment offers; resistance places the doctor in the position of having to encourage the patient to accept the treatment or offer an alternative (Stivers 2006). In contrast patients, as in this extract, do not necessarily conform to the doctors' preference for agreement and challenge prepositions and maintain contrary preferences (Boyd and Herritage 2006). In lines 29-31 the doctor re-states the care plan, the pauses and quiet speech throughout suggests he is aware the mother does not necessarily concur with the care plan. There is also a shift in responsibility for the type of investigations required to the senior doctor, lines 30 and 31 ('they're going to want' and 'they might want'). This is confirmed in the doctor's account of the encounter:

> 'Headaches are quite a problem and have become worse and I think she finds then worrying, emm, well, he'd had several operations in the last month to try and determine whether he has a problem with his shunt and the consultants had decided that almost certainly there weren't shunt problems. So emm our concerns are different, so yes mums are concerns are slightly different'. *Admission 2, junior doctor*$_1$

The descriptions of extracts 5 (Figures 33) and 6 (Figure 34) differ in the way care plans are presented and negotiated. In extract 5 a definitive course of treatment is not offered but alternatives are provided for further consideration in relation to establishing a cause of the illness symptoms (lines 28 and 31). Deciding the cause of the child's illness symptoms is framed in a way that any decisions will be based on agreement between the child and the doctor evident by the use of 'we' and 'our' ('we are going to have to scratch our heads together', line 28, 'think about what we need to do', line 29, 'let's have a think', line 36) (Collins et al 2005). In contrast, decisions about the type of investigations that will be undertaken in extract 6 are presented as information giving and the discussion is centred on medically controlled options consistent with a unilateral approach to parent-professional collaboration (Collins et al 2005).

Findings from the questionnaire item relating to involving parents in care decisions were variable (Table 16); health professionals responded positively to this item with the majority of responses being ‘strongly agree’ or ‘agree’. In contrast parents responses were more variable and included ‘neither agree nor disagree’, ‘disagree’ and ‘strongly disagree’ responses.

4.6.2.2b Barriers and levers to effective parent-professional collaboration

A range of factors emerged in relation to facilitating or hindering effective parent-professional collaboration. Parents and healthcare professionals identified listening, information sharing, valuing parents’ experiences, establishing rapport and continuity with the professionals providing care for the child as ways of effectively engaging with parents. Parents’ accounts also highlighted the importance of including older children when decisions were being made about their care. Examples of ways of enabling parents to be involved in their child’s care included:

> ‘They listen really well. They know him anyway because he’s been in that often. It’s cause it’s always the same lot of nurses, there’s no new ones whenever you go no matter if it’s day night or weekend they’re all the same ones, so they all know him’. *Admission 3, mum*

> ‘What is it that they do? Right, well they won’t just ask you, they will ask (child’s name), which being 13, I thinks’ a good thing because he can obviously speak for himself. It is nicer if (child’s name) can explain to them how he’s feeling and what pain he actually felt. I think it is mainly a listening thing and taking into account your concerns. They don’t leave you lying around waiting wondering what’s happening’. *Admission 8, mum*

> ‘I think she probably felt happy that one, there was a familiar person and two that having previously recognised the problem, I’d recognise it again. So we were both in quite quick agreement, you know’. *Admission 5, senior doctor*$_1$

> ‘They hadn’t been since she was a baby, so I just explained that she would have the CT and X-Rays and just talked through what both of them were. And they seemed very happy with that’. *Admission 12, junior nurse*$_1$

> 'Yes I do feel I was very well informed. There was a lot of waiting around in the afternoon but the nurse who was liaising with us came in several times to check that we were ok. The neuro doctors were involved in other cases and I thought that was quite right because to me (child's name) didn't seem terribly ill, and I felt that the nurse was liaising very well between us and the doctors'. *Admission 12, mum*

Establishing rapport is one way of engaging effectively with parents and was evident in the recorded interactions and has been described in Section 4.6.1.1. The illustrative case presented in Figure 35, provides evidence of rapport building being incorporated into parent-professional interactions. Rapport building is evident from the opening sequence of the senior nurse-parent interaction (lines 1-8) when the child's recent hospital admission is summarised. In the context of establishing a diagnosis of shunt malfunction, the area of analytical interest in this example relates to empathising with parents about the difficulties in identifying shunt malfunction in children.

Figure 35: Building rapport with parents

Extract 7: rapport building (mum-child-senior nurse extract from the start of the interaction, total interaction 6 minutes)

1	$SNurse_1$	emm (.4) so my name's (name) I'm Sister on here. emm (.) and
2		<you're (child's name) mum↓> emm (.) h. you phoned me earlier (.)
3		about an hour or so didn't you=
4	Mum_{13}	yeh=
5	$SNurse_1$	to say that (child's name) had been in last week he had a shunt↑
6		revision, is that correct↑
7	Mum_{13}	he had a complete new shunt revision yes
8	$SNurse_1$	right ok
9	Child	and I've been into to school
10	$SNurse_1$	you've been to school↑
11	Mum_{13}	he went just went in to see them
12	$SNurse_1$	ok hhh.(laughter) that's fine but today he's been complaining of some
13		headaches (.) sorry I'm- it's just (.) you've hhh. you've got a spider in
14		your hair
15	Child	(joint laughter) what were in your hair mum
16	$SNurse_1$	(child's name) hhh. mummy had a little spider in her hair hhh. (.) are
17		you ok↑
18	Mum_{13}	[hhh. (laughter)
19	$SNurse_1$	[hhh. (laughter) so he was complaining oh headache
		(20-56 sequences continues with mum explaining illness symptoms, with turns designed to facilitate the mother to tell her story)

56	Mum_{13}	whereas since I brought him on home <u>Tuesday</u> he's (.) kind of made
57		good progress (.) each day↑
58	$SNurse_1$	yes
59	Mum_{13}	and then today he's gone back <u>again</u> I don't know if it's the signs↑(.) =
60	$SNurse_1$	that's ok↑ cause often children you↓ know don't↑ follow set (.) you=
61	Mum_{13}	[no
62	$SNurse_1$	[know stages↑=
63	Mum_8	no
64	$SNurse_1$	and sometimes <it's that (.) they're just a little bit off colour> and you
65		can't quite put your finger on (.) but you know but you know yourself↑
66	Mum_8	yes=
67	$SNurse_1$	the're not quite a (.) hundred percent themselves (.) emm especially↑
68		(.) if he did bounce↑ back after he had the shunt revision done (.) <u>so</u>
69		it's↑ always <u>best</u> to come emm (.) and get it checked out really just for
70		your piece of [mind ↑
71	Mum_{13}	[yes that's that's [what worrying me (unclear)
72	$SNurse_1$	[especially with it being a weekend and
73		things (.) so erm, what I'll just need to do <I mean obviously he's
74		feeling a bit better now and he looks ok> emm (.) we'll do his
75		<u>temperature</u> and <u>blood pressure</u> and all that and just check that over
76	Mum_{13}	ok

This interaction is primarily between the senior nurse and mother, although the child does contribute to the interaction (lines 4 and 15). In contrast to extract 5 (Figure 33) the nurse constructs her turns in a way that selects the mother as the next speaker. This is evident in the opening sequences where introductions take place and the nurse is establishing the reason why mum has sought medical advice through the use of 'your (child's name) mum' (line 1), '(child's name) had been in last week' (line 5), and 'he's been complaining' (line 12). Referring to the child in the third person when a parent and child present for consultation selects the parent as the next speaker (Stivers 2001). Consequently, the dialogue in the remainder of the sequence is primarily between the mother and the nurse.

Listening to patients' stories is one of the ways health professionals can attend to patients' concerns and understand their illness (Clark and Mishler 1992). The nurse enabled the mother's telling of her story which is evident by her acknowledging the mother's talk with minimal utterances, such as the 'yes' in line 58. In line 62 the nurse's response to the mother's turn completed at line 61, suggests that she perceives that the mother's descriptions of her child's symptoms is coming to an end. In line 60 the mother emphasises again that 'he's gone back again' immediately followed by 'I don't know if it's the signs'.

The nurse links her response to the mother's uncertainty about illness symptoms (line 60) and the mother's previous assessment that her child was making good progress (line 56) in her pre-closing sequence with an offer of support for the mother decisions to bring the child back to the ward 'it's↑ always <u>best</u> to come emm (.) and get it checked out' (line 69), 'for your piece of mind' (line 70). The mother's narrative is primarily presented in her own terms and the nurse's responses display understanding, empathy and agreement with the mother's account (Clark and Mishler 1992, Ruusuvuori 2007).

A range of factors emerged that hindered effective parent-professional collaboration. Parents' perceived that effective communication with health professionals was hindered by not being listened to, being excluded when health professionals grouped together to discuss their child's care (for example during ward rounds), not being kept informed of care plans and receiving conflicting information. In contrast, health professionals' perceptions of the factors that created barriers to communicating effectively with parents were more likely to relate to time constraints due to workload pressures and deficiencies in the ward environment such as a lack of privacy when interacting with parents. Participants provided examples of these factors operating in practice:

> 'She (nurse) wasn't recording everything, so she was looking at me all the time, the nurse was listening. I didn't have this with the doctor at all and was more concerned with getting a social care number. I did tell them that we'd been given permission to sign for anything. I needed to know what was happening so I could let family know back at home. I was just having to guess because nobody told me anything. All they told me was they were keeping her in'. *Admission 7, dad*

> 'They talk amongst themselves and then they'll come back, whereas I think it would be better if they talked to you'. *Admission 10, mum*

> 'There is so much conflicting information really. I didn't know it was a gravity valve. I was told it was a high pressure valve…. They don't seem to take on board what your saying, that's my feeling. No they really have their own agenda and that's what we are on now their agenda'. *Admission 2, mum*

> ‘It would be helpful if you could meet parents in a quiet room because on the ward it’s always quite noisy and if we did have more time to actually sit with them and talk to them and explain things and answer any of their questions so’. *Admission 10, junior doctor$_5$*

4.6.2.2c Perceptions of parent-professional collaboration

Perceptions of parent-professional collaboration were variable. Collaboration was described in terms of working together, team work, involvement in care and involvement in treatment decisions. Shared decision-making was perceived as problematic because following a diagnosis of shunt malfunction surgery to revise the shunt is the only realistic option. Health professionals’ accounts about the meaning of collaboration were often contradictory not only between health professionals but within individual professionals accounts; for example working in partnership was described as central to the care of the child and family but the doctors’ role was perceived as one of leading the management of the child’s care. For some professionals parent-professional collaboration was primarily about ensuring parents understood the child’s care requirements in order to obtain consent for treatments. In contrast, working collaboratively was also described in terms of the value parents added to care decisions and the need to build effective and lasting relationships with the child and family. Examples of parents’ and professionals’ descriptions of parental involvement in their child’s care included:

> ‘Vitally important to involve parents, paediatrics it’s very much a specialty that relies on team work with parents. It about working in partnership with parents’ rather than their contribution to decisions. Clinicians obviously deal with children with different problems, so that emm will have a better understanding of the problem as a whole, although parents might know their child better. It’s essential that clinicians do lead the management…involving parents it’s more of a case of making parents understand the condition, or the cause of the symptoms. Working in paediatrics, one of the tenants must be including parents, but the emphasis is on good communication, decision-making is more about listening and education. *Admission 1, junior doctor$_1$*

> ‘I think you’ve got to work together you know and that’s it’. *Admission 4, mum*

> ‘When you’re an adult being treated by doctors then you have the right to be informed and make decisions yourself about your treatment given the information from the doctors on which to base a decision but (child’s name) is only 8 years old and therefore we are acting in her best interests’ *Case 12, mum*

> ‘Involving parents is important. Anything we do we have to get parental consent so it is important but it has to be completely informed. As long as the parents can understand what we are trying to explain to them and what our concerns are and they can process that and take it in adequately, parents have an equal role in decision-making along with the healthcare professionals’. *Admission 10, junior doctor*$_5$

> ‘I think they should be involved to some degree and you need to listen to them and explain and usually they are on the same page as you anyway’. *Admission 12, junior nurse*$_1$

> ‘I think the value a parent contributes is really quite high and probably not recognised as such. Where we fall down is actually not to do with lack of that belief but time constraint, when you’re on call you’re going in and focusing on a set of specific questions of what you’re wanting to assess. I think parents sometimes they want to talk about their concerns and the anxieties they experience so we kind of miss that, we don’t address that a lot of the time and it can set off a chain reaction for the whole future because a shunt is for life and sometimes when you set that of bad it can run the whole experience bad over a long term’. *Admission 5, senior doctor*$_1$

In summary, there were similarities and differences between parents’ and health professionals’ perceptions in relation to the barriers and levers that facilitated or hindered effective parent-professional collaboration. Effective parent-professional collaboration appears not only to be influenced by the actions of health professionals but their beliefs about the meaning of collaboration. The recorded interactions provided evidence of practice that is collaborative in nature. There was also evidence of practice not being collaborative in nature which was more likely to occur in situations when parents rejected professionals’ judgements about the cause of the child’s symptoms or treatment decisions.

4.7 Discussion

This section will discuss, explain and contextualise the nature of parent-professional interactions in the context of diagnosing shunt malfunction identified in the study findings and by making links to the wider literature.

4.7.1 The nature of parent-professional interactions

Current health policy advocates a model of care delivery that is participatory and collaborative in nature (DH 2001a, DH 2005a, 2005b, 2007, 2009). Integral to the concept of patient collaboration are the interactions that occur between patients and health professional (Drew et al 2001). The quality of these interactions can influence the effectiveness of information exchange, the development of patient-professional relationships, rapport building and the way care is negotiated at each stage of the care pathway (Gordon et al 2009). The literature review presented in Chapter 2 identified that parents' perceived that building effective relationships and working collaboratively with health professionals was essential to the management of their child's condition (Balling and McCubbin 2001, Ray 2003, Maltby et al 2003, Dickinson et al 2006, George et al 2006, Nuutila and Salanterä 2006, Miller et al 2009). Incorporating CA into the methods adopted in the study presented in this chapter offered a way to explore how collaboration operated in practice and identified patterns of behaviours within parent-professional interactions (Drew et al 2001).

Collaboration in health care consultations is more likely to occur during sequences relating to treatment planning which is usually the final activity within the consultation because patients and professions are orientated towards treatment plans having joint responsibility (Robinson 2003, Stivers 2006). The evidence relating to parent-professional encounters has identified that parents do not typically respond to the delivery of the diagnosis and accept professionals' judgements with minimal utterances, whereas parents actively respond to treatment decisions (Stivers 2006). In the study presented in this chapter, collaborative processes were evident in the findings of the interactional data. However, findings differed from those described in Stivers' (2006) study; first, parents contributed to diagnostic sequences, and although their contribution was

more likely to be in response to an explicit invitation from health professionals, they also offered possible causes for their child's illness symptoms. Second, parents were as likely to reject as accept health professionals' judgements in relation to the possible cause for the child's illness symptoms. Third, parents were more likely to accept care plans offered by health professionals and when this occurred there was minimal input from parents. Differences in the findings may reflect different care context, parents in this study had vast experience of their child's condition; whereas Stivers' (2006) study of the negotiation of treatment decision between doctors and parents although related to acute care encounters, the encounters were for new health problems. In addition, in the findings of the study presented in this chapter, the final sequences within the parent-professional interactions related to planning investigations in order to establish a diagnosis rather than offering a definitive treatment plan.

Resistance to treatment decisions, whether active or passive is problematic, not only in terms of the interactional consequences but can influence the outcome of the interaction (Stivers 2006). The interactional consequences result in health professionals' constructing subsequent turns explicitly aimed at securing acceptance of prior treatment offers which parents may continue to resist. Evidence suggests this resistance influences health professionals' behaviours for example doctors prescribing treatments such as antibiotics that may not be appropriate (Schwartz et al 1997, Butler at al 1998). Although relating to establishing the cause of illness symptoms findings from the interactional data from the study presented in this chapter provided evidence of tensions within the interactions when parents resisted professionals' judgements. Analysis of subsequent sequences did not identify this resistance influenced treatment plans. This was reflected in the follow-up interviews were the life threatening nature of shunt malfunction appeared to be the influencing factor in relation to care planning. However, parents who did not feel their views were valued were more likely to have disagreed with professionals' judgements about the cause of their child's illness symptoms.

4.7.2 Parent-professional collaboration when establishing a diagnosis of shunt malfunction

The findings of the study presented in this chapter identified the importance of parent-professional collaboration when establishing a diagnosis of shunt malfunction in children. In this clinical context, there was evidence parents knowledge of their child and previous experience of shunt malfunction was used along with the clinical assessment when health professionals' made a judgement about the child's illness symptoms. However, the process of including parents was not always transparent; health professionals' perceived that they included and valued parents' contribution to care decisions, while parents did not always perceive that their contributions were valued. These findings were consistent with the findings of the literature review (Chapter 2), which identified parent-professional collaboration was variable (Bailing and McCubbin 2001, Maltby et al 2003, Ray 2003, Fawcett et al 2005, George et al 2006, Nuutila and Salanterä 2006, Sullivan-Bolyai et al 2006).

Although collaboration was a desirable goal for parents and professionals, the findings from the study presented in this chapter suggest the meaning of collaboration was variable and often contradictory. The range of terms used to describe parent involvement and a lack of clarity in relation to the meaning of terms such as shared decision-making and collaboration, outlined in Chapter 1, Section 1.6 may hinder professionals' ability to meaningfully apply these concepts in practice. Lack of understanding and commitment to using a collaborative framework to underpin care delivery and parents' and health professionals' differing views of collaboration may account for the variations in practice, and parents' dissatisfaction when interacting with health professionals (Kawick 1996, Mead and Bower 2000, Bruce et al 2002). Shared decision-making where information is exchanged about treatment preferences to reach an agreement on a plan of care, assumes a range of treatment choices exist (Charles et al 1997). When a child presents with potential shunt malfunction the priority of care is to reach an accurate diagnosis rather than planning treatments. Findings from the study presented in this chapter suggest collaboration in this clinical context is not about shared decision-making in relation to treatments but about the value health professionals' place on parents' experiences, and the way

these experiences are incorporated into clinical decision making. As collaborators in their child's care parents' expected to be included at each stage of the care pathway; health professionals' perceived involvement to occur primarily at the information gathering and treatment planning stages.

Collaboration when diagnosing shunt malfunction is based on health professionals' valuing parents contribution to care in relation to three domains; 'knowledge of their child', 'experiences in detecting shunt malfunction', and 'as the expert in their child's care'. Valuing parents across these domains may enable professionals to move from a position of care prescriber to one of collaborator. The findings in the study presented in this chapter identified a range of actions that participants' perceived would facilitate collaborative practice. These were active listening, establishing rapport, enabling parents to express their opinions, effective information sharing, mutual care planning and establishing parents' desired level of involvement. These were similar to the findings identified in the literature review (Chapter 2), where a range of levers and barriers were identified in relation to involving parents in care including information provision and developing effective relationships between parents and professionals (Bailing and McCubbin 2001, Swallow and Jacob 2001, Fawcett et al 2005, George et al 2006, Nuutila and Salanterä 2006). Collaboration and the expert parent will be further explored in Chapter 5, Section 5.3 when the findings from the empirical studies reported in this chapter and Chapter 3 are drawn together.

4.8 Issues of rigour

Chapter 3, Section 8, outlined the application of the terms reliability and validity to establishing rigour in qualitative research findings. This next section will describe the measures employed to ensure the study findings presented in this chapter are valid and reliable. In addition the transferability of the findings to other settings will be discussed. Personal perspectives which have influenced the study findings are discussed in the final chapter (Chapter 5, Section 5.4).

4.8.1 Validity

Establishing the validity of the findings of the study presented in this chapter related to applying the analytical methods for each element of the data comprehensively and systematically in order to ensure they were based on a critical investigation of the data. Validity was achieved by:

- Detailed analysis and comparison of all cases identified in the interactional data relevant to the study, using recognised procedures associated with CA (Silverman 2005). Transparency of these procedures is evident by tabulating the different patterns of interactions that emerged (Tables 13,14 and 15) and providing in-depth narratives of the illustrative cases;
- Ensuring the interview schedule was used flexibility in order to obtain data of sufficient depth and relevance (McCann and Clark 2005);
- Audio-recording the interviews enabled the interviews to be transcribed verbatim, the accuracy of transcriptions was checked by comparing transcriptions with the audio recordings (Tuckett 2005);
- Representing the range of participant perspectives was achieved by actively seeing out similarities and differences across participants' accounts prior to developing the final themes and concepts (Tuckett 2005);
- Using rich and thick extracts enables the reader to evaluate whether the findings accurately reflect the data (Slevin 2000, Tuckett 2005).

Strategies used to reduce research bias such as engaging with other researchers have been outlined in Chapter 3, Section 3.8, and were maintained when undertaking this study. Research supervisors had a key role in relation to ensuring biases were reduced. This included reviewing: the transcripts of the pilot interactions in order to reach an agreement about the sequences of talk of analytical interest to the study; the five follow-up interview transcripts used to develop the coding index in order to reach a consensus about the appropriateness and meaning of categories prior to applying the coding index across transcripts. In addition to the measures described the interactional data (audio-recordings) along with the CA transcripts and preliminary analysis for the cases of interest were verified by an experienced CA researcher. This was essential to the validity of the interactional data. It was not possible to use data sessions (where a group of CA researchers work on common data to ensure accuracy of transcriptions and analysis) because the ethical committee required assurances that access to the data were limited to the research team.

4.8.2 Reliability

Data triangulation and auditing the decision trail are associated with demonstrating the reliability of qualitative research findings (Long and Johnson 2000). In relation to the study presented in this chapter the range of data collection techniques and analytic procedures enabled different aspects of parent-professional collaboration to be explored. The use of multiple data sources enhances the credibility of qualitative research because, as in this study, comparison can be made across findings (Sandelowski 1995, Tobin and Begley 2004). Findings from the different data sets were drawn together to provide a cohesive account of patient-professional collaboration in relation to diagnosing shunt malfunction in children, which adds to the reliability of the findings.

Reliability is dependent on meticulously record keeping and demonstrating a clear decision trail throughout the research and in the case of this study managing different data sets (Sandelowski 1995, Slevin 2000). A research journal was maintained and used as described in Chapter 3, Section 3.8.2. Reflecting on journal entries was an essential part of the iterative processes involved in bringing together study findings and identifying where findings from each of the data sets were affirmed or refuted. Differences and similarities across data sets have been accounted for in the presentation of the study findings (Section 4.6.2). Describing the analytical stages in-depth (Section 4.3.5) enables judgements to be made on the quality of the decisions made during data analysis (Sandelowski 1995, Slevin 2000).

4.8.3 Transferability of the findings

The concepts relating to the transferability of qualitative study findings have been described in Chapter 3, Section 3.8.3. In relation to the study presented in this chapter it is likely the findings represent the participant group because the recruitment criteria were inclusive resulting in a diverse sample. In addition, collecting naturally occurring data reflected real world events. It is likely the findings may be applicable to other settings; for example children with long-term conditions such as diabetes, epilepsy and asthma may also experience life

threatening complications and the explanations of parent-professional collaboration in relation to the expert parent would be equally applicable.

4.9 Ethical issues

The development of study information and consent forms has been described in sections 4.3.2 and 4.4.2 respectively. This section will outline the ethical issues ensuring: consent was an informed choice; participants were treated respectfully and sensitively; the information remained confidential.

4.9.1 Maintaining participants' rights

Prospective participants had the right to decide whether or not to participate in the study. Participants were informed of their right to withdraw from the study at any time without explanation. Details of who to contact if participants had any concerns about the study were provided in the study information leaflets. Parents were informed that any decisions they made in relation to participating or not would not influence their child's care. It was not assumed that once a health professional agreed to participate they would be willing to do so again. A new consent was obtained for each recorded encounter, mostly in writing. It was not assumed that participants who consented to participate in the interactional element of the study would automatically participate in the follow-up interviews. Only those participants indicating a willingness to take part in the interviews on the consent form were contacted to arrange an interview.

4.9.2 Treating participants respectfully and sensitively

Treating participants respectfully included valuing participants' time and commitment to participating in the study and respecting their views (Smith 1992, Kvale 2006). Inconvenience was minimised by undertaking telephone interviews at a time convenient to participants, which included evenings and weekends. Respecting participants' views included ensuring measures were taken to accurately reflect participants' accounts as outlined in Section 4.8. In addition, valuing parents' accounts can be achieved by disseminating study findings (Johnson 2007). To date, dissemination of key findings to health professionals

has primarily been through conference presentations (Chapter 1, Figure 1). However, additional strategies will include: summarising key findings and disseminating to all participants; accepting an invitation to present the findings at the regional neurology seminars; publications in appropriate peer review health related journals.

4.9.3 Maintaining confidentiality

Maintaining confidentiality related to three areas: ensuring participant's personal details remained confidential; maintaining the anonymity of participants when reporting the study findings; storage of audio-recordings and transcripts. Participants were allocated a unique identifier. This was used on all electronic data relating to participants. Pseudonyms were used when referring to participants within data transcripts and when data extracts were used to illuminate study findings. In addition, when participants' referred to each other, the child, professionals and services by name within the interview, these were removed during transcription. Only I held information about participants' identities and contact details. Anonymity is not possible when recording interactional data: the senior nurse gaining consent was aware of the parents and professionals who participated and those involved in the interactions were aware of the other participants. The parent study information leaflets provided information in relation to the members of the healthcare team who would be aware of they had participated in the study.

When not in use the recorder was stored in a locked office on the ward. In adherence with the ethics committee recommendations audio-recordings of the interactions will be destroyed once data analysis is completed and the telephone interview audio-recordings were destroyed within three following transcription. All transcripts will be destroyed within three years after completion of the thesis. All data were stored on a password protected computer. Participants were assured that all data obtained would remain confidential and could only be accessed by members of the research team. Data routinely collected from the ward in relation to the number of children admitted for potential shunt complications were anonymised and referred to by the unique identifier. These

procedures were made clear on the study information leaflets given to all participants.

4.10 Study strengths and limitations

The strengths of this study relate to the rigorous application of methods that enabled an in depth investigation of parent-professional interactions. The use of a range of data and applying complementary analytical methods facilitated different aspects of parent-professional collaboration to be explored. This included identifying the levers and barriers that facilitate effective parent-professional collaboration and participants' perceptions and satisfaction with healthcare encounters. Data elicitation techniques generated rich data which enabled a detailed account of parent-professional collaboration in the context of diagnosing shunt malfunction to be presented. This is a novel study in that no other study appears to be have explored parent-professional collaboration in this clinical context.

There are several limitations to this study. Parents do not reflect the diverse minority-ethnic communities within UK society. There were missed opportunities to capture interactions between parents and nurses; although parents agreed to participate and parent-doctor interactions were recorded, the junior nurses' were reluctance to participate. The ward experienced a particularly high workload during data collection, which resulted in the senior nurse not always being available to approach parents in a timely manner because of other work commitments, resulting in lost opportunities to recruit parents. In addition, the senior nurses used their clinical judgements in relation to approaching parents and reported that in several situations responding to the child's immediate needs prevented them from broaching the subject of the study. Follow-up interviews were not undertaken with two doctors and although they had expressed a willingness to participate in the interview arranging the interview was problematic. One doctor's workload resulted in the interview being postponed on three occasions and eventually abandoned and another doctor's rotational post finished, follow-up contact details were not available. It was not possible to video record the interactions because of the nature of the ward environment. Analysis of non-verbal communication may have added to depth to the analysis of the

observational data. Although developed from two validated tools, the parent and professional satisfaction questionnaires were not validated. Personal experiences may have influenced the study findings and are accounted for in Chapter 5, Section 5.4.1.

4.11 Chapter summary

This exploratory study of parent-professional interactions highlighted the importance of collaboration when establishing a diagnosis of shunt malfunction in children. A significant aspect of managing hydrocephalus in children included recognising illness symptoms indicative of shunt malfunction, which may be unique to individual children, and establishing a definitive diagnosis of shunt malfunction. The life threatening nature of shunt malfunction and unpredictability of symptoms influenced parents' and professionals' actions in relation to managing the child's illness symptoms. Parents would often seek health professional advice and professionals would instigate diagnostic investigations as part of routine care even when they thought it was unlikely the child's shunt was malfunctioning.

Professionals integrated parents' knowledge of their child and experiences of previous shunt related illnesses with the clinical assessment when planning the child's care. However, although health professionals' described valuing parents concerns, parents' perceived that their views were not always valued. Analysis of the parent-professional interactions provided evidence of collaborative processes operating in the clinical setting but there was also evidence of tensions within the parent-professional interactions, particularly when junior doctors were interacting with parents who had considerable expertise in the management of their child's condition. Collaboration in the context of a child presenting with the symptoms that may indicate shunt malfunction is about reaching an accurate diagnosis rather than planning treatments.

Chapter 5:
Thesis discussion and conclusions

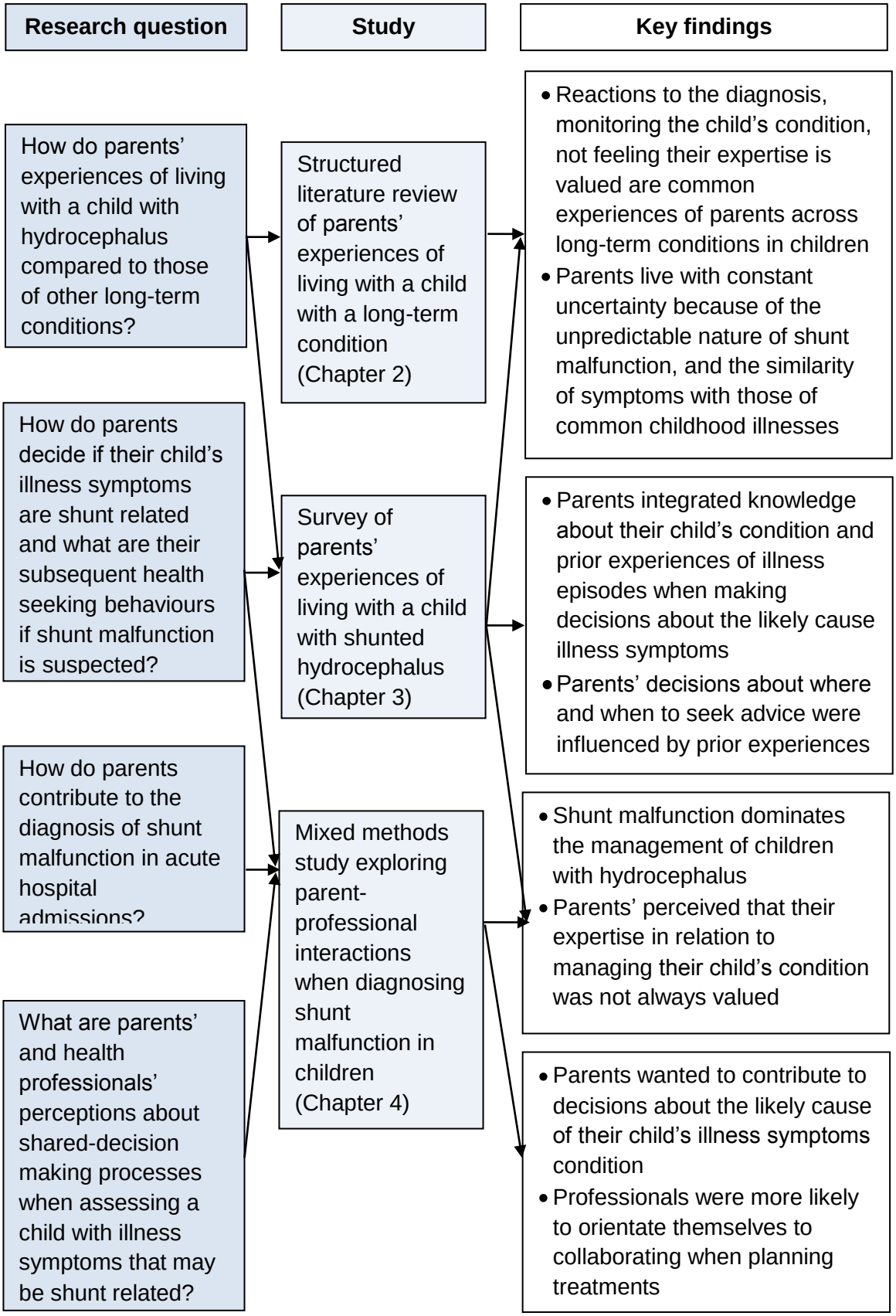
5. Introduction

This chapter draws together the findings from the studies reported in Chapters 2, 3 and 4. First, a summary of the key findings will be presented. Second, an integration of the findings that relate to the development of expertise in parents and effective parent-professional collaboration will be provided. Third, the credibility of the findings will be discussed in relation to the researchers' objectivity and the rigour with which the research was undertaken. Fourth, future directions for policy, clinical practice and research will be indicated.

5.1 Summary of key findings

The work presented in this thesis explored parents' involvement in the care of their child's hydrocephalus and shunt and the ways in which parents and professionals collaborate when making a diagnosis of shunt malfunction in children. The relationship between the studies presented in Chapters 2, 3 and 4, which used different methods of data elicitation in order to achieve the thesis objectives, and the key findings are presented in Figure 36.

Figure 36: Relationship between the research questions, studies and key findings



From the studies presented five key issues emerged. First, parents' reactions to their child's diagnosis, a desire to develop the skills and expertise to monitor and respond to changes in their child's condition and perceptions that health professionals do not always value parents' contribution to care decisions are similar across long-term conditions (Chapters 2 and 3). In addition, a significant feature of living with a child with hydrocephalus was the constant uncertainty associated with the unpredictable nature of shunt malfunction, and the similarity of symptoms with those of common childhood illnesses. For both parents and health professionals recognising shunt malfunction dominates the management of children with hydrocephalus (Chapters 3 and 4). What is important about this finding is the way this dominance affects the behaviours and decisions of parents and professionals. Parents' and professionals' behave in similar ways when making a differential diagnosis. This meant parents sought healthcare advice by accessing secondary care directly and health professionals organised CT scans as part of routine care even when their initial impressions suggested it was unlikely the child's shunt was malfunctioning. Prior to undertaking this thesis my assumptions about parents' lack of knowledge in relation to recognising shunt malfunction and perceiving that there was a need for an intervention to improve parents' knowledge, may be useful to the novice parent but unhelpful to the expert parent. The key message from these findings is that for both parents and health professionals the only reasonable course of action when a child with hydrocephalus is ill is to rule out a malfunctioning shunt.

Second, parents' and health professionals' identified effective communication and collaboration as a means of ensuring optimal care for the child (Chapters 3 and 4). Both parents' and professionals' identified similar strategies for enabling collaborative care, such as information sharing and rapport building. However, there were differences between parents and professionals in relation to when within the care pathway collaboration should occur. Parents wanted to collaborate at both the information gathering and the diagnostic stage. In contrast, health professionals tended to orientate themselves to collaborating during information gathering and when planning treatments. This mismatch may explain the tensions experienced by both parents and professionals in some consultations when parents' disagreed with professionals' judgements.

However, both parents and health professionals recognised that when a diagnosis of shunt malfunction was established the only reasonable course of action was surgical revision of the shunt. The key message from these findings is that for both parents and health professionals establishing a diagnosis of shunt malfunction required working collaboratively but the position in the care pathway were optimal collaboration could occur differed.

Third, the shared decision-making paradigm, where parents and health professionals exchange treatment preferences to reach an agreement on a plan of care, is not a helpful one to guide interactions in this clinical context. As highlighted in Chapter 1, Section 1.4, there is a diagnostic judgement to be made but ultimately only one course of action. When a child presents with potential shunt malfunction the priority is to reach an accurate diagnosis rather than planning treatments. Further, as parents' satisfaction when seeking health care advice for suspected shunt malfunction was linked to the way professionals' engaged and involved them in decisions about the likely cause of illness symptoms, a model of collaboration is more appropriate (Chapters 3 and 4). As highlighted in Chapter 1, Section 1.6, terms used to describe patient involvement are poorly defined; however shared-decision making is primarily geared towards making treatment decisions, whereas collaborative processes can be applied throughout the health care consultation, including establishing a diagnosis. Parents developed considerable expertise in recognising the symptoms of shunt malfunction in their child and were able to distinguish between shunt related illness symptoms and those associated with common childhood illnesses (Chapters 3 and 4). The key message from these findings is that the challenge for health professionals is to integrate parents' expertise with their clinical assessment when planning the child's care.

Fourth, parents' judgements about their child's symptoms and their illness decisions when managing shunt problems were at times influenced by meeting the needs of all the family members (Chapter 3). Parents were constantly balancing the vigilance needed to identify signs of shunt malfunction with living a 'normal' family life. The key message from this finding relates to health professionals' judgements about parents' management of their child's

hydrocephalus needs to take into consideration this social context in order to collaborate effectively with parents.

Fifth, living with a child with hydrocephalus is a life-long dynamic experience (Chapters 3 and 4). Parents are constantly adapting, changing and learning. Health professionals only ever have a snap-shot view of the child and family's life, encountering many different children and families during their clinical practice (Chapter 4). The key message from these findings is that it is unclear what aspects of these differing perspectives can be integrated to improve a joint understanding of the condition.

The key findings outlined add to the empirical body of knowledge about parents' experiences of living with a child with a long-term condition and parent-professional collaboration. To-date research exploring patient-professional interactions has been primarily undertaken with adult patients. The second empirical study undertaken as part of this thesis is a novel study, in that no other study appears to have incorporated a micro-interactional element alongside broader qualitative methods to explore parent-professional interactions in this clinical context and in relation to the child with a long-term condition. In addition, this thesis contributes to the body of literature relating to qualitative research methods; two papers have been published (Chapter 1, Section 1). The first adds to the debates about theoretical versus pragmatic design challenges when undertaking qualitative research; the second provides a working example of the application of the framework approach. A third paper, in progress, is focusing on the challenges of interviewing parents together when exploring their experiences of family life.

5.2 Revisiting expertise in parents

From the preceding section a fruitful direction to improve services for parents living with a child with a long-term condition is to consider the integration of parents' expertise with that of the healthcare team. The following section will revisit the concept of the expert parent.

Findings from literature review (Chapter 2) identified that parents develop considerable expertise in managing their child's long-term condition (Gibson 1999, Bailing and McCubbin 2001, Dickinson et al 2006, Ray 2003, Kirk et al 2005, Nuutila and Salanterä 2006, George et al 2006, Cashin et al 2008, Hewitt-Taylor 2009, Miller et al 2009). Through experience parents are responsive to their child's needs and provide highly individualised care; this was not always possible when the child was hospitalised and care was delivered by health professionals (Bailing and McCubbin 2001, Ray 2003, Kirk et al 2005). The process of developing this expertise was described as blending knowledge and skill acquisition with experiential knowledge in order to adapt to changes in the child's condition (Bailing and McCubbin 2001, Kirk et al 2005, Cashin et al 2008). Findings from the studies undertaken as part of this thesis (Chapter 3, Section 3.7 and Chapter 4, Section 4.7) suggest that becoming an expert parent in relation to recognising and responding to illness symptoms involved the process of integrating knowledge of hydrocephalus and its treatment with the child's usual behaviours and prior experiences of illness episodes in the child. For some parents this integration of knowledge and experience when differentiating between general illnesses and shunt malfunction became intuitive.

Most of the expert patient literature refers to the patients' self management of their condition, where perceived self-efficacy improves individuals' confidence to manage their condition effectively and make informed health decisions, and does not relate to parents' making decisions on behalf of their child (Lorig and Holman 2003, Bury et al 2005, Foster et al 2007). In this situation the parent is akin to the professional, caring for another. In this context, what is missing is explaining how a parent moves from a novice to an expert in relation to managing their child's condition. In the absence of any descriptions within the literature relating to the process of becoming an expert parent, findings from studies undertaken as part of this thesis are now compared to the seminal work of Dryfus and Dryfus (1986). Drawing on their observations of the way highly skilled individuals from chess players to airline pilots operated, they developed a five-stage typology relating to developing expert practice: the novice, advanced beginner, competent, proficient and expert. These stages are not exhaustive but represent how individuals with limited experience, the novice, operate by mastering

technical skills with the aim to accomplish immediate goals, through to the expert, where knowledge and experiences are applied differently depending on situational contexts, often working from intuition. Moving from a novice to expert is not solely achieved by gaining experience and knowledge but is a process of change and developing the skills to critically analyse new situations and effectively problem-solve (Dryfus and Dryfus 1986). The novice to expert model has been used to explain the development of health professionals from the newly qualified practitioner to the expert practitioners, particularly within nursing (Benner et al 1996). Unlike beginners who rigidly apply rules, theories, protocols and procedures to guide practice, expert practitioners work more intuitively (Dryfus and Dryfus 1996).

From the data presented in Chapters 3 and 4, there are examples of parents moving through these stages. Constantly being alert for shunt related illness symptoms and the frequency of hospital admissions for possible shunt malfunction resulted in parents developing considerable experience in managing their child's condition. For some parents this included being able to distinguish between the symptoms of shunt malfunction and those indicative of common childhood illness. These parents described being attuned to the specific and often subtle cues in their child that indicated a problem with the shunt. In addition, making a differential diagnosis in relation to illness symptoms being shunt related or not were often based on intuition. For parents living with a child with complex needs these skills appeared to be highly developed. Parents' described with detailed precision subtle differences in the presentation of similar symptoms that were caused by different conditions; for example the difference in headaches that were the result of migraine and those that were more likely to be shunt related. It is unlikely all parents become experts; whilst for others there is a need to support them to develop the expertise to effectively manage their child's care.

Taking this approach further, tentative links with the concepts of 'novice', 'competent' and 'expert' might be a useful way of explaining parents' responses and actions when identifying shunt malfunction. At the time of diagnosis parents appear to operate at the level of novice, where they focused on gaining

information about their child's condition and being hyper-vigilant in observing their child for signs of shunt malfunction. Parents were reliant on written information that listed the symptoms that might indicate shunt malfunction and would seek advice based on written and professional guidance. Parents were more likely to defer decisions about their child's care and treatment to health professionals.

In contrast, competent parents were able to build on experiences of illness episodes in their child and appeared more proficient in identifying symptoms of shunt malfunction specific to their child. Through these experiences and detailed knowledge of their child's development parents' learned to differentiate between childhood illnesses and shunt malfunction. These parents were less likely to rely on written lists, being more inclined to understand and interpret their child's responses to illness. These competent parents were likely to seek advice from healthcare professionals to confirm their assessment of the likely cause of their child's illness symptoms.

Expert parents appeared confident in their ability to identify shunt related illness symptoms and trusted their own judgments, which were often based on tacit knowledge. These findings are similar to a longitudinal study that explored how mothers living with a child with a long-term condition developed the necessary expertise to meet their child's needs and became empowered when consulting with healthcare professionals (Gibson 1999). Findings from Gibson's (1999) study indicated that mothers, through realising they had intimate and detailed knowledge of their child and child's condition, began to trust their own judgements when identifying and responding to illness symptoms in their child. If necessary the mothers' challenged health professionals' assessments and decisions. The notion of the 'expert mother' was linked to the process of empowerment and the concept of critical reflection (Gibson 1999). Within the context of this thesis the potential life threatening consequence of shunt malfunction appeared to be the catalyst for developing the expertise to manage the child's condition. In other contexts, frustrations when interacting with health professionals and securing appropriate services to meet their child's needs were

the catalyst for developing the expertise to manage their child's condition (Gibson 1999, Dickinson et al 2006).

Expert parents are highly attuned to changes in their child which develops from having a detailed understanding of the child's specific behaviours, skills and developmental stage. Reframing parents as experts in diagnosing their child's problems may explain parents' difficulties in articulating how they know something is wrong with their child. Expert parents appear to function in a similar way to expert practitioners who operate at sub-conscious levels. Expert practitioners simultaneously draw on prior experiences and assimilating new experiences into the sub-conscious and are attuned to subtle changes that suggest the patient has an unmet need (Dryfus and Dryfus 1996).

5.3 Enabling collaboration between expert parents and professionals

Understanding the nature of 'expert parents' in terms of the attributes that constitute becoming an expert, and the ways health professionals engage with and incorporate expert parents' opinions into care decisions when working with children with long-term conditions may facilitate better parent-professional engagement and collaboration. The literature review (Chapter 2) identified that parents have an overwhelming desire to work collaboratively with health professionals based on the premise this will facilitate the best care for their child and optimise their child's health (Bailing and McCubbin 2001, Ray 2003, Kirk et al 2005, Dickinson et al 2006, George et al 2006, Nuutila and Salanterä 2006, Cashin et al 2008). Parents' perceived that effective parent-professional collaboration would result in a process of negotiation and involvement in decisions about their child's care (Fawcett et al 2005, Dickinson et al 2006). However, there was variability in relation to parent-professional collaboration with some parents' perceiving that their expertise and contribution to care was not valued (Bailing and McCubbin 2001, Ray 2003, Maltby et al 2003, Fawcett et al 2005, George et al 2006, Nuutila and Salanterä 2006, Sullivan-Bolyai et al 2006).

Embedded within current UK health policy is the notion of choice, particularly treatments choices, which requires patients to become active collaborators in

care decisions (DH 2001a, 2005a, 2007, 2009). There are difficulties in operationalising this policy: treatment choices are not always a reality; there are likely to be variations in patients' desires to be actively involved in care decisions; health professionals' may not have the pre-requisite skills to engage collaboratively. Although parent-professional interactions take place they may or may not be collaborative in nature. The current emphasis on shared decision-making primarily centres on treatment decisions and for the clinical context of interest in this thesis may be focussing on the wrong part of the care pathway. In this context collaboration is not about treatment preferences but the accuracy and comprehensiveness of the information required to make good clinical judgements and an accurate diagnosis.

Collaboration, when the patient is a child, involves engaging with and developing effective relationships with parents. Findings from the literature review (Chapter 2) highlighted that the quality of parent-professional relationships was variable and the process of developing effective relationships with health professionals can be stressful for parents (Balling and McCubbin 2001, Swallow and Jacob 2001, Ray 2002, Dickinson et al 2006, Nuutila and Salanterä 2006, Miller et al 2009). Developing effective parent-professional relationships has been described as an evolving process that is initially professionally dominated but through time moves to one of collaboration (Dixon 1996). It is likely that parents move from a professionally dominated to a collaborative model of care in parallel with moving from the novice to expert as described in the preceding section. Decision-making is a model of care lying within the professionals' domain (Dixon 1996). In contrast, decision-making that occurs in collaborative with the patient becomes a shared venture (Cahill 1996, Dixon 1996). Parents and professionals may find their relationships are challenged as the balance of power shifts from a professionally dominated to a collaborative paradigm.

A collaborative paradigm is appropriate when engaging with expert parents living with a child with a long-term condition. When parents seek advice from health professionals they bring to the consultation their unique knowledge of their child, and in relation to children with long-term conditions their experiences in managing their child's condition. In contrast, health professionals bring their professional

knowledge, diagnostic reasoning skills, experiences of treatments and responses to treatment from other patients. When making a judgement about the child's illness symptoms, health professionals need to integrate parents' precise and detailed knowledge of their child and prior responses to illness with their own clinical assessment (Pinkus 2006). In the context of the management of the child with shunted hydrocephalus, this can be best achieved by effective parent-professional collaboration, where parents' knowledge and judgements about their child's illness symptoms are combined with the health professionals' clinical assessment.

A recurring finding throughout this thesis related to parents' perceptions that interactions with health professionals were not always collaborative in nature. Although parents were satisfied with the services they received such as having direct access to the children's neurological ward, promptness in organising diagnostic investigations and surgery if the shunt required revising, at times parents' felt they were not listened to and their experiences were not valued. In relation to establishing a diagnosis of shunt malfunction, Chapter 4, Section 4.6.3 collaborative processes such as listening to and valuing parents' experiences, and involving parents in diagnosis and treatment decisions were enabled by the actions and attitudes of health professionals. Effective collaboration involved enabling parents to express their opinions using active listening and responding to parents' concerns, building rapport with parents, valuing parents' knowledge and experiences with effective information exchange and mutual care planning.

5.4 Critical appraisal of methods

The strength of the findings of this thesis are based on the in-depth exploration of parents' management of their child's condition and their interactions with health professionals. However, the extent to which these findings are valid depends on the rigour in which the research was undertaken. The measures taken to ensure the validity and reliability of the findings of each study have been presented in Chapter 3, Section 3.8 and Chapter 4, Section 4.8. This section appraises the researchers' rigour with reference to the measures undertaken to reduce bias in relation to personal influences.

5.4.1 An account of personal biases

Reflexivity and reflection are intrinsically linked to the credibility of qualitative research findings because the actions, decisions and personal beliefs of the researcher impact on the way the research methods are employed and meanings are constructed from the data (Sandelowski 1993, Cho and Trent 2006, Bradbury-Jones 2007). Reflexivity is the processes of bringing forward and accounting for preconceived assumptions (Freshwater and Rolfe 2001, Dearnley 2005). Becoming a reflexive researcher requires the ability to critically reflect on personal values and preconceptions relating to the study focus (Cho and Trent 2006, Bradbury-Jones 2007).

Researchers' assumptions about the world and their beliefs broadly relate to the paradigms of positivism, constructivism, advocacy and pragmatism (Creswell 2008). Prior to undertaking the work for this thesis, I would have positioned myself as a pragmatist, where the prerequisite desire for knowledge was based on finding solutions to problems. This position emerged from over ten years clinical experience of caring for children with acute care needs. The nature of the child's presenting condition resulted in service and care delivery being action orientated; for example the care of children with hydrocephalus focussed on the child's immediate assessment and ensuring prompt treatment for the child with a malfunctioning shunt. I presumed the issue of recognising shunt malfunction in children could be addressed by developing parents' skills and knowledge in relation to identifying whether illness symptoms were a result of a common childhood illness or shunt malfunction. The solution was to develop, test and implement a decision aid for parents.

During the early stages of undertaking this thesis, through supervision meetings and exploring the literature, my initial assumptions were challenged which changed the focus of this thesis. Although remaining fundamentally a pragmatist, viewing parents' experiences through a constructivist lens not only resulted in a greater understanding of parents' experiences of living with a child with hydrocephalus, but a realisation that valuing their experiences could impact on the way health professionals' collaborated with parents. During the analysis of parents' accounts of living with a child with hydrocephalus it became apparent

that parents developed considerable skills in relation to recognising shunt related illness symptoms in their child. In addition, there were a range of factors that influenced parents' decisions when seeking health care advice. Exploring parents and health professionals contribution to the diagnosis of shunt malfunction, rather than testing a decision aid that would assist parents with recognising shunt malfunction as originally planned, was more appropriate in this clinical context. Findings from the study presented in Chapter 3 identified that parents' perceived that their ability to contribute to care decisions was not always valued. This finding influenced the methods undertaken in the second study undertaken as part of this thesis, presented in Chapter 4, which included collecting and analysing observational data in order to explore in-depth parent-professional interactions as they occurred in the clinical setting. Decision aids are designed to help patients understand treatment options when there is more than one reasonable choice, and are therefore not appropriate in the context of shunt malfunction (O'Conner et al 2009).

Becoming a reflexive researcher was enhanced by having two experienced supervisors from different professional backgrounds with a wide range of research experiences. Through monthly supervision meetings, where open dialogue was encouraged, my established perspectives were challenged resulting in a more critical approach to undertaking the empirical studies undertaken as part of this thesis. In addition to the supervisors' role in developing the skills the novice researcher requires to become an analytical critical thinker (Li and Seale 2007), they had a key role in relation to ensuring the credibility of the studies undertaken by challenging decisions and assumptions (Holloway and Wheeler 2002). This was particularly important during data analysis when interpretations were discussed and debated until a consensus was reached that reflected a shared understanding of the data (Mays and Pope 1995).

Engaging with other researchers, including supervisors, was not only beneficial in relation to challenging assumptions about study findings but also in enhancing my personal development. A range of opportunities were available to engage with other researchers whilst undertaking this thesis including: research seminar

presentations with the School of Healthcare; national and international conference presentations; discussions with colleagues (clinical practitioners, other doctoral students). These opportunities facilitated the development of alternative ideas that ultimately shaped the study findings. Knowledge and skills in the application of research methods were developed by undertaking a post-graduate certificate in research, a Masters level qualitative methods module, and specific skills training such as NVivo and CA workshops (Appendix V).

5.4.2 An account of research methods biases

Reflection is the process of evaluating the research methods employed and considering the changes that would be made if the study was repeated or a similar study was undertaken (Carolan 2003, Hand 2007). Measures taken to reduce researcher bias in relation to the development of the interview schedules and patient satisfaction questionnaires have been outlined in Chapter 3, Section 3.4 and Chapter 4, Section 3.5. Adopting qualitative methods resulted in direct involvement with participants when gathering data and becoming immersed in the data during analysis. Concerns about personal influences related to: the impact of my own professional socialization and unique perspectives of caring for children with shunted hydrocephalus in relation to data collection and analysis; reconciling tensions between the professional and researcher role. However, familiarity with the context of the study facilitated the collection of rich data because I was able to be responsive to participant cues and explore new avenues of enquiry as necessary within the interviews.

Engaging with families when undertaking interviews in the family home has been described as chaotic and complex (MacDonald and Greggans 2008). The competing demands of trying to be a competent researcher and collecting meaningful data while responding to the environment were at times emotionally, physically and intellectually challenging. Interruptions and distractions such as children being present throughout the interview were common. Contingency plans for these events had not been considered in advance but ultimately disruptions have to be accepted as part of being a guest in the family home. Flexibility in relation to managing disruptions was essential and contributed to establishing a rapport with the family (MacDonald and Greggans 2008). At times

disruptions resulted in difficulties in remaining focussed and it was necessary to take stock and go through the interview schedule to regain focus and redirect questions. Continuing with the interview if one parent left the room was always a dilemma and required decisions to be made in the field, which were influenced by the timing of the interruption and being receptive to the family needs, such as meeting any time constraints parents had expressed.

In many ways engaging with family life, such as conducting interviews while playing games with children, became part of the natural flow of the interview process and added to gaining a deeper understanding of participants in the context of everyday family life (MacDonald and Greggans 2008). Entering the family home is a privilege and I found the experience a humbling. For example parents' accounts were often emotive particularly in relation to coping with uncertainty in relation to their child's condition. In addition, the overall warmth, humour and the receptiveness towards meeting their child's needs had a lasting impression. This counterbalanced the sometimes negative attitudes of living with a child with chronic illness that is portrayed in the literature (Green 2007).

In contrast, the telephone interviews were not subjected to the disruptions experienced with the face-to face interviews. It was easier to simultaneously follow the interview schedule, record notes and redirect questions in response to participants' answers. This was achieved at the expense of developing a rapport with participants because non-verbal communications such as eye contact were absent. Data obtained were highly focused but may have lacked depth.

Although supporting the position that the researcher should not influence the data by engaging in open dialogue about their personal opinions of topics under discussion, reciprocal conversations can be appropriate when the researcher has the ability to offer support (Wilde 1992, Carolan 2003). Tensions between the professional and researcher role were uncommon and related to information provision. For example a parent enquired if I was aware of any services for children who have needle phobia. This straight-forward request for information was within my domain of expertise; answering did not compromise the researcher role.

Over-immersion in the research setting can result in difficulties in remaining objective and an inability to critically analyse the data in-depth in order to fully explore participants' accounts (Robinson and Thorne 1988, Dearnley 2005). Familiarity with the context of the study hindered the initial stages of the analysis. My own professional socialisation and clinical experiences resulted in preliminary analysis being inflexible and driven by a medical approach to exploring the data. Undertaking qualitative data analysis shared similarities with the experiences of other novice qualitative researchers (Li and Seale 2007). The process of attaching labels to preliminary codes was initially abstract in nature and did not fully represent the extracts from which they were derived. There was a gross underestimation of the time required to undertake the early stages of the analysis. Yet these stages are essential if the findings are to be credible. Working with supervisors was invaluable because they challenged decisions at each stage of the analysis. Asking 'what are participants' really describing' when considering units of data and using participants' own words assisted with ensuring the labels attached to the data reflected participants' accounts.

5.5 Study implications and future directions

To-date concepts relating to parent-professional collaboration in the context of parents living with a child with a long-term condition are poorly described. Understanding how parents develop expertise in relation to managing their child's condition and the ways health professionals' engage with and incorporate expert parents' opinions into care decisions when working with children with long-term conditions may facilitate better parent-professional collaboration. Current health policies espouse a model of care delivery based on effective parent-professional engagement and collaboration (DH 2001a, DH/DfES 2004, DH 2005a, 2005b, 2007, 2009). In the context of long-term conditions, engaging effectively with patients is centred on the concept of shared decision-making to be enacted through the expert patient agenda.

The implications from the findings of the empirical studies undertaken as part of this thesis relate to policy, education and practice. First, health policy should take into account that a shared decision-making paradigm is not appropriate in all clinical contexts. Findings from the study presented in chapter 4 suggest a

model of collaboration is more appropriate when there is uncertainty in relation to the cause of illness symptoms and no treatment choice exists. Furthermore, the shared decision-making model has not been widely translated into practice, partly because the clinical environment is not always conducive to providing information in a timely and unhurried manner and health professionals' lack the skills to facilitate a process where there is equity in the decision-making process. In contrast a model of collaboration, where the focus is on information exchange in order to reach an agreed plan of care may be more appropriate.

Second, integral to the concept of patient collaboration are the interactions that occur between patients and professionals. Effective patient communication is a core professional and clinical skill and the quality of these interactions can influence the effectiveness of information exchange and the development of patient-professional collaboration. While recognising communication skills training is a mandatory element of health professional education, greater focus could be placed on exploring professionals' attitudes and beliefs about the purpose and value of effective patient-professional engagement and collaboration. As highlighted in chapter 4, health professionals' perceptions about the purpose of working in partnership and collaborating with parents was dominated by a belief that the goal was to obtain consent for treatments and adherence to care plans. Education programmes could strengthen the inclusion of parents' viewpoints as a way of addressing the ongoing disparity between parents' and health professionals' perceptions of parental involvement and collaboration.

Third, findings from the studies presented in Chapters 2, 3 and 4 highlight parents' and professionals' perceive that the implementation of parent-professional collaboration is variable. This may be due to a lack of shared understanding of concepts relating to parent-professional engagement and collaboration. Engaging effectively with parents has mutual benefits in that health professionals' rely on parents' knowledge of their child when determining the cause of illness symptoms and to implement and monitor treatment plans. Similarly, parents' expectations of being involved in decisions about their child's care will be realised. Healthcare practice needs to identify ways of addressing

the variability in relation to professionals' willingness to collaborate with parents, particularly in situations when parents' viewpoints are incongruent with their own.

Based on these implications a possible programme of research exploring parent-professional collaboration in the context of long-term conditions in children is proposed and presented in Figure 37.

Figure 37: Parent-professional collaboration: future research directions

Research focus	**Research methods**
Identify the similarities and differences between parents' and health professionals' perceptions of the meaning of parent-professional collaboration in the context of living with a child with a long-term condition	Participatory action research using mixed methods such as a concept analysis, Delphi study and focus groups
Evaluate the current provision of self-management programmes for parents living with a child with a long-term condition and explore parents' uptake, experiences and perceptions of these programmes	Survey of self-management programmes using questionnaires, interviews
Develop and evaluate a training programme for health professionals centred around the concepts of collaborative practice and the acquisition of the skills required to effectively engage with parents	Appreciative enquiry and evaluation
Develop and pilot a tool to measure collaborative practice, and evaluate whether the implementation of a model of collaborative care could improve parent-professional collaboration in clinical practice	Mixed methods such as observation, questionnaires, individual interviews

5.6 Conclusion

In summary, the research presented in this thesis revealed that parents living with a child with hydrocephalus gain considerable experience in managing their child's condition. More specifically they are able to distinguish between the symptoms of shunt malfunction and common childhood illness in a way that is similar to specialist professionals reaching a diagnosis. The uncertainty associated with shunt malfunction influenced parents' decisions about when and where to seek healthcare advice.

When interacting with health professionals there was evidence of collaborative practice. However, there was also evidence of parent-professional interactions which were not collaborative in nature. There appears to be a disparity between parents' expectations when consulting with health professionals in relation to suspected shunt malfunction and practice. Collaborative practice, when parents' knowledge and expertise enables them to operate at the level of expert and challenge health professionals' judgements, appears difficult for some health professionals, which impacts on the effectiveness of parent-professional interactions. Further research exploring the reasons for this disparity between parents' and professionals' perceptions of collaborative practice is warranted. The development and evaluation of interventions aimed at enhancing collaborative communication at each stage of the care pathway are required.

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Appendix I: Scoping review findings

In preparation for undertaking this PhD a scoping review was undertaken to identify empirical studies about parents' experiences of living with a child with shunted hydrocephalus and/or parents' involvement in their child's care. Medline, PSYCINFO, ASSIA, EMBASE, BNI and CINAHL data bases were searched from January 1995 to December 2003. The searches were re-run frequently, until December 2009. An illustration of the search strategies, using Medline, is presented in the example below. Additional search strategies included accessing the web of science search engine, public health electronic library, the ASBAH national resource centre, SIGLE and Google scholar.

Medline data base via OvidSP host system: January 1995- December 2009		
Final update 6/1/2010		
Search terms		**Results**
1	hydrocephalus or hydrocephaly mp. [mp=title, original title, abstract, name of substance word, subject heading word, unique identifier]	8506
2	shunt* or cerebrospinal fluid shunt* or ventricular shunt*	22762
3	1 and 2	3421
4	(parent* or mother* or father* or famil* or guardian* or carer* or foster*).mp. [mp=title, original title, abstract, name of substance word, subject heading word, unique identifier]	601161
5	(child* or paediatric or pediatric or daughter or son).mp. [mp=title, original title, abstract, name of substance word, subject heading word, unique identifier]	680504
6	4 and 5	142670
7	3 and 6	105
8	(experience* or perception* or view* or thought* or attitude* or perspective*).mp. [mp=title, original title, abstract, name of substance word, subject heading word, unique identifier]	772340
9	involvement or participation or collaboration or partnership	229047
10	interact* or communicat*or information or information provision	501090
11	shared-decision making	963
12	8 or 9 or 10 or 11	1398425
13	7 and 12	26
14	limit 13 to (english language and humans and yr="1995 - 2009")	18

A total of 32 papers were identified from the data base searchers potentially relevant to the focus of this thesis. Six related to quality of life of children with spina bifida and hydrocephalus and two evaluated health service provision for

children with hydrocephalus. The remaining studies described treatment options or the long-term outcomes for children with shunted hydrocephalus in relation to physical disabilities, learning difficulties and behavioural problems. The studies identified were not directly related to the focus of this thesis but did inform the background context to the studies undertaken as part of this thesis

No empirical studies were identified from the web of science and public health electronic library searches. One study was obtained from the ASBAH national resource centre, an empirical study exploring the impact of living with a child with spina bifida and hydrocephalus, and although informative focussed on the impact of the child's physical limitations for the child and family.

Findings from the scoping review suggested there to be a paucity of studies relating to parents' experiences of living with a child with hydrocephalus. In addition no studies were identified in relation to parent-professional interactions in the context of shunt malfunction.

Appendix II: Search Strategies

Medline, PSYCINFO and CINAHL databases were searched between January 1999 and December 2009. The same search terms were applied for Medline and PSYCINFO but modified for CINAHL because it is accessed via a different host system. An illustration of the search strategies, using PSYCINFO as the example, is presented below.

PSYCINFO data base via OvidSP host system: January 1999- December 2009		
Final update 6/1/2010		
Search terms		**Results**
1	(parent* or mother* or father* or famil* or guardian* or carer* or foster*).mp. [mp=title, original title, abstract, name of substance word, subject heading word, unique identifier]	413721
2	((long-term or long-term or chronic or disabling or long-standing or long standing) adj (disease or illness or condition*)) [mp=title, original title, abstract, name of substance word, subject heading word, unique identifier]	11559
3	complex needs	372
4	medically fragile	81
5	2 or 3 or 4	11994
6	(child* or paediatric or pediatric or daughter or son).mp. [mp=title, original title, abstract, name of substance word, subject heading word, unique identifier]	458238
7	1 and 5 and 6	2019
8	(experience* or perception* or view* or thought* or attitude* or perspective*).mp. [mp=title, original title, abstract, name of substance word, subject heading word, unique identifier]	976522
9	((parent* or mother* or father* or famil* or guardian* or carer* or foster*) adj2 (experience* or perception* or view* or thought* or attitude* or perspective*s)).mp. [mp=title, original title, abstract, name of substance word, subject heading word, unique identifier]	34350
10	7 and 9	336
11	limit 9 to yr "1999 -2009"	202
12	limit 10 to “childhood or adolescence”	119
13	limit 12 to “English language”	113
14	limit 13 to "empirical study"	102

Results of search: 158 Medline, 102 PSYCINFO, 96 CINAHL (Total 356)

Appendix III: Assessment of the quality of the papers based on CASP tool

Author/s	CASP appraisal tool criteria for qualitative studies									
	Clear Aims	Methods appropriate	Appropriate recruitment	Appropriate data collection	Rigor of data analysis	Researcher influences considered	Clarity of the findings	Interpretations justified	Transferability	Relevance
[1]Balling Mc. (2001)	✓	✓	✓	✓	P	×	✓	×	✓	✓
Bowes et al (2009)	✓	✓	✓	✓	P	×	✓	✓	✓	✓
Callery et al (2003)	✓	✓	✓	✓	P	×	✓	✓	✓	✓
Cashin et al (2008)	✓	✓	✓	✓	✓	×	✓	×	✓	✓
Dickin. et al (2006)	✓	✓	✓	✓	✓	×	✓	✓	✓	✓
Fawcett et al (2005)	✓	✓	✓	✓	×	×	×	×	✓	✓
George et al (2005)	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓

✓ criteria statements met **x** criteria statements not met **p** criteria statements partially met

[1]Mixed-methods or quantitative study

Author	Clear aims	Methods appropriate	Appropriate recruitment	Appropriate data collection	Rigor of data analysis	Researcher influences considered	Clarity of the findings	Interpretations justified	Transferability	Relevance
Gibson (1999)	✓	✓	✓	✓	×	×	×	×	×	✓
Goble (2004)	✓	✓	✓	✓	✓	✓	✓	×	✓	✓
[1]Green (2006)	✓	✓	✓	✓	p	✓	✓	×	✓	✓
Heaton et al (2005)	✓	✓	✓	✓	p	×	✓	×	✓	✓
Hewitt-Taylor (2009)	✓	✓	✓	✓	×	×	✓	×	✓	✓
[1]Hovey (2003)	✓	✓	✓	✓	×	×	✓	×	✓	✓
[1]Hovey (2005)	✓	✓	✓	✓	×	×	✓	×	✓	✓
Johnson (2000)	✓	✓	✓	✓	✓	×	✓	×	✓	✓
Kirk et al (2005)	✓	✓	✓	✓	✓	✓	✓	×	✓	✓

✓ criteria statements met **x** criteria statements not met **p** criteria statements partially met

[1]Mixed-methods or quantitative study

Author	Clear aims	Methods appropriate	Appropriate recruitment	Appropriate data collection	Rigor of data analysis	Researcher influences considered	Clarity of the findings	Interpretations justified	Transferability	Relevance
[1]Knafl, Zoel.(2002)	✓	✓	✓	✓	✓	×	✓	×	✓	✓
Lauver (2008)	✓	✓	✓	✓	✓	×	✓	×	✓	✓
MacDonald, Call.(2007)	✓	✓	✓	✓	✓	×	✓	✓	✓	✓
Maltby et al (2003)	✓	✓	×	✓	✓	×	✓	×	✓	✓
Marshall et al (2009)	✓	✓	✓	✓	✓	×	✓	✓	✓	✓
Miller et al (2009)	✓	✓	✓	✓	✓	×	✓	✓	✓	✓
Monsen (1999)	✓	✓	✓	✓	✓	×	✓	✓	✓	✓
Mulvaney et al (2006)	✓	✓	✓	✓	✓	✓	✓	×	✓	✓
[1]Notras et al (2002)	✓	✓	✓	✓	×	×	×	×	✓	✓

✓ criteria statements met **x** criteria statements not met **p** criteria statements partially met

[1]Mixed-methods or quantitative study

Author	Clear aims	Methods appropriate	Appropriate recruitment	Appropriate data collection	Rigor of data analysis	Researcher influences considered	Clarity of the findings	Interpretations justified	Transferability	Relevance
Nuutila, Sal.(2006)	✓	✓	✓	✓	✓	×	✓	✓	✓	✓
Ray (2002)	✓	✓	✓	✓	p	×	✓	×	✓	✓
Ray (2002)	✓	✓	✓	✓	p	×	✓	×	✓	✓
Sallfors Hal.(2003)	✓	✓	✓	✓	p	×	✓	✓	✓	✓
Sanders et al (2007)	✓	✓	✓	✓	×	✓	✓	✓	✓	✓
Sullivan-B. et al (2006)	✓	✓	✓	✓	✓	×	✓	✓	✓	✓
Swallow Jac. (2001)	✓	✓	✓	✓	✓	✓	✓	×	✓	✓
Waite-J. Ma.(2008)	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Wennick, Hal.(2007)	✓	✓	✓	✓	✓	✓	✓	✓	×	✓

✓ criteria statements met **x** criteria statements not met **p** criteria statements partially met

[1]Mixed-methods or quantitative study

Appendix IV: Participant materials

A sample of participant materials is included:

1. Parent invitation from the ASBAH advisor for study 1 (Chapter 3)
2. Parent information leaflet for study 1 (Chapter 3)
3. Child and young people's information leaflet for study 2 (Chapter 4)
4. Health professional consent form for study 2 (Chapter 4)

1. Parent invitation from ASBAH advisor (Study 1, Chapter 3)

ASBAH
1966-2006 Challenging the future
Association for Spina Bifida and Hydrocephalus

ASBAH Northern Region
ASBAH House North
64 Bagley Lane
Farsley
Leeds
LS28 5LY
T 0113 255 6767
F 0113 236 3747
E nro@asbah.org
www.asbah.org

22 February 2006

to the parents of

Dear parents of

I am inviting you and/or your partner to take part in a study asking about your experiences of living with a child with hydrocephalus. The title of the study is **"parents' experiences and perceptions of living with a child with hydrocephalus'**. About 20 parents are being contacted and invited to take part in this study. You have been invited because has a shunt inserted to treat hydrocephalus.

Please take time to read the study information leaflet before deciding if you and/or your partner would like to participate. This study is being carried out by Joanna Smith as part of her PhD research. Joanna is a children's nurse and university lecturer. If you would like to know more information about this study, Joanna will be happy to answer any questions you may have. Joanna can be contacted at the School of Healthcare, University of Leeds by telephone (0113 3431187) or e-mail (hcsjsm@leeds.ac.uk).

If you and/or your partner wish to take part in this study please complete and return the enclosed form in the prepaid envelope within 7 days of receiving the letter.

Yours sincerely

Bernadette Baldwin

Bernadette Baldwin
ASBAH Area Adviser
West Yorkshire

2. Parent information leaflet (Study 1 Chapter 3)

Parents' experiences of living with a child with hydrocephalus: a research study

We are inviting you to take part in a study asking about your experiences of living with a child with hydrocephalus. Before deciding to take part in the study please take time to read the following information and, if you wish, discuss it with your family and friends. If you and or your partner would like more information about this study, or if there is anything that is not clear, please contact Joanna Smith who will be happy to answer any questions you have. Joanna is based at the School of Healthcare, University of Leeds and can be contacted by telephone (0113 3431187) or e-mail (hcsjsm@leeds.ac.uk).

What is the purpose of the study?
This study will help us understand what it is like to bring up a child with hydrocephalus. Your views will help the hospital and Association for Spina Bifida and Hydrocephalus (ASBAH) know how to improve their services. The study has been approved by Harrogate Research Ethics Committee.

Who are we?
The people involved in the study are: Joanna Smith, a children's nurse, who is undertaking this research as part of her PhD studies. Professor Francine Cheater and Dr Hilary Bekker from University of Leeds are supervising Joanna's research.
Both Ward 48 at Leeds General Infirmary and ASBAH are supporting this study. Dr John Livingston, Consultant Paediatric Neurologist, Sharon Peacock, Nursing Sister and Bernadette Baldwin, the West Yorkshire region advisor for the ASBAH are guiding the study.

Why have I been chosen?
We are inviting about 20 parents to take part in this study who have a child with a shunt inserted to treat hydrocephalus.

Are there any benefits from taking part?
You will not benefit directly by taking part, but your views will help us to understand the issues that are important to parents in relation to living with a child with hydrocephalus. This may help us when planning for healthcare services for children with hydrocephalus and other long-term conditions.

Do I have to take part?
It is up to you whether or not to take part. If you take part you will be asked to sign a consent form and will be given a copy to keep. If your partner wishes to take part in the study, they will also be asked to sign a consent form.

You are free to withdraw at any time and without giving a reason, even if you have signed the consent form. A decision to withdraw at any time, or not to take part, will not affect the standard of care your child receives, now or in the future. If you choose not to take part, we will not contact you again.

What will happen to me if I take part?
If you participate in the study you will need to return your contact details to Joanna by completing and posting the enclosed form in the prepaid envelope provided. Joanna will then contact you and arrange an interview. You can choose to speak to Joanna either in your own home, at the University of Leeds or at Leeds General Infirmary. The interview will last approximately one hour and will be audio-taped. If your partner wishes to take part in the study, you and your partner will be interviewed together. You will be offered opportunity to comment on the transcript of the tape-recording.

Will my taking part in this study be kept confidential?
All information collected about you and your child during the course of the study will be kept strictly confidential. Your name will be removed from the transcription which means only Joanna Smith will know what you have said.

What can you do if you are not satisfied with any part of the process?
If you have a complaint about your involvement in this study you can contact Claire Skinner, Research Grants Manager at the University of Leeds, who is independent to the study. She can be contacted by telephone; 0113 3434897 or e-mail: c.e.skinner@leeds.ac.uk

What will happen to the results of the study?
Joanna will analyse your responses together with those of the other parents who take part in the study. Some quotes will be used from all participants' answers to help explain the key views and experiences of parents. These quotes are not linked to participant's names but are useful when presenting reports about this study to the Leeds General Infirmary, ASBAH or as part of Joanna's PhD. This study may result in publications in a healthcare journal or presentations at a healthcare conference.

What should I do if I wish to take part in this study?
If you would like to take part in this study please complete the attached form within 7 days and return it to Joanna Smith in the enclosed prepaid envelope.

Thank you for taking time to consider taking part in this study.

3. Children and young people's information leaflet (Study 2, Chapter 4)

A project on how doctors and nurses find out if your shunt is working properly

This leaflet tells you about a project that is looking at how doctors and nurses find out if your shunt is working properly. If after reading this leaflet you would like to know more about the project then you can get in touch with Jo Smith. Jo can be contacted by telephone (0113 3431187) or e-mail (hcsjsm@leeds.ac.uk).

Who are we?

Jo is a children's nurse and undertaking this project as part of her university studies. She is being helped by some researchers at the university and the doctors and nurses based at the hospital.

What are we asking you for?

We are asking you and your parents to allow us to tape-record your chats with the doctors and nurses when they try to find out if your shunt is working or not.

Why are you being asked?

We are asking all young people and children admitted to the ward if they have a problem with the shunt, and their parents, to take part in this study.

Why are we doing the project?

We want to know if we can improve the way doctors and nurses talk to children and young people, and their parents, when in hospital.

Will you benefit from taking part?

You will not benefit directly by taking part, but other people might.

Do you have to take part?

It is up to you if you want to take part in the project or not. If you do not want to take part in the project, we will not ask you again. If you want to take part in the project we will ask you to sign a consent form and give you a copy to keep. Even if you start to take part in the project you can change your mind at any time. You do not have to give a reason if you change your mind. The

care you get will be the same if you do or do not take part in the project.

What do I do if I want to take part in the project?

If you want to take part in the project you do not have to do anything. The nurses on the ward will check that you understand what the project is about. A nurse will ask you to sign a consent form. We will tape-record the nurses and doctors talking to you and your parents when they are trying to decide if your shunt is working.

Who will know I have taken part in the study?

The doctors and nurses who talked to you, your parents, and the project team will know you have taken part in the study. The tape-recordings will only be listened to by the protect team and will be destroyed when the project has finished. We will not put you name on any reports when we write the project up.

Can you complain if you are unhappy about any aspect of the project?

The person you can complain to is Claire Skinner, who works at the university. Claire can be contacted by telephone (0113 3434897) or e-mail (c.e.skinner@leeds.ac.uk).

What will happen to the project when it is finished?

Jo will write a full report of the project as part of her studies. She will present a summary of the project to hospital and student doctors and nurses. Jo will also write a short report about the project to put in health journals. You will not be named in any reports.

What should I do if I wish to take part in this study?

If you wish to take part in the project please let one of the nurses on the ward know.

Thank you for taking time to think about taking part in this study.

4. Health professional consent form (Study 2, Chapter 4)

Parents' involvement in decisions when their child is admitted to hospital with suspected shunt malfunction

Name ……

Profession ……

Grade ……

Please tick to confirm

I confirm that I have read the information sheet about the study	☐
I have had the opportunity to ask questions	☐
I understand the purpose of the study	☐
I understand all information collected in the study will be held in confidence and if it is presented or published, all my personal details will be removed	☐
I confirm that I will be taking part in this study of my own free will, and I understand that I may withdraw from it, at any time, and for any reason	☐

I agree to take part in the first part of the study that involves audio-recorded my interactions with parents during the initial assessment of the child.

Signed …… Date ……

Ward Sister …… Date ……

Are you willing to participate in the second part of the study that involves a short telephone interview with Joanna Smith?

The interview will focus on your perceptions of involving parents in decisions about their child's care and will take place within 7 days after the child's discharge from hospital.

Yes ☐ No ☐

If yes, please provide a contact telephone number ……

The best time best times to contact you are ……

Appendix V: Research training

Education and training	Date
Endnote training	4/3/2004
Scientific theory: putting theory into practice	24/4/2004
Post graduate certificate in research (M Level)	Sept 2004-June 2005
Research ethics training	26/1/2005
Systematic review module	9-12/5/2005
Qualitative research module (M Level)	Jan-March 2005
Introduction to NVivo	2/6/2005
An introduction to effective poster presentations	27/2/2006
Using power point to produce poster	14/3/2006
Avoiding misconduct in research	28/3/2006
Speed reading	29/3/2006
Advanced literature searching	6/3/2006
Writing for research workshop	19/3/2007
Four fundamental of quality in qualitative research workshop	18/8/2007
Communicating your research to a non-specialist audience	9/11/2007
Conversation analysis: introduction, University of York	27-29/4/2008
Conversation analysis: sequencing, University of York	16-19/3/2009
Conversation analysis: word selection, University of York	29/6-2/7/2009
NVivo8 project specific workshops	3/11/2009
Thesis writing and surviving your viva	4/2/2010
Managing long documents	24/3/2010
Conferences	
RCN Children and Young People Field of Practice International Conference, York	1-2/10/2004
RCN International Research Conference, York	21-25/3/2006
RCN Children and Young People Field of Practice International Conference, Bristol	14-16/8/2006
European Health Psychology Society International Research Conference, Maastricht	15-18/7/2007
RCN International Research Conference, Liverpool	21-25/4/2008
RCN, Children and Young People Field of Practice International Conference, Liverpool	11-12/9/2009