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Tokenism or true partnership: Parental involvement in a child's acute pain care

Jackie Vasey

Submitted in accordance with the requirements for the Professional Doctorate

The University of Huddersfield

School of Human and Health Sciences

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Abstract

Background

Despite the growing evidence about acute pain management in children and the availability of practice guidelines, children still experience unnecessary pain when in hospital. Involving parents in their child's pain care has been identified as being central to the pain management in children. However, little is known about how parents and nurses work in partnership in acute children's wards to care for the child experiencing pain. This thesis explored the experiences and perceptions of parents and nurses and the extent to which parents are involved and partners in the child's pain care, and the factors that influence parental involvement in care. The family-centred care practice continuum was the theoretical framework that underpinned the study.

Methods

A qualitative ethnographical study using non-participant observation and follow up interviews was undertaken. Fourteen nurses and 44 parents/grandparents participated, recruited from the children's wards of two district general hospitals. The framework approach underpinned data analysis.

Findings

While some evidence of parental involvement was identified, the study revealed variations in the way parents are involved in their child's pain care. A range of challenges were highlighted in relation to the implementation of family-centred care as an approach to promote parental involvement in care. Parents wanted to be more involved in their child's pain care, and act as an advocate for their child, particularly when they perceived their child's pain care to be sub-optimal. At times nurses created barriers to parental involvement in pain care, for example, by not communicating effectively with parents and planning pain care without involving parents. The 'Pillars of Partnership in Pain Care Model' is offered as an alternative approach to engaging with parents, to address the barriers to involvement and assist nurses shift from a paternalistic approach to involvement to one of working collaboratively with parents in the context of the care of child in pain.

Conclusions and implications for practice

Parental involvement in their child's acute pain care can improve the child's pain experience, increase parents' satisfaction in care and reduce parental anxiety. The challenge for nurses is to embrace parental contribution to care and develop the confidence to support parents to advocate for their child.

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Chapter One: Background

1.1 Thesis overview

This thesis explores parental involvement in their child's acute pain care. Despite the growing evidence relating to the management of acute pain in children and practice guidelines (Association of Paediatric Anaesthetists, 2012; Royal College of Nursing, 2009), children still experience unnecessary pain when in hospital (Kozlowski et al., 2014; Shrestha-Ranjit & Manias, 2010). Involving parents in their child's pain care has been identified as being central to pain management in children (Department of Health, 2003; Royal College of Nursing, 2009; Royal College of Physicians and Child Health, 2004). However, little is known about how parents and nurses work in partnership in acute children's wards to care for the child experiencing pain.

This thesis is presented in eight chapters: Chapter One presents the rationale for the study, examines acute pain care in children and introduces the concept of family-centred care; Chapter Two critically reviews current research relating to parental involvement in children's pain care; Chapter Three examines the epistemological underpinning of ethnography, the chosen methodological approach; Chapter Four describes the data collection methods, observation and interviewing and the framework approach that underpinned data analysis and their application; Chapter Five draws together and presents the findings providing a seamless account of parental involvement in their child's pain care within the context of family-centred care; Chapter Six synthesises and critically analyses the three core concepts that emerged from the findings "parents as advocates for their child" and " nurses promoting involvement and partnership" and nurses unintentionally preventing involvement and partnership". The "Pillars of Partnership in Pain Care Model" is presented as an approach to partnership working. Chapter Seven outlines issues relating to rigour and presents a personal reflexive account of undertaking the study. The final chapter outlines implications and implementation of the model for practice, and future research directions.

1.2 Overview of pain care in children

There are a range of reasons why children experience acute pain, such as minor accidents to major injuries as a consequence of trauma, and acute common childhood illnesses. In addition, pain is frequently experienced by children in acute hospital settings following surgery and during investigations such as blood sampling and therapeutic procedures such as wound care (Czarnecki et al., 2011). While pain has a role in protecting a person from harm, it is an unpleasant experience which can be minimised by appropriate pharmacological and non-pharmacological interventions (Melzack & Wall, 1996). The relief of pain is a fundamental human right (International Association for the Study of Pain (IASP), 2010) and children have the right to effective pain care (United Nations Convention on the Rights of the Child, 1989). Effective pain care has been identified as central to quality of care for children within the National Service Framework for Children, Young People and Maternity Services (Department of Health, 2004). This section will offer a definition of pain, outline the assessment and management of acute pain in children and consider ways of improving the quality of pain care for children by involving parents in their child's pain care.

1.2.1 Defining pain

Although a range of definitions have been offered, pain is difficult to define because it is a complex and multifaceted phenomenon that is highly subjective and individual in nature (Monte-Sandoval, 1999). Pain has been defined as:

> " An unpleasant and emotional experience associated with actual or potential tissue damage, or described in terms of such damage. Pain is always subjective. Each individual learns the application of the word through experiences related to injury in early life" (IASP, 1979, p. 249).

The definition was subsequently updated to reflect that not all individuals have the ability to communicate verbally:

> "The inability to communicate in no way negates the possibility that an individual is experiencing pain and is in need of appropriate pain relieving treatment" (IASP, 2001, p.2).

While less precise, McCaffery's (1968) definition:

> "Pain is what the experiencing person says it is, existing wherever they say it does" (p. 11),

remains popular because it reflects both the values of the individual and the individuality of the experience.

The definitions presented emphasise the importance of the individual's perceptions of pain. However, these definitions may not be appropriate for children, because the child's level of cognition and development will impact on how each child verbalises, localises and exhibits their pain experiences. Consequently pain care in children should take into account the age and developmental stage of the child, and differences in responses to pain across childhood.

1.2.2 Assessment and management of pain

Pain has historically been poorly managed in children and children continue to receive pain care that is suboptimal (Kozlowski, et al., 2014; Shrestha-Ranjit & Manias, 2010; Twycross, Finley & Latimer, 2013). Pain care follows similar stages to the nursing process and involves, assessment, planning of interventions, implementing care management strategies and the evaluation of care delivery.

Assessing children's pain is challenging because not all children are able to verbalise their pain and young children in particular are dependent on others to infer pain from their behavioural and physiological responses (Drendel, Kelly & Ali, 2011). Poor pain care has been attributed to lack of knowledge in recognising and assessing pain in children (Royal College of Nursing, 2009). Inadequate pain assessment can result in inappropriate interventions to relieve pain (American Medical Association, 2013). Complementary guidelines, such as the two-step pain ladder, have been developed to link pain assessment with appropriate interventions (World Health Organisation, 2012). Further guidelines have been published which aim to guide health care professionals to manage children's pain effectively (Association of Paediatric

Anaesthetists of Great Britain and Ireland, 2012; Royal College of Paediatrics and Child Health, 2004).

Pain assessment is a key role of children's nurses in acute children's wards, as they are the health professionals who have most contact with children and families (Stinson & Jibb, 2014). Developmentally appropriate pain assessment tools have been developed to specifically support children, families and nurses to measure pain intensity. However, pain assessment is ongoing and involves wider clinical judgment of location, duration and valuing the child's description of their pain (Johnston, 1998). Self-report is the "gold standard" of pain assessment when children are able to verbalise their pain (Melzack & Katz, 1994). However, for pre-verbal or non-verbal children, parents can have a significant contribution to pain assessment, as they can recognise subtle changes in their child's pain behaviour (Stinson & Jibb, 2014).

Pain assessment is the first step in pain management, and guides the most appropriate intervention to relieve the pain. Pharmacological interventions, such as multimodal analgesics are the cornerstone of acute pain care, with non-pharmacological interventions, such as positioning and distraction offered as adjunctive therapies (Penrose, Palozzi & Dowden, 2014). The range of pharmacological interventions requires the nurse to have in-depth knowledge of analgesic properties. Furthermore, nurses are required to provide clear discharge medication instructions to parents, who have a key role in pain care at home.

1.2.3 Consequences of ineffective pain care

Short and long term physiological and psychological effects of poor pain care have been reported (Schechter, Berde, & Yaster, 2003; Taddio, Shah, Gilbert- MacLeod & Katz, 2002). For example, there is a link between poorly managed acute pain and development of chronic pain (Fortier, Chou, Maurer & Kain, 2011) and behavioural sensitivity to pain has been linked to early pain exposure (Taddio et al., 1997). In children, consequences of unrelieved pain include: physical effects such as rapid shallow breathing or increased heart rate; psychological effects such as increased anxiety and fear; prolonged recovery rates which may result in an extended hospital stay (World Health Organisation, 1997).

Children report that being in pain is one of the worst experiences of being in hospital (Commission for Health Improvement, 2004). Children do not always feel they are listened to or believed and perceive that nurses do not always provide them with analgesia as soon as requested (Polkki, Pietila & Vehvilainen, 2003). Children expect nurses to be empathetic and gentle and while children and families continue to report moderate to severe pain, they are generally satisfied with their pain care (Twycross & Collis, 2013b). Findings from this study suggest that children and families may expect to experience pain and perceive pain as unavoidable. The literature suggests that more can be done to improve children's pain experiences, including inviting children and families to participate in decision-making about pain management interventions (Nillson, Hallqvist, Sidenvall & Enskar, 2011).

Pain teams with a remit for guiding pain care have been advocated to improve overall management of pain in both adults and children (Frigon, Loetwiriyakul, Ranger & Otis, 2009; Mackintosh & Bowles, 2003). However, in 2000, only 80% of hospital trusts were identified as having a pain service, with few providing a specific pain service for children (Clinical Standards Advisory Group, 2000). In addition to the disparity of service provision, there is no consensus relating to the structure and function of pain teams (Sanders & Michel, 2002). Children cared for in district general hospitals, where children's services are often marginalised, can impact on the range of services available (Department of Health, 2010b). While it is recommended that a member of the acute pain service visits children's surgical wards every day (Royal College of Anaesthetists, 2010), health professionals without the knowledge and skills required to work with children and families may not be best placed to meet the child's pain care needs.

1.2.4 Involving parents in their child's pain care

Policies and guidelines have highlighted that parents can have a vital role in contributing to their child's pain care (Department of Health, 2003; Royal College of Nursing, 2009; Royal College of Physicians and Child Health, 2004). Although the National Service Framework for Children: Standards for Hospital Services (Department of Health, 2003) ten year plan, included six specific children's pain care standards and advocated parental involvement, to date research suggests that there

is little evidence that involvement is occurring (Coyne & Cowley, 2007; Twycross & Collis, 2013b). Children's nurses are pivotal in ensuring the child's pain care needs are met and consequently ideally placed to involve parents in their child's pain care (Czarnecki et al., 2011).

Parental participation in all aspects of pain care can be beneficial for both children and parents and with appropriate support, parents can provide a pain history and be involved in assessment, decisions regarding interventions and monitoring of pain care (Kristensson-Hallstrom, 1999). Parental presence and involvement can positively impact on the child's pain experience in hospital (Lim, Mackay, Liam & He, 2011; McMurty, Chambers, McGrath & Asp, 2010). Parental presence has been found to have both a preventative and therapeutic effects; can reduce children's pain; decrease the length of hospital stay and enable more effective use of staff time (Department of Health, 2010b; Diaz-Caneja, Gledhill, Weaver, Nadal, & Garralda, 2005; Kain et al., 2007).

Benefits for parents have been attributed to reducing feelings of helplessness when their child is acutely ill (Greenberg, Billet, Zahurak & Yaster, 1999; Twycross & Stinson, 2014). Pain is a major concern for parents when children are admitted to hospital (Johnston, Gagnon, Peplar & Bourgault, 2005). While research about pain management in children has increased in the last three decades, there has been less emphasis on parental involvement, which may have contributed to children continuing to experience unnecessary pain (He, Polkki, Peitila & Vehvilainen-Julkunen, 2005). Parental involvement in a child's acute pain care in hospital is linked with the concepts such as partnership in care and family-centred care, which will be discussed in Section 1.3.

1.3 Frameworks underpinning the care of children

Children's nursing has evolved considerably over the last century. The most significant change has been a shift from one of paternalism, to involving parents in their child's care and sharing care decisions (Department of Health, 2007, 2010b). Despite this shift, there remain inconsistencies in how parents are involved in their child's care and in decisions about their child's care (Tallon, Kendall & Snider, 2015).

This section presents a critical review of the two of the key philosophies underpinning children's nursing: partnership in care and family-centred care.

1.3.1 Partnership in care

Partnership in care is a concept that is claimed to be central and embedded in children's nursing and has the potential to facilitate a collaborative approach to care delivery (Smith, Swallow & Coyne, 2015). Current health policy recommends that nurses should work in partnership with their patients and in children's nursing this includes involving parents in care decisions and encouraging participation in their child's care (Department of Health, 2003, 2004, 2007, 2010a; Entwistle, 2009). Partnership in care models were developed as a framework to help nurses involve and support parents, and children as appropriate, in the care of children. Casey's partnership model, widely adopted within the UK, was underpinned by the assumption that children are best cared for by their parents with support from nurses, and provided a guide for nurses on working in partnership with parents (Casey, 1988; Casey, 1995). At the time of inception, partnership working was a relatively new concept and with an absence of models or theories that specifically related to the care of children and families, was readily embraced by children's nurses and nurse educators (Lee, 1998).

However, Casey's model has not been evaluated in relation to its contribution to nursing theory, subsequent implementation in practice and the impact on care delivery (Lee, 1998). Nurses have reported that partnership in care is ideological and does not necessarily reflect their relationships with parents (Coyne & Cowley, 2007). Similarly, nurses appear to find operationalising the concept of partnership working challenging, resulting in lack of effective implementation in practice (Smith et al., 2015). Assertions that Casey's (1995) model is a middle range theory, as opposed to a practical working model, may have contributed to nurses struggling to identify how they embed the model into their everyday practice, highlighting a gap between the theory and practice of partnership working (Fawcett, 1995). Furthermore, models of patient centred care, including partnership in care remain poorly defined with different health professional groups and individual practitioners attaching different values and meaning to the concept embodying partnership working (Franck & Callery, 2004; Power & Franck, 2008). Darbyshire describes partnership in care as an "amorphous

and ill described concept" (Darbyshire, 1993, p. 1672). The absence of shared understanding and poor application of current partnership models implies that: parent-nurse relationships cannot be characterised as a partnership; are out of date; and do not reflect parents and nurses expectations (Coyne & Cowley, 2007).

1.3.2 Family-centred care

Parental involvement and partnership working are widely associated with the concept of family-centred care (Smith, Coleman & Bradshaw, 2010; Jolley & Shields, 2009; Shields, Pratt, Davis & Hunter, 2007). Family-centred care is an all-embracing concept reflected in the way care is organised, planned, delivered and evaluated around the whole family (Coyne, O'Neill, Murphy, Costello & O'Shea, 2011; Shields, Pratt & Hunter, 2006). Family-centred care is claimed to be a philosophy that defines children's nursing, acknowledging that nurses caring for children view the family as an integral part of the child's life (Coleman, Smith & Bradshaw, 2007; Department of Health, 2004; Simons, Franck & Roberson, 2001; Smith et al., 2010; Tallon et al., 2015). While it has been advocated that children's nurses would not contemplate an approach to care that did not involve families in care (Clayton, 2000), evidence suggests that family-centred care is not consistently and effectively embedded into practice (Coyne et al., 2011; Shields et al., 2006).

Lack of a comprehensive definition of family-centred care has resulted in lack of clarity and therefore difficulties in implementing family-centred care in practice (Coleman, 2010a; Darbyshire, 1994; Franck & Callery, 2004). Family-centred care has been described as both a care delivery method and a philosophy, further muddying the waters (Bruce et al., 2002). Although family-centred care is accepted and regarded as the ideal philosophy to underpin care and the principles are acknowledged by children's nurses, its actual implementation remains challenging (Coyne et al., 2011). Consequently, family-centred care is often perceived as idealist rather than a reality of practice (Franck & Callery, 2004). Research about the impact of family-centred care on care outcomes is limited. A comprehensive systematic review of the effectiveness of family-centred care identified only one study which met the inclusion criteria (Shields et al., 2012). If the benefits of the implementation of family-centred care have not been robustly evaluated, its continued adoption as the model to underpin children's nursing is questionable. However, many aspects of

family-centred care, such as experiences of nurses and parents' satisfaction cannot be quantified, suggesting the need for more qualitative exploration of the merits of family-centred care.

Family-centred care has been claimed to be a central component of children's nursing for many decades (Coleman, 2010a) with family's active participation and involvement in decisions about their child's care a central component of nursing care (Carter & Dearmun, 1995). The underpinning espoused philosophy of family-centred care is that parents can choose to become partners in care. The nurse acts as a facilitator and guide, through empowerment, negotiation and participation. The emphasis on choice for parents is an important aspect of family-centred care and ensures that parents are not utilised as part of the workforce and expected to undertake caring and nursing tasks (Coyne & Cowley, 2006; McCann et al., 2008). Parents may not wish to be burdened with caring tasks or have the skills to undertake them (Lee, 2004). Parents have been described as efficient and willing sources of labour and "captive prisoners" with nurses controlling and expecting parents to deliver care in the absence of negotiation or agreement (Meadow, 1969). Nurses dominate the nurse-parent relationship and have been criticised for being the gatekeepers of family-centred care, which seems incongruent with the aims of family-centred care (Darbyshire, 1994; Nethercott, 1993; Shields et al., 2006).

Shared decision-making is central to patient-centred care and is one way of addressing the power imbalance, because shared decision making requires a shift from a paternalistic to a more collaborative approach to care delivery (Entwistle, 2009). Models to support children's participation in decision making have been developed to support children to share power and responsibility for decision making (Shier, 2001). However, young children in hospital require their parents to act as proxy in the decision making process, requiring the nurse to relinquish power and share decisions with parents. Shared decision-making is gaining prominence in clinical practice, based on the premise that each party should contribute to care decisions; the patient brings their unique experiences and insights to the discussion and health professionals bring experiences and knowledge of care in similar situations, in order to mutually agree care pathways (Elwyn, Edwards & Kinnersley, 1999). In the context of children's pain care, nurses should understand and present

choices and potential outcomes for parents, listen to parent' views and concerns in order to support parents to make informed choices.

Parents want to be involved in their child's care (Power & Franck, 2008) and work collaboratively with healthcare staff (Mackean, Thurston & Scott, 2005). A concept synthesis of partnership in care and family-centred care found that lack of clarity and understanding of terminology has contributed to the problematic implementation of parent-nurse partnership working (Smith et al., 2015). Similarities between the two models were identified, such as valuing parent expertise and developing effective relationships between parents and nurses. Both models have been found to have inherent problems in both understanding of the underpinning concepts and subsequent challenges in implementing the concepts into practice. A collaborative approach has been suggested as being more meaningful to nurses. The suggested framework for involvement focuses on building effective relationships and involving parents in decisions about care, based on the recognition of parent knowledge and experience (Smith et al., 2015).

The recently published development of the parent-professional collaboration "Framework for Involvement" (Smith et al., 2015), although offering an alternative theoretical framework to explore parental involvement in pain care, has not as yet been evaluated in practice. As a concept, family-centred care is well established and the most commonly recognised conceptual approach for parental involvement at the time of commencing the study. While this study does not aim to test family-centred care as an intervention, family-centred care provided the conceptual framework to explore parental involvement in their child's acute pain care, and identify ways to enhance parental involvement.

1.3.3 Family-centred care practice continuum

The family-centred care practice continuum, underpinned by the concepts of family-centred care, describes the range of parental involvement, from nurse led to parent led care (Figure 1) (Smith et al., 2010) and offers a framework to enable nurses to individualise parental involvement depending on individual family needs, consistent with the underpinning espoused philosophy of family-centred care. This continuum is based on the principle that at times parents may have minimal involvement in their

child's care (for example on first contact with services or during emergency care) and at other times parents have increasing participation as nurses share or devolve care to parents (for example in the context of childhood long term conditions) (Smith et al, 2010; Smith et al., 2015). Individual family needs and preferences are unique and may change over time, represented by the two way movement along the continuum (Smith et al, 2010).

Figure 1: Family-centred care practice continuum conceptual model (adapted from Smith et al., 2010 p. 42)

No involvement	Involvement	Participation	Partnership	Parent/child led
Nurse-led	Nurse-led	Nurse-led	Equal status	Parent/child led

The continuum was based on the seminal work of Shelton, Jepson and Johnson (1987) who identified four key concepts of family-centred care: dignity and respect; information sharing; participation and collaboration. Several other studies were described as influencing the development of the continuum (Casey, 1995; Hutchfield, 1999; Nethercott, 1993). However, despite the acknowledgement of the family's central role in a child's care, it does not appear that children and families were involved in the development of the model. The model appears to be aimed at nurses and does not consider how parents and children would perceive or use the model (Smith et al., 2010).

Although described as a theoretical framework (Coleman, 2010a), the family-centred care practice continuum could also be described as a conceptual framework or model. The terms theoretical framework, conceptual framework or model are used interchangeably (Fain, 2004; Green, 2014). Coleman (2010a) states that as family-centred care has moved through parental presence to partnership working, one concept has replaced another. When concepts are organised enough to become

theories, this may determine whether the framework is theoretical or conceptual (Green, 2014). As there appears to be no firm consistent theoretical grounding, the continuum will be described as the conceptual framework and Figure 1 will be referred to as the conceptual model, which is a diagrammatical representation of a conceptual framework.

Much of the research indicates that parents want and expect to be involved in their child's care (Power & Franck, 2008; Smith et al., 2010). Partnership working, participation and involvement, are terms which are used interchangeably within the continuum, which could lead to a lack of clarity of a working definition and to questionable assumptions of parents and nurses working together to care for the acutely ill child (Coyne et al., 2011; Power & Franck, 2008; Smith et al., 2015; Thompson, 2007). Establishing parental wishes is the key to facilitating family-centred care to determine the level that parents are willing and/or able to undertake (Smith et al., 2010). The continuum was used to explore parental involvement in this study and while it appears to compartmentalise family-centred care and place involvement in care on a quantifiable measurement scale, in reality partnership working is a dynamic and continually evolving in response to the family and nurses' perceptions and experiences and the situation. Therefore the continuum and underpinning concept of family-centred care provided a lens through which parental involvement in a child's pain care was explored.

1.4 Chapter one summary

This chapter has outlined the importance of effective pain care for children in hospital. Pain care remains suboptimal at times and parental involvement has the potential to improve the pain experience for children (Lim et al., 2011; McMurty et al., 2010). Nurses are ideally positioned to improve pain care by enhancing parental involvement which has beneficial effects for both children and parents. There are variations in how parents are supported to be involved in their child's pain care and possible reasons for this have been outlined and include lack of understanding and implementation of models to support involvement in care. Although partnership in care models and the concept of family-centred care can guide the nursing care of the child and family, they are often perceived as idealistic and implementation into practice remains problematic. Despite the identified challenges of family-centred

care, the family-centred care practice continuum underpinned by the concepts of family-centred care has been identified as an appropriate framework to explore parental involvement in their child's acute pain care in this study.

Chapter Two: Literature review

2.1 Introduction

As highlighted in Chapter One, children's pain care can be suboptimal and parents are not always involved in their child's pain care, yet their involvement has been demonstrated to have beneficial effects for both the child and parents (Department of Health, 2003; Kain et al., 2007; Kristensson-Hallstrom, 1999; Lim, et al., 2011; McMurty et al., 2010; Naber et al., 1995). This chapter presents a critical review of the literature of parental involvement in pain care. The conceptual framework and model of family-centred care, highlighted in Chapter One, offers a way to explore parental involvement in their child's pain care. Although, there is a wealth of literature related to family-centred care and to pain care, only research that specifically examined pain care in relation to aspects of family-centred care, such as involvement and participation were included in the review.

2.2 Search question and objectives

This review aimed to synthesise and critically evaluate research relating to parental involvement in the child's pain care to answer the following question;

"What is known about how nurses work in partnership with parents to involve them in their child's acute pain care?"

The objectives were to:

1. Identify, describe and summarise research related to parental involvement in their child's pain care;
2. Critically appraise the quality of research that has explored parental involvement in the child's pain care;
3. Identify gaps in the literature related to parental involvement in children's pain care.

2.3 Methods

Critically reviewing the literature requires a systematic approach to: selecting appropriate studies; appraising studies for quality; and extracting appropriate data (Bettany-Saltikov, 2012). The methods used to undertake this review were informed by guidance from the Centre for Reviews and Dissemination (CRD) (2009). While the guidance is related to undertaking systematic reviews, the rigorous appraisal approaches were extrapolated to review the literature systematically. Systematic reviews, unlike structured literature reviews, are usually undertaken by a team of researchers to synthesise research findings across all of the available evidence, with thorough appraisal and re-analysis of the results of the study (Arksey & O'Malley, 2005). Systematic reviews are undertaken with the same degree of rigour to reviewing research evidence as undertaking empirical research (Hemingway & Brereton, 2009). While, a thorough structured literature review was undertaken and identified studies were appraised, it cannot be claimed that all of the relevant literature was identified and a meta-ethnographic synthesis was not performed (CRD, 2009).

2.3.1 Inclusion and exclusion criteria

Studies were included or excluded from the review based on the following criteria:

Inclusion criteria:

- Studies regarding parental involvement in a child's acute pain care, in hospital settings, including wards and assessment units, emergency departments and neonatal units and following discharge from hospital;
- Studies concerned with nurses or families' views and perceptions of children's pain care in hospital;
- Studies published in the English language;
- Studies between January 2001 and January 2014.

Exclusion criteria:

- Studies about chronic pain in children;
- Studies with young people over the age of 18 years;
- Studies solely about family-centred care;
- Review articles and non-peer reviewed articles.

2.3.2 Search strategy

Studies were identified by searching the following health and social sciences bibliographic databases: Science Direct; Medline; CINAHL; Cochrane; PUBMED; Ephost (CINAHL and Medline combined) and BN Index, because they index a wide range of healthcare topics. Additionally, as the search pertains to children, the charity group, Action for Sick Children was searched. Other grey literature such as the Kings Fund Research and Dissertation Abstracts Online, were also searched. While measures can be taken to extract relevant literature, up to twenty per cent will not be identified through database searches (Betran, Say, Gulmezoglu, Allen & Hampson, 2005). Therefore hand searches of journals such as “Journal of Pain and Symptom Management”, “Pain Management Nursing”, “Pediatric Nursing” and “Journal of Advanced Nursing” were also undertaken.

2.3.2.1 Sampling strategies

Databases were searched using key terms and the PICO framework was used to frame the search to ensure the search was comprehensive (Timmins & McCabe, 2005) (Figure 2). Intervention was used as an alternative to comparison (C) in PICO, as interventions were not being compared. Some key terms, such as “involvement”, could be both an intervention and an outcome. However, terms were placed in the most relevant section.

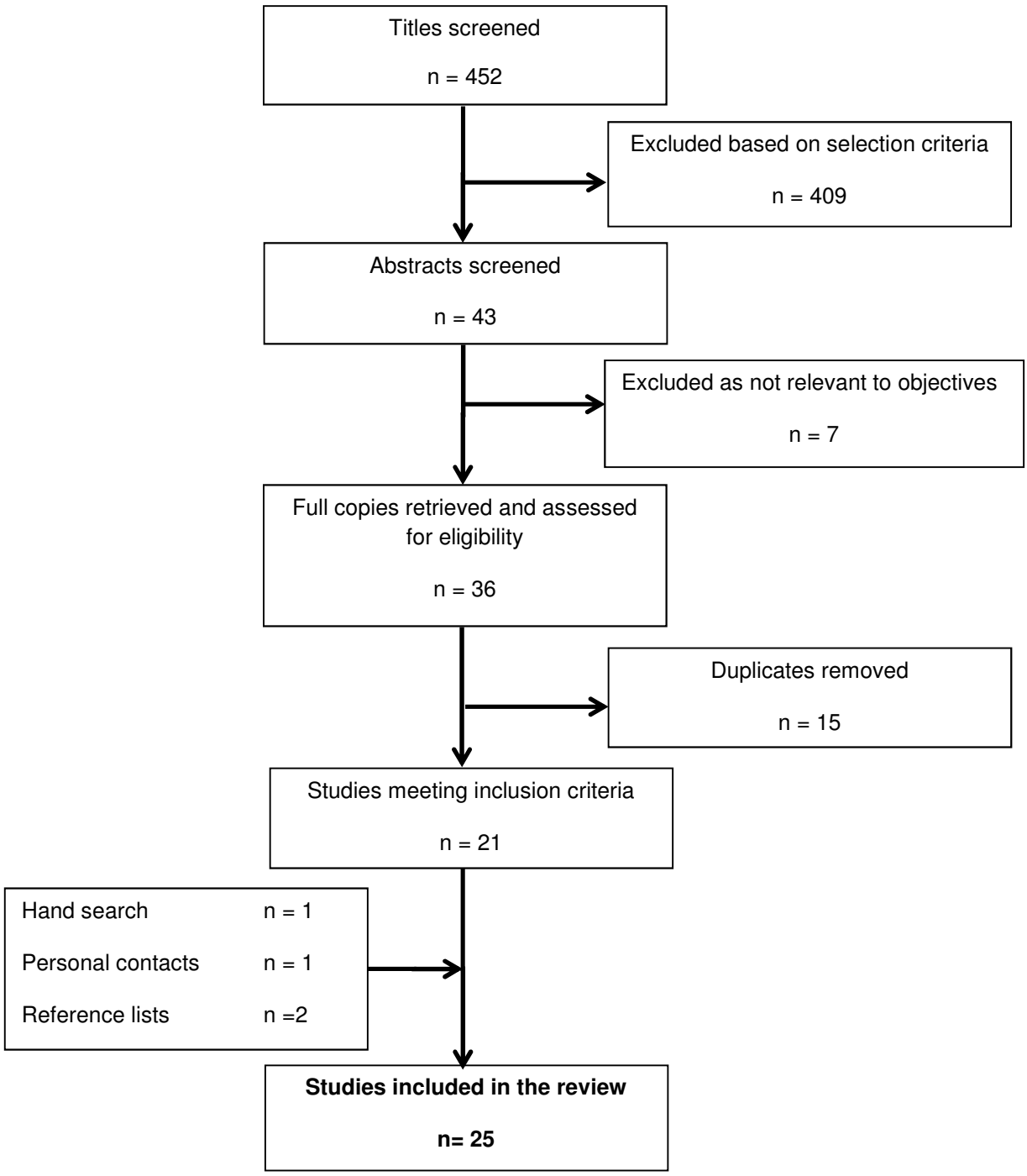
Figure 2: Search terms using PICO framework

Population 1	Population 2	Intervention	Outcomes	Study designs
Child* Young person* Paediatrics* Pediatrics* Parent* Family*	Nurse* Healthcare professional	Pain Pain care Acute pain Pain management Family-centred care*	Involvement Partnership Participation Experiences Beliefs Attitudes Knowledge Perspectives Advocacy	Qualitative research Quantitative research Mixed methods design

2.3.3 Study selection

The electronic data-base searches yielded a total of 452 potential studies (Figure 3). Abstracts were reviewed to determine if the study related directly to the focus of the review. Due to the limited number of studies that specifically met the criteria, all were considered where there was direct or indirect reference to parental involvement in the abstract. This proved effective as the vast majority of studies did not specifically feature parental involvement as a prominent aim of the study, but many of those studies reported on parental involvement in the findings. Studies involving specialist areas were included, such as neonates (Franck, Scurr & Couture, 2001, Gale, Franck, Kools & Lynch, 2004) and cardiac surgery (Huth, Broome, Mussatto & Morgan, 2003). While implications for generalisiblity and transferability may be limited, due to the specialist nature of these studies, they provided useful information about the nature of parental involvement in pain care, which could be applied across children's nursing practice. No studies were identified that explicitly sought to explore pain care related specifically to family-centred care. Twenty five studies met the inclusion criteria and were included in the review.

Figure 3: Flow chart of study selection process



2.3.4 Data extraction

I extracted data using a data extraction form, developed by combining and adapting two established forms to reduce bias when extracting data (Bettany-Saltikov, 2012; CRD, 2009) (Figure 4). The data extraction form provided a checklist that contributed to consistency in extracting and recording data from included studies. Study characteristics were identified by an initial scoping exercise prior to formal data extraction. The data extraction form was piloted prior to use with the first two studies reviewed and adapted accordingly to ensure appropriate data was included (Higgins & Deeks, 2009).

Figure 4: Data extraction form

Study characteristics	Study number	
	Source	
	Study title and author	
Participant details	Nurse	
	Parent	
	Child- age group	
Setting	General children's ward	
	Children's surgical ward/area	
	Neonates	
	Emergency department	
	Home	
	Specialist unit	
Purpose of study	Purpose of study	
Quality of study	Design	
	Theoretical perspective	
	Sample type	
	Sample size (nurse/parent/child)	
	Data collection method	
	Data analysis method	
	Limitations	
Study categories	Parents' experience of pain care	
	Parents' perspectives of pain care	
	Nurses' experience of pain care	
	Nurses' perspectives of pain care	
	Family-centred care	
	Parental involvement and partnership	
	Barriers to involvement	

2.3.5 Method of appraisal

A range of tools are available to critically appraise research, to ascertain methodological quality. No "gold standard" for critical appraisal tools exists and each tool has inherent flaws (Crowe & Sheppard, 2011). Some tools are specific to

research designs (Caldwell, Henshaw & Taylor, 2011; the web based Critical Appraisal Skills Programme (CASP) tools; Joanna Briggs Institute, 2007), and others are generic (Wooliams, Williams, Butcher & Pye, 2009). CASP appraisal tools were selected to appraise the studies as versions are available across research designs and a range of study approaches were included in the review. Design specific questions enabled the studies to be critically appraised. Despite the potential limitations of appraisal tools, a systematic review of studies can be achieved more rigorously and consistently by using a tool (Barbour, 2001).

2.3.6 Method of synthesising findings

The findings from included studies were brought together using thematic analysis (Burnard, 1991). The stages included: immersion in the data; extraction of words, sentences and numerical data to form codes; identification and refinement of "higher order" headings which capture grouped meanings of codes. An example of the process used to identify themes is presented in Appendix 1.

2.4 Findings

Twenty-five studies were included in the review: twelve studies adopted qualitative approaches; eight studies were underpinned by quantitative methods; and five were mixed method studies. Appendix 2 presents a summary outlining the characteristics of the studies included in the review. Only five studies reviewed specifically explored parental involvement in pain care on general children's wards, of which three adopted a qualitative research design (Gimbler-Berglund, Ljusegren & Enskar, 2008; Jongudomkarn, Foreron, Siripul & Finley, 2012; Twycross, & Collis, 2013a). Almost half of the studies focussed on post-operative care, and the remainder were undertaken in neonatal or other specialist areas. Two studies examined how parents managed their child's pain care following discharge (Jonas, 2003; LeMay et al., 2010). Although findings specifically focussed on discharge planning, the findings may not be applicable to other settings. However, pain care continues when the child is discharged home, and ward based nurses are often involved in providing discharge advice to parents (Howard et al., 2014).

2.4.1 Quality appraisal of the studies

Quality appraisal aims to identify the degree to which the studies are free from methodological bias and study findings are credible (Higgins & Deeks, 2009). However, different methodologies require different approaches to quality appraisal. For example, quantitative studies are concerned with validity and reliability, while qualitative studies are judged on authenticity and trustworthiness (Caldwell, Henshaw & Taylor, 2011). As rigour encapsulates both the concepts of validity of conduct and findings of quantitative research and credibility of qualitative methods and findings, different CASP appraisal tools were used. The principles across all CASP tools relate to three main areas: validity of the study; the results; and how useful the results are to practice. Appendix 3 presents a summary of the application of CASP appraisal tools.

Few studies stated the underpinning theoretical framework of their study and of those that did, family-centred care was identified only in studies related to neonates (Franck, Oulton & Bruce, 2012; Franck et al., 2001). Theoretical frameworks have the potential to guide every stage of qualitative research from developing the research questions to analysing and presenting the data to ensure a cohesive approach to the study (Green, 2014).

Of the quantitative studies, a range of methods were used, such as randomised experimental and control trials, exploratory/comparison and most frequently questionnaires. Questionnaires were developed specifically for three studies, (Polkki, Vehilainen-Julkunen & Pietila, 2002a; Polkki, Pietila, Vehilainen-Julkunen, Laukkula & Ryhanen, 2002b; Twycross & Collis, 2013b) which were not validated and therefore could impact on the credibility of the results. Questionnaires should be valid in terms of whether they are designed to answer the research question. Poorly designed questionnaires may not represent the attributes of the issues being studied (Parahoo, 2014). Other studies used a range of validated questionnaires including “barriers to optimal pain management” (Czarnecki et al., 2011) and the “pain belief questionnaire” (LeMay et al., 2010). Only one study identified issues related to validity, in that the tool was validated with and for Finnish parent participants but had been used within a North-American setting, without further evaluation (Kankunnen et al., 2008). One study (Huth et al., 2003) utilised a randomised controlled trial, which

is considered high on the hierarchy of evidence (Mann 1996) and the “gold standard” (Centre for Reviews and Dissemination, 2009).

Of the qualitative studies included, those that reported the methodology underpinning the research were based primarily on phenomenology (Jongudomkarn et al., 2012; Simons et al., 2001; Simons & Roberson, 2002) and the remaining qualitative studies were descriptive (generic) approaches. None of the studies reported using an ethnographic approach, therefore observed practice of how family-centred care is embedded into pain care does not appear to have been researched. Data were analysed by thematic or content analysis, which are the most common analysis methods in qualitative studies (Braun & Clarke, 2006; Miles & Huberman, 1994). Data were primarily collected using semi-structured interviews (Gale et al., 2004; Gimbler-Berglund et al., 2008; Lim et al., 2011; Rennick et al., 2011) and observation (Twycross & Collis, 2013b; Twycross et al., 2013). However, two studies used focus groups to collect data (Gale et al., 2004; Twycross & Collis, 2013a). Gale et al. (2004) used a combination of individual interviews and focus groups with choice of data collection methods which may accommodate the needs and preferences of the participants. However, participant interactions during focus groups may produce information that would be difficult in one-to-one interviews (Stewart & Shamdasani, 1990). The majority of qualitative studies used semi-structured interviews, and it is widely recognised that interviewing is the most frequently used method of gathering data for qualitative studies (Burnard, 2005). One of the advantages is that researchers can use open questions and explore participants’ responses in depth to gain insight into participants’ views and perspectives. The use of draw and write techniques facilitated children to express their views and aided data collection in one study (Twycross & Finley, 2013). One study used telephone interviews to collect data from participants (Jonas, 2003). Telephone interviews are typically less time consuming and may be more convenient for participants and researchers, but may hinder the development of effective participant-researcher rapport and therefore depth of information gained.

Mixed method designs were used in five of the studies, integrating qualitative and quantitative data (Polkki et al., 2002a; Polkki et al., 2002b; Twycross & Collis, 2013b: Twycross, & Finley, 2013; Vincent, 2007). Mixing methods has been claimed to

enhance the rigour of research findings because different methods can be complimentary and avoid limitations of single methods (Sandelowski, 2013). For example measuring quantifiable elements of pain, such as pain scores in pain assessment, could compliment children's and parents' experiences of pain care. Complimentary data collection, in a three phase study, whereby qualitative data was obtained by observing interactions and quantitative data were collected using questionnaires for young people and questionnaires for parents allowed for a broader exploration of pain care practices (Twycross & Collis, 2013b).

Participant numbers ranged from small samples of eight to 425 participants. Participant numbers in qualitative studies ranged from 10 to 169, the latter being relatively high for a qualitative study, but related to narrative accounts from a previous randomised controlled trial (Franck et al., 2012). Smaller samples would be expected in designs that explore participants' lived experience because of the depth of data collected. One study underpinned by phenomenology used a purposive sample obtained from a small number of participants to explore parents' experience in their involvement in their child's pain (Simons et al., 2001, Simons & Roberson, 2002).

In mixed method studies participant numbers ranged from eight to 192 and quantitative participant numbers from 51 to 425. Samples were largely convenience or purposive with specific groups including children and parents, often in a specific environment, such as a healthcare setting or following discharge. Some studies included a specific age range of children: 6-12 years (Lim et al., 2011), 8-12 years (Polkki et al., 2002a; Polkki et al., 2002b), while other studies compared different age groups of Finnish (1-6 years) and American (3-14 years) children. Restricting the age of children who participate or comparing different age groups can limit transferability as children have different developmental and care needs at different ages, which can impact on pain care (Mitchell & Ziegler, 2007).

Establishing whether appropriate ethical procedures were undertaken to ensure participant's rights are maintained and that the study has been subject to external review and designed to minimise risks and maximise benefits to participants is an essential part of the research process (Gibson & Twycross, 2007; Royal College of Nursing, 2006; Royal College of Paediatrics and Child Health, 2000). All of the

review studies indicated that ethical approval had been obtained, apart from one study described as an audit of practice where ethical approval was not required (Twycross & Collis, 2013a).

2.4.2 Themes

The synthesised findings of the review were categorised into one overarching main theme: barriers to parental involvement in their child's pain care. Although there was some evidence of parental involvement in pain care, the review highlighted that barriers to involving parents in their child's pain care were prevalent. Barriers included: different perceptions and understanding of parental involvement; poor communication and lack of parental support; variations in the provision of information to facilitate involvement; and knowledge deficits.

2.4.2.1 Perceptions and understanding of parental involvement

Studies reported differences in parents' views about whether they should be involved in their child's pain care and subsequently whether they were satisfied with their involvement. One study reported that parents' perceived that pain care was the role of nurses and doctors (Franck et al., 2012). In contrast, parents who perceived that their role was to be involved in their child's pain care were more satisfied with their child's pain care (Franck et al., 2001; Polkki et al., 2002a; Twycross et al., 2013). One study found that despite nurses perceiving that they adequately involved parents in care, some parents were dissatisfied and frustrated with their level of involvement (Simons et al., 2001). Parents also perceived that they had adequate opportunity for involvement in their child's care at a level they desired (Polkki et al., 2002a). Yet, another study found only 35% of nurses stated they would involve parents in pain care (Vincent, 2007). A mismatch between parents and nurses perception of the extent to which parents are involved in pain care could indicate a lack of understanding of each other's perspectives of involvement. Furthermore, some studies reported involvement in pain care without clarifying what this means for parents and nurses (Gale et al., 2004; Kankkunen et al., 2008; Unsworth, Franck & Choonara, 2007; Zisk, Grey, Medoof-Cooper & Kain, 2007).

Nurses and parents did not always appear to have a shared understanding of what parental involvement means. Undertaking non-pharmacological pain management

strategies was viewed by parents as being synonymous with involvement. Non-pharmacological methods included distraction, positioning and providing reassurance to their child (He, Polkki, Pietila & Vehvilainen-Julkunen, 2005; He et al., 2011; Lim et al., 2011; Polkki et al., 2002b; Simons et al., 2001). The findings from three of these studies may have been influenced by cultural differences of parents' roles when their child is in hospital in Asian countries (He et al., 2005; He et al., 2011; Jongudomkarn et al., 2012; Lim et al., 2011). In other studies, being at the bedside, holding and reassuring their infant and being informed of care were perceived by parents as being synonymous with involvement in care (Franck et al., 2001). Whereas, being present during procedures was perceived by parents and nurses as being involved in care, highlighting that a range of activities were perceived to equate to involvement (Rennick et al., 2011; Simons et al., 2001).

2.4.2.2 Poor communication and lack of support for parents to be involved

Poor communication was overwhelmingly found to be a barrier to parental involvement in pain care (He et al., 2011; Franck et al., 2012; Simons et al., 2001; Simons & Roberson, 2002). Poor communication led to a lack of understanding of roles in some studies (Gale et al., 2004; Polkki et al., 2002a; Rennick et al., 2011; Simons et al., 2001; Simons & Roberson, 2002; Twycross & Collis, 2013a). One study identified that parents felt the onus was on them to seek out information, rather than nurses providing information (Gale et al., 2004). Nurses assumed a passive role and expected parents to take responsibility for pain care (Simons et al., 2001; Twycross & Collis 2013a). Parents wanted to be given a choice about involvement rather than an expectation of involvement in their child's pain care (Rennick et al., 2011). Nurses sometimes did not appear to discuss aspects of pain care with parents, limiting parents' ability to be involved in care (Franck et al., 2001; Franck et al., 2012). Furthermore, the provision of information by nurses to parents about how they could be involved in pain care did not meet parents' needs or expectations (He et al., 2005; Polkki et al., 2002a). Some of the studies offered ways of overcoming poor communication, such as: nurses introducing the subject of parental involvement in care on admission with clear and mutually agreed goal setting (Simons et al., 2001); nurses should mutually agree pain goals with parents (Twycross & Finley,

2013); nurses need to communicate with parents in a way that enabled them to be involved in pain care (He et al., 2011).

A central finding was that parents want to be more involved in their child's pain care and perceived involvement to be a vital role (Gale et al., 2004; Franck et al., 2012). Both of these studies were undertaken in neonatal units, claiming that the unit's espoused philosophies were underpinned by the concept of family- centred care, which may account for parents' perspectives. However, other studies identified that when parents wanted to be more involved in care, they encountered lack of support. This was often directly attributed to lack of nurse support, such as nurses not formally inviting parents to be involved or including parents in pain care (Jongudomkarn, et al., 2012), and parents initiating involvement in care (Twycross & Collis, 2013b). Nurses' who were more experienced, had a higher qualification and children of their own were more likely to involve parents in care and had more positive attitudes towards involving parents (Gimbler- Berglund et al., 2008; He et al., 2005). One study reported that support from nurses assisted parental involvement in pain care (Lim et al., 2011), while other studies reported that parents were generally unsupported in undertaking pain care for their child (Franck et al., 2001; Franck et al., 2012).

Parents reported their own negative feelings and lack of knowledge of how to provide care which hindered their involvement in care (Lim et al., 2011). For example, parents were reluctant to approach nurses and wanted to feel more confident interacting with health professionals (Gale, et al., 2004; Rennick et al., 2011). These studies also found that parents wanted to be more involved in pain care but were sometimes prevented from doing so because of uncertainties about their role and nurses' reluctance to support them. Other studies found that nurse's negative attitudes (Polkki et al., 2002a) and non- verbal expressions discouraged parents from approaching nurses to seek out opportunities for involvement in care (Simons & Roberson, 2002). Parents wanted more consistency and sensitivity from nurses (Franck et al., 2012), while Gale et al. (2004) identified that parents felt unable to fulfil their parenting role, and nurses disregarded their concerns, indicating a lack of support. More support may have assisted parents to decide whether to stay with their

child during painful procedures which was found to be a particular concern in one study (Gale et al., 2004).

Nurses being busy and workload pressures were found to hinder support for involvement of parents in the child's pain care (He et al., 2011; Lim et al., 2011; Polkki, et al., 2002a; Twycross & Collis, 2013a). Parental involvement was perceived by nurses as increasing nursing workload (Simons et al., 2001). In contrast, increased workload of nurses was reported to result in additional responsibility placed on parents for monitoring their child's pain (Huth et al., 2003) and resulted in less time for nurses to guide and support parents (He et al., 2011).

2.4.2.3 Variations in the provision of information to facilitate involvement

Parental involvement in pain care appeared to be significantly influenced by how much information was provided by nurses. One study found that 81% of parents reported that they received verbal information about pain control and being provided with that information enabled them to be more involved in pain care (Franck et al., 2001). The other parents in this study stated they were dissatisfied with the amount of information about pain care provided. Many of the studies identified that parents wanted more information about pain management strategies (Franck et al., 2012; Gale et al., 2004; Jonas, 2003; Lim et al., 2011; Polkki, et al., 2002a; Simons et al., 2001). Lack of information about pain care contributed to lack of parental involvement and ineffective pain care in hospital (Kankkunnen, Vehvilainen-Julkunen & Pietila, 2002) and at home (Jonas, 2003).

Variations in the volume and content of information provided regarding pain care impacted on parent's involvement in care. Those parents who received most information, particularly in relation to risks and benefits, were more involved in their child's pain management (Tait, Voepel-Lewis, Snyder & Malviya, 2008). Other factors influenced the amount of information provided, such as whether nurses perceived that parents were too stressed or overwhelmed because of the acute nature of their child's condition to assimilate information provided (Simons & Roberson, 2002). The type of setting was also a factor, with parents in day surgery areas being provided with more information and subsequently reporting more satisfaction with the information provided (Jonas, 2003).

2.4.2.4 Knowledge deficits

Nurses' and parents' knowledge deficits related to pain care were reported in the studies. Lack of nurse knowledge was found to be a significant barrier to parental involvement in their child's pain care (Gimbler-Berglund et al., 2008; Kankkunen et al., 2008; Simons & Roberson, 2002; Twycross & Collis, 2013a; Unsworth et al., 2007; Vincent & Deynes, 2004; Zisk et al., 2007). Nurses' knowledge deficits were compounded when parents were knowledgeable about their child's care and were perceived as a threat to less confident and less informed nurses (Simons & Roberson, 2002). Furthermore, nurses were less likely to provide opportunities for parental involvement if they lacked the knowledge required to support parents (Vincent, 2007). In response to nurses' lack of knowledge, some studies identified education as central to enable nurses to involve parents in their child's pain care (Gale et al., 2004; Huth et al., 2003; Kankkunnen et al., 2008) and to overcome fears of feeling threatened when responding to parents desire to be involved in care (Simons et al., 2001; Simons & Roberson, 2002). However, nurses may have the knowledge required to effectively manage a child's pain and involve parents, but lack the skills or confidence to use their knowledge (Twycross & Collis, 2013a). In addition, no studies have identified a correlation between education and the ability to overcome barriers to involving parents in the care of their child's pain (Czarnecki et al., 2011). There appears to be a lack of application of knowledge that may be a contributory factor to lack of parental involvement in children's pain care.

Lack of parental knowledge also presented a barrier to their involvement in their child's pain care (Gale et al., 2004; He et al. 2011; Jongudomkarn et al., 2012; Kannunnen et al., 2002; Kankkunen et al., 2008; Lim et al., 2011) and was recognised by both parents (Lim et al., 2011) and nurses (Kankunnen et al., 2002; Kankunnen et al., 2008; Twycross & Collis, 2013a). Lack of knowledge and misconceived beliefs, resulted in parents being reluctant for their child to receive medication (Czarnecki et al., 2011; Kankkunnen et al., 2008; Simons & Roberson, 2002; Vincent, 2007). Parent reluctance for their child to receive medication was also related to unfounded embedded cultural beliefs about medication (Jongudomkarn et al., 2012). While nurses recognised their own knowledge deficits, they expected parents to possess knowledge they did not have, highlighting a tension between

nurses' expectations related to parents' knowledge (Simons & Roberson, 2002). Polkki et al. (2002a) found that parents felt that nurses generally recognised that they as parents had expert knowledge. In contrast, nurses felt that parents exaggerated their child's pain (Twycross & Collis, 2013a). Although one study reported that parents' pain scores corresponded with the child's pain score (Huth et al., 2003), another study found that nurses perceived that parents under or over-estimated their child's pain (Zisk et al., 2007), highlighting conflicts between nurses' and parents' views on parental knowledge.

2.5 Discussion

The review has highlighted several key issues in relation to what is known about how nurses work in partnership with parents to involve them in their child's acute pain care, which are now discussed. Chapter One has highlighted that the terms partnership working, collaborative working, participation and involvement are used interchangeably and lack of clarity may result in assumptions and misconceptions about how parents and nurses work together to care for the acutely ill child (Coyne et al., 2011; Power & Franck, 2008; Smith et al., 2015; Thompson, 2007). As involvement of parents is required for parents and nurses to work together, the term "involvement" will be used to encapsulate the activities that describe parents and nurses working together (Smith et al., 2010).

Differences in how parents and nurses understand and perceive involvement and partnership working were evident in this review and in the wider literature and contribute to the variations in implementing parental involvement in practice (Franck & Callery, 2004; Power & Franck, 2008). Parental involvement is a component of family-centred care and occurs at the nurse-led end of the family-centred care practice continuum (Figure 1, Chapter One) (Smith et al., 2010). Despite family-centred care being espoused as an ideal philosophy to support nurses and parents working together, as discussed in Chapter One, this does not necessarily translate into practice (Coyne et al., 2011; Coyne, Murphy, Costello, O'Neill & Donnellan, 2013; Mikkelsen & Frederikson, 2011).

The lack of understanding and implementation of family-centred care further compounds the different interpretations of what constitutes involvement. A range of

activities are described by nurses and parents as central to parents' involvement in pain care, such as parents participating in non-pharmacological methods, staying with the child in hospital and being present for procedures (He et al., 2005; He et al., 2011; Lim et al., 2011; Franck et al., 2001; Rennick et al., 2011; Simons et al., 2001). However, parents could be involved in other aspects of pain care, such as assessment, monitoring their child's pain, implementing pharmacological management strategies and evaluation of pain relieving interventions (Avis & Reardon, 2008; Kristensson-Hallstrom & Elander, 2004). Parents and nurses may perceive pharmacological interventions as in the remit of health professionals, which may account for absence of parental involvement in some aspects of pain care (Blower & Morgan, 2000; Coyne, 1995).

Parental expectations of involvement with pain care also impacted on perceptions of involvement, with some parents satisfied with the level of involvement (Franck et al., 2001; Polkki et al., 2002a; Twycross et al., 2013), while other parents were not sure what was expected of them (Blower & Morgan, 2000; Rennick et al., 2011). Some parents perceived that it was their role to advocate on behalf of the child when pain is not well controlled (Simons & Roberson, 2002; Ygge & Arnetz, 2004), while others appeared to accept moderate to severe pain as inevitable (Twycross & Collis, 2013b; Twycross & Finley 2013; Twycross, et al., 2013). In one study 58% of children in the study experienced severe pain and 24% experienced moderate pain (Twycross & Collis, 2013a). Trends of unrelieved pain in children have also been highlighted in other studies (Shretha-Ranjit & Manias, 2010; Taylor, Boyer & Campbell, 2008). While there are evidenced based guidelines to promote effective pain care, these are clearly not being utilised in practice (Taylor et al., 2008). Parents appear to acknowledge pain is expected and accepted (Twycross & Finley, 2013) and nurses seem to be colluding with this perception. If nurses agree realistic pain care goals with parents then parents are in a good position to advocate on behalf of their child when pain care is suboptimal (Jaakola, Mervi, Kaarianen & Palkki, 2013; Simons & Roberson, 2002; Twycross & Collis, 2013b; Twycross & Finley, 2013; Twycross et al., 2013).

Effective communication between parents and nurses is central to promoting parental involvement in care (Simons & Roberson 2002; Watt-Watson, Everden & Lawson,

1990). However, the review and wider literature highlights that this is not consistently taking place (Kawik, 1996; Neill, 1996b; Polkki et al., 2002b; Simons et al., 2001). There is often an unspoken assumption that parents know what is expected of them without nurses clarifying this with parents. Simons et al (2001) report that parents were not invited or supported to be actively involved in their child's pain care and therefore became passive participants. Furthermore, this was not questioned by parents, as they thought that challenging nurses would make them unpopular, illustrating the power nurses hold with regards to parental involvement in care. Positive attitudes and approachability of nurses has a positive impact on parent involvement (Gimbler- Berglund et al., 2008; He et al., 2005). Parents who wanted to be involved in their child's pain care, want to be supported to do so, by nurses.

Not involving parents when they wanted to be involved in care has negative consequences for their emotional wellbeing. Parents reported being stressed by lack of information, involvement and support (Gate et al., 2004). This led to parents feelings of helplessness (Polkki et al., 2002a), and frustration (Simons et al., 2001). The more involved parents were in their child's care, the less stressed parents appeared to be (Gale et al., 2004) and being involved gave parents a sense of being useful when contributing to care (Rennick et al., 2011). However, not all parents want to, or are able to, be involved in their child's pain care (Rennick et al., 2011). Parents have competing demands on their time and face financial struggles which impact on their desire to be involved in their child's pain care in hospital (Callery 1997a; Darbyshire, 1994; Tallon et al., 2015).

Facilitation of parental involvement appears to be strongly influenced by the provision of information to parents by nurses. Parents generally indicated that they wanted more information (Franck et al., 2012; He et al., 2011; Jonas, 2003; Lim et al., 2011; Polkki et al., 2002a; Kankkunen et al., 2002). Lack of information can create a barrier to parental involvement just as providing information can facilitate involvement. The amount of information provided to parents was decided by nurses (Simons & Roberson, 2002). Similarly, nurses made decisions about whether parents are able to cope with being provided with information depending on how they respond, emphasising a paternalistic approach. Information provision is controlled by nurses because of the power imbalance (Kankunnen et al., 2008). Nurses have been

reported in the literature to be reluctant to relinquish control, which may account for resistance to providing information to parents (Coyne, 1995; Kawik, 1996; Neill, 1996a). Similarly, less confident and informed nurses were threatened by knowledgeable parents, which may also account for nurses' reluctance to provide information (Polkki et al., 2002a; Simons & Roberson, 2002).

Parents cannot be expected to have the knowledge that nurses have and therefore are vulnerable in the relationship and reliant on nurses to provide relevant information (Neill, 1996b). The review findings highlight the need to improve nurse's knowledge regarding children's pain care and to enable them to reciprocate this to parents (Simons & Roberson, 2002; Twycross, 2010; Twycross & Collis, 2013a). If nurses are able to articulate their knowledge to parents, children who would undoubtedly benefit from their parents input (Kain et al., 2007; McCarthy & Kleiber 2006; Skene, 2010). This requires considerable educational input to shape ideas of new nurses and post-registered education to redefine and realign existing knowledge. It would appear that the key to nurses releasing the power is to empower them with the knowledge and communication skills to enable parents to become involved in their child's pain care, to the extent decided by parents. Viewing education as the key to improving pain care should be considered with caution however, as even when nurses have theoretical knowledge, this may not always be applied to practice (Czarnecki et al., 2011; LeMay et al., 2010; Twycross, 2007), and education may not be enough to change pain care behaviour (Simpson, Kautzman & Dodd, 2002). Nurses need to understand how to implement family-centred care (Franck et al., 2001), have pain care knowledge and combine and apply this in every day practice as standard. Therefore, considering education as a solution to inadequate pain care may be too simplistic.

2.6 Review Limitations

This review aimed to identify studies that explored involving parents in their child's pain care. While some of the studies explicitly explored parental involvement (Franck et al., 2001; Franck et al., 2012; He et al., 2011; Jongudomkarn et al., 2012; LeMay et al., 2010; Lim et al., 2011; Polkki et al., 2002a; Polkki et al., 2002b; Rennick et al., 2011; Simons et al., 2001, Simons & Roberson, 2002; Twycross & Finley, 2013), others were based on broader exploration of pain care. Only two of the studies

identified family-centred care as the underpinning theoretical framework and these were undertaken within neonatal settings.

A limitation of the review is that it is not exhaustive and other studies may have included aspects of parental involvement but was not apparent from screening the title or abstract. Some studies explored specialist areas such as neonates (Franck et al., 2001; Franck et al., 2012; Gale et al., 2004) and cardiac units (Huth et al., 2003) which could impact on transferability of findings to general acute children's wards, as specialist areas can involve more prolonged and intensive contact between nurses and parents (Guba & Lincoln, 1994). Similarly, most of the studies focussed on post-operative care impacting on transferability to general acute care areas. However, excluding these studies would considerably limit the scope of the review.

2.7 Chapter summary

Synthesis of the review findings has identified an overarching theme; barriers to involvement and partnership working. Variations in how parents are involved in their child's pain care include a range of responses from parents who are satisfied with involvement, to parents wanting to be more involved. Parents have a valuable role in a child's acute pain care, but require information and support to overcome the barriers to involvement (Callery & Smith, 1991; He et al., 2005; Polkki et al., 2002b). Barriers to involving parents in pain care included: different perceptions and understanding of parental involvement; poor communication; and lack of parental support; variations in the provision of information to facilitate involvement; knowledge deficits. The review highlighted the influence of the nurse in facilitating or creating barriers to parental involvement. Nurses are ideally placed to support parental involvement and yet appear to be creating barriers to parental involvement. Power and control feature in the review and there is a power imbalance which places parents at a disadvantage when they try to become involved in their child's pain care. The findings from the review have highlighted a need for further exploration of the extent to which parents are involved in their child's pain care and identification of the factors that influence nurses to promote parental involvement. Furthermore, no studies were identified that explored pain care in relation to family-centred care in acute children's wards and involved both parents and nurses.

Chapter Three: Methodology

3.1 Introduction.

This chapter examines the epistemology and ontology of ethnography, the methodology underpinning this study and the appropriateness of the chosen methodology to meet the study aim and objectives. First, the aim and objectives of the study will be outlined. Second, epistemological and ontological principles underpinning qualitative research and the rationale for adopting a qualitative approach are presented. Finally, the rationale for ethnography as the selected qualitative approach is presented, with consideration of the philosophical underpinnings of ethnography and relationship to nursing research.

3.2 Study aim and objectives

Chapter One and Two have highlighted that parental involvement in a child's acute pain care can have a positive effect on the child's pain experience. Yet parental involvement is not consistent, despite the availability of guidelines and policies to support parental involvement in care (Department of Health, 2010; Royal College of Nursing, 2009). What remains unclear is why there are continued variations in parental involvement as reported in the literature and in the researcher's professional practice and experience. The study aimed to explore parental involvement in the child's acute pain care. The specific objectives of this study were to:

1. Observe and analyse the interactions and experiences of the child, parent and nurse in the child's pain care in acute care settings, within the ward based culture of espoused family-centred care;
2. Examine the extent to which parents are partners and are involved in their child's care;
3. Identify the factors which may influence parental involvement in their child's pain care;
4. Explore ways in which parental preferences for involvement in their child's care can be identified, facilitated and enhanced.

3.3 Rationale for adopting a qualitative methodology: epistemological and ontological considerations

The epistemological and ontological assumptions underpinning qualitative research are based on the principles that the nature of knowledge is embedded in human experiences, which are unquantifiable. Methodology, associated with the wider concepts of ontology, epistemology and theoretical frameworks, is defined as “a way of thinking and studying social phenomena” (Strauss & Corbin, 1998, p.1). Philosophical assumptions underpin the methodology of the study and influence all stages of the research process and enables meaningful conclusions to be drawn from the findings (Burns Cunningham, 2014; Crotty, 1998). Congruence between the methodology and research methods can assist in ensuring the research question is answered adding validity to the findings.

In preparation, and in the early stages of the research, it became apparent that exploring the interactions of parents and nurses in complex situations was congruent within the constructivist research paradigm (sometimes referred to as the naturalistic paradigm). The epistemological roots of the constructivist paradigm are based on the premise that reality is socially constructed and shaped by the people experiencing it, adopting a critical view about what we know about the world (Gergen, 1999). Furthermore, realities are based on the context in which they occur, and are influenced by current and past cultural, political and social norms (Darlaston-Jones, 2007). At the macro level, parental involvement in a child’s care in hospital has evolved over the last century and is shaped by changes in economic, political and technological shifts, but predominantly changing societal views of children, and a greater recognition of children’s agency (Bowlby, 1953; Department of Health, 2010b; Ministry of Health 1959; Robertson, 1989). However, at the micro level, the realities of the parent, child and nurse interactions are linked and the relationships formed influence parental involvement in care. The perspectives’ of parents, children and nurses will have similarities and differences and are likely to change over time. Capturing what involving parents in their child’s pain care means for parents and nurses is underpinned by the recognition that multiple realities can best be revealed by qualitative investigative approaches.

Constructivist approaches contest an assumption of empiricism and realism. Central to this study was an acknowledgement that interactions between parents and nurses in an emotionally charged environment such as an acute children's ward, are dynamic, shifting and respond to contextual and environmental influences. This contrasts to positivist approaches to undertaking research, which view reality as universal, objective and quantifiable (Darlaston-Jones, 2007). The differentiation, between positivist and constructivist stances present dichotomous views of reality and consequently how research can examine reality. Positivism rejects individual differences in favour of a universal reality for all and has historically dominated health research, which has been viewed as superiorly scientific to constructivist approaches (Holt, 2011). However, nursing research frequently aims to explore the "human" aspects of patient care that generates research questions that cannot be addressed by positivist approaches. While positivist and constructivist approaches have the potential to generate complementary, but different types of knowledge, the positivist approach would not be sufficient to generate the required type of knowledge, and therefore understanding, about experiences that are important to nurses and families, as it fails to recognise the uniqueness of people and their experiences (Darlaston-Jones, 2007; Kelle & Erzberger, 2004).

While it was apparent that the knowledge required to address the research aim would be anchored in participant accounts and behaviours that are unquantifiable, it was important to ensure that the research approach best met the study aim and objectives. When considering the range of qualitative approaches available, I frequently revisited the purpose of the study to remain focussed on what I was really trying to find out. Inadequate consideration to the nature of the knowledge required to address the research problem has the potential to lead to incongruence between the methodology and methods being applied to the study and can result in poor understanding and application of methods (Greener, 2011; Smith, Cheater & Bekker, 2011). Central to this study was a desire to gain knowledge about how parents were involved in pain care and therefore an observational study design was appropriate. While observing participant interactions provides knowledge about "what" people do, it does not capture participants' insights from their experiences of events that have occurred. "Why" participants do what they do in relation to pain care required further exploration from their perspectives. Eliciting this type of knowledge from semi-

structured interviews was underpinned by the assumption that knowledge about why and explanations of what people do, cannot be objectively determined. Rather, participant reality is multifaceted and is influenced by multiple realities and socially constructed meaning and consequently knowledge generated through research is also a social construction (Hammersley & Atkinson, 2007). Rejecting the notion that meaning is an object waiting to be discovered, as in objectivism, social constructivism aims to understand human meaning and experiences as co-constructed by the interactions between the researcher and participants. Furthermore, within the constructivist paradigm, methodological approaches usually facilitate opportunities for researcher/participant interaction.

Qualitative research methodologies are particularly suitable when research questions are difficult to answer by manipulation of variables, such as when little is known about a topic or when exploring complex human interactions (Morse & Field, 1996). In the context of this study, participant realities are dependent on their perspectives and experiences. For example, nurses' perspectives are anchored in their understanding and subsequent application of family-centred care principles, and their knowledge about pain care. Nurses' professional and personal beliefs, values and experiences also permeate their reality of parental involvement in pain care. In contrast, parents are often, but not exclusively, reliant on nurses sharing information and giving "permission" to be involved in their child's care. Parents' own or their child's current or previous beliefs and experience of pain will inevitably impact on their perspective and desire to be involved in care.

Qualitative approaches assist with fostering a deep understanding of phenomena such as what influences and impacts on parent-nurse interactions and how this manifests in parental involvement in a child's pain care. Detailed insights can be developed from prolonged observation and exploring participant experiences in the context that they take place (Spradley, 1980; Sandelowski, 2000). Interviews typically enable detailed descriptions of participant experiences and perceptions of events, providing rich, thick descriptions that represent their perspectives (Spencer, Ritchie & O'Connor, 2003). Ethnography has been described as being an interpretive act of "thick descriptions" (Geertz, 1973, p. 9) emphasising how symbolic meanings are exemplified by participant descriptions, enabling the researcher to interpret and make

sense of everyday actions and behaviours. Similarly, an ethnographic qualitative design facilitates the researcher to be flexible in the context of real world situations, adapting to transient and fluctuating interactions as often encountered in clinical care areas.

Qualitative approaches are widely adopted in nursing research, due to the nature and complexity of the range and diversity of research questions about nursing care, such as pain care (Simons et al., 2001; Twycross & Finley, 2013). While some aspects of pain can be quantitatively measured, for example, using validated tools such as the "barriers to optimal pain management" survey tool (Czarnecki et al., 2011), parents' and nurses' experiences of parental involvement requires a more explorative approach to understand what this means to parents and nurses. However, the wide range of qualitative approaches available, each with differing epistemological and ontological underpinning and therefore different application, reflects the challenges of choosing appropriate methods (Snape & Spencer, 2003). Although, there are no definitive ways of classifying qualitative methodologies, qualitative methodologies have shared principles, such as locating the researcher in the real world. Here, the intention is to make the world visible by presenting interpreted participant accounts, which are usually gleaned through observation in the natural setting and interviews (Denzin & Lincoln, 1994). From the vast range of qualitative methodologies, the most commonly adopted include ethnography, phenomenology and grounded theory, each emulating from the well-established disciplines of anthropology, psychology and sociology respectively. Rationalising the choice of qualitative approach can be challenging, but can be overcome by ensuring choice is driven by the research aims. The next section will rationalise the choice of methodology within the qualitative domain.

3.4 Rationale for adopting an ethnographical approach

The aim and objectives of the study were to observe and examine parent-nurse interactions to understand why there are inconsistencies in parental involvement in the child's pain care. This can be best achieved by capturing parent-nurse interactions in the "field". The field in this study is the care of acutely ill children within the environment of an acute ward. Nurses claim to work within an espoused shared philosophy of family-centred care, whereas most parents expect to be welcomed and

participate in some way in their child's care (Coyne et al., 2011). This shared view is in part reflected in the open access for parents who are able to stay with their child throughout their stay. Similarly, nurses work within a culture that places value on caring and involving patients (children and their parents) in their own care (Clayton, 2000; Department of Health, 2007, 2010a). However, as highlighted in Chapter Two, there are inherent tensions in embedding the concept of family-centred care into practice. Underpinning the study with an ethnographic approach aimed to maximise capturing parent-nurse interactions within the culture of an acute children's ward (the field) where and when these interactions occurred.

Ethnography with origins in anthropology is defined as "the art and science of describing a group or culture" (Fetterman, 1998, p 1). Ethnography is assumed to originate at the University of Chicago in the 1920's, where students were sent "to the streets" to look and listen, learn, explore and begin to develop an understanding of the environment (Deegan, 2001). The "streets" in this study were the children's wards in two district general hospitals, which in contrast to early ethnographic work are familiar to the researcher. Park and Burgess, early pioneers in the Chicago school of ethnography, trained ethnographers and wrote numerous books about their students' work based on a series of studies which were aptly named "The Hobo" and "The Gang" (Deegan, 2001, p 12). Park and Burgess emphasised how ethnographic researchers could locate themselves in the culture being investigated as a means of developing deep insights into the culture. The groups in my study may not be as distinctive as "gangs" or involve a gang culture. However, an ethnographical approach can be used to explore more subtle groups of individuals with a common set of values and beliefs, such as children and families and children's nurses on acute children's wards (Barton, 2008).

Ethnographical approaches were introduced into healthcare research as an alternative to the dominant positivist approach and has gained popularity in response to the recognition of the need to understand care within cultural contexts (Periera de Melo, Sevilha, Gualda & Atunes de Campos, 2014). Ethnographical approaches are not new to nursing and has been adopted in human sciences since the 1980's (Gelling, 2014). In children's nursing, ethnographic approaches have been used to observe and examine the experiences of the child, family and nurse while the

researcher is immersed in the environment and culture with its inherent richness (Hunt & Symonds, 1995; Pereira de Melo et al., 2014). Similarly Hunt & Symonds (1995), whose study considered social meaning of midwifery, asserted that ethnography was particularly suited to the complex task of exploring health professionals at work. Although ethnographical approaches are suitable to observe the way family-centred care is operationalised in practice, Shields et al's. (2006) review of 11 qualitative studies of family-centred care highlighted that none undertook an ethnographic approach. Furthermore, none of the researchers in the studies identified in the literature review presented in Chapter Two adopted an ethnographic approach. Yet, the review highlighted the paucity of studies which explored pain care across the range of common childhood illnesses within the setting of general children's wards. By undertaking an ethnographic approach, this study aimed to provide new and further dimensional insights into pain care within family-centred care.

One of the strengths of an ethnographic approach is that participant perspectives are valued and central to the data collection and analysis, with the potential of findings to improve services from the participants' perspectives (Holden & Littlewood, 1991). Moreover, ethnographical approaches are about "learning about people", as opposed to "studying people" emphasising the person and inherent cultural focus of this approach (Spradley, 1979, p. 3). Parent-nurse interactions can be best understood by observing interactions and from participants' perspectives. The researcher has to be close to those interactions for a prolonged period to capture actual practice and explore participants' perspectives of events. Therefore, exploration of families, who are intermittently part of this culture and nurses as a constant part of this culture, was undertaken using an ethnographic approach. Spradley (1980) refers to participants as actors, each playing a part based on their unique perspectives. Ethnography has been linked with symbolic interactionalism, which has been defined as "the symbolic interactionist approach that rests upon the premise that human action takes place in a situation that confronts the actor and the actor acts on the basis of defining the situation that confronts him" (Atkinson, Coffey, Delamont, Lofland & Lofland, 2001, p.27). Nurses are key actors who could be described as willing "natives" to the cultural environment. It has been claimed that nurses control the extent to which family-centred care and parental involvement in care are implemented or maintained

(Shields et al., 2006). Here, parents and children unexpectedly become part of the culture when the child becomes acutely unwell.

While ethnographic approaches have been adopted by nurse researchers, because it focuses on patient groups and shared beliefs and understandings as observed in clinical areas, it is not as widely adopted as other qualitative research methods, such as grounded theory and phenomenology. Reasons for this could be due to practicalities of gaining access to clinical areas which may be perceived as hard to reach, due to ethical constraints and the time required for prolonged observation (Pereira de Melo et al., 2014). Access to acute children's wards was crucial in this study, as ethnographical approaches are essentially field orientated. Prolonged periods of observation in the participant world within the cultural setting was key to illumination of patterns that capture meaning, which is accomplished through describing, interpreting and analysing participant perspective in their own voice. Nurse-parent dyads and their perceptions of their interactions and how these impact on parental involvement in pain care can only be viewed through observing and giving them a voice and representing their realities. Other qualitative research approaches also aim to present the participant experiences and perspectives or "voice", such as phenomenology, which lends itself to examining the views and experiences of parents and nurses (Miller, 2005). Jongudomkarn et al. (2012) and Simons et al. (2001) used in-depth interviews to present phenomenological accounts of parents' and nurses' experiences of pain care. However, in this study phenomenology was not adopted because interviewing participants focussing on their lived experience may not account for the cultural and organisational influences impacting on the complex interactions that take place in clinical areas. Central to this study was recognising the importance of both parents' and nurses' perspectives and how these are enacted in practice, whereas a participant led approach, such as phenomenology, may have caused tension in representing both accounts equally (Snelgrove, 2014). Acknowledging the impact of cultural influences on the behaviours of participants was key to capturing potential influences on parent-nurse interactions, within the context of family-centred care.

Access to the field was gained through appropriate ethical approval as described in Section 4.3. However, the practicalities of gaining access do not fully prepare the

researcher for the realities of fieldwork, which created some challenges. Challenges predominantly related to the tensions between insider and outsider perspectives (Cudmore & Sondermeyer, 2007). Ethnography has been described as a radical methodology which requires the researcher to experience the lives of others, which can potentially impact not only on the participants, but on the researcher. As an observer over a prolonged period of time, I became more aware of the influence my presence was having on participants, particularly nurses. Furthermore, some of the observations where pain care was inadequate were distressing for me both personally and professionally. Reflexive and reflective accounts in Chapter Seven, explore these issues further. Researchers using an ethnographic approach should be prepared for the emotional consequences of fieldwork, which are more acute for researchers in nursing (Pereira de Melo et al., 2014).

Traditionally in ethnography, the researcher is unfamiliar with the culture (Streubert Speziale & Carpenter, 2007). However, recently more emphasis has been placed on the value of focussed ethnographic studies in nursing where nurses study their own culture because of an ability to explore the 'nuances' of nursing practice (Rudge, 1995; Skene, 2010). This has raised issues about the researchers' influence on the behaviour of those being observed and potential personal and professional bias infiltrating data collection, analysis and construction of meaning from the data. The ethnographic stance of the researcher as primarily a data collection instrument inevitably results in the researcher becoming part of the data. However, with prolonged immersion, insider familiarity can be transcended with the participant perspectives dominating the data, rather than researcher familiarity (Da Matta, 1987). Furthermore, while it is impossible to remain outside of one's own subject area, reflexivity can assist with minimising the insider bias that may occur (Manias & Street, 2001) and is paramount in ethnographic studies (Koch & Harrington, 1998). Making sense of the insider position is more important in studies adopting an ethnographic approach than in any other approach, due to the relative closeness of the researcher to the participants and participant world. This is particularly important when undertaking research with children who could be more susceptible to being influenced, either intentionally or unintentionally, towards the researcher's personal and professional beliefs about care. However, Reinharz (1997) asserts that the researcher requires some insight into the phenomena being studied to understand

more clearly the deeper meanings of the phenomena being studied. Furthermore, being reflexive facilitates nurses to question assumptions about their nursing identity, practice and values, leading to a shared perspective referred to as inter-subjectivity (Pellatt, 2005).

Intrinsic to the ethnographic approach is an openness to people, to enable people to be investigated for who they are, and what they do, without judgement or personal bias being applied. Part of reflexivity is acknowledging and protecting against judging people by the researcher's personal and professional standards (Lambert, Glacken & McCarron, 2011). As a children's pain care expert, my values and beliefs were underpinned by in-depth knowledge which could have impacted on all aspects of the study. Guarding against this and avoiding pre-judgements helped to minimise insider influence. Respecting participant perspectives and feelings are paramount to enable a more naturalistic exploration. Spradley (1980) advocates that researchers using an ethnographic approach adopt a "childlike" or an "apprentice" stance in the field in an attempt to understand social phenomena from the participant point of view. While this approach may assist in viewing the participants and setting through an outsider lens, it seemed to be somewhat deceptive and covert and was not undertaken.

Observation, listening and formal or informal interviews are most associated with ethnographic approaches. While full immersion and participation in the culture or "field" during data collection is usually associated with ethnography (Spradley, 1979) for ethical, professional and pragmatic reasons this was not adopted. This study aimed to explore a culture that is well known to the researcher, by non-participant observation. Lambert et al. (2011) offer different interpretations of ethnography and suggest that a consensual definition and agreed procedure for ethnographical research is lacking. While there is a lack of a consistent application of ethnography and a claim that ethnography lacks clearly defined characteristics (Hammersley & Atkinson, 2007), there are common principles. These include an aim to describe social phenomena through narrative description, having observed the phenomena in the environment in which it occurs, without quantification (Hammersley & Atkinson, 2007). Settings for data collection are selected specifically for the appropriate qualities of the environment and participants and should be natural and undisturbed, with the researcher not attempting to change or influence the setting (Miles &

Huberman, 1994). Unlike positivist approaches, ethnographers make no attempt to control either the environment or participant behaviours. Rather, researchers adopting an ethnographic approach are interested in understanding how a particular culture works, and how the culture is maintained and adapts to changing circumstances, with emphasis on relationships and behavioural regularities, patterns or rules (van Maanan, 1988). Similarly, researchers adopting an ethnographic approach aim to observe routine and predictable, rather than unusual behaviour (Fetterman, 1998). Parent-nurse interactions are natural, everyday occurrences in children's wards and although they vary in how they support parental involvement in pain care, are part of usual practices.

While ethnographical studies are not always informed by theoretical frameworks, theories to support patient (parent) involvement do exist, such as family-centred care and partnership in care models. This may account for the absence of grounded theory approaches within the studies reviewed in Chapter Two. In contrast to grounded theory which aims to generate theory through inductive examination of the data, the ethnographic stance does not aim to generate theory, but describe and understand the data and setting. Unlike most ethnographical approaches, grounded theorists reject the notion of pre-defining established theory before embarking on research (Robson, 2002; Strauss & Corbin, 1990). However, similarities between ethnographical approaches and grounded theory are evident. Both approaches view human beings as individuals who are responsive to their contexts and therefore the natural setting is the best place to collect data. Similarly, central to both approaches is the inclusion and application of iterative methods of data analysis which should be concurrent during data collection. Domain analysis is often associated with ethnographic approaches and involves describing semantic relationships among cultural meaning, followed by taxonomic and componential analysis (Spradley 1980). However, similar to grounded theory, the processes involved in domain analysis, can lead to theory development, which was not the aim of the study. Constant comparative analysis to develop theory, associated with grounded theory, has the potential to focus on selective coded data to identify emerging concepts, rather than representing participant accounts in their entirety (Holloway, 2005; Rintala, Paavilainen & Astedt-Kurki, 2014; Strauss & Corbin, 1998). Again, this appeared incongruent with ethnographic approaches where representing participant accounts

are central to the methodology. To avoid misrepresenting the participant perspectives, the framework approach that underpinned the data analysis is more consistent with describing data, remaining as close to the participant perspective as possible. Framework approach has been described as an iterative process, in contrast to entirely inductive approaches, such as grounded theory, and enables a clear audit trail from the original data to interpretations of findings (Ritchie & Lewis, 2003; Smith & Firth, 2011). The application of the framework approach is outlined in the following chapter.

Lack of recognised methods and procedures associated with ethnography may account for researchers avoiding ethnographic approaches in favour of other qualitative research approaches (Savage, 2000). Criticisms relate to confusion about terminology which situates ethnography as both a process and product. Within the discipline of anthropology, ethnography was regarded as a theoretical framework, as opposed to a methodological framework, based on differing views and philosophical stance (Atkinson & Hammersley, 1994). Furthermore, numerous adaptations of ethnography have emerged, resulting in pluralistic practices, each situated with different philosophies of what constitutes legitimate knowledge (Atkinson & Hammersley, 1994). One such adaption is critical ethnography which has emerged as an alternative ethnographic approach and focuses on the influence of power dynamics in social situations with an aim to support greater equality for people who are oppressed (Madison, 2012). Mahon and McPherson (2014) adopted critical ethnography to explore the impact of power and social behaviour on nurse's decisions to remain or leave bedside nursing. Similar to ethnography, critical ethnography situates within specific cultural contexts and locates the researcher's stance and reflexivity. However, critical ethnographers make no claim to be apolitical in their approach or value free in their interpretations (Mahon & McPherson, 2014). Therefore, unlike ethnography, knowledge generated in critical ethnographic studies does not present a realist view and value-neutral representation of languages and behaviours of a culturally specific group (Hammersley & Atkinson, 2007). While power relationships are known to exist in nursing, making assumptions about this before undertaking the study had the potential to introduce presumptions, which are incongruent with presenting impartial participant views. However, power relationships can significantly influence parent-nurse interactions related to parental involvement in

the child's pain care and a critical ethnographical approach may have offered a different perspective and could be considered for future studies.

3.5 Chapter summary

This chapter has critically explored different epistemological and ontological viewpoints to establish the most appropriate methodological approach for this study. Clarifying the methodology prior to embarking on a research study is essential and can facilitate a robust research design, utilising appropriate methods to achieve the research aim. A qualitative, ethnographical approach was deemed as the most appropriate approach to explore parent-nurse interactions in the clinical setting because it captures real life experiences of parents, children and nurses in the cultural environment they take place, which is congruent with meeting the study aim and objectives. Chapter Four will outline the methods used to undertake the study.

Chapter Four: Methods

4.1 Introduction

This chapter presents the methods used to explore parental involvement in a child's acute pain care. The chapter outlines: the setting; ethical approval; sample selection; data collection methods; data analysis and ethical considerations. As outlined in Chapter Three, an ethnographical approach underpins the study design and the methods adopted are congruent with a field focussed ethnographic exploration.

4.2 Setting

Participants were recruited from a NHS Trust in the North of England, comprised of two hospitals on two different sites. The sites were specifically selected as they represented the settings where children were likely to experience pain and where family-centred care is claimed to underpin practice. Site one, was situated in a large District General Hospital and comprised a 26 bedded children's ward, caring for children aged from one day old to 16 years of age. There were 12 single cubicles, two four bedded areas and a six bedded assessment unit. In the children's assessment area children referred from the emergency department and General Practitioners were assessed. In the assessment area, decisions were made regarding whether the child could be discharged, needed to stay in the area for observation or required admission as an in-patient. In addition, there was a two bedded high dependency area and an area for children requiring surgery. There were approximately 300 referrals a month to this site (Local Health Informatics, 2014). Site one was typical of most children's wards in District General Hospitals in that care was led by doctors and services managed by the Matron for Children's services. All trained nurses were RN Child trained which complies with recommendations for the required number of children's nurses on duty at any one time in children's wards (Royal College of Nursing, 2007). All children, apart from children with surgical and orthopaedic conditions were admitted to this site.

Site two, was a smaller unit than site one and was partly nurse-led, by nurses with advanced practice roles, referred to in the NHS Trust as, paediatric nurse practitioners. Advanced nurse roles are becoming more common in children's wards, and despite the impetus stemming from European Working Time Directives

(Department of Health, 2004) that reduced doctors working hours, advanced nursing roles have the potential to enhance care delivery, because of additional education that focuses on diagnostic and treatment skills, advanced clinical reasoning and higher levels of critical enquiry (Hervo, Longden, Kelly & Rajah, 2014). The impact of variations in service provision and leadership structures across the two sites could have impacted on the data collected and were considered during data analysis and are discussed in the Chapter Six. Site two was an 11 bedded in-patient unit admitting infants and children from 4 months to 16 years of age with a range of medical and surgical conditions. Approximately 200 children were referred to the unit each month. Unlike site one, children with acute surgical and orthopaedic conditions were also cared for in this unit. While it was planned to predominantly access site one, it became apparent after three days that there would be insufficient data to meet the research aims as pain care was rarely discussed. This was a significant finding in itself, but in order to meet the study objectives this second site was accessed.

Each unit had open visiting policy and facilities for parents to stay with their child overnight. Parents slept at the side of their child's bed. There was a parent's room on each site and parents were provided with information sheets outlining facilities and inviting parents to be part of the child's care. At the time of the data collection, the ward philosophy was being updated to reflect "service user/carer involvement". There was a pain team for the trust. However, this was an adult focussed team and there were no children's nurses in the team. The presence of a pain team has been found to improve pain care, particularly in post-operative pain care (Frigon et al., 2009). However, children's pain teams are usually confined to larger tertiary centres and children's hospitals and the impact of children's pain teams on outcomes does not appear to have been reported on in the United Kingdom (Kost-Byerly, Chalkiadis & Davidson, 2012).

4.3 Ethical approval

Ethical approval is required before undertaking research with patients in a NHS organisation and was successfully achieved through research governance processes of the Integrated Research Application System (IRAS) and National Research Ethics Services (NRES) (Galbraith, Hawley & De-Souza, 2006). Prior to undertaking the study, ethical approval was gained from the university School Research Ethics Panel

(SREP), the NHS Research Ethics Committee (REC) and the site specific Research and Development Unit. Each NHS Trust has their own research management processes and the Director of Services and Matron for children's services were aware of and supported the study. Minimising risk and protecting all participants, particularly children who are vulnerable was considered before, and when, undertaking the study. The ethical considerations and issues are outlined in Section 4.8.

4.4 Sample selection

Sampling strategies in ethnographic studies are purposive as participants are drawn from a specific setting and have the knowledge required to meet the study aims. The sample for this study was a purposive sample of families and nurses. In qualitative research, purposive, selective and theoretical sampling are the most commonly adopted strategies with a focus on small samples to generate rich, in-depth data (Miles & Huberman, 1994). Common to qualitative sampling, recruitment, data collection and analysis usually occur simultaneously until the researcher recognises that there are no new insights emerging from the data (Coyne, 1997; Lincoln & Guba, 1985). Selective sampling has more emphasis on predetermined sampling criteria, whereas in theoretical sampling, normally associated with grounded theory, flexible sampling criteria are applied with people who display characteristics associated with the phenomena under investigation (Higgingbottom, 2004). Whereas, purposive sampling is described as judgmental sampling that involves conscious selection of participants by the researcher while minimising bias (Crookes & Davis, 1998). Qualitative research has been criticised for lack of transparency in processes used when recruiting participants (Coyne, 1997; Higgingbottom, 2004; Miles & Huberman, 1994). Clearly identifying how the sample was identified to reflect the participants within the specific culture can assist the reader to understand the researchers' decisions about sampling (Higgingbottom, 2004).

Participants were included if the family was being cared for in shared area of the ward and nurses who happened to be present on duty on the days of observation. Inclusion criteria were applied; all children across the age range and families who were not in single rooms and all nurses on duty at the time of observation were invited to participate in the study. Families being cared for in single rooms were not

included to avoid intensive intrusion on individual families. Representing children across the age range had the potential to add breadth to the data and potentially maximise the generalisability of study findings and while this is not the ultimate goal of ethnographic studies, may contribute to credibility and rigour in sampling (Mays & Pope, 2000).

Some exclusion criteria were applied when recruiting participants. While no children were excluded based on age, most neonates and younger infants were nursed in single rooms because of increased risk of infection due to their developing autoimmune systems, which excluded this group on the grounds of being in a single room. Children without the presence of their parents were not included as they did not meet the aims of the study.

As in most qualitative studies, the exact number of families and nurses recruited could not have been pre-determined and was guided by the emerging themes during preliminary data analysis (Roper & Shapira, 2000; Tuckett, 2004). Sample sizes in qualitative research are variable and unpredictable because of their iterative and emergent nature (Murphy, Dingwall, Greatbatch, Parker & Watson, 1998). However, it was proposed that 10-20 families and 10-15 nurses would be likely to meet the study aim and objectives and that data collection would cease when preliminary analysis suggested new themes might not emerge. As the recruitment and therefore obtaining consent from nurses, children and families could only occur during the period of observation, recruiting nurses and families could not be undertaken in advance of the study.

All but one family who were approached agreed to participate in the study, resulting in a total of 58 participants (Table 1 and further outlined in Appendix 4 and 5); 27 mothers, 14 fathers, two grandparents and one aunt (across 30 families) and 14 nurses. Characteristics of participants were recorded that may have assisted with data analysis: for example child's age and reason for admission, and nurses' length of experience as a children's nurse, qualifications (professional and academic) and staff grade.

Table 1: Sample and number of participants interviewed

Child	Age (years)	Condition	Participant
Tom	22 months	Wheeze	Father
Henry	4	Intussusception- Surgical Emergency	Both Parents And Paternal Grandparents
Yovan	4	Enlarged Lymph Nodes	Mother
Tim	18 months	Tremor	Both Parents
Sam	14 months	Wheeze	Mother And Another Relative
Alice	15	Limp	Mother
Raul	5	Tonsillectomy	Both Parents
Emily	3	Wheeze	Mother
Jake	4	Renal Problems	Father
Frances	4	Tonsillectomy	Both Parents
Ben	5	Tonsillectomy	Both Parents
Steven	4	Tonsillectomy	Both Parents
Leanne	4	Breathing Problems	Mother
Jonathon	5	Tonsillectomy	Both Parents
James	2	Grommets	Mother
Robert	7	Dental Extractions	Mother
John	8	Abdominal Pain	Mother
Fred	10	Fractured femur	Mother
Rajiv	10	Laparotomy/Abdominal Surgery	Both Parents
Dan	4	Fractured Radius And Ulna	Mother
Paul	7	Dislocation Elbow	Mother
Jack	14	Knee Injury	Father
Jeremy	11	Appendicectomy	Both Parents
Callum	10	Testicular Pain	Mother
Amy	2	Fractured Femur	Mother
Maddie	14	Removal Of Exostosis Knee	Mother
Helena	15	Abdominal Pain	Mother
Heath	9	Fractured Radius And Ulna	Both Parents
Evie	2	Removal Of Foreign Body From Foot	Mother
Richard	4	Orchidopexy	Both Parents
Nurse	**Band**	**Years of experience**	**Qualifications**
Hannah	5	1.5	Diploma
Lorraine	5	15	Diploma
Harriet	5	3	Degree
Carmel	5	12	Diploma
Grace	6	20	Degree
Jane	5	1.5	Degree
Lauren	5	1.5	Degree
Karen	6	20	Degree
Rosie	5	3.5	Diploma
Pam	5	18	Degree
Liam	6	20	Masters
Annette	6	8	Degree
Teresa	5	5	Diploma
Colleen	5	22	Diploma

4.5 *Recruitment procedures.*

Appendix 6 outlines the recruitment and consent procedure. Nurses were briefed by the matron of children's services in advance of the study during ward meetings. On the observation days consent was gained from nurses who were asked to provide brief information to children and families about me and the research and seek permission for me to approach them. If children and parents agreed I then provided further detailed information verbally and written in the format of information sheets prior to gaining written consent. All families were given time to decide whether to participate prior to gaining informed consent. The aim was to give nurses, children and families at least 30 minutes to consider their response. The same process was undertaken for new children and families being admitted into the observation area. While it was not intended to exclude specific conditions, it was neither appropriate nor safe to approach families if the child was critically ill. Recruitment procedures aimed to prevent the family/child from being coerced into agreeing to participate in the study and reassure them that their child's care would not be affected if they did not agree.

Although children were not the study participants, they were observed and present during interviews with some parents and their consent was gained depending on their age and developmental stage. Considering children's developmental stages was crucial when providing information and gaining consent (Mitchell & Ziegler, 2007). Further exploration of the ethical issues associated with consent, are outlined in Section 4.8.1. Information was adapted for different age groups in an attempt to ensure appropriate information was provided to support the child's decision whether to participate. The leaflets were designed to cover the following age groups; 6-10 years (Appendix 7), 11-15 years (Appendix 8) and Gillick competent young people (Appendix 9). Parental involvement in explaining the study was essential for all age groups of children, particularly younger children (National Research Ethics Service, 2011). When gaining consent, the study was discussed with families, rather than children and parents separately. This enabled all members of the family to contribute to the decision to consent. Consent from the person with parental responsibility was gained as this is legally required in younger children (Children Act, 1898: Adoption and Children Act, 2002). Older children who appeared to understand the information

and consider the implications of having their care observed, were asked for their consent to take part in the study (Gillick v West Norfolk and Wisbech AHA, 1986). While there is no recognised criteria for assessing Gillick competence, assessing the young person's intelligence and maturity to understand the information provided, consequences of consent and that this is provided without coercion, then consent is as effective as if provided by an adult and cannot be overruled (Griffith, 2013). This approach was used to ensure young people's autonomy was respected. No children/young people refused. Parent information leaflets (Appendix 10 and nurse information leaflets (Appendix 11) were also developed.

The information leaflets were designed based on guidance for researchers which included suggestions for providing information and gaining consent in children (National Research Ethics Service, 2011). The leaflets were piloted with parents and children of relevant age groups to ensure they were clear and free from ambiguity. Changes were made to reflect the feedback. For example, younger children wanted more pictures, so more pictures were added.

Consent forms were used to record permissions from participants to be included in the study (Appendix 12). The forms were handed to the participants with the relevant information sheets. I read through the information leaflets and consent forms with the parent and child participants prior to leaving them for a short time. I did not want to assume that parents and children could read. Equally, I did not want to embarrass any of the participants by drawing attention to them if they had poor literacy skills. Furthermore, reading from the sheets ensured that I provided consistent and detailed information.

4.6 Data collection methods

In order to meet the study aim and objectives data were collected by non-participant observation with follow up semi-structured interviews, which is congruent with an ethnographic research design.

4.6.1 Non-participant observation

Capturing interactions on a children's ward while they occur was central to the study and was achieved by non-participant observation. Observation has the potential to

examine how people behave in a way that is not always the same as what they say they do (Baillie, 2013). I observed in the clinical area for an average of 6 hours per day for 12 days in total over a 3 week period. Understanding what happened during care episodes was further enhanced by talking to those involved and listening to their views. Understanding the interactions between participants as they occurred was crucial to represent practice (Lambert & Loiselle, 2008). Therefore, I positioned myself in clinical areas in bays where more than one child/family were present. I sat at the edges of the bay (depending on bed positions and parent seating) to observe interactions between nurses and a number of families, with particular attention to nurse-parent verbal and non-verbal communication in relation the child's pain care and how nurses involved parents in care. Most nurse–parent/child interactions take place by the bedside in children's wards and therefore observing in this location enabled me to observe and hear interactions between nurses and parents. Observation is fundamental to understanding another culture and can lead to powerful and revealing data (Baillie, 2013). Throughout the period of observation, nurses interacted with families on a number of occasions regarding the child's care, and pain care was sometimes part of this care. Therefore the observations only ever provided a snapshot of care for some families. There were variations in the amount of time nurses addressed pain care. Variations in the volume of data collection are a feature of ethnographic observation (Spradley, 1980).

While observation is an everyday event, particularly in acute hospital wards, observation for the purposes of research, whether overt or covert, is an invasion of privacy (Kennedy, 1999). Where I positioned myself impacted on how intrusive I appeared and I sat at a reasonable distance so that I did not appear covert, but not too close so that participants were not constantly aware of my presence. To encourage nurses to practice as they normally would, I tried to remain quiet and unobtrusive. Nurses may have acted in a way that they perceive to be correct, as they were aware that I am a children's nurse and lecturer. The "Hawthorne effect" whereby, those being observed changed their behaviour as a result of being observed is an inherent potential source of bias within observational studies (Baillie, 2013; Ellis, 2013). To minimise the potential impact of my presence on participant behaviour, I aimed to build an informal rapport by asking participant general questions about themselves. For example, in the staff room, I talked to nurses about

where they trained to be a nurse, in an informal rather than an intrusive tone, to try to put them at ease. Similarly, when gaining consent and providing information, I talked to children about toys, television and holidays (as it was Easter at the time of observation) to try to appear less like a stranger watching them. Initially nurses and parents appeared to be aware of my presence, but gradually over the observation period, nurses and families appeared to continue as would be expected in the ward environment. Prolonged observation times can assist with normalisation of behaviour in participants, referred to as habituation (Twycross, 2007). Except when children talked to me, they did not appear to change their behaviour and did not appear to be aware of my presence.

In ethnographic research, the researcher becomes part of the group experiencing the group activities (Deegan, 2001; Spradley, 1980). The researcher can adopt a range of approaches, which have been categorised as "the complete participant, the participant-as-observer, observer-as-participant and the complete observer" (Gold, 1958). However, the distinction between non-participant and participant observer is unclear (David & Sutton, 2011). For example, Spradley (1979) described his ethnographic study of alcoholics on skid row, did not require him to become an alcoholic and live as an alcoholic in order to learn about this culture. So, while I refer to my interactions as non-participant in terms of not being actively involved in care delivery, the distinction between participant and non-participant are blurred. By adopting a non-participation role, the impact of my influence on the behaviour of the participants was minimised. Theoretically adopting a non-participant role requires the researcher to remain detached from the people they are observing (Spradley, 1980). However, while this approach can reveal powerful and valuable data, it can lead to potentially complex and ethical challenges (Baillie, 2013). Observing care interactions as an experienced children's nurse raised many issues and when children and parents approached me, I became aware that my experience as a children's nurse may have affected my responses. Therefore, I may have unintentionally adopted a participant observation stance, which may have affected participant behaviours and subsequently the data I collected. In order to minimise "going native", I kept a reflective diary and reflexively considered the impact of my presence and prior experience as a children's nurse.

Field notes taken in a busy workplace are subject to limitations for a number of reasons (Kennedy, 1999). Limitations include difficulty observing without appearing intrusive and accurate recording and capturing the subtle actions of the nurse or parent. Observations took place in a busy and challenging environment. When the nurse drew the curtains around the child's bed it was not possible to observe non-verbal communication and the interactions, although it was possible to hear interactions. Although direct observation can provide comprehensive data by capturing what is happening while it is happening, this may not be appropriate in intimate care situations (Vivar, 2007). This was challenging and was taken into account when collecting the data and a conscious attempt to minimise or avoid presence during intimate care was made.

Hand written field notes were recorded at the time of observation to enhance accuracy, unless there were multiple interactions occurring at the same time (Robson, 2002). When multiple interactions took place and it was not possible to record them at the time, I recorded them as soon as possible after the event. For accuracy and recall, I developed and used a pre-printed template for recording field notes (Emerson, Fretz & Shaw 2011: Walford, 2009) (Appendix 13). The template for recording field notes included an outline of the layout of the area being observed, and space to record detailed memos of what happened during care interactions and my initial thoughts about what happened. Meticulously recording notes, seating plans and diagrams are recommended as a memory aid with more detailed notes added at a later stage (Hodgson, 2005). Reflexive and reflective thoughts documented at the time of observed practice enabled contextual insights to be recorded and referred to when analysing the data, which can be lost when data is being analysed at a later date. Field notes are inevitably influenced by the researcher and reflexive accounts are central to remind the researcher of the contextual and environmental factors that influence the practice being observed (Hodgson, 2005). All interactions related to pain care that were observed were recorded in the timeline they occurred. Pre-determined criteria were not used in relation to the types of interactions that would be observed. Identifying each participant by a designated code enabled each "actor" within the family-nurse encounters to be easily identified, which was important during simultaneous interactions.

4.6.2. Interviews

Interviews are the most frequently used method of gathering data for qualitative studies (Burnard, 2005; Smith & Noble, 2014). Differences between types of interviews denote the extent to which they are structured and include structured, semi-structured and unstructured interview techniques (Whiting, 2008). As participant accounts were the primary source of data, the decision about the extent to which the interviews were structured was carefully considered to capitalise on capturing participant perspectives. Unstructured interviews could be used to capture a broad range of participant meaning related to care and involvement, and would be useful when little is known about a specific culture (DiCicco-Bloom & Crabtree, 2006). However, when exploring one aspect of care (pain care) in a culture that is known to the researcher unstructured interviews had the potential to generate much unrelated data not relevant to meeting the study aim.

Semi-structured interviews were undertaken with focussed questions to facilitate participants to reflect on the observed practice. Interview schedules for both parents and nurses were developed in advance to ensure I remained maintained focussed on meeting the study aim and objectives (Appendix 14 and 15 respectively). The interview schedules were developed from the key issues that emerged from the literature review (Chapter 2). Revising the interview schedules with my research supervisors assisted in avoiding asking leading or bias questions. In addition questions were 'piloted' with two nurses and two parents, and adapted slightly to ensure the participants understood the questions and the questions were appropriate to facilitate responses to meet the study aim.

Semi-structured interviews aid in directing the participants to discuss topic areas relevant to the study while being flexible enough to allow participants opportunity to discuss issues important to them (Moule & Goodman, 2009). Additionally, in this study specific questions were added to each individual interview schedules from the field notes of related observed practice that required clarification or detailed exploration. For example, one parent was asked about how they were involved in pain care in the post-operative recovery area, to clarify the source of their knowledge of post-operative pain care that they demonstrated during observation.

A pragmatic approach to selecting participants to interview was undertaken, as nurses were often too busy to be interviewed during the observation period and families were discharged or transferred to other areas. Therefore, follow up semi-structured interviews were undertaken with those participants who were available at the end of the period of observation and had consented to be interviewed. The interviews were undertaken in a private, or quiet, area of the ward or unit were possible, such as empty side rooms and offices and were audio-recorded. However, the location of the interview was led by parents and some parents chose to be interviewed at their child's bedside to remain with their child. This created some privacy issues with the potential for the interview to be overheard. Closed curtains and lowered voices were used as an attempt to maintain privacy.

Interviewers can inadvertently influence the quality of the data collected (Gerrish & Lacey, 2010). For example, when interviewing, the seating position, body language and verbal and non-verbal language used will impact on how the participants engage in the interview. Building rapport with the interviewee is essential to ensure meaningful data is collected (Clark, 2006; Parahoo, 2014). Skills of effective interviewing include active listening to build rapport, which is particularly important when there is limited time to form a relationship with the participants (Doody & Noonan, 2013). It has been suggested that researchers should develop their interview skills over time and consult with other experts (Doody & Noonan, 2013). Prior to undertaking the data collection, I observed my supervisor, an experienced researcher, undertaking an in-depth interview as part of her research, enabling me to observe her interview techniques. What I learned from this experience was that it is acceptable and advantageous to allow the participant sufficient time to consider their response, as it is tempting to interrupt because of the awkwardness of gaps and silences in the conversation. I reflected on this experience, along with drawing on my experiences of intervening in a range of contexts from working in clinical practice and education, when undertaking the interviews.

4.7 Data analysis

This section will present the methods and processes undertaken to analyse the data, which was underpinned by the framework approach. First, a rationale for selecting the framework approach is presented. Second, application of the framework approach is outlined, including, data management, descriptive accounts and explanatory accounts. Third, themes and core concepts that emerged from the data analysis are presented.

4.7.1 Rationale for selecting the framework approach

The framework approach was selected as the most appropriate analysis method because it enables researchers to manage and analyse data simultaneously while ensuring a clear audit trail which can strengthen the rigour and credibility of the findings (Ritchie & Lewis, 2003). The approach provides a clear and transparent map from the original data to describing and interpreting the findings and goes some way to counter criticisms that qualitative data analysis lacks clarity and rigour (Ward, Furber, Tierney & Swallow, 2013). Historically, lack of clarity of accounts of data analysis led to the view that data analysis was “shrouded in intellectual mystery” resulting in readers being unable to evaluate the processes involved (Spencer et al., 2003, p. 199). Data analysis approaches in qualitative research are underpinned by the epistemological assumptions and nature of knowledge required to meet the aims of the study (Spencer et al., 2003). Distinctions between the various approaches appear to be related to their specific focus and aims, such as the use of language in conversation and discourse analysis (Tesch, 1990), descriptions of cultures as in ethnography (Spradley, 1979), or whether the aim is to build theory as in grounded theory (Strauss & Corbin, 1988). However, a common approach to analysing data is to generate themes, concepts or categories, as in thematic analysis. Thematic analysis is often used for qualitative research analysis, although the approach is often implied rather than explicitly stated (Braun & Clark, 2006). The framework approach, which was developed from similar principles of thematic analysis, is being increasingly utilised in nursing research, because it offers a systematic and transparent structure to the analytical processes (Smith & Firth, 2011).

Other approaches, such as domain analysis are often used for ethnographic data analysis, based on the premise that the use of language is the main focus of eliciting cultural meaning (Spradley, 1979). While the use of language can reveal much about an unknown culture, the culture is known to the researcher limiting the need to elicit meaning from the use of language. Similarly, domain analysis aims to access tacit knowledge from the participant perspectives, which is implicit to the researchers' experience and knowledge, again limiting the usefulness of this approach. In contrast, the framework approach is more congruent with developing insights from within a culture that is known to the researcher, by focussing on participant perspectives, experiences and meaning, as it presents participant accounts as central to the data.

The framework approach is a matrix based system of organising, ordering and synthesising data, developed during the 1980's to analyse social policy documents (Ritchie, Spencer & O'Connor, 2003). This approach enhances transparency in the way that the data is analysed at each stage, allowing for movement through the interconnected stages and levels of abstraction. The approach has been described as an analytical hierarchy, whereby qualitative findings are built from original data, also described as conceptual scaffolding (Ritchie & Lewis, 2003). In contrast to entirely inductive approaches, such as grounded theory, the framework approach uses an iterative approach whereby the researcher moves back and forth until a complete and coherent account of the data emerges (Smith & Firth, 2011). Interpretation and eliciting meaning are two separate, but intertwined processes (Ritchie et al., 2003). While the aim is not to generate theory, as in a grounded theory approach (Strauss & Corbin, 1987) or undertake domain analysis (Spradley, 1979), the identification of core concepts are the ultimate outcome of the framework approach. Unlike thematic analysis, which despite widespread use, has been criticised for a lack of clear guidelines (Attride-Sterling, 2001), the strengths of the framework approach include an emphasis on a transparent data analysis process with clarity about the links between each stage of the process.

4.7.2 Application of the framework approach

The framework approach involves three interconnected stages: data management; descriptive accounts and explanatory accounts:

- Data management involved immersing in the data, re-reading until completely familiar with the data and arranging into initial themes using a coding matrix. Data was assigned to themes and categories in the coding matrix;

- Descriptive accounts involved making links between categories and themes. Data were constantly reviewed and re-ordered until a clearer picture emerged. Substantial themes were grouped into abstract concepts, described as conceptual scaffolding;

- Explanatory accounts involved identifying and exploring patterns within concepts and themes. It was important to continually re-check original data to ensure that observed practice and participant accounts were being accurately reflected and the themes and concepts were a true representation of the data. Explanatory accounts also involved interpreting the themes and concepts to establish meanings and explain how they could be applied across practice settings. This stage may result in the development of typologies which categorise participants into discrete groups (Spencer et al., 2003).

Most qualitative approaches consist of two main components; data management and making sense of the data by describing and explaining the data (Morse & Richards, 2002). While the two stages are not necessarily always linear or chronological, the data need to be placed into some order in order to describe the data coherently (Ritchie & Lewis, 2003). The framework process expands the second stage into two components: descriptive accounts; and explanatory accounts. While ethnographic research aims to describe data, it is not purely descriptive, as description involves some degree of selection and interpretation of meaning (Hammersley & Atkinson, 1995; Mason, 2002). The researcher will inevitably attempt to explain the findings with some degree of objectivity and subjectivity characterised by what they make of the experience (Spencer, 2001). Appendix 16 outlines the application of the framework approach

4.7.3 Data management

Both the interview and observation field notes were transcribed. Field notes have been described as selectively gathered and filtered and therefore, not “true” data (Ritchie et al., 2003, p. 22). However, field notes are central to ethnographical approaches as they represent a large part of the “story”, and therefore were transcribed, with some verbatim extracts, where captured, and included as data. Using computer software packages designed to support qualitative data analysis was considered. However, the use of software packages may reduce opportunities for researcher to become immersed in the data. In contrast, the process of transcribing the field notes and interviews by the researcher can assist in becoming familiar with the data (Moule & Goodman, 2009).

All participant accounts from the interviews and transcripts of the field notes were uploaded into an Excel spread sheet, with one spread sheet per participant interview. Again in relation to field notes, each day of observed interactions were uploaded into separate spreadsheets. While all verbatim accounts from interviews were included, it was not possible to include all field data because of the volume and depth of data obtained from emersion in the field. It was important to ensure that the selection of data included was made clear and more importantly presenting a rationale for what has been discarded. Reducing the data to identify themes, as in this approach, can result in loss of context and meaning if not carefully considered (Streubert, Speziale & Carpenter, 2007).

Once uploaded onto the spread sheet the verbatim interview accounts and field note data were then reviewed and key phrases were extracted into the coding matrix (Spencer et al., 2003). Initially the themes and concepts remained close to participant own words, but in later stages were replaced by abstract analytical constructs. The process continued by repeatedly reading the transcripts and identifying initial categories and adding them in the coding matrix. Within qualitative data analysis, the term categories have a range of interpretations: Miles and Huberman (1994) refer to categories produced from qualitative data as variables, while other authors describe categories in terms of grouping data (Richards & Richards, 1994). The latter description fits with the framework approach. Richards and Richards (1994) advocate retaining links and revisiting the original data constantly, as integral to the analysis

process. Conversely, Strauss (1987) recommends breaking up or “fracturing” of the data to free the researcher up to interpret the data at higher levels of abstraction. The framework approach highlights the importance of maintaining links with the original data and emphasises this as an integral and irrefutable asset to rigour.

Initially, a typical and atypical example from nurse and parent transcripts were coded and initial categories established. This enabled a broad picture to develop and a range of experiences to be analysed (Ritchie et al., 2003). Finally, the remaining transcripts and field note transcripts were analysed following the initial coding process and any initial categories not identified before were added. Therefore, at the end of this process, all data were extracted and placed in the matrix. (Figure 5 provides an example of a coding matrix used to identify initial categories).

Figure 5: Coding matrix.

Participant	Verbatim extract	Description	Initial categories
N4 (198-210) Lots of questions about the actual tool, I don’t know what I’d be thinking, I think they’d be, maybe they’d be wondering how its being used and how useful it is and erm, yeah, how those smiley faces relate to their child. But I don’t now what, I’ve never really been, I’ve never really been asked about it, I never have, yeah, I don’t know what I’d think if they started asking lots of questions about the tool. I might think, you know, sometimes think when parents start asking a lot of questions, you sort of think are they a nurse, are they a doctor, do they have a lot of knowledge that, you can sometimes feel quite threatened actually when parents ask a lot of questions and you start thinking oh hang on, then they start using words and you think are you a nurse or a doctor or something, you know, have you got knowledge and that can feel a bit oooh, you know, I’d better watch what I say here.	when parents start asking a lot of questions, you sort of think are they a nurse, are they a doctor, do they have a lot of knowledge/ you can sometimes feel quite threatened / I’d better watch what I say here.	Knowledgeable parents/nurses feeling threatened.	Nurses threatened by knowledgeable parents

Initial categories were placed in an initial coding index (Figure 6). Coding can be undertaken by cutting and pasting sections of transcripts and placing under headings to maintain data control, while avoiding data destruction or disposal (Bryman & Burgess, 2002, p 216). Excel spread sheets were utilised to organise the data into a

coding index of initial categories, facilitating movement across relevant extracts, to the original verbatim extract.

Figure 6: Initial coding index

Nurses threatened by knowledgeable parents
Parents having information/knowledge- empowerment
Parents asking questions
Parents expectations
Parents taking control of pain care
Parents speaking up for their child
Parents knowing their child's pain behaviour
Parents with knowledge negotiating pain care with nurses
Parents acknowledging they too stressed to take in information initially
Nurses involving parents in pain assessment
Parents beliefs that being more assertive= being more involved
Nurses not providing parents with information

The next stage of data management involved refining the initial coding index into linked categories, requiring data to be labelled and sorted into manageable and related groups or initial themes (Ritchie et al., 2003). Grouping of initial categories was undertaken manually, so that they could be sorted and re-sorted into initial themes. Repeated exposure to the data resulted in familiarisation and subsequent refining of categories and initial themes, as an iterative process. Organising the data into initial themes allows for comparison and grouping of similar data. This process is referred to as collapsing of categories and grouping under broader headings with other similar categories (Burnard, 1991). For example, it became clear that at times nurses prevented parental involvement and at other times parents took control of their child's pain care. Therefore data were grouped or categorised under these and other similar headings (Figure 7).

Figure 7: The refined coding Index

Initial categories	Initial themes
6.1 Parents wanting to contribute more/ be involved more	Parents indicating that they want to be more involved
6.3 Parents asking questions	
6.4 Parents expectations	
6.5 Parents taking control of pain care	
6.6 Parents speaking up for their child	
6.7 Parents with knowledge negotiating pain care with nurses	
6.9 Parents beliefs that being more assertive= being more involved	
6.10 Parents indicating that they do not want further involvement (5.10)	
6.11 Parents being determined	
6.12 Parents- not wanting to "nag" busy nurses (5.12)	
6.13 Parents caring for child's pain without involving nurse	
6.14 Disagreement/debate between nurses and parents about a child's pain (7.6)	
6.15 Parents assessing child's pain (4.5)	
6.20 Parents ability to accurately describe pain (5.17)	
6.21 Parents knowing when analgesia required (5.18)	

The process of data analysis then moves on to refining and describing the initial themes to begin to explain the themes. However, the stages of the framework approach are not clearly defined and the process is ongoing and iterative with data management continuing throughout.

4.7.4 Descriptive accounts

The initial themes and categories were reviewed and re-grouped into refined themes. For example, it became clear that parents had knowledge of their child and knowledge of pain care and therefore these two initial categories were combined. The initial themes and categories were constantly refined as new insights emerged. Due to the way that the data is organised, it was possible to continuously check the original transcript to ensure that the original data had not been misrepresented in the process. Associations between themes contribute to the whole picture and assist with development of abstract concepts (Ritchie et al., 2003). For example, while previous stages indicated that nurses created barriers to parental involvement, some of the factors which influenced involvement emerged as data analysis progressed. This was similar with parents, as revisiting the initial themes highlighted the ways in which parents appeared to be taking control of their child's pain care. Figure 8 illustrates that parents had expectations of involvement in their child's pain care and undertook measures to be more involved at times. Generating themes from data is a common feature of analysis of qualitative measures (Smith & Firth, 2011). This is an

interpretative method whereby data are systematically analysed for illuminating descriptions of the phenomenon (Lewis & Ritchie, 2003). Therefore the descriptive accounts can begin to make sense of the vast amount of data in a structured way, whereby, rich and meaningful insights are created.

Figure 8: Refinement of initial themes and categories

Initial categories	Initial themes	Refined final themes
4.3 Parents knowing their child's pain behaviour	Knowledgeable parents	Knowledge of child articulated and informs care
4.4 Parents not acknowledging pain (5.13)		
5.2 Parent occupation		
5.14 Parent knowledge of analgesia/pain management techniques- eg distraction/ how to give child medicines (6.17)		
5.15 Parents describing pain care(6.18)		
5.16 Parent being able to assess their child's pain- know when not in pain (6.19)		
5.17 Parents ability to accurately describe pain (6.20)		
5.18 Parents knowing when analgesia required (6.21)		
4.1 Parents knowing the child	Parents knowing their child	
4.2 Nurses recognising that parents know the child (5.7)		
4.3 Parents knowing their child's pain behaviour		
6.3 Parents asking questions	Parent expectations of involvement	Expectations of involvement in pain care
6.4 Parents expectations		
6.5 Parents taking control of pain care		
6.9 Parents beliefs that being more assertive= being more involved		
6.13 Parents caring for child's pain without involving nurse		

4.7.5 Explanatory accounts

Having managed the data and described how the themes were extrapolated from the data, explanatory accounts complete the analytical processes. The level of abstraction assigned to the data can be variable (Spencer et al., 2003), ranging from purely descriptive accounts to development of abstract concepts and themes. The framework approach emphasises the latter and in relation to the study the aims to understand parental involvement in a child's pain care, to establish what this means to parents and nurses, and subsequently, children's experience of pain. Analysis

should portray participants' subjective experience, rather than selective interpretations of the data, which are claimed to reduce reality in the aim of wider generalisation (Spencer et al., 2003). Regularities and patterns should be established in a quest for what are referred to as "repeatable regularities" (Kaplan, 1964). While the framework approach does identify regularities in participant's accounts, it also enables irregular experiences to be differentiated, as it does not discount any participant data.

Final themes were then examined for relational concepts. Conceptualising data is a later stage of data analysis and provides a framework to begin to explain the phenomena under investigation (Hennink, Hutter & Bailey, 2011). The challenge is to remain as close to the raw data as possible, without distorting it. Associated patterns can be developed, with constant reference to original data to ensure participant accounts are accurately reflected. The interconnected stages enable the researcher to move backwards and forwards across the data until a coherent account emerges (Ritchie & Lewis, 2003).

Constant refinement of themes can contribute to the development of a conceptual framework, by identification of core concepts. Three core concepts were identified from the final themes. The three core concepts are; parents as advocates for their child; nurses promoting parental involvement and partnership and nurses unintentionally preventing parental involvement and partnership. The core concepts and related themes are presented and explored in relation to the findings in Chapter Five.

4.8 Ethical considerations

This section will outline the ethical consideration relating to the study which related to: gaining informed consent; power imbalance; ensuring confidentiality; and managing risk. Issues related to observations in clinical areas, which raised ethical issues are explored further in Section 7.3, my reflexive account of undertaking the study.

4.8.1 Gaining informed consent

It is the responsibility of the researcher to ensure that participants choose if they want to be involved in a research study, and recruitment strategies were not coercive. Gaining consent from children, families and nurses is challenging in a busy children's ward. First, children are acutely ill sick and families are anxious about their child. Second, gaining consent from children of different ages requires understanding of the law related to consent and in depth knowledge of children's cognitive and developmental stage development (Gold, Hall & Gillam, 2011; Hirtz & Fitzsimmons, 2002). Third, nurses are engaged in clinical care, which takes priority.

Children and families are already under considerable stress by virtue of the child being acutely unwell (Tanner et al., 2013). It was not the intention to increase stress for children and families. Observing and asking parents to be interviewed is intrusive and can add to their stress. Tensions between the benefits of research in enhancing knowledge can be in conflict with protecting vulnerable participants, such as children. Children have historically been excluded from research on the grounds of protecting them (Spriggs & Caldwell, 2011). However, as a children's nurse who believes that children's voices should be heard, therefore raises concerns about excluding them from research. Valuing children means valuing their unique input into research (Matutina, 2009). While the focus of the study is the interactions between the parent and nurse, the child was present during observation periods and often during interviews. Children have the right to be listened to, provided with information and their wishes and feelings taken into account, but continue to report that they are not involved in care or listened to (Commission for Health Improvement, 2004; Kennedy, 2010). Involving children in decisions affecting them is becoming more established (Department of Health, 2010a; United Nations, 1989). If truly informed and valid consent is obtained from a child, then the child can be treated as any other research participant (Department of Health, 2009).

All, but one, child and family who were approached agreed to be observed. Consent from children was gained with the support of their parents. Parents are generally considered experts on their child, knowing them and their needs, and are therefore in a position to inform their child about the research (Buchanan & Brock, 1989). However, despite my extensive experience of gaining consent from children and

families, I was aware that the children were acutely unwell and in an unfamiliar environment, which may impact on their ability to provide a truly informed consent. In addition, I had limited time to get to know the child and family. Consent is complex in children and requires the person gaining consent to have expertise in gaining children's consent within ethical and moral codes and the law (Coyne, Neill & Timmins, 2010; Department of Health , 2009; Fleischman, 2005). The law asserts that children under the age of 16 years who are not Gillick competent require the person with parental responsibility to provide consent (Department of Health, 2009; Griffith, 2013). Lack of clearly defined criteria for assessing Gillick competence can hamper robust assessment of young people's ability to provide their own consent. However, respecting autonomy is imperative particularly in young people, as it gives young people a sense of control (Kirk, 2007; Waller, 2011).

Children's assent to take part in research is an option (Higgingbottom, 2004), where assent is defined as "a child's affirmative agreement to participate in research" (Medical Research Council, 2007, p 41). However, this is described as not legally mandated, unlike consent and should not be confused with informed consent (Spriggs & Caldwell, 2011). While assent provides the child with the opportunity to express their concerns and opinions, it still requires the person gaining assent to ensure the child's understanding, which is central to consent. In addition, assent needs to be supported by the parent (Piercy & Hargate, 2004). Although gaining assent was considered as an option, ultimately in order to respect the autonomy of the child, children were provided with study information and invited to consent to taking part in the study.

Nurses are engaged in clinical care and their priorities should be the care of the child. Gaining informed consent was limited by the amount of time nurses had to consider their decision as to whether to take part in the study. Furthermore, many of the qualified nurses were former students from my institution who may have been intimidated by their former lecturer requesting consent, which links with power imbalance, discussed in the next section.

4.8.2 Power imbalance

Power imbalance is inevitable in a researcher-participant relationship (Mahon & McPherson, 2014). Power imbalance can manifest in participants agreeing to participate when they do not want to. Explaining verbally and confirming in writing that their care would not be affected in any way appeared to reassure parents, who may perceive that their child's care may be affected if they refuse. Only one parent refused and provided a reason that her child had been examined by junior doctors repeatedly and she did not want any further intrusions. In relation to children, unequal power relationships between children and adults exist and are mirrored in research processes (Punch, 2002). The authority divide may incite children to provide unwilling consent to an adult and relative stranger, but can be overcome by the use of appropriate language and communication. Similarly nurses may be concerned that the researcher may think "they have something to hide" if they do not agree. Some of the nurses in this study may have felt obliged to agree as they were former students at my institution. To maintain honesty and openness and integrity in terms of credibility, when asking participants to participate and provide consent, I informed them that I was a children's nurse, lecturer and researcher (Nursing and Midwifery Council, 2015). Openness can contribute to giving participants control and choice and can assist to redress the power imbalance, by making them aware of all relevant facts. It would be unethical to expect participants to be open and honest while concealing researcher details.

Children were encouraged to share their views about the research without judgement and provided with a "way out" by making it clear that refusal or withdrawal was unequivocally acceptable (Kirk, 2007). Respecting children's (and families') views is an intrinsic role of a children's nurse, so did not present any specific challenges. However, research has a different purpose and does not directly contribute to the child's care at the time. Rather, it aims to influence future care and is partly to fulfil my needs to complete the study, as opposed to theirs. Acknowledging that the choice is with the participants and treating them with respect aims to neutralise the perceived power of the researcher.

Research with humans is inevitably an intrusive process (Lewis & Lindsay, 2000). This is particularly pertinent in ethnographical studies were the researcher is

engaged in prolonged observational periods (Gelling, 2014). Parents may wonder if they are being scrutinised, for example, in relation to their parenting skills. Darbyshire (1994, p. 17) coined the phrase “parenting in public” highlighting that parents may feel uncomfortable with a stranger watching their every move and behave in a way which they perceive as socially acceptable. Similarly nurses’ behaviour may have been affected by researcher presence. This was emphasised by one nurse stating in the interview “I haven’t done it (spoken to parents in detail about pain care options) because you were there”. The “Hawthorne effect” can occur, whereby participants behave in what they perceive as being socially, or in this case, professionally acceptable. However, nurses (and families) did not appear to be aware of my presence after a short time and reverted to what appeared to be normal uninhibited behaviour, referred to as habituation (Twycross, 2007).

4.8.3 Confidentiality

Participants are more likely to provide open and candid accounts if they understand that their data and identity will remain confidential (Rose, 1994). All participants were assured that they and their data would remain anonymous both verbally and this was also detailed in the information and consent forms. In adherence with ethics committee requirements, confidentiality and anonymity was maintained by ensuring all participant details, documents and audio recordings were coded and allocated a unique identification number, details of which was stored under secure locked conditions. Pseudonyms were used to ensure no participant details were included in the study report. Data was shared only with supervisors and will be destroyed three years after the completion of the study. Electronic documents were stored in password protected files in the university personal storage area, which is a secure storage space.

4.8.4 Managing risk

Observing clinical areas for research purposes can highlight poor practice. Preparing for how to manage poor practice if observed or discussed during the interviews was discussed with my supervisors. In addition, I reviewed relevant legislation and guidance relating to my professional and research roles (Medical Research Council, 2004: Nursing and Midwifery Council, 2015). When working with children, including when undertaking research, the safety of the child is paramount (Matutina, 2009).

The matron and nursing staff were informed verbally that while my role was non-participant, I would intervene if a child was deemed at risk of harm. This information was also included in the written participant information sheets. While it may have affected the matrons' or nurses' decision to be involved, informing them of my obligation to intervene may have prevented ethical dilemmas at the data collection and analysis stage. Children and parents were also informed that I would not be involved in care to try to minimise attempts by children and families to approach me for interventions. The issues that arose relating to whether it is possible to be truly non-participant in research are discussed further in Section 7.3.

4.9 Chapter summary

This chapter has presented the methods used to undertake an observational and explorative ethnographic study of parental involvement in the child's acute pain care. Ethical considerations have been outlined, which are particularly pertinent to protect vulnerable participants within healthcare settings. The final themes developed from the data analysis using the framework approach (Ritchie et al., 2003) will be presented and integrated into the findings chapter to present a seamless account of the study findings.

Chapter Five: Findings

5.1 Introduction

This chapter presents and draws together the findings from the observational (n=58) and interview data (n= 9) to provide a seamless account of family-centred care in relation to pain care. The three overarching concepts labelled 'parents as advocates for their child', 'nurses promoting involvement and partnership' and 'nurses unintentionally preventing involvement and partnership' along with the associated themes will be described (Figure 9). Direct extracts will be used to illustrate the themes and bring the data to life (Franck et al., 2012). In addition, extracts will provide evidence of both participants' accounts and observations of practice to assist the reader when making judgements about the credibility of the findings. Consistent with an ethnographic approach, the findings will be presented as a description of the culture and social behaviour of participants in real world contexts (Streubert Speziale & Carpenter, 2007). Chapter Six presents a critical evaluation of the findings.

Figure 9: Involving parents in pain care: concepts and themes

Concepts	***Themes***
Parents as advocates for their child	• Satisfaction with involvement in pain care • Parents initiating pain care • Ensuring that their child's pain care needs are met • Knowledge of child informs pain care
Nurses promoting involvement and partnership	• Communicating and planning pain care with parents • Providing information about pain care • Involving parents in decisions about their child's pain care • Valuing parents' contribution to their child's pain care • Understanding and implementation of family-centred care
Nurses unintentionally preventing involvement and partnership	• Not communicating and planning pain care with parents • Selective provision of information about pain care • Not involving parents in decisions about their child's pain care • Not valuing parents' contribution to their child's pain care • Poor organisation and systems support • Lack of understanding and implementation of family-centred care

5.2 Parents as advocates for their child

A dominant feature to emerge from both the interview and observation data relates to parents attempting to be an advocate for their child in relation to their child's pain care. The themes associated with being an advocate for their child were interlinked and included, 'ensuring their child's pain care needs were met' 'initiating pain care' and ensuring 'knowledge of their child informed pain care'. In addition, being an advocate for their child was linked explicitly to the theme labelled 'satisfaction with involvement', which appeared to drive parents' advocacy role and will be described first.

5.2.1 Satisfaction with involvement in pain care.

Parents' accounts revealed a wide variation of satisfaction in terms of involvement in their child's pain care, ranging from highly satisfied to dissatisfaction with care. Parents who were satisfied with care described how the explanations they had been given met their needs or expectations and that they did not want to be more involved in their child's pain care, as illustrated in the following extracts:

> '*Erm, no, I felt it was ok, when he came back from his operation, the nurse sort of told us and showed us on his chart, you know, what, erm, pain relief he'd had when he was down there, so, erm, no, I felt quite happy with things, yeah, yeah'.* Family 12, Steven aged 2 years, interview

> *Parents in the day surgery area discussed their child's pain care, that had been described to them in recover, with relatives and appeared to be satisfied. They did not state that they wanted more information or to be more involved.* Family 7, Raul aged 5 years. Family 15, James, aged 5 years, field note extracts

Many parents wanted greater involvement in their child's pain care and undertook strategies to become more involved, such as attempting to manage the child's pain without the support of the nurse (as described in section 5.2.4) or persistently highlighting their dissatisfaction with pain care. The factors that were observed and parents described in relation to dissatisfaction with their involvement in pain care

related to seeking more information about their child's pain care and how they could be involved in managing their child's pain, for example:

> *I would be happy to be more involved. I do think , feel that there are some things that possibly we haven't done that I don't know whether I should ask them to show me how it's done- like making sure she is comfortable, doing her nappy- I could help with that. You know I'm a bit worried to move her at times, I don't want to hurt her. You know, her pillows- I still can't do them myself…but if I knew what I was doing and they were happy for me to do it, then yes I am happy to do it'.* Family 25, Amy 2 years, 10 months, interview

Parents' accounts suggest they were concerned that their views about the pain their child was experiencing were not being taken seriously or managed appropriately, as highlighted in the field note extract:

> *Henry's mother and paternal grandparents approached me to ask what I thought about his pain, as I had been observing him during episodes of pain. They expressed anxiety that their repeated concerns were not being taken seriously.* Family 2, Henry, aged 4 years, field note extract

Conversely, other parents who were also not satisfied with their child's pain care did not always communicate their concerns to nurses. In addition, some parents' accounts suggested they expected their child's pain care would not always be optimal. The following extract illustrates parents' perceptions about their satisfaction about being involved in their child's pain care, elicited from interview:

> *'…so at the beginning, I probably got a little bit stressed out about the fact that he was in agony and they didn't appear to be rushing to sort it out… erm, but I totally understand why… you know, I've no complaints about it, just the way it is, do you know what I mean?* Family 18, Fred aged 8 years, interview

Nurses' accounts revealed that they acknowledged the level parents wanted to be involved in their child's pain care was variable, reflecting individual preferences and circumstances. Nurses recognised that parents who wanted to be involved in their child's pain care were determined to ensure their contribution to care was realised, as highlighted in this account:

> ‘I *don't think she (mum) would have gone this time if the doctors had tried to discharged him… and I think was just very determined that she needed something doing and she wasn't happy to take him home. I think she was a little bit, not clued up, but I think that she was more determined that something needed to happen, because she knew he was definitely in pain’.* Nurse 1, Hannah, interview

Alternatively, nurses also described that some parents did not want to be involved in their child’s pain care, preferring nurses to retain responsibility for the child’s pain care, for example:

> *‘I usually ask parents, you know, what would you like me to do and often they are just like do whatever, do whatever you think is best and then in that case, yeah, that’s, that would be fine. When their children are ill, parents just want to hand over responsibility to somebody else and that’s fine. If they say just give them whatever you think is best, then that’s what I will do, but I still think it’s important to tell them why you’re doing what you’re doing, yeah’.* Nurse 8, Karen, interview

Despite recognising variations in parents’ preferences for involvement, nurses described being concerned when parents did not want to be more involved in care and strived to involve them. The following interview extract highlights nurses’ accounts of parents’ involvement in their child’s pain care:

> *‘I might be a bit worried that the parent was disinterested, erm, you’d maybe sort of think oooh, you know, are they just worried, are they anxious or are they really not interested’.* Nurse 8, Karen, interview

A key finding across nurses’ and parents’ accounts related to how expectations of involvement and pain care linked with satisfaction with care. Parents’ accounts suggested that they expect and accept that children may receive more intense or frequent care episodes during the early stages of the child’s illness episode which became less frequent after the first day in hospital, for example:.

And I felt today, probably because it is day two as well so we are here- yesterday we got a lot of care and fuss because we were new'. Family 25, Amy aged 2 years 10 months, interview

Parents revealed that they did not always report their concerns about their child's pain to nurses because they were concerned about how they would be perceived by nurses. However, parents were observed communicating their concerns with relatives and friends in preference to the nurse and on occasions asked my opinion about their child's pain care. The following extract from interviews illustrates the varying expectations of parents:

Amy's mother described to her parents and friends how Amy was shaking she was in so much pain and said that she was grumpy because her leg hurts. The friend replied "go and ask them, I would". Amy's mother responded "I don't like to nag". Amy's mother did not seek a nurse. Family 25, Amy aged 2 years 10 months, field note extract

While parents' accounts highlighted differences in expectations of pain care, those expectations were sometimes based on misconceptions about pain care. Parents did not always recognise the difference between trade and generic names of medications, resulting in misunderstandings about what pain relief their child had received. Similarly, the following accounts illustrate that parents are not always aware of the significance of inappropriate pain care:

'They wouldn't give him any sort of pain relief whatsoever until they'd weighed him. So they made him get on the scales to weigh him at the local hospital with a fractured femur, which he weren't too chuffed about, because we know how much he weighs'. Family 18, Fred aged 8 years, interview

'but they gave her Calpol, not Paracetamol. Erm, it just didn't touch her at all… I don't think it was enough'. Amy aged 2 years 10 months, interview

5.2.2 Parents ensuring that their child's pain care needs are met.

Parents' accounts and observation of parents with their child highlight that they attempted to ensure their child's pain care needs were optimised. Parents described frustration with hospital procedures and practices that did not ensure their child's pain care needs were met, such as inadequate prescriptions for analgesia:

> *But I know that's part of the procedure, so that's what they did and they gave him, erm, pain killers for him, specifically for him. When we came here, they gave him a bit of Calpol and it didn't touch him. Erm, and one of the nurses came to me and said he hasn't been written up for the right dosage for his size, I said well that's quite evident because he's in agony, and why at one hospital when you're the same Trust, do we weigh to make sure we give for the right dosage and we don't here, erm, didn't have an answer because it's not her that writes it up, it's the doctor'.* Family 18, Fred aged 8 years, interview

In addition, parents described pain relief as being given in response to their child experiencing pain rather than analgesia being administered in anticipation of the pain the child may experience. Parents' accounts revealed this practice prompted them to initiate care and discussions about care to ensure their child's pain care needs were met, highlighted in the following interview extracts:

> *'He was getting the spasm pains in his leg, erm, because he's erm, quite a big boy for his age, the dosage wasn't quite correct for him. So he wasn't getting the pain relief that he needed really. Erm, plus the spasms were frightening for him and it was the scariness that made it worse for him…they kept him fairly pain free during the day, didn't they, erm, but it was literally he'd seem ok one minute and then be in total agony the next. So there wasn't any warning of it's building up, erm, so then they had to react rather than proactively keep him pain free. Erm, that, I think that's just the nature of the injury.' F*amily 3, Fred aged 8 years, interview.

> *''I just did not want to be fussing, but I knew the time she's had it and the time she was getting tetchy so I knew it was due, and no-one was coming… so, I might have 'hummed' and 'ahed' if I had been on my own for a while, but I*

would have ultimately gone and asked for it (analgesia)- yeah'. Family 25, Amy aged 2 years 10 months, interview

However, in contrast nurses' highlighted that some parents did not seek assistance or support if their child was experiencing pain. The following extract highlights nurses' perceptions of the role of parents in ensuring that the child's pain is communicated to nurses:

'This mother was saying he is just not himself and explained how he is when he was happy. I think sometimes parents do need to speak out a bit more'. Nurse 1, Hannah, interview

Parents revealed wanting more information about their child's pain care, particularly the administration of medication in preparation for discharge. Parents' accounts highlight that they wanted to ensure their child's pain care was being met and that knowing more would enable them to participate in care decisions, for example:

'I don't know how it's been written up, but sometimes they've given him the Ibuprofen and the Calpol...Ibuprofen's just slightly off, it's sort of like a creamier colour than the white one, which is the Paracetamol. So sometimes he's had both, sometimes he's just had the Paracetamol, so I was just wondering if they'd just given him the strong one, which was fine, because he'd had the Paracetamol in the morning. I just wanted to know what he'd had really'. Family 18, Fred aged 8 years, interview

Nurses perceived that parents did not think that doctors believed parents' accounts of their child's pain. Nurses appeared to support parents' advocacy role, by supporting and prompting parents to express their experience of their child's pain to medical staff. Nurses described their role as a buffer between doctors and parents, the following example highlights supporting parents' advocacy role:

'She said she hoped he was awake when the doctor arrived and kind of had one of his little spells to show them how he was. I think she felt that nobody was listening to her. So she said she videoed him cos they are getting worse. Because I'd seen them, I had said to her you know maybe show the doctor when the doctor comes back in'. Nurse 1, Hannah, interview

5.2.3 Parents' initiating pain care

Parents described a range of situations when they knew their child was in pain, which they tried to alleviate by undertaking non-pharmacological strategies to manage the pain. Parents were frequently observed assessing and managing their child's pain without requesting the nurse to be involved. Parents used age appropriate words and gestures in an attempt to assess their child's pain. The following extracts from interviews and field notes illustrate how parents assessed and attempted to manage their child's pain:

> *'Henry was clutching his abdomen, Father asked what it feels like- hurt or sick? Henry stated that "it makes me feel sick" and cries again. Father asks if it is hurting. When Henry says it does- father asks Henry if he wants him to rub his tummy hard?'* Family 2, Henry aged 4 years, field note extract

> *'Amy was crying and nurses did not come to bedside. Mother asked "what are you scared of, that it might hurt… does your leg go funny, get hurty? Amy mumbled "mm". Mother said to Amy that "your painkillers are wearing off, is it a bit ouchy… where does it hurt?". Later, Amy needed her nappy changing. Mother tried to distract her while she tried, but could not manage. She did not ask for the nurse's help. Later when nurses came to give Amy oral analgesia, nurse left it with mother to administer. Amy's mother used strategies such as simulating giving to teddy'.* Family 25, Amy aged 2 years, 10 months, field note extract

Parents were also observed to use distraction, stroking, simulation and verbal reassurance to assist with their child's pain relief. These interventions were initiated by parents and appeared to be independent of nurse support. The following field note extract illustrates how parents attempted to meet some of their child's pain care needs:

> *Parents were frequently observed, repositioning their child to make them more comfortable and during observation, Dan's parents described how they read to him to distract him when he was in pain during the night*. Family 20, Dan aged 4 years, field note extract

Although parents initiated non-pharmacological strategies to manage their child's pain, parents accounts revealed that they also initiated pain care with nurses, such as alerting nurses to when analgesia was due to be administered. Parents' accounts suggest that they had an understanding that in some situations pain could be predicted and prevented, for example:

> *'I did, erm, we knew that the physios were coming about half past one, so we, me and the nurse had discussed this morning that probably more appropriate to have something before the physios came to sort of take the edge off before they starting messing with him. Erm, I went to remind the nurse that, I think they're coming at half past one aren't they, so if they give it him about one, it'll have kicked in and then I went to the loo. So when I came back, I said have they been and he said yeah, I've had that clear liquid, which, stronger one that they gave him ready for the physios. So we'd had the discussion earlier on and then I just reminded them that it were due. It were me. (*when asked who instigated the original conversation)'. Family 18, Fred aged 8 years, interview

5.2.4 Knowledge of the child informs pain care

A dominant feature of parents' accounts related to detailed knowledge they have of their child and that this detailed knowledge and understanding places them in an ideal position to contribute to their child's pain care. Knowing their child related to: knowing how their child normally responds to pain; recognising the difference between pain and tiredness and pain and anxiety in their child; indicators of pain in their child, such as facial expressions, body posture and behaviours. Parents were observed to articulate their knowledge about their child's behaviour to nurses, such as suggesting explanations for their child's behaviour, for example that the child is in pain, upset or bored.

> *Maddie's mother was talking to the nurse- 'last time she was upset. We thought she had pain, but I think she was just upset. Yes, I think she was just upset. She is anxious and it might seem like she is in pain. She is not in pain'*. Family 26, Maddie aged 14 years, field note extract

Parents' accounts highlighted that parents were able to describe different responses to pain in their child and used terms such as their child's 'threshold' for pain or 'pain barriers'. The following extracts highlight parent understanding of pain and how pain may be manifested by their child and impact on their behaviour:

> *They said it was going to be obviously painful and things like that, so erm, but I know what he's like, he's mine, yeah, he's a tough little man… Erm, I think so, yeah, yeah, I can't, obviously he's my son, so I know what he's like and you know, I know like his threshold if you like and erm, yeah, yeah, I do, yeah'* Family 12, Steven aged 2 years, interview

> *'Because you're not a softie are you? …and he was screaming, weren't you?… they just asked Fred, but I think when it' s your child, you can tell in the face even when they're not in pain or they don't, not saying that they're in pain, like he's not just said now because he's all flushed and he's tired now. But you can tell when something's brewing I think a bit more than, yeah, he might not say that he's in pain and he might say to me it hurts mummy and then somebody will say are you alright, do you know what I mean, when well a minute ago he were alright, you know, and you quite obviously aren't alright, but'.* Family 18, Fred aged 8 years, interview

Nurses did not always ask children about their pain and were observed to frequently direct questions about the child's pain to the parent. However, on a number of occasions, parents redirected pain assessment to the child and encouraged their child to inform the nurse about their pain, Parents appeared to recognise the importance of involving the child in expressing their pain, as illustrated in the following account:

> *When the nurses asked me about his pain…but I didn't answer, I let him only say because I didn't want to influence what he was going to say, erm, and he's found it really easy, he just pointed to it and I felt quite confident in what he was pointing to, related to what he got, so yeah*. Family 21, Paul, aged 7 years, interview

> *Henry's mother was talking to the nurse about Henry's pain and she consistently looked at Henry and used phrases such as "didn't you?" and 'you*

were a brave boy, but it hurt too much didn't it?' Family 2, Henry aged 4 years, field note extract

Similarly, parents described that their child understood the meaning of the pain score and redirected questions from the nurse about the child's pain to the child. In younger children parents' facilitated the child to be involved in conversations about the pain. The following extract illustrates how parents encouraged their child to express their pain to the nurse:

'I don't know to be honest, I think you know, focusing more on him because he was the one that was going to have to answer the questions, so, which is the right, you know… I just saw the faces, I didn't read in depth what it said, but she sort of said on a scale of, you know, this being happy there's no pain and this being sad and it really hurts and you feel like crying, so she sort of explained it like that and then he felt quite comfortable in picking out where he was.' Family 21, Paul aged 4 years, interview

Parents' accounts suggested that they had a range of knowledge about pain assessment and management. Although the way parent's gained knowledge of pain care was not explored in detail, some parents identified the internet or previous hospital episodes as sources of information, as the following extract illustrates:

'Well we know that because, erm, my niece, his cousin, broke her femur when she was twelve years old, didn't she, and she's been to see him and we were, we've been discussing this, she said yeah, the spasms are dreadful aren't they and we've been having the conversation how long does that last, and plus we've also spoken to a nurse about how long does it last.' Family 18, Fred aged 8 years, interview

'Yovan's mother was asked by the nurse about allergies during routine admission questioning and stated that he was allergic to Ametop. The nurse did not discuss alternatives. When the doctor spoke to the mother he asked about putting on "numbing cream" (Ametop). The mother suggested the "spray" (Ethyl Chloride spray). Family 3, Yovan aged 4 years, field note extract

Nurses assessed parents' understanding and experiences of pain care and appeared to group parents into those who had knowledge of their child's pain care, or those that found it difficult to understand the information provided. The following extracts highlights one of the ways that nurses perceived parents with knowledge:

> *'Some, I would say some definitely knew about it, whether they have talked to other parents at school or anything like that. We will have that sort of a conversation. Others, I think they sort of nod and you don't really get ... they are sort of trying to take in – all the information you are giving.'* Nurse 2, Lorraine, interview

In summary, the concept labelled 'parents as advocates for their child' has highlighted that parents' involvement in their child's care is variable. Parents' satisfaction with involvement ranged from highly satisfied to dissatisfaction with involvement. Parents attempted to advocate for their child by becoming involved in care using a number of strategies; which included: initiating care independently; ensuring their child's pain care needs are met by seeking nurse support to care for the child's pain; using their knowledge of the child and pain care to inform care, particularly when the child's pain care is viewed by parents as being suboptimal.

5.3 Nurses as facilitators to involvement and partnership

The findings suggested variability in how nurses involved parents in their child's pain care, ranging from promoting involvement and partnership to preventing involvement and partnership. Preventing involvement appeared to be unintentional and will be explored in Section 5.4. This section presents the findings related to how nurses promoted involvement and partnership.

On occasions nurses appeared to facilitate parental involvement in pain care in their interactions with parents. The ways in which nurses facilitated involvement were related to: communicating and planning care with parents; providing information; involving parents in decisions about their pain care; valuing parental contribution; understanding and implementation of family-centred care.

5.3.1 Communicating and planning care with parents

Some examples of nurses and parents planning care together were observed and reported during the interviews. Nurses conveyed that it was important to listen to parents' views about their child's pain care when collaboratively planning care. Nurses recognised that parents often needed support to be involved in care, as highlighted in this account:

> *'The family, I think, erm, the most important thing is listening to the family because quite often, again they necessarily haven't got the words to explain, but they just know something isn't right, so giving them time to talk …trying to tease out what's going on in their head, are they just worried that their child's in pain or have they got anything specific…when parents come to you and say there's a problem, there's something that's triggered in their head for them to come … the best person to ask about the child is their parent, they know their child and if they think something is wrong, then they're the person you need to listen to really…yeah, but I think listening to them and trying to sort of tease out what is going on is important.* Nurse 8, Karen, interview

> *'I tend to go to the bedside with the parent and discuss with the parent and the patient what is the pain, what type of pain it is, where is the pain and do a pain score and I also try and ascertain, if it's a very small child, what is making the mother or father or family feel that the child is in pain… because often the child themselves can't tell you, so what is it that's made the family say that they're in pain... I think it's also important to accept, to let them know that you've listened to them and that you've accepted their worries and … what you're going to do about it.'* Nurse 8, Karen, interview

Nurses reported that parents had an important role in the process of planning and implementing care. Furthermore, nurses were at times observed to support parent suggestions and strategies regarding managing the child's pain and actively encouraged and supported parents to become more involved in pain care, for example:

'I said you know is there any positions where he is more comfortable when he is in pain. And she said he kept turning onto his front- like a bit of a ball. So I encouraged her to do that.' Nurse 1, Hannah, interview

'Even if it's a simple thing like a child's in pain and they won't take medication from a stranger, so you have to get the family on board to give the medication, to, you know, they know does the child need a spoon or a syringe, they know does the child like pink Calpol or white Calpol, they know, parents know, you can't separate the two…I'm not someone who thinks, like I said before, if they say this is what I would do at home and if it's practical, then I'm more than happy to go along with it as long as it is a safe thing to do. I don't mind, you know having a discussion of what they want to do, yeah.' Nurse 8, Karen, interview

Similarly, some parents reported that they were confident that nurses would respond to their child's pain, for example:

' 'No, I mean obviously, I know, you know, he will be in a bit of pain and things like that, but I know that, you know, if I ask for pain relief or something, then they'll, you know, he will get it, so yeah, yeah.' Family 12, Steven aged 2 years, interview

Although nurses were not observed to use pain assessment tools, nurses acknowledged that some children could accurately describe their pain, although this could be dependent on their age. The following extracts illustrate how nurses perceived children's assessment of their pain:

'He was quite mature for his age. He was only 4 but he knew exactly what pain he had and he would tell you that he was number 4… He was kinda really good at explaining his pain…. I think mum kind of agreed at a lot of the time with what Henry was saying.' Nurse 1 Hannah, interview

'I think they are both twelve, so they have a good understanding as well, I can ask and assess their pain quite well today, I'm quite lucky with the age range that I've got today. Erm, ask the ones that you know are going to be in pain.' Nurse 7, Lauren, interview

5.3.2 Nurses providing information

Nurses providing information about pain care, particularly analgesia, was a dominant feature of both nurses' and parents' accounts and observations. This predominantly related to children undergoing surgery, and was less evident in children with other illnesses. Parents' accounts confirmed that nurses provided information about pain care following surgery, for example:

> *'So we go through all that they are going to have pain relief and everything and what pain relief is-…then I do tell them the consequences of not giving it-(analgesia) that they could get an infection because they are not eating and that sort of thing.'* Nurse 2, Lorraine, interview

Nurses acknowledged that they provided parents with a great deal of information in a short space of time, which may be overwhelming for parents. Repeating information about pain care featured in the findings as illustrated in the following account:

> *Can be quite a good 15 minutes giving 'em, throwing 'em if you want, all this advice (about pain relief)… if I had thought I don't think you are getting this, I will repeat myself... because again they do not always pick up stuff, do they, they are not focussed, so I will always- I haven't just done it cause you were there'.* Nurse 2, Lorraine, interview

Nurses' accounts suggested that when they perceived parents did not desire any further information, they still provided information. Being aware of the consequences of poor pain care was cited as a reason for persisting in providing information. The following extracts illustrate how nurses provide information and rationalise decisions about provision of information about pain care:

> *''If they are slouching down in the chair and looking at their watch kind of thing – I go, I will go back over it because I've seen children the consequences with this. So I will repeat it again and the importance of it.'* Nurse 7, Lauren, interview

5.3.3 Involving parents in decisions about their child's pain care

There were no occasions where nurses were observed to overtly involve parents in pain care decisions. Communication between nurses and parents about how parents could be involved in decisions about their child's care such as outlining options or negotiating care were largely absent. However, nurses reported that it was important to support parents' views and listen to parents views, for example:

> *'But it would have been good to have had time to have a chat with his mother to see if he's normally quiet, because some children are quite pale anyway aren't they, but yeah, sometimes I will use the parents to help me assess them, because obviously you don't always see what they look like when they're well, when they come into hospital.'* Nurse 3, Lorraine, interview

> *'I don't think I would have allowed the doctor either to discharge him (*agreeing with parent).' Nurse 1, Hannah, interview

5.3.4 Valuing parental contribution

Parents' and nurses' accounts highlighted differing views on how parents could contribute to care. Nurses' views of parents' contribution to pain care appeared to be influenced by a range of factors such as how knowledgeable parents were perceived to be. Parents were viewed as knowledgeable if they worked in a healthcare setting and were regarded as being sensible and well informed. The following extracts highlight nurse perceptions of knowledgeable parents:

> *'She knew….Mum worked in a GP surgery…I think mum was very knowledgeable…erm, she was a very sensible mum and she was very clued up.'* Nurse 1, Hannah, interview

> *We tried to keep on top of it- but I think she knew when it was due as well. Them telling us how they feel. Explain to us how they feel they will be more comfortable, especially if it's like a baby or a small child… I don't think we would have been as knowledgeable in regards to his acting differently (if mother did not work in a surgery).'* Nurse 1, Hannah, interview

Nurses viewed parents as being valuable in the practical aspects of the pain care and described enlisting parents' assistance in the assessment of pain (as discussed in Section 5.2.5) and administration of medication. The following extract highlights how nurses' perceived parent contribution to the child's pain care:

> *'For little ones they sometimes take it better off the parents rather than the nurse, erm,* Nurse 2, Lorraine, interview

5.3.5 Understanding and implementation of family-centred care

During interviews nurses were asked to describe their understanding of family-centred care. All nurses stated that they "undertook" family-centred care in their practice. Nurses appeared to consider parental presence as being synonymous with family-centred care. The environment of both sites provided facilities for parents to stay overnight with their child. Parents were permitted to visit at any time and facilities for drinks were available within the ward area on both sites. All children, except one, were observed to have a parents stay overnight. The child who did not have a parent stay with him informed me that his parents were away on holiday and he was visited by his grandparents. Nurses' accounts indicated that family-centred care was "encouraged" (Section 5.3.6). However, there were no policies or guidelines evident in the clinical area relating to family-centred care. The following accounts highlight nurses' perceptions of family-centred care:

> *'Some parents don't stay, some parents go, some are with grandparents, like one child is today, erm, I just sort of see what they give to me as to how much they want back, does that make sense?'* Nurse 7, Lauren, interview

> *'Well no, obviously the family as well because, erm, particularly on here, usually we have at least one parent and often two. So it's the whole family as well…often the person who's asking for the pain relief isn't the patient themselves, it's often the family that initiate saying that they are in pain and so yeah, it's the whole family as well.' Nurse 8, Karen, interview*

Parents were not asked directly about family-centred care, but were asked about their involvement in care. Parents accounts highlighted throughout the findings

presented in this chapter and during observation indicate that they were able to stay with their child and were provided with information.

5.4 Nurses unintentionally preventing involvement and partnership

Despite some limited evidence in the findings related to nurses promoting parental involvement in their child's pain care, planning care together does not appear to be embedded into everyday practice. For example, nurses perceived that they involved parents in their child's pain care, yet they were frequently observed implementing pain care without discussing this with parents. During observation, there were also occasions when pain care was not discussed at all with parents. For example, in one of the assessment units, pain was not observed to be assessed or discussed throughout the observation period.

5.4.1 Not communicating and planning care with parents

While some nurses stated that it was important to listen to parent views, listening to parents was primarily related to eliciting their views about their child's current pain experience rather than actively encouraging participation in care decisions. Similarly, nurses were observed to exclude parents from planning and implementation of pain care at times. The clinical setting appeared to influence the level of pain care communication that took place between nurses and parents. For example, there was a notable absence of pain care discussions in the general assessment unit (site one). Communication between nurses and parents about pain care was generally much more evident in the day surgery area (site one), nurse-led assessment unit (site two) and the surgical ward (site two). In the general ward on site one, there was minimal communication between nurses and parents about the child's pain care and during observation there were long periods where nurses did not interact with children and families at all. At times parents were observed to have been excluded from discussions about their child's pain care between nurses and doctors, even when they were present, for example:

> '*On site two, the doctor and nurse came to see Amy and her mother together. Amy was in obvious distress. The doctor tried to distract Amy while he looked at the traction. Amy was clearly upset. The nurse or doctor did not speak to Amy's mother until they attempted to look at the ring of the traction and then*

asked her to hold up the sheet while they examined Amy's leg. They did not attempt to provide explanations of what they were doing or provide analgesia before the examination.' Family 25, Amy aged 2 years and 10 months, field note extract

Nurses stated that even though parents were present in the recovery area, discussions took place about the child's pain care away from the parents. The following extracts highlight how nurses exclude parents from involvement in their child's pain care:

'They hand it (information about surgery and analgesia) over obviously in recovery to us. It's usually away from the parents – just because the parents are with the child.' Nurse 2, Lorraine, interview

'They'll get the notes and go through the operation with me, "this is what they have had". They usually point it out. "And this is the analgesia they had". Some will read it out, others will just go down- you will just follow sort of down (the list of analgesia administered during surgery)' Nurse 2, Lorraine, interview

Although nurses' accounts suggest that pain assessment tools were used when assessing pain in children and families; the use of pain assessment tools were not observed during the observation period. Nurses were observed to ask the child or parents about the child's pain in more generic terms. Similarly, children's nursing notes were reviewed and there was no evidence of pain assessment tools being used and pain scores documented, although some parents did indicate that pain scales had been explained to them, for example:

'I haven't seen them over here I don't think, you know, with the smiley faces.' Nurse 7, Lauren, interview

'We'd shown her the pain charts that we have with the smiley faces on previously…I think a lot of the time like explaining to them that sometimes it might benefit them taking them for a little walk round the ward to ease some pain. Just little things like that.' Nurse 1, Hannah, interview

'When they ask him, you know, on a scale of one to ten if you're absolutely happy and it's zero and things like that, erm, really that's the only thing I suppose isn't it that they've asked us.' Family 18, Fred aged 8 years, interview

Nurses were observed to ask parents about their child's pain without using an assessment chart. For example, Frances's parents were asked "how is her pain now?" Family 10, Frances, aged 4 years, field notes.

While nurses did not overtly claim that they did not always believe children's assessment of their pain, nurses' accounts suggested that nurses perceived that children could lie about their pain, as highlighted in the following interview extract:

'You knew he wasn't lying. You knew he wasn't putting the pain on as such. You knew he was genuinely in pain.(Henry).' Nurse 1, Hannah, interview

5 4.2 Selective provision of information

In relation to the provision of information, nurses made decisions about when, where and how much information they would provide to parents. Similarly, nurses reported selecting what information would be provided and withheld, for example, if they perceived the child was in severe pain, the first priority was to manage the pain. The following extracts highlight how nurses select when to provide information:

'Absolutely, if it's a situation where, particularly when a child is in severe pain, sometimes you need to get the medication in quickly and say I'm going to get him something now, I need him to have it now, to get on top of this and then you can have those discussions after… we need to sort this now and then have that discussion later…if somebody's anxious, it's, they often don't take information on board. I still think it's important to try and offer them the information, but you know, if somebody's crying, I'm not going to start giving them a lecture about Paracetamol and things.' Nurse 8, Karen, interview

We discussed that on his admission when - not straight away when he arrived, but later on in the evening.' Nurse 1, Hannah, interview

Nurses appeared to filter the information provided to parents, and described situations that warranted more or less information. For example, some types of

surgery required more in depth information. The following extracts highlight the rationale nurses presented for making decisions about provision of information:

> *'Yeah, I probably wouldn't overload them with information because they obviously wouldn't take it all in, you know, the basic sort of things. I wouldn't bombard them with a load of information, I'd just give them as much as I thought was necessary, so not too much in a normal situation. But erm, mostly I would keep people up to date with information, I will tell them as and when I know.'* Nurse 7, Lauren, interview

> *Anyway, with the adenoids and tonsillectomies, I go into it a lot more…going into to it deeper, saying they will definitely be sent home on Calpol and Brufen.'* Nurse 2, Lorraine, interview

> *''If it was like Paracetamol, Ibuprofen, that sort of stuff, erm, I wouldn't commonly tell them about it unless obviously they asked'.* Nurse 7, Lauren, interview

Nurses appeared to place an emphasis and importance on providing information to parents about pain care. However, although nurses appeared to be selective about the information they provide to parents about their child's pain care, the findings suggest that when parents indicated that they did not want any further information, or appeared disinterested, nurses provided information anyway, as highlighted in the following accounts:

> *'I would still try and talk to them about it and still explain, but if they're obviously not listening, you can't go into great depth, but I still think it's important, even though they don't appear to be listening, to still explain what you're doing and still try and involve them.'* Nurse 8, Karen, interview

> *'If they're (parents) not asking loads of questions and they're not wanting that information, I'll still give it to them anyway. It's important that they're kept up to date and they know everything.* Nurse 7, Lauren, interview

5.4.3 Not involving parents in decisions about their child's pain care.

Nurses' accounts illustrated that they made decisions about a child's pain care and that those decisions did not always involve the parents. For example, nurses would make decisions about administering analgesia without parental involvement and decisions were presented to parents as a *fait accompli*, for example:

> *'Try and decide if I think, erm, pain relief is needed and I'll, I usually explain to the parents what I'm going to do before I do it because I think, especially if you're giving medicines to children, you need to have the parents on side because it's usually the parents that end up giving the medicines… You're the one that's deciding on medications and prescribing them.'* Nurse 8, Karen, interview

Nurses described how pain care was their role and that they were responsible for decisions about pain care. While nurses stated that they should inform parents of their decisions about the child's pain care, nurses appeared to perceive that it was the nurses role to make decisions. The following extracts summarise nurses' perceptions of making decisions about pain care in children:

> *'Obviously it's my role to identify when a child's in pain (emphasis on "my").'* Nurse 2, Lorraine, interview

> *'I think it's really important to explain to parents why you've made that decision and not just to approach them with a spoonful of medicine',* Nurse 8, Karen, interview

Parents were observed trying to establish what was happening with their child's care with relatives, as opposed to discussing care with nurses. Nurses were rarely observed to discuss options for pain care and were not observed to negotiate decisions or involvement through formal communication. Parents were frequently observed waiting for nurses to discuss the plan of care and parent accounts identified that nurses did not share decisions about pain care, for example:

> *'But I still feel I am still not quite sure… what they are going to do with this traction. And I think that is possibly because they're not quite sure…but that's*

the only thing that makes me anxious'. Family 25, Amy aged 2 years and 10 month, interview

Parents were observed to discuss their child's pain care between them during observation. For example, Rajiv's parents were discussing whether Rajiv's pain would be "as bad when he gets home". They discussed how they would manage it, but were unsure how to do it. Family 19, Rajiv, aged 10 years, field note extract

5.4.4 Not valuing parental contribution

While some nurses valued parental knowledge and recognised that parental knowledge could enhance the child's pain care, others stated that they felt threatened by knowledgeable parents. Nurses described how they felt defensive when parents had nursing or medical knowledge, as highlighted in the following account:

'Sometimes think when parents start asking a lot of questions, you sort of think are they a nurse, are they a doctor, do they have a lot of knowledge that, you can sometimes feel quite threatened actually when parents ask a lot of questions and you start thinking oh hang on, then they start using words and you think are you a nurse or a doctor or something, you know, have you got knowledge and that can feel a bit oooh, you know, I'd better watch what I say here…I have asked people before, are you a doctor or a nurse because you seem to know quite a bit and I don't mind, and I just say I'm just being nosy…if they were asking lots of questions, I might just make light of it, make a little bit of a joke about it, but it can be quite threatening when you get a parent that seems to have a lot of knowledge and it can put you on the back foot a bit and make you feel a bit defensive about what you're doing.' Nurse 8, Karen, interview

Nurses' accounts highlight that nurses and parents disagreed about the child's pain at times. Nurses appeared to suggest they did not always agree with parents' assessment of the child's pain, often perceiving children were not in pain, even when parents had reported that their child was in pain, for example:

'More to try to keep on top of it- not that he was in pain. A lot of the time when she was asking he was quite settled.' Nurse 1, Hannah, interview

'I mean the child, sometimes you go and the child's lying there in bed, looks, you'd look at them and think oh they're not in pain, but mother and father might say oh but he is, I think he's in pain because of, this is just not right.' Nurse 8, Karen, interview

To ensure that their child's pain care needs were met, parents were observed to attempt to influence decisions about their child's pain care by persisting in ensuring their views were taken into account, as illustrated in the following extract:

Henry had been admitted three times with similar symptoms and his mother had indicated that healthcare staff did not believe her. She had videoed him while in pain. He was diagnosed with an acute surgical emergency problem during the observation. The following extract is an account of an encounter with this nurse, a doctor and Henry and his family:

'Dr- when did it start?

Mother- he was in constant pain, screaming, rolling around. Then he goes to sleep, exhausted. (mother was quite emotional).

Dr- do painkillers help

Mother- personally, I don't think they work.

Nurse- he sleeps after pain

Dr- pain is better since he has been in hospital.

Mother- no, same

Dr- pain would wake him up

Mother- I think he sleeps in pain

Nurse- but not painful enough to wake him

Mother- still in pain though

Nurse- I know what you mean' Family 2, Henry aged 4 years, field note extract

In contrast, nurses reported that parents underestimated their child's pain or had not considered that their child was experiencing pain. Nurses were observed to attempt to initiate pain care when parents were unaware that their child could be experiencing pain, for example:

> *'So it makes, not a difference in regards to keeping on top of pain relief and things like that but just managing the care and not realising actually maybe how much pain they are in sometimes (referring to parents not knowing how much pain their child has).'* Nurse 1, Hannah, interview

> *'Toms father asked the nurse if he was due any medication for his cough. The nurse suggested analgesia as well as a bronchodilator. Father indicated that the Paracetamol was for his temperature and when the nurse suggested Tom may be in pain the father responded by saying the coughing makes him sweat.'* Family 1, Tom aged 22 months, field note extract

Similarly, when parents reported that their child was experiencing pain, being "seen" to be responding and implementing pain care was highlighted by nurses. Providing medication for the parents' benefit was reported even though nurses disagreed that the child was in pain. When parents appeared to be dissatisfied with pain relieving measures, nurses tried to justify their actions and appease parents by reassuring them or providing more information as highlighted in the following nurse accounts:

> *'Especially if the child is crying and they think "have they had anything given" so I do sort of give, tell them the list of stuff, even though it doesn't mean anything apart from probably Morphine… if you are looking at parents and you are thinking they are getting upset or they are getting cross.. and I think then you have got to justify, you've got to go through everything. And justify the reason why and maybe that they are still distressed and look at ways to deal with it… cause they are aware, you know… you can see the distress in the parents…are they believing you that there is nothing else and the drugs that they've had?.'* Nurse 2, Lorraine, interview

'It's the parent, for the parent to feel that the pain is being dealt with that's important… recognising when a child is in pain, particularly the toddlers or the non-verbal children, you've got to have the parents, you've got to, and often what, it sounds silly, but often with a child in pain, it's not only the child's pain you're treating, it's the fact that the parents are anxious and you're seen to be doing something. So you can't separate the child's pain from the family because it's all tied in together'. Nurse 8, Karen, interview

5.4.5 Poor organisational and system support

Parents' and nurses' accounts highlighted that the workload of nurses impacted on how nurses interacted with parents in relation to pain. For example, parents were observed to approach nurses for pain care interventions when nurses were busy to ensure their child received appropriate pain care, which is supported by this nurse account:

'And obviously with the workload a little bit- she would say can Harry have some Paracetamol…er, I think in regards to pain, a lot of the time, cos depending on how busy we are on the ward, and what parents kind of come to us.' Nurse 1, Hannah, interview

In contrast, parents were sometimes reluctant to approach nurses when they perceived they were busy and attempted to manage the child's pain care themselves as discussed in Section 5.2.4. Nurses recognised how being busy impacted on parents, while parents were hesitant to approach busy nurses, for example:

'Yeah, well I am always a bit like that. I always worry what people think when they are busy. It's busier today as well. I just did not want to be fussing' . Family 25, Amy aged 2 years 10 months, interview

Nurses reported and perceived that there was an absence of pain care guidelines and assessment tools. The trust pain care guidelines were stated to be out of date and currently being updated. An adult pain team was observed to visit site two on one occasion. This was for a child following major abdominal surgery. Other children who reported severe pain were not referred to the pain team.

5.4.6 Lack of understanding and implementation of family-centred care

From nurses' accounts, it appears that they found it difficult to articulate family-centred care and they had differing views on what this meant in practice. Nurses did not refer to attributes central to family-centred care, such as negotiation, empowerment, participation or partnership, but described family-centred care in practical terms, such as facilitating parents stay with their child and being given a choice about being present during procedures, for example:

> *'Whatever we are doing we try to encourage the parents to stay, to be with the children through procedures. Again, we do offer the choice.. you know.. " do you want to go and have a coffee while he has his bloods done or would you like to come with him- especially babies and things?...I think it works, it's something, er, I wouldn't even be able to er, decipher it really because it's just encouraged, it's the whole package.'* Nurse 2, Lorraine, interview

Despite nurses claiming to aspire to family-centred care, nurses were not observed to overtly discuss with parents how they could be involved in their child's pain care or negotiate care with parents. Parents were observed to wait to be "told" what was happening and when they could accompany their child, for example to the anaesthetic room. The following extract highlights parents' uncertainty about how involved they are in pain care:

> *James' mother was sat beside his bed prior to surgery, when the nurse came to undertake the theatre checks. The nurse verbally quoted on the checklist that James had received a "pre-med". James' mother indicated that she was not aware that the pre-medication was pre-emptive analgesia and asked why he had this before his operation, indicating that it had been given without explanation. James' mother did not attempt to go with the nurse to theatre and waited to be informed that she could accompany her child. Family 15, James, aged 2 years, field note extract*

In summary, parents' and nurses' accounts and field notes of the observed practice suggests considerable variability in the ways that nurses promoted or prevented partnership working. While parents and nurses reported that they planned the child's pain care together, observation of interactions and nurses' accounts also highlight

that they made decisions about a child's pain care independently. Nurses making decisions without parents appeared to be related to whether they agreed with parents' interpretations of their child's pain and whether they valued parents in the pain care process. Other influencing factors that emerged from the findings were organisational support and nurses' understanding of, or lack of understanding of, family-centred care.

5.5 Chapter summary

This chapter has presented the findings from the observations and interviews. The findings have been presented as three core concepts: parents as advocates; nurses promoting parental involvement and partnership; and nurses unintentionally preventing involvement and partnership. Parents' accounts and observations indicate that parents attempted to advocate for their child by becoming involved and used a number of strategies to enable involvement in their child's pain care. However, nurses either facilitated involvement or prevented involvement, influenced by how they perceived the value of parental contributions to their child's pain care and how they made decisions about the child's pain care. Chapter Six will present a synthesis and critical analysis of the findings in relation to the literature and policy.

Chapter Six: Discussion

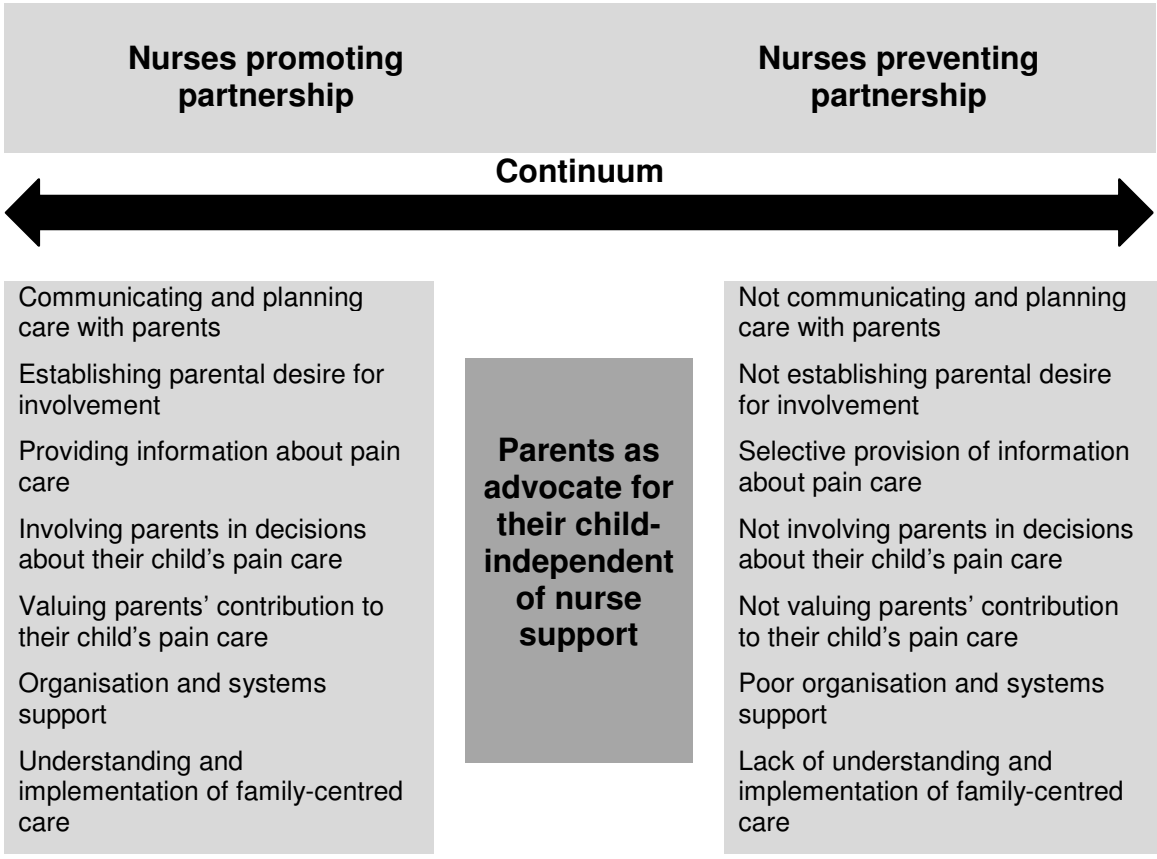
6.1 Introduction

This chapter presents a synthesis and critical analysis of the study findings, which will be contextualised, by contrasting with the published research reviewed in Chapter Two. First, the conceptual framework illustrating the interactions between nurses and parents in relation to the child's pain care will be outlined. Second, the three core concepts "parents as advocates for their child", "nurses promoting involvement and partnership" and "nurses unintentionally preventing involvement and partnership" that emerged from the findings will be explored. These concepts were integrated into the conceptual framework in order to conceptualise parent-nurse interactions that underpin partnership working. Third, partnership and overcoming barriers to partnership working will be examined. Finally, the theoretical perspectives of family-centred care and pain care, outlined in Chapter One, and in particular the family-centred care continuum that guided the exploration of parental involvement in their child's pain care will be critiqued in relation to its application to the study findings. The Pillars of Partnership in Pain Care Model is presented as an alternative approach to partnership working.

6.2 The conceptual framework

The conceptual framework has been developed to represent the findings reported in Chapter Five (Figure 10). The framework presents a continuum representing the range of ways in which nurses either promoted or prevented parents' involvement in their child's pain care. The findings did not identify that nurses intentionally or deliberately prevented parental involvement, therefore, it has been assumed that preventing parental involvement was unintentional. The related aspect of parent advocacy is central to the conceptual framework and represents how parents act as an advocate whether supported or unsupported by nurses. While parents may attempt to become involved in their child's care by being an advocate on behalf of their child, whether or not supported by nurses, this can be enabled or hindered by nurses' actions. The model reflects the study findings in that, despite nurses being in a position of power based on their knowledge and experience, parents were often the drivers of active involvement, with nurses either promoting or preventing parental involvement.

Figure 10: Conceptual Model: promoting or preventing partnership working



6.3 Parents as advocates for their child

In younger children or children who are acutely ill, parents usually undertake the role of being an advocate for their child. Being an advocate for their child's pain care emerged as a dominant finding in the study and was associated with parents' level of satisfaction with their involvement in care. Parents who were less satisfied with their child's care were determined to be more involved in their child's care, and this was driven by a desire to ensure pain care was meeting their child's needs. Gaining knowledge about their child's care and using knowledge of their child to influence care was central to parent involvement in care. Advocacy is based on an assumption that an individual's or group's rights and best interests are paramount and central to the provision of ethically driven care (Blais & Hayes, 2011; Spence, 2011). However, differing views on what constitutes as rights can impact on how nurses' advocate for,

or support parents to advocate for, vulnerable populations such as children (Jones & Smith, 2014).

One of the key features of children's nursing, particularly for the young child, is supporting parents to be an advocate for their child (Spence, 2011). Although examples of nurses supporting parents in their role as advocate were evident in the findings presented in Chapter Five, nurses were also observed hindering parents endeavours to be an advocate for their child. For example, by being selective in providing information to parents, nurses restricted parents' ability to understand pain care and consequently identify whether their child's pain care needs had been met adequately. Similarly, findings from this study mirrored the literature: parental lack of knowledge; parental contribution to care decisions not being valued; lack of clearly defined roles; variability in the quality of information sharing by health professionals; uncertainties when communicating with health professionals; being overwhelmed by healthcare professionals and the environment, hindered parents' advocacy role (Holm, Patterson & Gurney, 2003; Neill, 1996a; Neill, 1996b; Smith et al., 2013). The nurses' role as advocate is poorly understood, and by extension and by association, their role in supporting parents to advocate is open to interpretation and can be misunderstood (Cole, Wellard & Mummery, 2014). Evidence suggests parent-nurse relationships are fragile and that parents perceive a lack of recognition for their role as the primary advocate for their child (Clark & Fletcher, 2008).

The findings from this study suggest that parents appeared to learn early during their child's episode of care that they needed to be an advocate for their child and persist in ensuring their role as the child's advocate was recognised by nurses. Being an advocate for their child is one of the key drivers underpinning parents' desire to be involved in their child's care (Holm et al., 2003; Ygge & Arnetz, 2004). With few exceptions, parents are the constant in the child's life and normally have day to day responsibility for decisions about their child's health and well-being (Bradshaw & Coleman, 2007). However, in healthcare environments, particularly during acute illness episodes, parents' advocacy role is often eroded.

Parents as advocates for their child linked with ensuring their child's pain care needs were met. Parents attempting to ensure their child's care needs were met by raising concerns when they perceived their child's pain care was sub-optimal was a feature

of this and other studies (Holm et al., 2003; Jaakola et al., 2013). In highlighting poor care, parents have been described as a “voice for the child” (Holm et al., 2003, p. 305; Jaakola et al., 2013). While health policy supports older children to be given a voice and active involvement in their care (Department of Health, 2001, 2003, 2004), less emphasis is placed on parents being a voice for younger children. Self-report by the child is the gold standard in pain assessment (Royal College of Nursing, 2009) and it is important to emphasise, that while this study did not focus on involvement of children in pain care, involvement of children who are able to communicate their pain is paramount.

Parents acting as a proxy for the child’s voice can be problematic and in young children relies on parents’ interpreting the child’s behaviour and responses. However, parents know the child’s behaviour and prior responses to strategies that have been effective in managing the child’s pain (Stinson & Jibb, 2014). Parents’ ability to speak up to ensure their child’s care needs are met can be facilitated or hindered by a range of factors, such as nurses eliciting parents opinions as an equal and involving parents in decisions about their child’s care (Coyne et al., 2011: Coyne et al., 2013; Ford, Davenport, Meier & McRee, 2011; Holm et al., 2003; Maclean, et al., 2005). However, parents’ perceive that they are unable to approach nurses is an example of parents being hindered to raise concerns (Twycross, et al., 2013).

Nurses are ideally placed to coach and support parents in their role as advocate for their child and support parents to become involved in their child’s pain care, as nurses have most contact with families in hospital (Kristensson-Hallstrom & Elander, 2004: Manworran, 2007). However, from the study findings presented in Chapter Five, parents were observed attempting to be involved in their child’s pain care, whether supported by nurses or not, particularly when they perceived pain care to be inadequate. Parents’ determination and persistence to be involved is consistent with other studies, as the desire to ensure their child’s pain care needs are met often overrides the challenges and barriers to involvement (Clark & Fletcher, 2005; Neill, 1996a; Neill, 1996b). Parents’ natural instinct is to protect the child particularly in the context of pain care, as seeing their child in pain is particularly distressing for both the child and parents (Holm et al., 2013; Jaakola et al., 2013). Nurses in this study recognised parents were determined in their role in securing optimal care for their child.

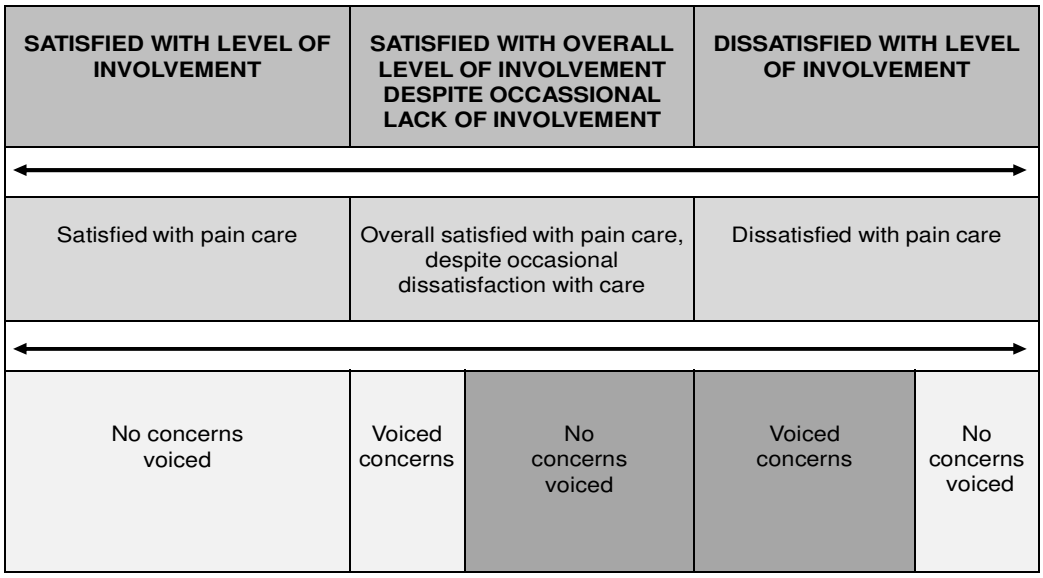
Parents perceived that being vigilant and monitoring their child was central to their advocacy role and recognised when busy nurses are not able to care for their child as well as parents desired (Ygge & Arnetz, 2004). Evidence suggests that parents are capable of recognising subtle changes in their child's condition, but they may not always understand the significance of changes (Callery, 1997b; Smith et al., 2013). Similarly, in the findings from this study, some parents were observed as being aware of changes in their child's condition and alerted nurses to these changes, while some parents did not recognise or respond to changes in their child's condition. However, some parents appeared to be attempting to advocate despite not always having the knowledge to underpin their actions. In contrast, other parents were observed to be unaware of poor pain care practices, evident from observation and parent interviews, such as inappropriate interventions following trauma. Previous research has identified poor pain care is not necessarily recognised by parents, even if their child had experienced moderate or severe pain (Twycross & Collis, 2013b; Twycross & Finley 2013; Twycross et al., 2013). In addition, parents tend to report being generally satisfied with their child's pain care, which may relate to common misconceptions that some moderate to severe pain should be expected and accepted during acute illness (Twycross & Finley 2013; Vincent et al., 2012; Woodgate & Kristjanson, 1996).

Reluctance to criticise or challenge nurses could account for parents stating that they are satisfied with care, when pain care is inadequate (Simons et al., 2001). In contrast, parents in this and other studies have been vocal about raising concerns when they perceived poor pain care (Jaakola et al., 2013). Attributes required for advocacy such as experience, knowledge and power could be extrapolated for parent-child advocacy, because parents often take the proxy position for their child, particularly with younger children (Simmonds, 2008). Parents who wanted to be more involved, utilised these qualities of advocacy, as they attempted to use their experience and knowledge of the child to influence pain care.

6.3.1 Parental satisfaction with involvement in care

In this study parent satisfaction with pain care was variable. The previous section outlined how parents attempt to advocate on behalf of their child which appeared to be linked to their perceived satisfaction with involvement in their child's pain care. Parents who were satisfied with their child's pain care indicated that they were also satisfied with their involvement in their child's pain care. In contrast, parents who were dissatisfied with their child's pain care indicated that they were dissatisfied with their level of involvement in care. The final stage of the framework approach may result in the development of typologies (Ritchie, 2003). Figure 11 illustrates the link between parental involvement and satisfaction with care. Parents who were dissatisfied or occasionally dissatisfied with their involvement in care did not always voice those concerns. However, parents who were mainly dissatisfied with their involvement in care were more likely to voice those concerns, indicated by the darker shaded areas.

Figure 11: Parent satisfaction with involvement in care typology



The typology distinguishes the likelihood of parents voicing concerns based on the relationship between their level of satisfaction and level of involvement with their child's pain care. Parents who indicated that they were satisfied with the level of

involvement in this study appeared to have been provided with sufficient information and were satisfied with nurse's decisions regarding their child's pain care. The level of information appeared to meet the parents' needs and expectations. However, this seems to reflect parents' satisfaction with the provision of information and care, rather than the level of involvement in care. Satisfaction with involvement in their child's pain care appears to be synonymous with parent satisfaction with the care provided.

The link between satisfaction with pain care and satisfaction with involvement was a significant finding and reflected a link between expectations of care involvement and satisfaction with pain care. It would appear that if pain care meets parents' expectations, parents were satisfied with not only pain care, but with involvement in pain care. Other studies have explored parents' expectations of pain care (Twycross & Collis, 2013b; Twycross & Finley 2013; Twycross, et al., 2013) and parents' expectations of involvement (Corlett & Twycross, 2006) and found that pain care expectations were often based on misconceptions and expectations of involvement were not always supported by nurses. Furthermore, the findings indicated that while most parents' voice concerns about dissatisfaction with pain care and involvement, a minority do not. Those parents who did not voice concerns were observed to discuss their concerns with relatives and friends as opposed to nurses. This model could be evaluated further with parents and nurses to examine the links between parental expectations, satisfaction with involvement and satisfaction with pain care, and explore why some parents do not voice their concerns to nurses.

Evidence suggests that for both parents and nurses, their expectations of the level parents are involved in pain care, is often based on personal beliefs (Hughes, 2007; Rennick et al., 2011). Although parents generally want to be involved in their child's pain care, they want to choose their level of involvement (Neill, 1996a; Simons et al., 2001). If parents choose not to be involved in care, they want nurses to value their decision and not make judgements about their lack of involvement (Rennick et al., 2011). In contrast, nurses expect parents' input into the care of children, whereas parents expect nurses to care for the child (Coyne & Cowley, 2006). It has been suggested that the pendulum has swung from excluding parents in care provision that occurred during the mid-twentieth century, to expecting parents to be involved without clarifying the meaning of involvement or explicitly negotiating care with

parents (Coyne, 2013; Coyne & Cowley, 2007; Hughes, 2007). Nurses in this study did not formally establish parents' expectations of being involved which is mirrored in the literature (Simons et al., 2001; Twycross, 2007; Woodgate & Kristjanson, 1996). Consequently neither nurses nor parents have clear expectations of each other's contribution to care (Sousa Antunes, Carvalho & Casey, 2013). This lack of clarity can lead to tensions in the nurse-parent relationship with nurses not meeting parents' expectations, and parents, as in this study, attempting to take control of care of care without the support of nurses (Brown & Ritchie, 1990; Smith et al., 2010). Research has found that there is an unspoken assumption by nurses that parents were satisfied with their level of involvement in care, while parents were largely dissatisfied and frustrated with their lack of involvement (Simons et al., 2001).

Conversely, parents may not want the responsibility of making decisions about their child's care and treatment, particularly in acute illness episodes (Balling & McCubbin, 2001; Smith et al., 2013). Research about parents of children with long term conditions has found that while parents expect care to be negotiated (Dickinson, Smythe & Spence, 2006) they do not always want to take responsibility for decisions (Smith et al., 2013). While there are differences in long-term care, such as many parents having no choice but to undertake care-giving roles, compared to acute care episodes such as encountered in this study, parents may have similar concerns about being involved in their child's care (Smith et al., 2013). Acute care episodes are transient and short lived which may create a barrier to partnership working, as parents have little time to come to terms with their child's illness, let alone being involved in care delivery. Research has shown that families whose child had repeated admissions to hospital were more likely to feel able to contribute to discussions and care decisions (Neill, 1996a; Neill, 1996b). Conversely, parents experiencing hospital admission with their child for short acute care episodes may not feel able or willing to contribute to decisions (Balling & McCubbin, 2001).

Parents may be overwhelmed by their child's illness and hospitalisation, preferring nurses to undertake usual parental care tasks. Darbyshire (1994, p 17) coined the phrase "parenting in public" to describe parents undertaking their parent role in a strange environment, with an audience of qualified health professionals. This may partly explain why some parents are reluctant to undertake parenting roles, let alone pain care roles. Furthermore, parents may reject or even resent this role of care giver

in hospital, being imposed on them. Other priorities for parents, such as responsibility for siblings and work commitments, may account for some parents indicating that they are satisfied with the level of involvement in care, as they may be unable to commit to being more involved (Callery, 1997a).

6.3.2 Parents' initiating pain care

In this study, some parents attempted to become involved in their child's pain without "permission" or encouragement from nurses. Parents were frequently observed to use distraction, comforting, reassuring and stroking their child and using "teddies" to simulate administering medication. Parents using distraction as a pain care strategy, is well reported (Polkki et al., 2002a; Kankkunen et al., 2002; Woodgate & Kristjanson, 1996). In the findings presented in Chapter Five, nurses were occasionally observed to advise parents on strategies for managing their child's pain, such as "having a little walk" and "comfortable positioning". However, despite many parents being observed to undertake non-pharmacological interventions, evidence supports few parents being provided with support and explanations of how to implement non-pharmacological methods and their benefits (Twycross & Collis, 2013a). Research suggests that nurses perceive that it is within parents' remit to undertake some approaches to pain care, but this expectation is not clearly articulated by nurses to parents (Twycross et al., 2013).

Parents' desire to be more involved in the child's pain care was a dominant feature of this study and is mirrored within the wider literature (Jaakola, et al., 2013; Lim et al., 2011; MacKean et al., 2005; Neill, 1996a; Watt-Watson et al., 1990). Furthermore, disparity between parent's desire to be involved and nurse support for the desired level of parental involvement was evident in this study and is reflected in the wider literature (Lewis et al., 2007; Macdonald, Liben, Carnevale & Cohen, 2012; Murphy & Fealy, 2007). Parents perceived that they could have been provided with greater information to be more actively involved in care. Regardless of whether supported by nurses, some parents took steps to be more involved such as actively managing their child's pain using non-pharmacological methods. Literature highlights that some parents regard involvement in pain care as a vital role and parental duty (Coyne, 1995; Franck et al., 2012). Being involved is viewed by parents as being essential for advocacy (Holm et al., 2003). For many parents involvement in their child's pain care

is important because they have responsibility for pain care prior to the child coming into hospital and following discharge. Parents make numerous decisions about children's pain care at home without any external help from health professionals. However, in the hospital setting, the role of parents in their child's pain care is less clearly defined (Carter & Simons, 2014).

In the study findings presented in Chapter Five, nurses placed much emphasis on parents being present with the child and providing information to parents, and appeared to regard this as parental involvement in their child's pain care. The literature supports differences in nurse and parent understanding of involvement in care. For example, nurses consider that parents should be involved in usual parenting tasks such as washing and feeding their child, (Coyne, 1995; Meadow, 1969; Ygge, Lindholm & Ametz, 2006). Conversely, some parents perceived that nurses took over their parenting roles indicating a lack of communication and clarity about the roles of parents and nurses (Neill, 1996a). Parents wanted to continue with their parenting roles but some wanted to be more involved in what may be considered medical and nursing care (Coyne, 1995; Blower & Morgan, 2000). Medical and technological advances have seen a shift from acute childhood illness dominating child health service provision, towards supporting children and families undertaking technical roles and complex care particularly in families of children with long-term conditions (Smith, Cheater & Bekker, 2013). However, nurses considered technical roles as within their domain and can find sharing or handing over care decisions to parents challenging (Kristensson-Hallstrom & Elander, 2004).

Parents in this study reported that they were often stressed by the lack of information and lack of value placed on their input into care decisions. Not being involved in care and reduction in "normal" parenting roles is stressful for parents, resulting in anxiety (Neill, 1996b; Uhl, Fisher, Docherty & Brandon, 2013). Similarly, parents are anxious about handing over responsibility for their child to relative strangers**.** Research has highlighted parents' concerns about the competency of nursing staff which may lead to conflict and tensions between parents and nurses (Diehl, Moffitt & Wade, 1991). In this study some parents reported concerns about their child's condition or their child was in severe pain but perceived that health care professionals did not believe them.

Similar findings have been reported where parents' concerns were not acknowledged in acutely ill children (Callery, 1997b).

Some parents acknowledged that not knowing what was happening regarding their child's pain care resulted in them responding defensively during interactions with healthcare professionals. Not knowing what was happening also prompted parents to initiate discussions about pain care with nurses, a finding that concurs with other research (Twycross, et al., 2013). Parents wanted to participate in care, such as the usual care they would provide at home, but were insecure about undertaking these roles in hospital, a finding supported by Gale et al. (2004). However, this is in contrast to Polkki et al. (2002b) who found that parents were guided by nurses in assisting with usual parent care provision, such as supporting the child to adopt comfortable positions. Research has found that parents wanted to be confident in their role and become actively involved in their child's care. Undertaking care gave them a sense of contribution to their child's recovery (Rennick et al., 2011). Despite wanting to be more involved in care, some parents were reluctant to approach nurses and felt that asking nurses about pain care may be seen as questioning nurses' judgements (Simons et al., 2001). Similarly, parents in this study regarded themselves as being "fussy" or "nagging" if they bothered busy nurses and did not want to get in the way, as highlighted in other studies.

6.3.3 Parental knowledge of child informs care

Parents being knowledgeable and knowing their child are closely linked. However, there are differences; parents may know their child but have limited knowledge of pain care in hospital (Lam, Chang & Morrissey, 2006). Parents' accounts indicated that they gained prior knowledge from previous experiences that they had encountered and from information sources such as the internet. Parents are able to filter information gained from the internet to ensure it was up to date and appropriate (Holm et al., 2003; Kankkunen et al., 2002). Other studies have found that parents use prior knowledge to be involved in and influence decisions about care or used informal support from friends and family (Carter & Simons, 2014; Holm et al., 2003). Parents in this study were observed to discuss their concerns and seek advice from relatives and friends, rather than nurses and on a number of occasions approached

me to voice concerns. This concurs with Kankunen et al. (2002) who found that parents used media or friends for advice instead of nurses.

Nurses' accounts of knowledgeable parents were varied, describing parents as sensible, determined or threatening. Nurses described sensible parents as having prior knowledge and understanding of pain care. This is in contrast to evidence from other studies that found that nurses underestimated parents' knowledge (Fereday, Oster & Darbyshire, 2010; Polkki et al., 2002a). In this study parents drew on past events when their child had a similar experience. Some parents used this knowledge to ensure a range of analgesia were prescribed, while others claimed that their child's behaviour was due to anxiety rather than pain when the nurse thought the child had pain. The findings suggest that parents can distinguish between pain and anxiety. Parents' having knowledge and expertise has been explored in other studies and while parents can be described as experts, there is limited research into how parents develop expertise (Callery, 1997c; Elliot & Williams, 2008; Smith, et al., 2013). The concept of the expert parent has only recently begun to be examined and there do not appear to be any studies specifically exploring the expert parent in relation to pain care, despite being high on the agenda in terms of empowering patients in their own care (Department for Education and Skills, 2005; Department of Health, 2001, 2007).

Sharing and combining expertise between the clinical expertise of health professionals to evidence based knowledge and parents' knowledge gained from personal and prolonged contact with the child, can ensure the child's health needs are understood and met, to form a cohesive basis for participation (Callery, 1997a; Elliot & Williams, 2008; Ford et al., 2011; Smith et al., 2013). Evidence supports that parents have an innate ability to recognise subtle changes in their child's condition (Holm et al., 2003). As stated in Section 6.2 parents perceive their advocacy role as monitoring their child and have been described as vigilant (Holm et al., 2003). However, findings from this study found that rather than embracing parental knowledge, nurses reported being on the "back foot" when parents appeared knowledgeable, indicating nurses perceived that they were disadvantaged when parents were knowledgeable.

Being threatened by knowledgeable parents may be due to lack of nurse confidence in their own knowledge. Nurses' knowledge deficits have been found to be an obstacle to parental involvement in care (Broome, Richtsmeier, Maikler, & Alexander, 2000) and has been attributed to the variations in the amount of pain care education within pre-registration nurse education programmes (Simons & Roberson, 2002; Twycross & Roderique, 2013) with an average of 11.5 hours provided for pain care education in UK pre-registration nursing courses. While most higher education institutions indicated that they included current pain care guidelines in their teaching, almost a quarter of the institutions who responded to a UK national survey indicated that they did not include parent views of pain care and involvement when teaching pain care (Twycross & Roderique, 2013). Lack of knowledge about effective pain care and how to involve parents in care can affect nurses' confidence in pain care impacting on their ability to support parents to be involved in their child's pain care (Bell, 2013). Other research suggests that nurses had knowledge but did not always apply their knowledge into practice (Chiang, Chen & Huang, 2006; Twycross & Collis, 2013b). Improving pain care education and identifying why nurses do not always apply their knowledge into practice could contribute to improving pain care (Chiang et al., 2006; Simons, 2002).

Societal structures have been described as being influenced by what individuals possess in terms of capital, with knowledge being a form of capital (Bourdieu, 1990). This is particularly pertinent in healthcare, where knowledge and qualifications are argued to equate to power capital (Gibson, Britten & Lynch, 2012). Attempting to share that capital with parents may lead to participation, but can be hampered by parental lack of knowledge and anxiety related to their child's illness. Although variations in formal pain care education have been highlighted in the previous paragraph, nurses have some training in pain care, whereas most parents do not. This does not bode well for an 'equal footing' in pain care, unless nurses can manage to engage with parents on their intellectual level taking into consideration their anxiety levels, without appearing patronising (Elliot & Williams, 2008).

Parents in this study highlighted that they "knew" their child and child's responses to different situation, and some parents had prepared their child for hospital and involvement in pain care. Parents indicated that they knew their child's pain threshold and referred to their child as being tough or not being a softie. This is comparable to

findings that parents are able to identify their child's pain threshold and know what works best (Twycross & Collis, 2013b). Findings suggest that some parents were able to describe their child's pain behaviour and suggested that health professionals may not recognise the signs of pain as well as parents could. Parents are able to use verbal expressions, changes in daily activities, and behaviour to assess their child's pain and distinguish between the subtle differences between anxiety and pain behaviour (He et al., 2005; Kankunen et al., 2002; Kristensson-Hallstrom & Elander, 1997; Simons et al., 2001; Stinson & Jibb, 2014). This study found that some nurses recognised parental knowledge of their child in relation to pain care and some nurses responded to this by including parent views when making decisions about pain care.

6.4 Nurses as facilitators and nurses creating barriers to partnership working

This section will explore the core themes relate of nurses promoting or preventing partnership working, as outlined in the promoting or preventing partnership working conceptual model. The range of ways in which nurses prevent or promote parental involvement will be explored together, as represented in the continuum (Figure 10, page 102).

6.4.1 Nurses and parents communicating and planning care

Occasional encounters where nurses listened to parents' accounts of their child's pain and planned care with parents were reported in Chapter Five. Evidence suggests that listening to parents could change nurses' attitudes towards pain care (Jongudomkarn et al., 2012; Vincent, 2007). Nurses reported that listening to parents was seen as crucial in pain care, and this was particularly highlighted by nurses in advanced roles, who have developed advanced assessment skills. Nurses acknowledged that the best person to ask was the parent who was the expert in knowing their child, but recognised that parents did not always have the words to explain their views or concerns and nurses described how they "teased" information from parents. Other studies have identified the expertise of parents in their child's care (Simons et al., 2001; Woodgate & Kristjanson, 1996). Similarly, nurses viewed parents as an asset, especially during pain assessment or when the child had learning disabilities because nurse were unsure how to interpret child's behaviour (Gimbler-Berglund et al., 2008). However, other studies have identified that parental

involvement is hindered by lack of integrating parents' personal knowledge of the child with the nurse's professional knowledge (Callery, 1997b).

Nurses recognised that children are more likely to tell their parents about their pain (He at al., 2005). Findings reported in Chapter Five indicate that some nurses appeared to rely on parents to inform them about their child's pain behaviour. Expecting parents to take an active role in alerting nurses when their child is in pain is also evident in the wider literature (Twycross & Collis, 2013b). Nurses sometimes valued parental involvement in administering medication and also considered suggestions made by parents.

Despite some relatively isolated occasions when nurses and parents communicated and planned care together, the findings from this study indicate an general absence of nurses communicating with parents about how they can be involved in pain care. Other studies confer with these findings and identify a lack of communication and negotiation between nurses and parents to establish parents' requirements for involvement in care (Kawik, 1996; Polkki et al., 2002a; Simons et al., 2001). Lack of communication leads to misunderstanding and missed opportunities for nurses to work in partnership with parents (Kawik, 1996; Neill, 1996a; Neill, 1996b; Polkki et al., 2002b; Simons et al., 2001). Negotiation of roles is claimed to underpin effective implementation of family-centred care (Dale, 1996; Smith et al., 2010). However, discussions about roles between nurses and parents were not overtly evident in this study. Lack of clarity and failure to effectively negotiate roles is well documented in the literature and central to the lack of effective implementation of family-centred care (Corlett & Twycross, 2006; Coyne et al., 2011; Coyne et al., 2013; Kawik, 1996; Lim et al., 2011; Neill, 1996a; Polkki et al., 2002b; Shields et al., 2006; Simons et al., 2001; Simons & Roberson, 2002). Furthermore, the literature suggests that parents are not in a strong position to negotiate with professionals (Knafl & Dixon, 1984).

Negotiation places the emphasis on both parties having a contribution to partnership working (Lee, 2007). Conversely, ineffective negotiation remains an obstacle to partnership working (Smith, 2010). Several models have been developed that aim to enhance negotiation, for example, "the negotiated care tool" which is claimed to enable parents to fully negotiate their involvement (McCann et al., 2008). Similarly, the "framework for involvement "developed by Smith et al. (2015) includes

negotiation as a central tenet of effective engagement of parents in their child's care. While this was designed for families of children with long term conditions, it could be transposed for enhancing negotiation between nurses and parents in acute pain care episodes. However, while the impact of this framework on practice has not been evaluated, it could offer an alternative approach to address the shortcomings of the implementation of effective negotiation. Currently, despite the availability of guidelines and models, negotiation of roles in pain care does not appear to be occurring in nurse-parent interactions as identified in this study or the literature reviewed in Chapter Two.

Interactions between nurses and parents were limited at times because of the long periods where nurses did not enter patient care areas. For example, in the in-patient area on site one, there were often gaps of up to an hour when nurses did not enter the bay where several children were inpatients. When nurses did enter, often the initiative was in response to an alarm such as infusion pumps or monitors and nurses entered and left quickly. Once nurses had responded to the alarm they left without interacting with children and families. Lack of interaction and opportunities to communicate about pain care, or indeed any aspects of care, appeared to impact on parent involvement. Literature suggests that nurses sometimes avoid contact with families as it may "open a can of worms" (Bell, 2013, p 412). This may be due to nurses perceiving they do not have time and that this will increase their workload (Bell, 2013). However, other research has highlighted the emotional burden of nursing and that those emotions may negatively influence nursing practice, resulting in nurses avoiding contact with patients (or parents) as a way of protecting themselves from the perceived anxiety that involving parents and sharing power may bring (Allan, 2006). Furthermore, Menzies-Lyth (1960) proposed that nurses create barriers as an institutional defence to protect themselves from the distress of being close to parents. While this work was undertaken over 50 years ago, findings indicate that that nurses may continue to avoid interactions with parents and findings discussed in Section 6.3.2 support nurses using technical knowledge as a barrier to involving parents. Nurses may use technical knowledge to block those feelings of anxiety, linked with the concept of the emotional labour of nursing (Fabricius, 1999). This may account for nurses' reluctance to relinquish their positional and knowledge

power by supporting parents to undertake technical roles. The impact of power and control is explored further in Section 6.4.3.

6.4.2 Nurses providing information

Nurses in this study were frequently observed to provide information to parents and when interviewed, referred to providing information as integral to involvement. The provision of information to parents and children appears to be synonymous with involvement in care (Betz, 2006; Bruce et al., 2002), and viewed as a pre-requisite to parent involvement (Henderson, 2003; Raghavendra, Murchland & Bentley, 2007). Parents require information to be able to be empowered, participate in and negotiate as partners in care (Coyne et al., 2011; Uhl et al., 2013). Informing and educating parents is seen as the first step towards active participation and establishing a partnership between parents and health care professionals (Huth et al., 2003).

In this study, while nurses identified that provision of information was required for involvement, some parents wanted more information, which is mirrored in the literature (Lam et al., 2006; Sousa et al., 2013; Woodgate & Kristianson, 1996; Ygge & Arnetz, 2004). Other study findings have highlighted that lack of provision of information was identified as a barrier to parental involvement (Twycross 2007; Twycross & Collis, 2013a; Watt-Watson et al., 1990), with parents feeling that they were reliant on nurses to learn about pain care (Gale et al., 2004) and wanted more information (Lim et al., 2011; Polkki et al., 2002a; Simons et al., 2001; Twycross & Collis 2013a; Twycross & Collis, 2013b). Not being provided with information has also been found to result in dissatisfaction with care and increased stress (Gale et al., 2004; Tait, et al., 2008; Watt-Watson et al., 1990).

Nurses in this study decided when, where and how much information would be provided. Timing and quality of information is important, as omissions may restrict parent decision making (Betz, 2006). However, nurses omitted to discuss pain care with parents at times and offered analgesia without any discussion of the rationale for their use. Nurses perceived parents were given a great amount of information and described this as sometimes “throwing it at them”. Too much information, particularly in a short space of time when parents are stressed can be overwhelming (Campbell-Yeo, Latimer & Johnston, 2008; Simons & Roberson, 2002). Nurses believed that parents would not take information on board if they were anxious and avoided “giving

them a lecture" about analgesia. While too much information can be overwhelming, too little may be detrimental for follow on care of the child particularly following discharge. Studies have shown that parents who are misinformed or not informed at all, have preconceived beliefs about pain medication and fear side effects and addiction, resulting in children receiving inadequate pain relief at home (Fortier, McLaren, Perrett-Karimi & Kain, 2009; Lim et al., 2011; Woodgate & Kristjanson, 1996; Zisk et al., 2007). Educating parents in hospital or ideally at pre-assessment for planned surgery may address this.

Information sharing, claimed to be a central component of family-centred care, is not always part of everyday practice suggesting that nurses do not always appreciate the value of information sharing (Lam et al., 2006). Evidence suggests that nurses perceive parents are provided with more information than they actually need which may result in a mismatch between nurses and parents beliefs about information needs (Simons & Roberson, 2002). However, findings presented in Chapter Five indicate that while some parents wanted more information, some were satisfied with the information provided. Reciprocal information sharing can help build rapport which is required for parents to feel able to participate (Espezel & Canam, 2003).

6.4.3 Supporting parents in pain care decisions

Nurses did not always involve parents in decisions about their child's pain care and initiated care without consulting with parents. Involvement in care decisions linked with the value nurses place on parents' contribution to their child's pain care, which is explored in Section 6.3.4. Shared decision making is central to family-centred care (Coyne et al., 2011; Murphy & Fealy, 2007). Not involving parents in decision-making processes reflects a paternalistic approach to care delivery and is situated at the nurse led end of the family-centred care practice continuum (Smith et al., 2010). Participation can only take place if parents are informed and are actively engaged in decisions regarding their child's care (Smith et al., 2010). In relation to pain care, being involved in decisions requires nurses to ensure parents are informed of the range of options for managing pain and supported to make decisions about the choices available (Bruce & Ritchie, 1990).

Parents in this study wanted to be involved and could contribute to decisions about their child's pain care, which mirrors findings in other studies (MacKean, et al., 2005;

Polkki, et al 2002; Sousa et al., 2013; Tait et al., 2008; Twycross & Collis, 2013a; Twycross & Collis, 2013b). Current health policy advocates active involvement, collaboration and partnership with patients and their families whereby involvement in decision making is paramount (Department of Health, 2003, 2004, 2009; Nursing and Midwifery Council, 2010). Yet, nurses continue to make decisions without parental involvement despite government recommendations (Department of Health, 2010a, 2010b; Kennedy, 2010). If as Coleman (2010b) suggests, family-centred care is based on the belief that children and families should be listened to and involved in decision making, then nurses making decisions without involving parents is a barrier to moving along this continuum.

Nurses are in an advantageous position to instigate shared decision-making, to enhance partnership working, while parents are in a disadvantaged position. Parents are in unknown territory and are usually stressed due to their child being ill (Darbyshire, 1994). Whereas, nurses are in a familiar environment and have the skills to manage the acutely ill children which can result in inequalities in power and control (Mulvay, 2001). Imbalance in power relationships such as between qualified healthcare professionals and patients (parents) has been claimed to be inevitable and can supress involvement in decision making for those with less perceived power (Henderson, 2003). Nurses are claimed to hold power and therefore control in practice which they may be reluctant to relinquish (Connell & Bradley, 2002; Coyne, 1995; Kawik, 1996). Meadow's (1969) analogy of the power nurse hold over parents offers the notion of the "captive mother", whereby parents are the "prisoners" of nurses' expectations of parents' role in the child's care. However, the partnership power balance "tilts" in different circumstances (Hopia, Tomlinson, Paarvilainen & Astedt-Kurki, 2005). The tilting may be towards the nurse or parent, for example parents may find it necessary to be assertive and advocate for their child, particularly if their child's care is perceived as inadequate, as found in this study. Over time parents can become more confident and assertive (Kirk, 2001; Neill, 1996a). Similarly, nurses may need to take control in emergency situations, where it may be inappropriate to delay interventions in order to negotiate care (Lee, 1999; McIntosh & Runciman, 2008). Professional elitism and subject specific knowledge (Gibson et al., 2012), once associated with inhibiting partnership working and shared decision making is claimed to be diminishing (McQueen, 2000). While there has been some

progress in partnership working and shared decision making, especially when considering the historical accounts of parent's being prevented from even visiting their child, the findings from this study suggest that parents are still being excluded from sharing care decisions.

Power and position appears to have a significant influence on nurse-parent relationships. The nature of power in health care is linked to the work of Foucault (1979), who examined the influence of power relationships. The subject-object phenomena described by Foucault asserts that medics, or in this case, nurses hold the subject position, and by definition parents adopt the object position, a position of less power. Foucault (1979) claimed that power can create both problems and possibilities. The possibilities can arise from questioning what are considered certainties. In this study, parents were the ones who pushed the boundaries of control and attempted to address the imbalance of power. However, both parents, and indeed nurses, could challenge the status quo of power relationships in children's pain care for the benefit of the child. Foucault (1979), asserted that those who are presumed to have power through knowledge (in this case nurses) adopt a "clinical gaze"; in this study nurses watched over the care of children's pain, yielding an invisible air of authority, which can create a barrier to parental involvement. While nurses are reluctant to relinquish this authority, some parents may be unwilling to challenge it. However, this study has found that many parents are willing to challenge positional authority, perhaps in an attempt to act as an advocate.

Similarities between patient and public involvement and parental involvement in the child's pain care can be drawn from the work of Arnstein (1969), who describes citizen involvement as citizen power. Arstein (1969) argues a ladder of assent that includes the stages of manipulation and tokenistic steps in the move towards citizen control. While nurses have not been found to be overtly manipulative in their actions, there were occasions where nurses have considered parents as useful in delivering nursing care. Similarly nurses admitted to involving parents as a means of " being seen to be doing something" as a way of appeasing parents when parents were not satisfied with pain care, suggesting a tokenistic approach rather than valuing parents contribution to care delivery . The central role of power is emphasised by Arnstein (1969), who suggested that for true involvement the impact of power must be understood and addressed. Although criticised for its single dimension and linear

model, Arnstein's (1969) theory lacked acknowledgement of other forms of power, such as knowledge power (Tritter & McCallum, 2006). Combining what has been described as expert professionals knowledge and lay knowledge (such as parents knowledge of their child) has the potential to redress the inequalities of power by the creation of "knowledge spaces" (Elliot & Williams, 2008). Lay person knowledge has been claimed to be a powerful and legitimate form of knowledge and expertise, because it has been gained through life experiences and can enhance the inclusive, reliable and valid knowledge of professionals (Popay & Williams, 1996).

The notion of agency may also explain the actions of both nurses and parents in relation to the child's pain care. Agency is defined as "the temporally constructed engagement by actors of different structural environments" (Emirbayer & Mische, 1998, p.970). Agency, described in Gidden's (1984) work on managerial structuration and class power, asserts that ultimate control within organisations or groups is not fixed and that the "actors" participating exert some power whatever their role or position. While Gidden's (1984) work related to organisation management, it resonates with the perceived power and control relationships between parents and nurses. Furthermore, the social systems, or in this case the socially constructed notion of authoritative nurses having control can constrain forming effective partnership relationships. Perceived barriers such as power positions can be influenced by the actions of the actors (Gidden, 1984), suggesting both parents' and nurses' actions can confront and change the structural barriers to involvement. Conversely, the need for positional security can lead actors (in this case nurses) to retain behaviours that may unintentionally or deliberately create barriers to parents being involved in the child care. The "actors" in this study were the nurses, parents and children. While children were not directly considered as actors within the study, they were present during the observation of practice and ultimately the rationale for parents' involvement in pain care is to improve children's pain experiences during acute illness episodes. To work in partnership, parents and nurses must understand each other's position and work towards a common goal; nurses would have to relinquish control and acknowledge the personal experience and knowledge of parents.

6.4.4 Valuing parent's contribution to pain care

Valuing parent's knowledge, experiences and contribution to care have been identified as core elements of both family-centred care and partnership models that underpin nursing (Smith et al., 2015). Valuing parent contribution to a child's pain care means involving parents in care delivery and decision making (Corlett & Twycross, 2006; Entwistle, 2009; Mackean et al., 2005). In this study, some nurses, particularly those with advanced roles, stated that they were responsible for pain care, suggesting a territorial view of pain care. Other research has highlighted nurses' beliefs that "they know best", which can devalue parent's contribution to their child's pain care (Henderson, 2003, p 501). Further evidence suggests that some parents perceive they are ignored and under-used and overlooked in relation to their potential contribution to care (Carter, McArthur & Cunliffe, 2002; Fereday et al., 2010; LeMay et al., 2010; MacKean et al., 2005; Polkki et al., 2002).

Valuing parental contribution is linked to believing and trusting parent views and suggestions. Parents in this study did not think that nursing and medical staff always believed their accounts of their child's pain. Research suggests nurses perceived that children and their parents overestimate pain and that parents wanted analgesics when the nurse deemed them as unnecessary (Manworran, 2000; Twycross & Collis, 2013b; Vincent, 2005). Not believing parents pain scores could suggest nurses' lack confidence in parent's judgment of their assessment of their child. This is in contrast to another study that found that surgeons perceived parents as reliable proxies and allies in the pain assessment process (Twycross, Williams & Finley, 2014).

Parental contribution to pain care appeared to be influenced by how useful nurses perceived parents to be. Nurses in this study described how they "used" parents to undertake tasks such as administering medicines. This indicates that nurses may perceive parents as having a functional role, which is evident in other studies (Coyne et al., 2011; Coyne et al., 2013; Darbyshire, 1993). Allocating tasks to parents is related to a paternalistic approach, is reflected in the literature, whereby nurses selected which tasks could be delegated to parents based on their perceived unpleasantness (Paliadeis, Cruickshank, Wainohu, Winskill & Stevens, 2005).

6.4.5 Organisational and systems support

A range of organisational and system support factors appeared to negatively influence involving parents in pain care including: nursing workload pressure; lack of guidelines; environment; and lack of designated children' pain teams. In this study nurses reported that workload pressures hindered involving parents in pain care. Other studies have found that workload demands negatively impacted on nurses being able to support and guide parents in the child's pain care (He et al., 2002; Lim et al., 2011; Polkki, et al., 2002; Tycross & Collis, 2013a; Ygge et al., 2006). Parents in this study recognised when nurses were busy they were reluctant to approach nurses to discuss how they could be involved. Parents also perceived that when nurses were busy, they did not always trust that care would be provided at the same standard if they left and stayed to ensure their child's safety (Fereday et al., 2010; Lam et al., 2006; Sousa et al., 2013). It appears that nurses' workload concerned parents and influenced their decisions to stay with the child.

In this study, it appeared that when nurses were busy, they expected parents to approach them for pain care, but at other times retained responsibility for pain care. Additional responsibility placed on parents to care for their child when nurses' workload increased is a feature in other studies (Huth et al., 2003). Similarly, nurses thought parents should report pain to nurses to help them when they were busy (Twycross & Collis, 2013b). Conversely, evidence suggests that nurses perceive that actively involving parents would increase their own workload (Simons et al., 2001). Expecting parents to take on more responsibility when nurses are busy appeared to be an unspoken assumption and arrangement. Nurses did not discuss this with parents, yet parents were observed to undertake more unsupervised and non-directed non-pharmacological pain care activities without prompting from nurses. It would appear that parents were socialised to fit in with nurses' routine. Parents often conformed to nurses' expectations without discussion or choice (Coyne, 2008).

Pain care guidelines and specifically parental involvement in pain care guidelines were absent in the clinical areas of this study. Nurses stated that they were being updated and were not available. Pain assessment tools were discussed but not observed to be used routinely. Pain assessment tools have the potential to enhance child and family involvement as they require the child and family to contribute to pain

assessment and subsequent decisions about pain care interventions (Royal College of Nursing, 2009).

Lack of guidelines, facilities and services designed to meet family-centred care is a dominant feature across the literature (Bruce et al., 2002; Coyne et al., 2013; Lam et al., 2006; Mackay & Gregory, 2011; Paliadelis et al., 2005). The design of the environment can influence parental involvement in care, positively or negatively, depending on the layout of the environment and facilities provided (Beck et al., 2009). The environment in this study provided facilities for parents to stay overnight with their child, make drinks and support unlimited stay with their child. However, despite nurses stating that they endorsed family-centred care, there were no guidelines evident in the clinical areas and nurses were unable to identify the source of their knowledge about family-centred care. Lack of accessible policies and guidelines regarding implementation of family-centred care are reflected in the literature (Mackay & Gregory, 2011).

Pain teams are reported to impact positively on pain care and may reduce nurse's workload if utilised effectively (Mackintosh & Bowles, 2003). However, the adult pain team was only observed to be involved with one child during this study. There appeared to be a number of other children who could have benefitted from input from specialist pain nurses, as their pain was did not appear to be well managed. It has been suggested that one of the roles of a children's pain team is to work at the bedside with families and promote a family-centred approach to pain care (Czarnecki et al., 2011). The pain team comprised of generalist nurses, drawn from the adult field of practice, may have impacted on how they promoted parental involvement in the child's pain care.

6.4.6 Nurses understanding of family-centred care

Family-centred care has been suggested to be a concept that is embedded into children's nursing and that children's nurse would not contemplate caring for a child without the involvement of the family (Clayton, 2000). Nurses claimed overwhelmingly to ascribe to family-centred care in this study and this is supported in the literature (Lim et al., 2011; Shields & Nixon, 2004). Despite nurses describing that they aspire to the principles of family-centred care, they were unable to define family-centred care and described it as a difficult concept to make sense of and embed in

practice. Nurses appeared to have different understandings of family-centred care, ranging from provision of information to parents being “allowed” to be resident or present during procedures. Research suggests that the concept of family-centred care is poorly defined and understood, which contributes to the lack of application into practice (Coyne et al., 2011; Coyne et al., 2013; Franck & Callery, 2004; Kuo, et al., 2012; Power & Franck, 2008; Shields et al., 2006; Uhl et al., 2013). Conversely other literature has found that practitioners have a reasonable understanding of family-centred care (Bruce et al., 2002). However, even when understood, the principles are not consistently applied in practice (Bruce et al., 2002). Active participation is central to family-centred care and yet nurses do not always highlight active negotiation and the shared process required for parents to be involved in care (Blount, Sturges & Power, 1990; Rennick et al., 2011). Active involvement in the study findings outlined in Chapter Five was restricted to normal parenting tasks and pain care tasks which nurses delegated such as medicines, as described in Section 6.3.2.

The family-centred care continuum, based on the theoretical aspects of family-centred care, includes terms such as empowerment, negotiation, and participation which were not used by nurses when asked about family-centred care. While the concept of family-centred care is claimed to be well accepted (Shields & Nixon, 2004) nurses appear to be unclear about the attributes associated with family-centred care and how to implement family-centred care in practice (Coyne et al., 2013; Davies, Baird & Gudmundsdottir, 2013; Hughes, 2007; Hutchfield, 1999; Lee, 2007; MacKay & Gregory, 2011; MacKean et al., 2005: Murphy & Fealy 2007; Paliadelis et al., 2005; Simons et al., 2001). Family-centred care has been described as a nebulous concept (Hutchfield, 1999; Nethercott, 1993) and challenges in implementing family-centred care have been identified (Callery, 1996a; Coyne et al., 2011; Coyne et al., 2013; Macdonald et al., 2012; Mackay & Gregory, 2011).

Evidence suggests that there are also differences between parents’ and nurses’ understanding of family-centred care (Macdonald et al., 2012). Furthermore, nurses perceived that parents lacked understanding of family-centred care and partnership working (Lee, 2007). Parents cannot be expected to have the knowledge to understand professional terminology related to partnership working and family-centred care and subsequently how they can be involved in their child’s pain care.

Nurses, however, are educated about the principles of family-centred care in pre-registration nursing curricula and the constructs that facilitate partnership working (Bruce et al., 2002). There do not appear to be any models of family-centred care that have been developed by combining the parent, child and nurse perceptions of embedding family-centred care into practice. A shift from a professionally based view to a family-centred view was advocated over two decades ago and yet family-centred care remains nurse focussed (Ahmann, 1994). The family-centred care continuum is about nurses and families and it appears that families are unaware of it and nurses are not implementing it effectively. Furthermore, the findings from this study have found that the family-centred care continuum is too complex in relation to pain care because the stages along the continuum appear rigid and hierarchical, a view supported by Cahill (1996). Rather than being instrumental in implementing family-centred care, it appears to restrict partnership by its prescriptive and inflexible nature. Cassidy & McIntosh (2014) suggest that rigid adherence to structural approaches to nursing decision making has resulted in lack of autonomy for nurses, resulting in poor care at Staffordshire and beyond. The concept of family-centred care has been found to be problematic both in terms of understanding and implementation in the literature. Findings from this study strongly indicate that embedding family-centred care into practice remains problematic.

6.5 Partnership working

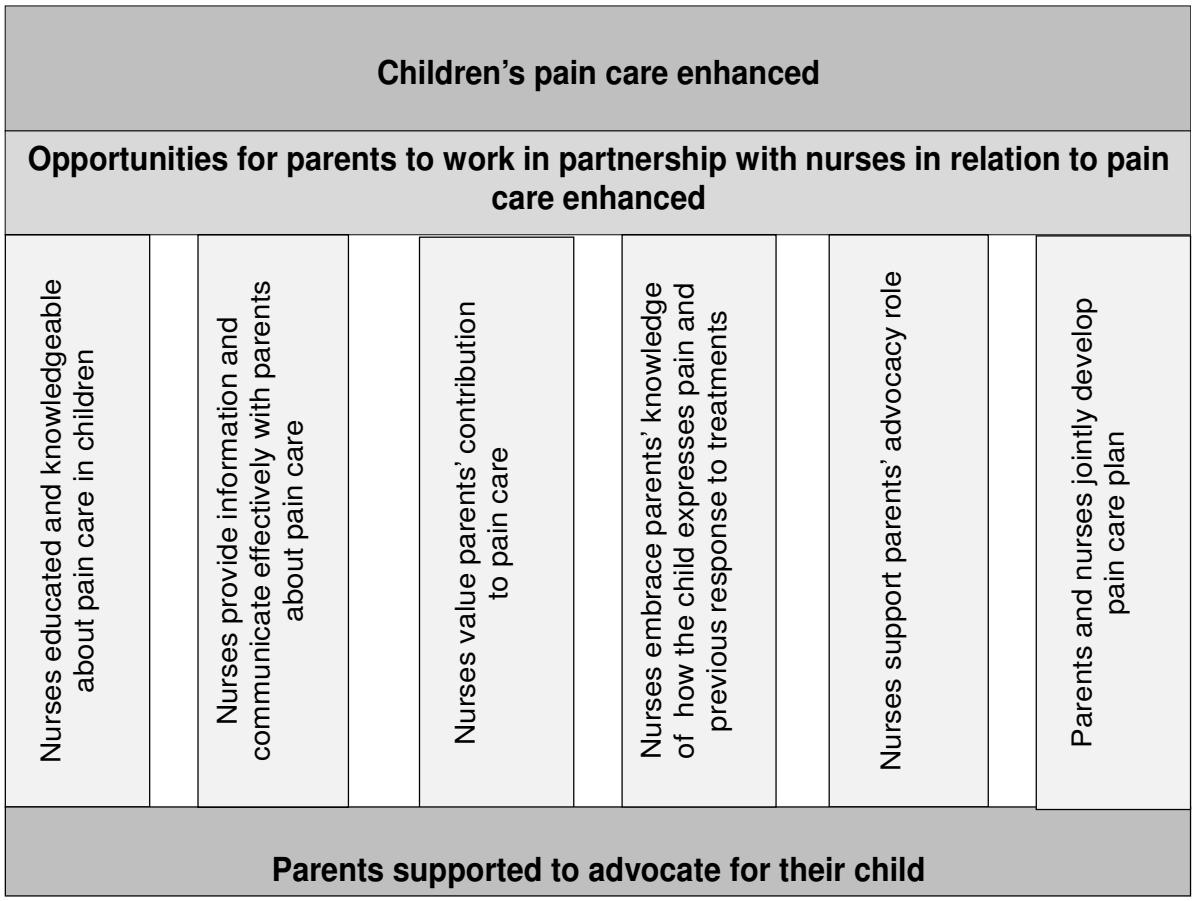
Partnership working and family-centred care are included in the range of patient-centred models of care, offering a way to involve parents in care (Smith et al., 2015). Common to both approaches is the ideology of patient involvement in care, and in child nursing, involvement of parents is dominant. However, while partnership working is claimed to be an attribute of family-centred care, it has been described as a philosophy distinguishing partnership working from family-centred care (Casey, 1988). The benefits of partnership working in children's pain care are evident in the literature and driven by policy (Chambers, Reid, McGrath & Finley, 1996; Department of Health, 2007). "Nothing about me without me" is the crux of the government white paper "Equity and Excellence: Liberating the NHS" (Department of Health, 2010a) emphasising the notion of patients (or parents) being involved in all aspects of care. Promoting partnership working is claimed to be internationally adopted, or in the United Kingdom at a rhetorical level at least (Coleman et al., 2003; Collins, Britten,

Ruusuvuori & Thompson, 2007). Research suggests that theoretically, working in partnership with nurses can reduce distress for the child and improve quality of care and meet needs of child and family (Coyne et al., 2013; Fereday et al., 2010; Uhl et al., 2013). Nurses are claimed to ascribe to partnership working and parents generally desire this (Chambers, Finley, McGrath & Walsh, 2003: Hamers & Abu-Saad, 2002). However, findings from this study show that nurses and parents rarely work in partnership, a finding reflected in the literature reviewed in Chapter Two (Power & Franck, 2008). Furthermore, as mirrored in this study, principles of partnership working do not appear to be embedded into practice (Baker, 1995; Bruce & Ritchie 1997; Coyne, 2013; Coyne et al., 2013; Franck & Callery, 2004; Murphy & Fealy, 2007). This view is supported in the literature which suggests that current models and theories of partnership are outdated and do not match parents' and nurses' experiences (Coyne & Cowley, 2007).

6.5.1 Overcoming barriers to partnership working; A "Pillars of Partnership in Pain Care Model"

Based on the findings presented in Chapter Five and exploration of the findings in this chapter, a Pillars of Partnership in Pain Care Model (Figure 12) has been developed as an alternative approach to support partnership working. The model is based on the premise that partnership working can be enhanced by parents being supported to advocate for their child to ensure that their pain care is effective. The model emphasises how the barriers can be overcome related to the concepts. While there are similarities to the concepts of the family-centred care continuum, the emphasis is on nurses communicating effectively with parents to establish how they can best support parents to be involved and be advocates for their child's pain care.

Figure 12 ***"Pillars of Partnership in Pain Care Model"***



The underpinning principles on the "Pillars of Partnership in Pain Care Model" are first, that parental desire and ability to be involved in care should be established on admission and reviewed frequently to accommodate parents' changing needs. Second, parents should be supported to advocate for their child. The pillars outline the steps required to support parental advocacy. Conceptual models have the potential to guide practice by offering a link between the idealist theories and practical application, which is the aim of this model (Walker & Avant, 2011). Redefining how nurses can enhance partnership working by supporting parents to be an advocate for their child has the potential to address the challenges to partnership working. A cultural change may be required to move from one of paying lip service to partnership working between nurses and parents based on the concepts of family-centred care, to one whereby parents are truly partners in care (Macdonald et al., 2012).

Underpinning the model is parents' desire to be involved in pain care. However, parents' desire and ability to be involved will inevitably vary between parents and at different times throughout the child's illness trajectory, because of differing views of pain care of children in hospital, anxiety and knowledge (Lim et al., 2011; Polkki et al., 2002b). Establishing parents' wishes requires effective early and ongoing communication with parents. Parents may be initially too anxious to decide on their level of involvement and this initial reluctance, if not re-visited, can result in parents not being invited to participate in care. Entering children's wards in an acute care situation for the first time is unknown territory for parents and it can take time for them to become accustomed to the hospital environment and roles of nurses. Therefore, it is important to ensure effective communication with parents about being involved in care throughout the child's stay. This is particularly challenging when the average length of stay is less than two days, as in this clinical area.

The challenge of ensuring parents are supported in care without coercion is essential to prevent parent burden. Parents may have valid reasons for not becoming involved in care and being an advocate for their child. Previous seminal studies have found the financial, emotional and social costs of a child being in hospital, impacts on parents' decisions to participate in care or not (Callery, 1997a; Darbyshire, 1994; Davidhizar & Bartlett, 2000). Regardless of parent commitments, nurses usually have some contact with parents even if this is limited and may use these opportunities to discuss their child's pain care with parents and offer support for parents to be involved in care decisions and care at a level they feel appropriate. While it is important to consider parents who are unwilling or unable to be involved, the findings from this study indicate that parents were present most of the time and were observed to be active in their child's care to some extent.

Supporting parents who want more active involvement in care requires a shift in focus from nurse led to parent led care and continuing in preparation for discharge. Effective transition to home care is dependent on how well parents are prepared and supported by nurses (Price & Thomas, 2007). When parents want to be involved, working in partnership reduces stress for parents emphasising the importance of establishing parental desire to be involved and supporting them to do so (Diaz-Caneja et al., 2005).

Nurses want to work effectively with families but are restrained by poor understanding and skills about how to implement family-centred care (Mackean, 2005; Roden, 2005). Therefore the Pillars of Partnership in Pain Care Model offers a guide to facilitate nurses to support parents to advocate for their child; establishing parents' needs for advocacy and supporting parents to advocate for their child; communicating effectively with parents; being knowledgeable about pain care and providing parents with appropriate information; embracing parental knowledge; valuing parental contribution to pain care; and developing pain care plans with parents (Ford et al., 2011).

6.6 Chapter Summary

Parents want to be involved in their child's pain care. However, they are not being supported by nurses to work in partnership in their child's pain care in acute hospital settings. Parents are attempting to be involved in pain care without support from nurses and often drive involvement and potentially partnership working. Parents are undertaking a participatory role on the basis of advocating for their child, often due to perceived inadequate care and subsequent dissatisfaction with care. The findings indicate a link between parents' satisfaction with pain care and satisfaction with involvement which appears to be related to parents' expectations. When parents are not satisfied with pain care and involvement, they do not always voice their concerns to nurses.

Nurses state they want to involve parents in care but do not always implement this effectively in practice. Reasons for this have been identified as lack of understanding of family-centred care, power and control conflicts, poor communication and support for parents. The Pillars of Partnership in Pain Care Model offers a way of overcoming the barriers to promoting parental involvement and partnership, by promoting nurse support for parent advocacy. Moving towards supporting parents to advocate for the child is complex and could face the same problems that occur with implementing family-centred care, such as poor communication between professionals and parents, and issues of control and power. Furthermore, the shift towards parental control in advocacy could be threatening for nurses. If nurses are to break down these barriers, they need to work with parents to enable parents to advocate on behalf of their child to the extent they are willing and able. Nurses need to be

knowledgeable and be prepared to share their knowledge and acknowledge that parents have intimate knowledge of their child, sometimes have pain care knowledge and may seek out knowledge from sources such as the internet, particularly if they are dissatisfied with care. Otherwise parents will continue to independently advocate for their child, potentially creating conflict and poor relationships between nurses and parents. Whereas, coaching parents by agreeing pain care goals and supporting parents to act as advocates to the level they indicate involves nurses providing positive reinforcement, which could contribute to a positive relationship between nurses and parents (Hopia et al., 2005).

Chapter Seven: Quality Issues

7.1 Introduction

Chapters Three and Four have presented the methodology and methods that underpinned this research undertaken as part of this Professional Doctorate. This chapter will present a critical appraisal of the research processes undertaken to demonstrate the rigour inherent throughout the study. Central to adopting an ethnographic approach is the way researchers' acknowledge their role in constructing and interpreting the data. Therefore, a reflexive account will be presented. Finally, the strengths and limitations of the study are outlined.

7.2 Ensuring rigour

Frameworks for evaluating quantitative studies, based on reliability, validity and generalisation are widely debated in relation to their appropriateness for establishing rigour in qualitative studies. Criticisms related to methodological rigour in qualitative research reflect a positivist resistance to the acknowledgement of the value of qualitative research, with quantitative research viewed as the "gold standard" (Morse, 2006; Sandelowski, 2004). One reason for this could be the absence of established standards for judging the merit of qualitative research (Rolfe, 2006). Alternative criteria to demonstrate rigour in qualitative studies have been developed to reflect different philosophical position and purpose (Noble & Smith, 2015). Therefore, the five criteria for establishing rigour in qualitative research will be utilised: credibility; dependability; confirmability; authenticity and transferability (Guba & Lincoln, 1994).

7.2.1 Credibility

The credibility of study findings depends on the integrity and trustworthiness of the research methods adopted and ways in which bias were minimised (Tuckett, 2005). During the planning stage, credibility was considered in relation to ensuring that the appropriate methodology and subsequent methods were selected to achieve the research aims (Smith & Noble, 2014). An ethnographical approach facilitated a value-neutral account of parent-nurse interactions without value laden bias and remaining as close as possible to what happened and what was said. The aim was to enable data to be gathered within the culture under investigation, both in terms of

people and the social environment, without imposing preconceived values. This required credibility to be considered in relation to both observing practice and when undertaking interviews with the participants.

First, non-participant observation to capture relevant interactions between nurses and parents were optimised by appropriate positioning within the setting, as I endeavoured to remain inconspicuous, yet able to observe interactions clearly. Non-participant observation by one researcher has been criticised as lacking objectivity, as it relies on the selective subjectivity of the researcher as to what is observed and recorded (Caldwell & Atwell, 2005). However, in most ethnographical studies, this cannot be avoided. It is possible that important data was not recorded during observation, as only a small number of care activities that took place could be captured due to multiple interactions occurring simultaneously. However, sustained periods of observation enabled prolonged immersion in the setting enabled me to become attuned to the social environment. In addition, my experience as a children's nurse assisted in identifying episodes of care that may include pain care. Ultimately exposure to real life encounters in real time, reflecting an ethnographic approach can contribute to truly represented participants' experiences (Pereira de Melo et al., 2014).

Second, follow up semi- structured interviews with a selection of consenting parents and nurses took place at the end of the period of observation. Triangulation of methods of data collection, such as comparison of observation and follow up interviews can help corroborate findings and contribute to credibility by overcoming inherent weakness or bias of a single method of data collect (Denzin, 1989; Tuckett, 2005). In this study observation and interview data were complementary. Observation as a data collection has limitations in that it does not deal with the unobservable, such as care omissions and participants' feelings and thoughts. In contrast, interview data relies on recall and may not reflect actual practice. Selection and availability of participants for follow up interviews was hindered by changes in the child's condition and care and by nurses' workload. Not all families and nurses were interviewed following observation. Greater opportunities to explore observed practice in follow up interviews may have enhanced the credibility of the findings by enabling more nurses and parents to explain and elaborate what was observed.

Nurses were often too busy to spare time to be interviewed and those who were able to, were frequently interrupted during the interviews, limiting the opportunity for these participants to expand on their perspectives. The fluctuating nature of acute clinical areas reflect the real world challenges of undertaking ethnographic studies, but in contrast can highlight the authentic contribution of participant accounts (Gelling, 2014).

Third, achieving credibility during the interpretation and analysis stage included ensuring participant accounts were transparent when interpreting and presenting the findings. Iterative analytical procedures using the framework approach to data management and analysis have contributed to a true account of the participant perspectives (Ritchie et al., 2003). A documented and clear audit trail of raw data to findings and interpretation with rich, thick descriptions enables the reader to establish if the interpretation truly reflects participant accounts (Morse, 2007). This can be further enhanced by respondent validation or member checking, by returning the transcripts to nurses and families (Burnard, 1991; Cresswell, 2008; Dearnley, 2005). However, member checking is not always viewed as having a useful purpose and members cannot always judge the validity of the research (Morse, 1991). Participants may be able to confirm the accuracy of transcripts but may be unfamiliar with theoretical frameworks and how they apply to the data unless follow up meetings were arranged to share the findings, which was not practicable within the study timeframe. Furthermore, it has been established that nurses do not always understand the principles of family-centred care, which may limit their ability to confirm and verify the interpretations of their accounts. Peer debriefing, whereby data analysis is discussed and debated with colleagues, can help challenge assumptions and ascertain whether other researchers would arrive at similar interpretations (Lincoln & Guba, 1985). Debriefing occurred throughout data collection and during research supervision meetings.

7.2.2 Dependability

Dependability relates to the consistency and accuracy of the findings and can be achieved by having a clear audit trail and recording decision making through the research processes (Robson, 2002; Ryan-Nicholls & Will, 2009). The methods chapter (Chapter Four) outlined the decisions related to the way the study was

planned and enacted, to help readers to assess the accuracy of the findings and follow the path undertaken and detailed by the researcher (Lincoln & Guba, 1985). The transient nature of care on general children's wards can impact on dependability as there is a lack of stability in terms of children and families, with constant turnover of families in the wards. However, ethnographers aim to present "a truth" rather than "the truth" (Streubert Speziale & Carpenter, 2007). Replicating the children's ward situation from this study may not be possible as the social reality of the ward is not constant, but changing continuously. However, it is likely that similar findings would be found with a similar sample and settings, and similarities when compared to other research as highlighted in Chapter Six.

7.2.3. Confirmability

Confirmability exists when credibility, transferability and dependability have been established (Farley & McLafferty, 2003). Accurate recording and interpretation of data, accounting for researcher perspective bias also contributes to credibility and confirmability. Throughout this thesis, I have acknowledged my experience of being a children's nurse and preconceived assumptions about family-centred care, which shaped the study and are likely to have influenced the findings. By acknowledging researcher bias, ethnographers aim to present participant accounts and views accurately, by minimising the impact of the values of the researcher (Mahon & McPherson, 2014). Detailed descriptions of participant interactions and narratives are presented in the findings chapter (Chapter Five), enabling judgements to be made about whether emergent themes reflect the data. While, like all researchers undertaking an ethnographic approach, the researcher cannot eliminate bias in presenting participant accounts and interpreted findings, reflexivity facilitates readers to evaluate how personal bias may have distorted the interpreted findings. Section 7.3 presents a reflexive account of the impact of personal bias and how this was managed to enhance confirmability and rigour.

7.2.4 Authenticity

Authenticity is concerned with ensuring that the range of participant realities are represented. Readers should develop a heightened sense of awareness to the issues being presented, and should be able to gain a perspective of the mood and

feelings of the participants (Guba & Lincoln, 1994). By presenting verbatim accounts, an attempt has been made to truly encapsulate the participant perspectives. Subtle mannerisms such as sighs, pauses and emphasis on words or phrases were noted and recorded to enhance authenticity by providing the reader with a sense of the non-verbal language, mood and context of the participants' accounts (Whiting, 2008). Similarly, the environment is truly authentic to the study and a detailed description was provided in an attempt to capture the true essence of a children's ward.

7.2.5 Transferability

Transferability refers to how well the findings are applicable to a similar setting or groups (Robson, 2002; Ryan- Nicholls, & Will, 2009). While ethnographical approaches, like other qualitative approaches, seldom aims for generalisability, readers of qualitative studies will inevitably evaluate whether they can utilise the findings in their practice setting or research focus (Payne & Williams, 2005; Ryan-Nicholls & Will, 2009). The selected sites represent a typical District General Hospital environment providing care to a diverse population (Health Informatics Service, 2014). Detailed descriptions of the sample and setting were provided to assist the reader to ascertain whether the findings were representative of other similar settings or groups (Lewis & Ritchie, 2003; Morse & Field, 1996). Two sites were accessed: one was typical of a children's ward in a District General Hospital and was led by medical staff; while site two was partly nurse led. Site two may limit transferability of the findings to some children's wards in some district general hospitals as this site predominantly provided surgery and orthopaedic care. Similarly, site two also included children admitted for assessment by nurses with advanced skills who were referred to as paediatric nurse practitioners. Children's nurse practitioners, who have undergone additional educational training are becoming more commonplace in district general hospitals, but this does not apply to all general children's wards and may limit transferability to areas without children's nurse practitioners (Freed et al., 2014).

7.3 Reflexive account

Personal bias is a threat to the trustworthiness of study findings because it can result in the interpretation of data that favours the researcher's perspective (Mauthner & Doucet, 2003; Seale, 1991). While personal bias cannot be completely eliminated, reflexivity can contribute to the quality of research studies by recognising, acknowledging and minimising the insider bias that may occur and is paramount in ethnographic studies (Hand, 2003; Koch & Harrington, 1998; Manias & Street, 2001; Sandelowski, 1993). Reflexive accounts can enable the researcher to examine their own assumptions and interpretations about the study and the reader to appraise the researcher's conduct throughout all stages of the study (Bradbury-Jones, 2007).

One of the challenges of being an insider with an emic perspective is attempting to observe reflexively from an etic perspective (Blythe, Wilkes, Jackson, & Halcomb, 2013). Qualitative researchers often share similar experiences and characteristics with their participants, and as a former children's pain nurse, my professional and personal views may impinge on the data or interpretation of the data (Blythe et al., 2013). Historically, emic perspectives have been considered to be in conflict with ethnographic approaches. It is becoming more accepted that nurses using an ethnographic approach are familiar with the phenomena they are studying. However, the ethnographer is required to acknowledge and reconcile their insider knowledge through reflexivity, as their personal views can affect the objectivity of the data collected and response to what is observed and heard during interviews (Blythe et al., 2013, Carolan, 2003; Dowling, 2006). Hearing what I want to hear, to confirm my intrinsic views, is a threat to presenting unbiased accounts. However, meticulous recording of written field notes and audio-recording and transcribing verbatim accounts of interviews enabled me to re-visit data and consider participant views more objectively.

Having insider knowledge can create intrinsic tensions in the "field". Having insider knowledge became apparent to participants with a risk that during observation and particularly interviews that the interaction could develop into a therapeutic encounter (Baillie, 2013; Bonner & Tolhurst, 2005). During observation this was particularly evident as families often approached me to discuss their concerns. As a children's nurse, wanting to be involved in care is part of my role, made it challenging to

distance myself from families who clearly wanted to talk to me. This was addressed by informing participants that any concerns would be passed onto nurses working on the unit. However, there were occasions where it was necessary for me to adopt a nurse role rather than a researcher role. Two specific incidents occurred that raised concerns and created tensions between my role as a researcher and role as a nurse. The first was a child who deteriorated during observation on the assessment unit. Nurses were nearby, but not responding to the child's needs. As an experienced European Paediatric Life Support Instructor, with knowledge to identify a child who has deteriorated and is at risk of respiratory failure, it became necessary to find and inform the nurse. This was an example of poor care with potential lapses in monitoring which was diplomatically discussed with the nurse concerned. Another incident illustrating poor practice involved a mother who stated that her son was "made" to get on weighing scales with a fractured femur. As this had not occurred on the unit being observed, but elsewhere, the incident was highlighted to the appropriate manager as unsafe and inappropriate practice. There is no doubt that researchers can find themselves faced with dilemmas when observing practice, and perhaps identifying poor practice could be seen as a positive consequence of being in the privileged position to be able to observe practice as a researcher (Johnson, 2004).

Other studies have reported similar dilemmas. Jones (1975) undertook a study where he identified that patients were being tube fed "boiling" feeds that were not tested to ensure they were at the right temperature and chose not to intervene. The rationale for not intervening was based on the view that intervening would be "unnatural" and "unscientific" stating that in reality, the incident would have happened anyway and been un-observed (Jones, 1975). Likewise, Skene (2012) undertook an ethnographic study of parental involvement in neonatal pain and encountered practice concerns. Skene (2012) suggests that researchers should have a strategy to address unsafe practice and claimed that she would have intervened. Similarly, as a registered nurse, professionally regulated by the Nursing and Midwifery Council (2015) and internally motivated by moral and ethical codes, I am obligated to intervene. Clearly when a child is perceived to be in danger of harm, which I am aware of due to my insider knowledge, my obligation is to intervene at the time, rather than reflect on and explore after the event. Had I been an outsider, I may not have recognised the signs

of harm and this would have absolved me from responsibility. It could be argued that if I was not there as a researcher, these issues may not have been noticed or raised. However, I had in the planning of the study given much thought to the ethical and professional issues relating to poor practice and decided that if I observed poor practice, then my duty was to intervene. While it may have affected the ward manager or nurse's decision to be involved, they were informed of my obligation to intervene, prior to agreeing to participate. Equally, if any safeguarding issues arose, my obligation was to disclose this information. The Medical Research Council (2004) asserts that disclosure is mandatory if risk, particularly to the child, is identified.

I continued to have strong personal and professional views about a child's acute pain care and the importance of parental involvement. There were times when this got lost in the mire of undertaking a doctoral study and the inherent challenges this brings when working in education and studying part-time. Going back to my roots as a nurse, working on the children's ward helped me to refocus on the ultimate goal of improving children's pain care. Being reflexive minimised the extent to which my personal views were imposed on the planning, enactment and analysis of the study findings (Hand, 2003; Manias & Street, 2001; Sandelowski, 1993). While, my views cannot be eliminated from the study and will have impacted on the findings, the competing obligations to ensure rigour have been acknowledged and maximised where possible.

Having experience and insight into the subjects and area being studied can have both beneficial and unfavourable effects. Beneficial effects included having contextual insight of the culture and organisation of care and needs of the participants and assisted with access to participants (Moore & Savage, 2005; Wilkes, Jackson, & Halcomb, 2013). Furthermore, insider knowledge and experience assisted with validation of the participants' accounts, as I was able to draw on my experience to understand the ways in which nurses' work and the language participants may use to explain their perspectives, which may be unclear to a researcher who is not a nurse (Morse & Field, 1996). The integral role of the researcher in the data collection and interpretation of the data can be acknowledged (Spencer et al., 2003) with the researcher being located as part of the data (Mason, 2002). However, to ensure my personal and professional view did not affect the

credibility of the data, I kept a journal from the inception of the study to completion, to record my thoughts and views to make them transparent and accessible. Critical reflection and "journalling" can be used as a tool to acknowledge personal views and ensure that the nature of nursing culture is not oppressed (Cudmore & Sondermeyer, 2007). After all, the research is about nurses (and families) undertaken by a nurse, and the nature of nursing should be at the forefront, not beleaguered by trying to be too objective. Indeed Greenwood (1984) argues that an insider view is imperative, to ensure participant views are not misinterpreted. Nurses have a central role in developing partnerships with parents and therefore presenting their perspective is crucial.

Keeping a journal provided an anchor to revisit my original aims and maintain focus. Believing that this study will not only benefit children by improving parental involvement, but also by potentially enabling nurses to overcome the elusive barriers to partnership working, demonstrates not only personal, but epistemological reflexivity. Epistemological reflexivity reveals the researcher's motivation for undertaking the study using the selected approach (Mahon & McPherson, 2014), in this study not only to meet the research aims but to positively impact on children, family and nurse experiences of pain care.

Two further aspects of the study were illuminating and required me to reflexively consider the impact on the study. First, not including children as main participants was in conflict with my strongly embedded views about children as the focus of care. Subsuming children's views into family research rather than including them as a distinct group of participants echoes traditional approaches (Christensen & James, 2000). As a children's nurse who wholly believes that the child's voice is paramount, this has been an issue that I have struggled with throughout. However, it does highlight the need for further research to include children's perspectives in the future. Second, my assumptions about family-centred care have been severely challenged and my unfounded belief that this is firmly embedded in children's care areas has emerged as a significant challenge to my clinical practice and academic knowledge, impacting on my beliefs and the study findings.

7.4 Reflection

Reflective accounts can assist the researcher to reflect on what went well and what could have been improved in the design and implementation of the study. Observing parent-nurse interactions in a busy children's ward was both an illuminating and a challenging experience. Undertaking the study from an ethnographic position, enabled an in depth exploration of parent-nurse interactions related to children's pain care. Despite the ethical issues that arose in relation to poor practice and the transient nature of the environment, limiting the opportunities to follow up some participant observations with interviews, observation and follow up interviews provided privileged and illuminating insights into participants' perspectives in relation to parental involvement in the child's pain care. As a children's nurse, my experience of interacting and communicating with families, children and nurses, enabled me to capitalise and draw on those experiences to discuss pain care in interviews to effectively capture participant accounts. On reflection, observation and follow up interviews were the most appropriate data collection methods to meet the study aims.

One of my most rewarding achievements in the research process was learning about structured approaches to data management and analysis, using the framework approach. The framework approach was a revelation and enabled me to manage and analyse the data methodologically, which is similar to the way I think and work. This has enabled me to feel confident that the findings reflect the participant views (Ritchie et al., 2003). The strengths of the framework approach are denoted by a logical, structured and transparent approach. I had attempted to use other approaches such as "domain analysis" (Spradley, 1980) and "the listening guide" (Mauthner & Doucet, 1998). These data analysis approaches did not appear to rigorously represent the data from the participants' perspective and concurrently meet the study aims. However, the framework analysis approach enabled participant realities to be represented and for patterns and themes to be assembled to meet the aims of the study and I would consider using this approach in future qualitative studies.

This thesis provides a detailed account of the study design, processes undertaken and findings. Regular supervision meetings have enabled me to reflect on research methods and become a reflexive researcher throughout undertaking the Professional

Doctorate. I have had three main supervisors during the doctorate, each with their own unique qualities and perspectives. While this could have been disruptive, it has actually allowed me to develop my knowledge and explore my own views and different perspectives in relation to undertaking qualitative research. During the last seven years, I have recognised some of my weaknesses in terms of writing at doctoral level, knowledge about research and critical thinking. The art of writing has been a particular challenge. However, with support from my supervisors, I have developed my critical thinking and developing the "Pillars of Partnership in Pain Care Model", which I anticipate will be of value to children's nursing professionals has been extremely rewarding.

7.5 Strengths and limitations of the study

7.5.1 Strengths

The strengths of this study are the unique focus of exploring parental involvement in pain care within the conceptual model of family-centred care from an ethnographic perspective. No other study appears to have explored pain care through this "lens" and therefore the findings make a unique contribution to knowledge about parental involvement in a child's acute pain care. Ethnographic exploration of involving parents in their child's pain care has been enhanced by undertaking the study in the practice setting. The findings have challenged the assumptions that family-centred care is embedded in children's care and found that the implementation of family-centred care in relation to pain care is not always optimal, adding to previous studies, but from a different perspective. The purpose of research is to generate new knowledge and disseminate that knowledge to enhance practice (Vivar, 2007). A new perspective of parents as advocates has emerged as a significant finding of this study and has prompted the development of the Pillars of Partnership in Pain Care Model as an alternative approach to involving parents in their child's pain care. Children deserve effective pain care and that includes parental involvement (Lim et al., 2011; McMurty et al., 2010).

The study has employed structured and logical methods across the stages of the study which have ensured a rigorous exploration of parental involvement in pain care in acute general children's wards in district general hospitals. Data elicitation

techniques have enhanced transparency and auditability of findings from original data, resulting in rich, detailed and true accounts of participant perspectives (Ritchie et al., 2003). Ethical considerations have been a priority of the study and protecting vulnerable participants such as children and anxious parents of acutely ill children, have been at the forefront of decisions about the study (Royal College of Nursing, 2004, 2006; Royal College of Paediatrics and Child Health, 2000; Gibson & Twycross, 2007). Similarly, as a children's nurse, recognising the demands on nurses, minimising disruption for busy nurses, has also been considered carefully. The focus on protecting participants is linked with the caring aspect of being a nurse, and while there was often a conflict between being a researcher and a nurse, the child, family and nurse have remained the primary consideration. This could be viewed as a potential limitation of the study, but did not influence data collection and analysis and therefore the findings.

Some of the findings support those from other studies, in terms of: poor understanding of family-centred care (Coyne et al., 2013; Darbyshire, 1996; Davies, Baird & Gudmundsdottir, 2013; Hughes, 2007; Hutchfield, 1999; Lee, 2007; MacKay & Gregory, 2011; MacKean et al., 2005; Murphy & Fealy 2007; Paliadelis et al., 2005; Simons et al., 2001); poor communication and lack of defined roles in a child's pain care (Corlett & Twycross, 2006; Coyne et al., 2011; Coyne et al., 2013; Kawik, 1996; Lim et al., 2011; Neill, 1996a; Polkki et al., 2002a; Shields et al., 2006; Simons et al., 2001; Simons & Roberson, 2002); parents want to be more involved in their child's care (Neill, 1996a; Simons et al., 2001); nurses' role in facilitating or preventing parental involvement, such as provision of information (Twycross, 2007; Twycross & Collis, 2013a; Watt-Watson et al., 1990). However, emergent findings have added new perspectives such as parents as advocates for their child and ways in which they implemented this and nurses being threatened by knowledgeable parents.

7.5.2 Limitations

Although a strong ethical code has underpinned this study, this may have resulted in some potential limitations. Not wanting to impose on families with an acutely ill child and busy nurses may have limited the opportunities to obtain more in depth data. Including the child would have added their perspective to parent-nurse encounters and added a further relevant dimension. Home follow up with family participants and

post-shift or day off interviews with nurses may have permitted more in-depth interviews, without the inevitable intrusions that real life care areas can bring. However, nurses are busy and their spare time is precious. Equally, interviewing families following discharge could be intrusive and may limit re-call (Clarke, 2006; Whiting, 2008). Despite the intrusion, follow up interviews are likely to have yielded much more rich detail.

A larger sample could have enhanced dependability of the findings by providing a wider range of responses (Lincoln & Guba, 1985). However, data saturation appeared to have been reached with the sample obtained and small samples are a common feature of qualitative ethnographic studies (Doyal, 2004; Higgingbottom, 2004). Additionally, the study captured a broad focus of pain care involving all children, regardless of their condition, rather than focussing on specific aspects of care, such as post-operative care. However, this has highlighted issues about lack of pain care related to children with medical conditions that is worthy of further exploration. The transient nature of the environment has limited the opportunity to follow through and follow up participant views at times and not all interactions could be captured simultaneously, reducing the scope of the data.

While there was an interpreter translation service that could be accessed to assist with explaining the study to non-English speaking families, the leaflets had not been produced in different languages because funding was not available. This may have resulted in exclusion of non-English speaking/reading participants which could have been a problem as the local population is of a relatively high ethnic population (Local Trust Informatics Service, 2014). In this study, all participants were able to understand English. However, non-English speaking minority populations were not represented.

The revelation that family-centred care is not as firmly embedded in clinical practice as previously assumed has created tension in relation to exploring parental involvement based on the conceptual framework of family-centred care. However, the family-centred care conceptual framework and model has enabled a distinction between the “ideal” model of family-centred care and the “reality” to be identified and explored in this study.

7.6 Chapter summary

This chapter has presented an account of the quality issues related to the study to enable the reader to judge the rigour and trustworthiness of the study. Issues such as credibility and transferability can impact on the way the data is collected and interpreted and in the way the findings are presented. The ways in which rigour was maximised have been presented with a focus on a transparent, robust and auditable account of the study. The inevitable influence of personal and professional bias on the conduct of the study has been explored and measures taken to enhance the integrity of the research outlined. The strengths and limitations of the study have been presented highlighting the novel perspective offered by using an ethnographic approach.

Chapter Eight: conclusion

8.1 Introduction

The chapter begins by first summarising the key issues that emerged from the findings in Chapter Five and evaluated in Chapter Six. The key issues are explored in the context of related literature, policy and the underpinning conceptual framework of family-centred care. Second, the implications for policy, education and clinical practice are outlined. Third, suggestions for future direction for improving children's pain care by enhanced parental involvement are offered including the "Pillars of Partnership in Pain Care Model" which offers an alternative approach to enhancing parental involvement in their child's pain care. Finally, the dissemination strategy is presented.

8.2 Summary of key findings

Three overarching key issues emerged from the findings of this study and were drawn together to develop the "promoting or preventing partnership working: conceptual model" (Section 6.2, Figure 10). First, parents acted as an advocate for their child, particularly when they perceived their child's pain care to be sub-optimal. Parents wanted to be more involved in their child's pain care, but frequently lacked support from nurses. Policy exerts that the patient, or in this study the child and family, involvement in care is central to quality care provision (Department of Health, 2010b; Kennedy, 2010). However, multiple factors influence parental involvement in care, which in part related to parent's desire for involvement and the attitudes and behaviours of nurses. In response to lack of support from nurses, parents attempted to meet their child's pain care needs without support. Lack of support culminated in anxiety for some parents and parents attempted to overcome this in a variety of ways. For example, by initiating and providing aspects of care, independently to health professionals, such as non-pharmacological pain care strategies. However, at times, lack of knowledge hindered parents' ability to provide care and be an advocate for their child and this manifested in two opposing situations. Parents' who recognised inadequate pain care were frustrated with care and in this study became assertive with nurses and tried to motivate nurses to address their child's pain needs. In contrast other parents did not recognise poor pain care, perhaps because of lack of knowledge of what constitutes adequate pain care and consequently were unable

to advocate on behalf of their child. If nurses were candid with those parents about how to identify effective pain care and supported them to advocate on their child's behalf, a more collaborative approach to care may operate, with the potential to improve the quality of pain care. Although nurses have clinical knowledge and a range of experiences, parents are willing, capable and sometimes determined to acquire knowledge of their child's care (Chambers et al., 2003; Hamers & Abu-Saad, 2002). Following the Francis report of the Mid Staffordshire events, the NMC has emphasised candour when interacting with patients as central to identifying poor care (Francis, 2013; NMC, 2015). It is not acceptable to conceal poor practice, but being open requires the nurse to have the knowledge and experience to recognise poor care and the courage to respond appropriately. Including parents and the wider team in discussions about addressing suboptimal care could be the start of quality improvements in pain care. Parents want to be more actively involved in their child's pain care and with support can act as an advocate for their child's pain care to improve the child and parent pain experience.

Second, nurses, who are ideally placed to support parents to advocate for their child, have different approaches to engaging parents. The findings indicated a continuum of the range of ways that nurses promote or prevent parental involvement and partnership. The findings highlight that few nurses supported parents by effectively communicating with them to identify parents' desire for involvement and how involvement could be embedded into care. Nurses frequently failed to support parents or value them as equal partners in care and created barriers to parental involvement. However, nurses did not overtly create barriers and appeared to be unaware these existed. The main barriers relate to position power and control that nurses have over parents, which manifests in nurses making decisions about a child's pain care without involving parents. This is exacerbated in the context of knowledgeable parents, which appears to pose a threat to nurse position of power and control. While nurses valued some input from parents, such as administering medicines, at times, parents were coerced to undertake these tasks. Similarly, nurses perceived that the provision of information equates to involvement. However, provision of information is a one way activity and controlled by nurses and does not value parent contribution as equal partners in care (Coyne et al., 2011; Huth et al., 2003; Salvage, 1992). The findings demonstrate that true partnership working,

whereby parents are equal partners in care, was largely absent. As nurses retain positional power, it would be expected that they would have overall control over parental involvement. Yet, parents were frequently observed to be the drivers of involvement and used their knowledge of their child and previous experience of pain care to inform pain care decisions and advocate on behalf of their child. Parents lack knowledge compared to nurses, in relation to pain care, which limits their ability to instigate active involvement.

Third, the study explored parental involvement in a child's pain care within the culture of espoused family-centred care, underpinned by the conceptual framework of the family-centred care practice continuum (Smith et al., 2010). In retrospect using the family-centred care practice continuum as the underpinning conceptual framework in an attempt to examine how parents are involved in care has created tensions, as my assumptions have been challenged. The framework has been found to have a poor theoretical underpinning and therefore there is no evidence base for its application to practice (Shields et al., 2012). Therefore, it may have been an inappropriate framework for exploring parental involvement and participation in pain care. The study findings have highlighted that nurses aspire to a philosophy of family-centred care as a method of care delivery, but at a rhetorical level. Involvement and partnership working are acknowledged to be central to this approach (Shields et al., 2012). However, poor understanding of how to apply the espoused philosophy and embed family-centred care into practice hinders parental involvement and partnership working. Nurses do not appear to be adopting the principles of empowerment, negotiation and participation, integral to family-centred care, to actively involve parents in their child's pain care, leading to a fragmented approach to involving parents. Findings from this study strongly support previous research that the concept of family-centred care is problematic both in terms of understanding and implementation (Coyne et al., 2013; Mackay & Gregory, 2011). As family-centred care as an approach to involving parents in their child's pain care, appears to be unsatisfactory, the "Pillar of Partnership in Pain Care Model" (6.5.1, Figure 12) has been offered as an alternative approach for parental involvement and partnership working between nurses and parents.

8.3 Implications for practice, policy and education.

Parental involvement in pain care is variable and influenced by a number of factors. The findings of this study make an important and unique contribution to knowledge. There does not appear to be any specific research that has adopted an ethnographic approach to exploring parental involvement in a child's pain care in general children's wards. However, new knowledge should have a purpose and ultimately the researcher has an obligation to ensure the benefits of research are systematically and productively translated into practice (Thompson, 2000).

8.3.1 Practice implications

The Pillars of Partnership in Pain Care Model offers an alternative approach for nurses to enhance partnership working (Section 6.5.1, Figure 12). Conceptual models can guide practice and further research into the topic (Franck et al., 2012), but require evaluating to determine their ability to improve practice and in the case of this study, in enhancing parental involvement in their child's pain care. Children's pain care should be effective and include all strategies to minimise the harmful physical and psychological effects of pain (Taddio et al., 2002; World Health Organisation, 1997). Those strategies include parents being involved in their child's pain care (Lim et al., 2010).

The Pillars of Partnership in Pain Care Model acknowledges that parents who want to be involved in their child's pain care require the nurse to socialise them into a participation role and relies on proactive encouragement from nurses (Holm et al., 2003; Simons et al., 2001; Twycross & Collis, 2013b). The model recognises and respects that parents may not wish, or are obliged, to be involved in their child's pain care. Rather parents should be provided with ongoing opportunities to be involved as they wish. However, parents who do want to be more involved may attempt to do so without the nurse's support, which is likely to be less successful. A new approach to partnership working requires a shift in focus from a paternalistic approach with nurses in control, to nurses supporting parents to advocate based on the parents desired needs. One way of supporting parents to advocate for their child could be to introduce mutually agreed pain goals at the beginning of the child's hospital stay as proposed by Twycross & Finley (2013). This would clarify parent expectations and

help them to match their expectations to what effective pain care should be. Figure 11 (Section 6.3.1) illustrates how satisfaction with pain care appears to be viewed by parents as being synonymous with satisfaction with involvement. Furthermore, satisfaction with pain care and involvement is inextricably linked with expectations of pain care and those expectations are sometimes based on misconceptions about what constitutes effective pain care. Providing parents with appropriate information to recognise whether the child's pain care is adequate and the opportunity to speak up if this is not achieved, by open, honest communication, is required. True partnership is based on the assumption that parents and professionals are "capable individuals who become more capable by sharing knowledge, skills and resources" (Dunst & Wolery, 1998, p 9). The Pillars of Partnership in Pain Care Model emphasises the value of sharing knowledge about the child's pain experience.

Supporting parents to raise concerns on behalf of their child if they perceive care to be substandard may appear altruistic, because nurses will be supporting parents to challenge their own care practices. Nurses in this study found parents with knowledge as threatening. Acknowledging that parents may be more knowledgeable about their child and in some cases options for pain care can help nurses to embrace partnership working and ultimately enhance pain care for the child (Kirk et al., 2005). The barriers to partnership working potentially created by nurses can be broken down by valuing parental contribution and regarding parents as allies rather than being threatened or paternalistic (Dunst & Wolery, 1998). If nurses can adopt a supportive role for parents to advocate they may be able to relinquish some of the control and potentially some of the stress (Willem, Buelens & De Jonghe, 2007).

While this study has focussed specifically on pain care, the approach of supporting parents to advocate for their child could be extrapolated and applied to all aspects of care. Pain care is one of a range of areas of care. Another example would be nutritional care that could benefit from parents being more involved in care and would contribute to ensuring their child's care needs are met.

8.3.2 Policy implications

Health policy already acknowledges the importance of involving patients (children and parents) in decisions about care and in care delivery (Department of Health, 2007, 2010b; Entwistle, 2009; Kennedy, 2010), but is limited in application to children's pain care. Policy based on the espoused philosophy of family-centred care may not be meeting the needs of families, as this has been found to be incongruent with enhancing parental involvement in their child's pain care. The paradigm shift in practice towards involvement of patients, or parents in this case, is an ongoing strategy, requiring the right approach to meet the needs of families. Patients (parents) will continue to drive improvements in care and service delivery, but this will be much more successful if nurses support and work with them towards care improvement. As with all change, the transition can create tensions. Nurses will need to move with the times and embrace the inevitable shift, with parents as allies in pain care, as opposed to resisting the involvement of parents.

8.3.3 Implications for education

It is timely to explore the findings of this study in light of "Shape of Caring" review of nurse education (Lord Willis, 2015; Smith, 2015). The future of child nurse education is currently being debated with a strong indication that there is a desire to move towards a more generic nursing programme of study. Although there is a consultation stage, if a generic course is adopted, this could further limit the opportunity to equip nurses with specific knowledge not only about effective pain care for children, but also knowledge of supporting parents to advocate for their child confidently. Children deserve to be cared for by healthcare staff with appropriate training and the right skills to meet their needs (Department of Health, 2014). While the literature suggests that nurses lack pain care and family-centred care knowledge which could be countered by more education (Broome, 2000; Coyne et al., 2011), this study did not specifically explore education or identify specific issues related to education as a contributory factor. However, new knowledge from research is the cornerstone of education and if adopted should equip future and current nurses with evidence based knowledge on which to base their practice.

8.4 Future directions

Future research could add to these findings by: evaluating the Pillars of Partnership in Pain Care Model; evaluating the parent satisfaction with involvement in care typology (Figure 11, 6.3.1) with children, parents and nurses; including children perspectives in future development of the models; working with nurses as researchers in further studies to explore decision-making in relation to pain care.

The Pillars of Partnership in Pain Care Model offers an approach to supporting parents to advocate on behalf of their child to enhance the child's pain care. While models can usually be empirically evaluated, it would be challenging to attribute the outcomes of improved pain care to the model alone (Fawcett, 2013). However, the Pillars of Partnership in Pain Care Model integrates the multiple factors that impact on parental involvement and suggest what needs to be in place to enhance opportunities for parents to work in partnership to enhance the child's pain care. Further ethnographic exploration may be appropriate to examine the effectiveness of the model, from the perspective of the child, family and nurse in relation to their satisfaction in involvement in pain care. Furthermore, evaluating and developing the Pillars of Partnership in Pain Care Model with the child and family could overcome some of the shortcomings of the family-centred care conceptual framework and model, which despite being about children and families, does not appear to have been developed with children and families.

Further exploration of the links between satisfaction with pain care, satisfaction with involvement in their child's pain care and expectations as outlined in Figure 11 (Section 6.3.1) could identify ways to ensure parents expectations are realistic and based on sound knowledge This could be achieved by potentially introducing pain goals as discussed in Section 2.5, which would also support parents' advocacy role.

Children are largely absent from this study, as the focus was on parent and nurse interactions. Children's perspectives are crucial to expand the findings from this study and could be incorporated into the study proposed to test the Pillars of Partnership Model. A study of children's perspectives could also provide invaluable insight into how parental involvement impacts on children's pain care experience. Including or

focusing on pain care in children with predominantly medical conditions could add a further insight into children's pain research.

Nurses were not involved as co-researchers in this study. While I am a part time practicing children's nurse, involving practitioners who have more consistent contact with children in acute children's wards could add a different perspective. Academia focussed research has been referred to as toxic dualism, whereby research is undertaken by academics who then disseminate findings to practicing professionals (Darbyshire, 2008). Implementing findings may be more successful and become embedded in practice if clinicians are involved in identifying areas for research, contribute to the research process and ultimately undertake the research. Despite practitioners facing numerous barriers, such as relentless demands in clinical practice, lack of funding and lack of research skills, their engagement with designing and undertaking the research would make a positive contribution to understanding how parents could be more involved in their child's pain care.

8.5 Dissemination strategy

In addition to wider dissemination through presentations and publications, findings from the study will be integrated into pain care teaching in pre and post-registration nurse education in my institution. As a result of this study and networking with colleagues from local trusts, I have advised on numerous pain care guidelines which enabled me to ensure parental involvement is embedded in guidelines with an aim to influence subsequent care. I have frequently engaged in Twitter discussions about pain care for the Evidence Based Nursing Journal. Figure 13 outlines the dissemination strategy.

Figure 13: Dissemination strategy

Presentations
Vasey, J., Smith, J., Kirshbaum, M. and Chirema, K. International Family Nursing Conference 2015 'Tokenism Or True Partnership: Parental Involvement In The Child's Acute Pain Care'. Odense Denmark, 18-21st August 2015
Vasey, J., Kirshbaum, M. and Chirema, K. (2013) 'Tokenism or true partnership: Parental involvement in the child's acute pain care facilitated by nurses within a culture of family-centred care in general children's wards; Preliminary findings'. In: 11th International Family Nursing Conference, 19th - 22nd June 2013, Minneapolis, Minnesota, USA
Vasey, J (2010) 'Tokenism or true partnership: a child's acute pain care and a family-centred culture'. In: Personal and Public Lives: Exploring Relationships, Roles, and Responsibilities: An international

and interdisciplinary conference, 7th - 9th September 2010, University of Huddersfield, UK
Vasey, J. and Sharp, A. (2010) 'From the cot in the corner'. In: 2010 UK Simulation in Nursing Education Conference, Jun 9, 2010 - Jun 10, 2010, University of Huddersfield, UK
Vasey, J (2008) 'Consent and refusal: selective respect for a young person's autonomy?'. In: RCN Conference and Exhibition for Nurses Working with Children and Young People, Friday 19th - Saturday 20th September 2008, Gloucestershire, UK
Vasey, J. and Currell, K. (2008) 'From The "Cot in the corner'. In: 2nd Children & Young People's Nursing Clinical Skills Conference: Striving for excellence, 18 July 2008, School of Nursing and Midwifery, Cardiff University
Future presentations
RCN- February 2015. Winner of one of the research awards from the Nursing Children and Young People, supported by the Royal College of Nursing's Research in Child Health community. - A condition of the award is to present study findings at a RCN affiliated conference.
Publications
Vasey, J. (2014) 'Back to square one'. *Evidence Based Nursing Blog*. http://blogs.bmj.com/ebn/.
Vasey, J (2014) 'Realistic goals can help manage children's post-operative pain effectively'. *Nursing Children and Young People*, 26 (2), p. 13. ISSN 2046-2336
Vasey, J (2009) 'Consent and refusal: selective respect for a young person's autonomy'. Journal of Community Nursing, 23 (4), pp. 32-34. ISSN 0140-0908
Future publications
Power and control relationships between nurses and parents of acutely ill children. Journal of Advanced Nursing
Ethnographic researcher facing practice dilemmas. Nurse Researcher
Ethics of accessing vulnerable child participants for research during stressful episodes of care. Nurse Researcher

8.6 Chapter summary

In summary, the research study presented in this thesis has examined parental involvement in a child's acute pain care. While there is some limited evidence of parental involvement, the study has revealed continued variations and ongoing problems associated with the implementation of family-centred care as an approach to promote parental involvement. The findings from the study identified that parents want to be more involved and act as advocates for their child, particularly when they perceive their child's pain care is inadequate and attempt to be involved whether or not they are supported. Parental involvement has mutual benefits for parents and nurses and if effectively implemented can improve the child's pain care experience. The barriers to effective parental involvement are largely related to nurses creating barriers to parental involvement. An alternative approach to engaging with parents has been suggested, the Pillars of Partnership in Pain Care Model, which aims to address the barriers to involvement and assist nurses to shift the focus from control over parent involvement to confidently supporting parents. Further research to ascertain the views and experience of children would permit a more cohesive and informed account by including those who are most affected by parental involvement.

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Appendix 1: Themes developed from coded data, based on Burnard's method (Burnard, 1991)

Study details	Codes	Categories	Theme
Franck et al. (2001)	Parents identified that being at the bedside, holding and calming the infant and being informed are synonymous with involvement	Different perceptions of parental involvement	Barriers to involvement
Rennick, et al. (2011)	Parents perceived that being present during procedures was involvement.		
Simons et al. (2001)	Nurses perceived that parents being present was involvement		
He et al. (2005)/ He et al.,(2011)	Nurses perceived contributing to non-pharmacological methods as involvement		
Polkki et al. (2002a)	Parental involvement not clearly defined or articulated		
Gimbler-Bergland et al. (2008)	Nurses recognised their lack of knowledge in pain care	Variations in nurses' knowledge	
Twycross & Collis (2013a)	Nurses who may have knowledge do not always apply this knowledge into practice		
Simons & Roberson (2002)	Knowledge deficits contribute to less parental involvement		
Vincent et al. (2007)	Lack of nurses' knowledge reduces opportunities for parental involvement		
Lim et al. (2011)	Parents identified that their lack of knowledge hindered involvement in pain care	Variations in parental knowledge	
Jongudomkarn et al. (2012)	Cultural beliefs of parents can negatively impact on parental involvement		
Simons & Roberson (2002)	Nurses expect parents to have knowledge they do not have		
Twycross and Collis (2013a)	Nurses perceived that parents over or underestimate their child's pain		
Kankunnen et al. (2002); (2008)	Parents held misleading and incorrect beliefs about children's pain		

Appendix 2: Outline of the selected studies

	Author (s)	Design/method	Setting	Participants	Findings
1	Czarnecki, et al. (2011)	Quantitative. Cross sectional design. Survey using the "Barriers to optimal pain management" (modified) survey tool. Likert scale response. Some narrative comments	Children's teaching hospital in Wisconsin.	Trained nurses in all care areas. 970 surveys distributed. 272 returned.	Barriers (18 included in tool) identified. In top five were; Low priority given to pain management; Parents reluctance to have children receive medication.
2	Franck et al. (2001).	Quantitative- Survey- questionnaire	Tertiary neonatal intensive care units in a large US city hospital (50 beds)	Convenience sample of 95 parents of neonates/infants Multiple ethnicities represented.	Parents generally satisfied. Significant number felt unsupported by nurses. Variations in parental involvement.
3	Franck et al. (2012).	Qualitative. Thematic analysis of written accounts following a randomised controlled trial.	4 regional neonatal intensive care units in London	Parents- 84 intervention group. 85 control group.	Parents expressed strong desire for more information, sensitivity and consistency. Communication by NICU staff influenced parent ability to be involved to their desired level. Most parents saw involvement as a "vital role".
4	Gale et al. (2004)	Qualitative Exploratory descriptive design- semi-structured interviews/focus groups Thematic content analysis	2 neonatal intensive care units in London	12 Parents- purposive sample	Infant pain was stressful for parents. Being supported decreased stress. Parents felt it was their role to relieve pain.
5	Gimbler-Berglund et al. (2008).	Qualitative Semi structured interviews. Content analysis.	One paediatric ward in a medium sized Swedish hospital.	20 nurses	Child behaviour, diagnosis, the organisation and nurses influenced care.
6	He et al. (2005),	Quantitative Polkki's questionnaire (validated in Finland). Likert scale.	5 hospitals in China. 12 surgical wards. Random sample	178 nurses participated (out of 187).	Chinese nurses prepare parents to be involved in non-pharmacological methods. Nurses with more experience, were older, had a higher nursing position and had children of their own guided parents more.

7	He eta l. (2011).	Quantitative. Quasi-experimental. Pre intervention and post intervention questionnaire survey. Intervention-education lecture and booklet. Theoretical framework – identification of behaviour change strategies. SPSS used to analyse the data.	7 wards in two public hospitals in Singapore.	Convenience sample. Singaporean nurses. 134 pre-test questionnaires and 112 post-test questionnaires included.	Found parents lack information about their child's pain care. Recommend clear explanations. Found that nurses provided more guidance following the intervention. Also recommend that nurses communicate with parents more rigorously.
8	Huth et al. (2003)	Quantitative Randomised, repeated measures experimental design, with a comparison group. Medication attitude questionnaire. SPSS.	Children's teaching hospital in US	51 children (3-16 years old) having cardiac surgery	Parent education booklets significantly increased parental knowledge and attitudes and can assist active participation.
9	Jonas (2003)	Qualitative. Structured telephone interviews.	Regional paediatric hospital in the UK.	Purposive sample of parents. 89 parents participated.	Parents managed the pain at home if they were given information and analgesia prior to discharge. Nurse most likely to discuss pain care at home rather than the doctor. Some felt information was poor or absent. Acknowledged increased burden on families. In dedicated day surgery areas parents were more satisfied with information.
10	Jongudomkarn et al. (2012).	Phenomenology. In depth interviews. Thematic analysis.	5 hospitals in Thailand	Convenience sample of 45 parents in Thailand	Looked at cultural beliefs about pain. Parents indicated a preference for traditional remedies. Parents wanted to help but were reticent to approach nurses for help. Cultural beliefs influenced parent's perception of pain.
11	Kankkunen et al. (2002).	Qualitative. Interviews with conductive content analysis.	One hospital in Finland.	17 Finnish families. Children aged 1-7 years	Lack of information contributed to ineffective pain care. Parents held misleading beliefs about children's pain

				old, following outpatient surgery.	that could have been addressed by discharge advice.
12	Kankkunen et al. (2008)	Quantitative. Parents Perception of Children's Analgesia (PPCA) questionnaire. Cross tabulation and x2 analysis	Finland- 10 central hospitals- day surgery USA- one inner-city hospital	315 Finnish parents (children aged 1-6 years) 110 American parents (children aged 3-14 years)	Found American parents thought analgesia should be given before pain becomes severe- but not Finnish. Parents had incorrect perceptions of analgesia and gave inadequate doses of medication because of their misconceptions. Recommend that parents receive instruction about pain care at home to dispel misconceptions.
13	LeMay et al. (2010).	Randomised trial- experimental and control group.	Emergency department of a large tertiary children's hospital in Canada	Parents in emergency department -98 experimental and 97 control group	Found written educational material had no impact on pain care. Recommend active participation rather than passive provision of information.
14	Lim et al. (2011).	Qualitative. Semi-structured interviews. Thematic analysis.	Three children's surgical wards in Singapore	Purposive sampling. 14 parents.	Support from nurses assisted with parental involvement. Parent's negative feelings, lack of knowledge, and nurses being busy hindered it. Parents wanted more involvement and support from nurses and time to rest. Found parents used distraction, massage, positioning, presence, monitoring pain. Parents stated that child would prefer parent to nurse to help with pain.

15	Polkki et al. (2002a).	Mixed methods. Questionnaire. SPSS used to analyse data.	Surgical wards at five hospitals in Finland	192 Parents of children aged eight to twelve years (167 mothers and 25 fathers).	98% believed had adequate opportunity for participation as they desired, but 23% felt they did not have a clearly defined role in their child's pain care. Parents mostly wanted to be provided with information. Factors hindering parental participation The nurses' lack of time (32%) and negative feelings (19%) were more hindering factors than lack of information/understanding (10%) and underestimation of the parents' expert knowledge (6%), as viewed by the parents. Parents wanted more information, to be more involved and decision making. Clarification of roles important finding.
16	Polkki et al. (2002b).	Same study as above. Mixed methods. Questionnaire. SPSS used to analyse data.	Surgical wards at five hospitals in Finland	192 Parents of children aged eight to twelve years (167 mothers and 25 fathers).	Parents used cognitive behavioural methods such as preparatory information, distraction, positive reinforcement and relaxation, physical methods such as positioning and massage, and emotional support such as being present, touch and comfort. Found that positive reinforcement and comfort- used more in children who were in hospital for 2-30 days than those in for up to 2 days. The more severe the pain- the more parents used methods such as imagery, distraction and positive reinforcement.
17	Rennick at al. (2011).	Qualitative. Descriptive design. Semi-structured interviews. Thematic analysis.	Three Canadian paediatric intensive care units.	Convenience sample-65 mothers	Explored impact of touch and talk technique during painful procedures. Parents being there (present), being comfortable and confident found to be important. Parents wanted to be given a choice not

					expected to participate or not. Gave parents a sense of contributing to care.
18	Simons at al. (2001)	Qualitative. Phenomenological approach. Interviews- nurses and parents.	A large urban children's hospital in England	Purposive sample. 20 parents/ 20 nurses. Children had moderate to major surgery during last 48 hours and had a Morphine pump.	Found parental involvement superficial and limited. Parents describe a passive role, felt frustrated and only a minority said they were satisfied with their child's pain care, while nurses perceived adequate involvement. Concluded a lack of communication and non-negotiation of roles.
19	Simons & Roberson (2002).	Qualitative. Derived from study 18 above Phenomenological approach. Matched interviews- nurses and parents.	A large urban children's hospital in England	Purposive sample. 20 parents/20 nurses	Nurses recognised their knowledge deficiencies, but expected parents to have knowledge they did not possess. Poor communication and knowledge deficits are obstacles to effective pain care. Found many parents needed more information, while some were overwhelmed, or too stressed to take it in. Parents relied on children's verbal report of pain, while nurses relied on parents to alert them to pain. Parents in a good position to act as advocates for their child if pain care is sub-standard. Nurses, who are in best position to educate parents are lacking in knowledge.
20	Twycross & Collis (2013a).	Qualitative. Two modified focus groups as part of a larger study. Content analysis.	One hospital in the south of England.	30 nurses.	Nurses identified barriers related to staff, children, parents and the organisation. Nurses and medical staff lacked knowledge. Staff shortages and workload affected the quality of care. Nurses may not take an active role as they could and expected children and parents to take responsibility for pain care. Nurses felt that parents exaggerated their child's pain.

21	Twycross & Collis (2013b).	Mixed methods. 3 phase study. Questionnaires and observation.	Two general children's wards in one English hospital	All nurses, parents and children were included during the observation period. Questionnaires returned- 17 for young people (11 years and above). 17 for parents.	Parents involved in decision making but initiated by them. Little evidence of non-pharmacological methods. Children and families felt pain care was acceptable and were happy with the quality of care, despite having reported experiencing moderate to severe pain. Over half young people experienced severe pain.
22	Twycross & Finley (2013).	Mixed methods. Exploratory research. Interviewed using draw and write technique or semi-structured format. Parent questionnaire. Content analysis.	One unit in a tertiary children's hospital in Canada.	8/10 children aged over 5 years. 10 parents.	Most children suffered moderate to severe pain. Generally families were satisfied with care. Recommended setting a pain goal with parents.
23	Twycross et al. (2013).	Qualitative. Participant observation. Content analysis.	One unit in a tertiary children's hospital in Canada.	10 children.	Most children and parents were satisfied even though child had moderate to severe pain.
24	Vincent (2007).	Mixed methods. Descriptive exploratory design. Descriptive and content analysis. Cognitive representations. Pilot study.	Children's inpatients units in a large children's hospital in the US.	20 registered nurses	60% of nurses used non-pharmacological approaches, and 35% identified family involvement
25	Zisk et al. (2007)	Quantitative. Explorative/comparative study.	Emergency department of a Children's Hospital Tertiary Centre in Philadelphia.	32 parents of children with fractured limbs.	Found parent's assessment of their child's pain generally corresponds with child's self report assessment – but at times parents under or over-estimated their child's pain

Appendix 3: CASP appraisal table

1 Qualitative study, 2 Quantitative study, 3 Mixed methods, ✓ Criteria met , **x** Criteria not met, **N/A** Not applicable, **P** Criteria partially met

author	Clear aims	Methodology identified and appropriate	Theoretical framework identified	Appropriate design	Appropriate Randomis-ation	Appropriate Recruitment/ response	Appropriate Data collection methods	Valid tools	Researcher influence acknowledged /minimised	Analysis appropriate	Clear results/ findings	Useful	comments
Czarnecki et al. (2011)	✓	✓	**X**	✓	**N/A**	**P**	✓	✓	✓	✓	**P**	✓	**2**
Franck et al. (2001)	✓	✓	✓	✓	✓	✓	✓	✓	**X**	✓	**P**	✓	**2**
Franck et al.,(2012).	✓	✓	✓	✓	✓	✓	✓	**N/A**	**X**	✓	**P**	✓	**1 based on mixed method with 2**
Gale et al. (2004)	✓	✓	**X**	✓	**N/A**	✓	✓	**N/A**	**X**	✓	✓	✓	**1**
Gimbler-Berglund et al. (2008)	✓	✓	**X**	✓	**N/A**	✓	✓	**N/A**	**X**	✓	**P**	✓	**1**
He et al. (2005)	✓	✓	**X**	✓	**N/A**	✓	✓	✓	**X**	✓	✓	✓	**2**
He et al. (2011)	✓	✓	✓	✓	**X**	✓	✓	✓	**P**	✓	✓	✓	**2**
Huth et al. (2003)	✓	✓	✓	✓	**P**	✓	✓	✓	**X**	✓	✓	✓	**2**
Jonas (2003)	✓	✓	**X**	✓	**N/A**	✓	✓	**N/A**	**X**	✓	✓	✓	**1**
Jongudomkarn et al. (2012)	✓	✓	**X**	✓	**N/A**	✓	✓	**N/A**	✓	✓	✓	**P**	**1**
Kankkunen et al. (2002)	✓	✓	**X**	✓	**N/A**	✓	✓	✓	✓	✓	✓	✓	**1**
Kankkunen et al. (2008)	✓	✓	**X**	**P**	**N/A**	**P**	✓	✓	**X**	✓	**P**	**P**	**2**
LeMay et al. (2010)	✓	✓	**X**	✓	**P**	**P**	**P**	**P**	**X**	✓	✓	**P**	**2**
Lim et al. (2011)	✓	**P**	**X**	✓	**N/A**	**P**	✓	**N/A**	✓	✓	✓	**P**	**1**

Polkki et al. (2002a)	✓	✓	**X**	✓	**N/A**	✓	✓	**P**	✓	✓	✓	**P**	**3**
Polkki et al. (2002b)	✓	✓	**X**	✓	**N/A**	✓	✓	**P**	✓	✓	✓	**P**	**3 same as above**
Rennick et al. (2011)	✓	✓	**X**	✓	**N/A**	✓	✓	✓	✓	✓	✓	**P**	**1**
Simons et al. (2001)	✓	✓	**X**	✓	**N/A**	✓	✓	**N/A**	**P**	✓	✓	✓	**1**
Simons & Roberson (2002)	✓	✓	**X**	✓	✓	✓	✓	✓	**X**	✓	✓	✓	**1**
Twycross, & Collis (2013a).	✓	✓	**P**	✓	**N/A**	✓	✓	✓	✓	✓	✓	✓	**1**
Twycross & Collis (2013b).	✓	✓	**P**	✓	**N/A**	✓	✓	**P**	✓	✓	✓	✓	**3**
Twycross, & Finley (2013).	✓	✓	**X**	✓	✓	✓	✓	✓	**P**	✓	✓	✓	**3**
Twycross et al. (2013)	✓	✓	**X**	✓	✓	✓	✓	**N/A**	✓	✓	✓	**P**	**1**
Vincent (2007)	✓	✓	✓	**P**	**N/A**	✓	✓	**P**	**P**	✓	**P**	**P**	**3**
Zisk et al. (2007)	✓	✓	**X**	✓	**N/A**	✓	✓	✓	**X**	✓	✓	**P**	**2**

Appendix 4: Child and family details

Shaded- site 1.

Non- shaded- site 2.

Child (anonymised)	Age	Condition (confirmed or unconfirmed at time of study)	Parents present	Notes
1. Tom	22 months	Wheeze	Father	2nd day
2. Henry	4	Intussusception- surgical emergency	Both parents and paternal grandparents	2nd day. 4th admission Parents agreed to be interviewed but child transferred
3. Yovan	4	Enlarged lymph nodes	mother	1st day
4. Tim	18 months	Tremor	Both parents	1st day
5. Sam	14 months	Wheeze	Mother and another relative	2nd day
6. Alice	15	Limp	mother	Turners syndrome
7. Raul	5	Tonsillectomy	Both parents	Day case
8. Emily	3	Wheeze	mother	2nd day
9. Jake	4	Renal problems	father	1st day
10. Frances	4	Tonsillectomy	Both parents	Day case
11. Ben	5	Tonsillectomy	Both parents	Both parents interviewed
12. Steven	4	Tonsillectomy	Both parents	Day case. Mother interviewed
13. Leanne	4	Breathing problems	mother	Had to intervene when Leanne deteriorated. Mother had agreed to be interviewed but child became too sick
14. Jonathon	5	Tonsillectomy	Both parents	Day case
15. James	2	Grommets	mother	Day case
16. Robert	7	Dental extractions	mother	Day case. Robert has a learning disability
17. John	8	Abdominal pain	mother	Transferred from site one to site two
18. Fred	10	fractured femur	mother	Mother and child interviewed
19. Rajiv	10	Laparotomy/abdominal surgery	Both parents	Pain team involved
20. Dan	4	fractured radius and ulna	mother	surgery
21. Paul	7	fractured dislocation elbow	mother	Mother and child interviewed
22. Jack	14	Knee injury	father	Bedrest
23. Jeremy	11	Appendicectomy	Both parents	1st day post op
24. Callum	10	Testicular pain	mother	Awaiting surgery
25. Amy	2 years 2 months	fractured femur	mother	Father working away. Mother interviewed.
26. Maddie	14	Removal of exostosis knee	mother	Second operation for same condition. Went for surgery and returned during observation
27. Helena	15	Abdominal pain	mother	? ovarian
28. Heath	9	fractured radius and ulna	Both parents	Day of operation
29. Evie	2	Removal of foreign body from foot	mother	Awaiting surgery
30. Richard	4	Orchidopexy	Both parents	

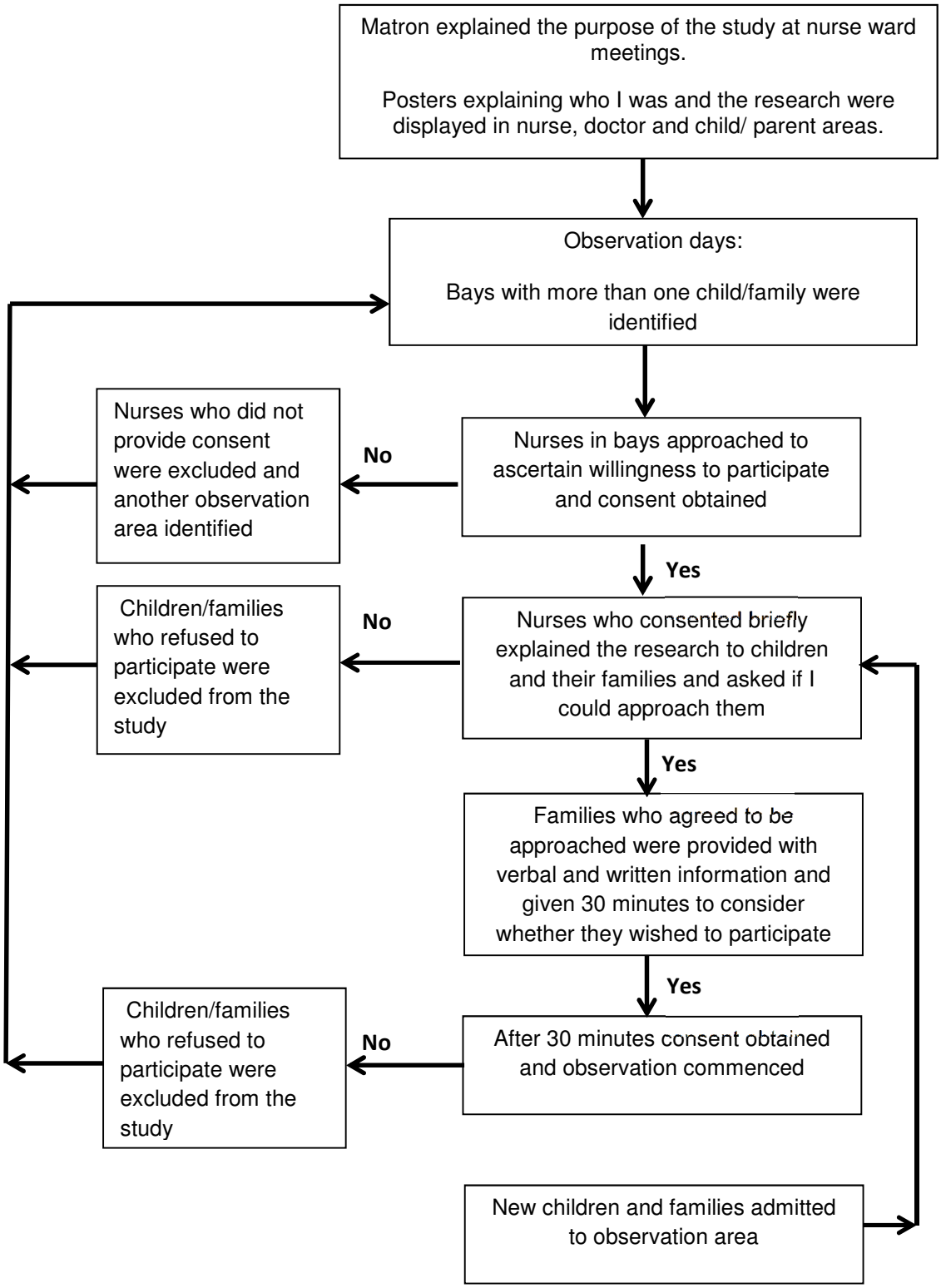
Appendix 5: Nurse details

Shaded area- site 1

Non-shaded area- site 2

Nurse (Anonymised)	Band	Years of experience	Qualifications	Notes
Hannah	5	1.5	Diploma	Interviewed
Lorraine	5	15	Diploma	Interviewed
Harriet	5	3	Degree	
Carmel	5	12	Diploma	
Grace	6	20	Degree	
Jane	5	1.5	Degree	Agency nurse
Lauren	5	1.5	Degree	Interviewed
Karen	6	20	Degree	On Master's course. PNP Interviewed
Rosie	5	3.5	Diploma	
Pam	5	18	Degree	
Liam	6	20	Masters	PNP. Planned to interview- was too busy
Annette	6	8	Degree	On Master's course. PNP
Teresa	5	5	Diploma	
Colleen	5	22	Diploma	

Appendix 6: Flowchart detailing recruitment and consent procedures



Appendix 7: Participant information leaflet- children 6-10 years

"A study looking at how parents are involved in a child's care in hospital"

University of HUDDERSFIELD
Inspiring tomorrow's professionals

Research participant Information sheet (child- aged 6-10 years)

Hello

My name is Jackie

I would like to ask you if you will be in my research study. It is up to you if you want to be in this research. It does not matter if you do not want to. This information explains why I am doing the research and why I am asking you. Please take time to think about this information and what I have said to you and let me know if you want to be in the study.

Why am I doing the study?

I am a children's nurse and a nurse teacher. I am doing research about nurses and families in hospital. I want to see if there is anything that can be done better.

What is research?

Research is like a project, survey or study and is a way of finding answers to questions.

What will I be doing?

I am here to look at nurses and families on the children's ward. I will sit and look at nurses and you and your family and write down what I see. I may ask if you will talk to me about what I saw.

Why am I asking you to take part?

You are going to be there when I am looking at nurses and your family. I may want to talk to you as well.

Do you have to take part?

You can say yes or no. It is up to you. If you say yes, you can still change your mind and say you do not want to do this anymore. That is ok.

Will anyone know it is about you?

No. I will not tell anyone your name or write your name down where anyone can see.

What do you need to do if you say yes?

You can just do what you would normally do. If I talk to you after, this will be just like a little chat and your parent/carer will be with you.

What if you are worried about anything?

You can talk to me or your parents/carers and we will try to answer your questions.

Have you got any questions you would like to ask now?

Are you happy to be in the study?

Yes ☐

No ☐

My contact details

Jackie Vasey

University of Huddersfield

j.vasey@hud.ac.uk

Thank you for taking the time to read this information sheet.

Appendix 8: Participant information leaflet- children 11-15 years

"A study looking at how parents are involved in a child's care in hospital"

Research participant Information sheet (young person aged 11-15 years)

Hi, my name is Jackie

I am inviting you to take part in a research study. Your participation in this research is voluntary and will not affect your care whatever your decision. You may change your mind and withdraw from the study at any time without saying why. Before you decide, it is important for you to understand why the research is being done and what it will involve. This information sheet explains why I am doing the study, and why I am asking you to be involved. If anything is unclear or you would like further information then please contact me on the details provided at the end of this sheet. Please take time to read through this information and decide whether or not you wish to take part.

What is the purpose of this research study?

I am a children's nurse and nurse teacher at the local university and I am doing a professional doctorate. As part of this doctorate I am doing research about how parents are involved in a child's pain care in your area. Research is a way of finding answers to questions and I want to find out about how families are involved in their child's pain care. Pain care includes assessment, interventions and evaluation. It does not mean you have to have pain to be involved. The research will be observing nurses and families, and where possible talking to/interviewing nurses and families after the observation. Involvement is

entirely voluntary. I am asking you to be involved as you will be on the ward when I am doing one of my observational sessions.

What is research?

Research is like a project, survey or study and is a way to answer questions.

How will I (the researcher) do this?

I will be sitting in a position where I can watch a few families on the ward and see how nurses and families talk to each other about care.

After, I may ask to talk to you and your parents about what was happening when I was watching you. This will be like having a chat and your parent/carer will be with you. This will be audio tape recorded.

Did I check if it is ok to do this research?

Before I can do this research, I have checked with a group of people called research ethics committee in the university where I work and in the NHS for the hospital. This is to make sure the research is fair.

Who will know it's about you?

Your name will not be written down anywhere, so no-one will know your name and no-one will know who I am writing about.

Do you have to take part in this research?

It is up to you. You can say no. Even if you say yes, later you can change your mind. If you do not want to be involved (even if your parents want you to) you will not be included. This will not affect your care in any way. You can ask to talk to me about it if you want.

What do you need to do?

You do not need to do anything differently than you would normally do. If you agree to talk to me about your experience on the ward, your parent/carer will be present and this will be in private. It is expected to take less than 30 minutes. The talk/interviews will be audio-taped.

What will happen to the study results?

The results will be included in the thesis for the Professional Doctorate which will be stored in the university library on completion. They will also be available in the university repository. It is also anticipated that the results will be published in journal articles and may be presented at conferences, so that the findings can be used in practice. The aim of the study is to look at what influences parents/main carers being involved in their child's pain care. It is hoped by identifying this, that it will lead to ways of improving this.

I will not tell anyone your name in any circumstances.

What if you are worried or something goes wrong?

Although, I will not be doing anything other than look at you and those around you and talk to you, if you have any concerns please contact me and I will do my best to answer your questions. Alternatively, you can contact the Director of Centre for Health and Social Care Research, Professor Annie Topping on 01484 473 974 or a.e.topping@hud.ac.uk.

My contact details

Jackie Vasey

University of Huddersfield

j.vasey@hud.ac.uk

Thank you for taking the time to read this information sheet.

Appendix 9: Participant information leaflet- “Gillick” competent young people

“A study looking at how parents are involved in a child’s care in hospital”

Research participant Information sheet – young person who is competent to provide consent independently (Gillick competent young person)

Hi, my name is Jackie

You are being invited to take part in a research study. Your participation in this research is voluntary and will not affect your care whatever your decision. You may change your mind and withdraw from the study at any time without giving a reason. Before you decide, it is important for you to understand why the research is being done and what it will involve. This information sheet explains the purpose and potential value of the study and how you may be able to contribute. If anything is unclear or you would like further information then please contact me on the details provided at the end of this sheet. Please take time to read through this information and decide whether or not you wish to take part.

What is the purpose of this research study?

I am a children’s nurse who currently teaches child nursing at the local university and I am doing a professional doctorate. As part of this doctorate I am doing research. Research is a way of finding answers to questions and I want to find out about how families are involved in their child’s pain care. The research involves looking at nurses and families, and where possible talking to/interviewing nurses and families after the observation. Involvement is entirely voluntary. I am asking you to be involved as you will be on the ward when I am doing one of my observational sessions.

What is research?

Research is like a project, survey or study and is a way to answer questions.

How will I (the researcher) do this?

I will be sitting in a position where I can watch a few families on the ward and see how nurses and families talk to each other about care. This will be for a few hours.

After, I may ask to talk to you and your parents about what was happening when I was watching you. This will be like having a chat and your parent/carer will be with you. This will be audio tape recorded.

Although I am a nurse, it is not expected that I will not be doing anything other than observing.

Did I check if it is ok to do this research?

Before I can do this research, I have checked with a group of people called research ethics committee in the university where I work and in the NHS for the hospital. This is to make sure the research is fair.

Who will know it's about you?

Your name will not be written down anywhere, so no-one will know your name and no-one will know who I am writing about.

Do you have to take part in this research?

It is up to you. You can say no. If you do not want to be involved (even if your parents want you to) you will not be included. This will not affect your care in any way. You can ask to talk to me about it if you want. If you agree you can sign your own consent form.

What do you need to do?

You do not need to do anything differently than you would normally do. If you agree to talk to me about your experience on the ward, your parent/carer will be present and this will be in private. It is expected to take less than 30 minutes. The talk/interviews will be audio-taped.

What will happen to the study results?

The results will be included in the thesis for the Professional Doctorate which will be stored in the university library on completion. They will also be available in the university repository. It is also anticipated that the results will be published in journal articles and may be presented at conferences, so that the findings can be used in practice. The aim of the study is to explore what influences parents/main carers being involved in their child's pain care. It is hoped by identifying this, that it will lead to ways of improving this.

I will not tell anyone your name in any circumstances.

What if you are worried or something goes wrong?

Although, I will not be doing anything other than look at you and those around you and talk to you, if you have any concerns please contact me and I will do my best to answer your questions. Alternatively, you can contact the Director of Centre for Health and Social Care Research, Professor Annie Topping on 01484 473 974 or a.e.topping@hud.ac.uk.

My contact details

Jackie Vasey

University of Huddersfield

j.vasey@hud.ac.uk

Thank you for taking the time to read this information sheet.

Appendix 10: Participant information leaflet- Parent

"Tokenism or true partnership: An observational study of nurse's involvement of parents/main carers in their child's acute pain care, within the culture of family-centred care".

Research participant Information sheet (parent/carer)

Dear parent/carer

You are being invited to take part in a research study. Your participation in this research is voluntary and will not affect your child's care whatever your decision. You may withdraw from the study at any time without giving a reason. Before you decide, it is important for you to understand why the research is being done and what it will involve. This information sheet explains the purpose and potential value of the study and how you may be able to contribute. If anything is unclear or you would like further information then please contact me on the details provided at the end of this sheet. Please take time to read through this information and decide whether or not you wish to take part.

What is the purpose of this research study?

I am a children's nurse who currently teaches child nursing at the local university and I am undertaking a professional doctorate. As part of this doctorate I am undertaking research about parental involvement in a child's pain care in your area. Research is a way of finding answers to questions and I want to find out about how families are involved in their child's

pain care. Pain care includes assessment, interventions and evaluation. It does not mean your child has to have pain to be involved. The research involves observing nurses and families, and where possible talking to/interviewing nurses and families after the observation. Involvement is entirely voluntary. I am asking you to be involved as you will be present when I am doing one of my observational sessions.

What is research?

Research is like a project, survey or study and is a way of finding answers to questions.

What permission have I got for this research?

I have gained all appropriate ethical permissions. I have the approval from the university, NHS and local trust research and development department. I also have the approval of the ward manager.

What will I be doing?

I will be sitting in a position where I can observe/watch a number of families and the nurse or nurses when they interact with parents. This is planned to be in the assessment area and in a “bay” where a number of families will be present. I will not be observing a single family by themselves, as this would be too intrusive. I will be taking notes throughout the observation.

I may ask if you and your child (if your child is old enough to contribute) are willing to talk to me about your experiences following the period of observation. You can choose to be observed and not agree to the interview/talk if you wish. However, this would provide an opportunity to improve the research and explain from your point of view what happened when the nurse interacted with you and your child. Interviews will be audio-taped.

It is not anticipated that I will be getting involved in your child’s care at any point.

Will anyone know it is you/your child in this study?

You and your child's identity will not be disclosed on any documents- you will be completely anonymous.

How do you give permission?

I will provide and discuss this information leaflet with you and ask for your consent. If you wish to discuss any part of this research with me, I will be available to talk to throughout the observation period.

What do you need to do?

You will not be expected to do anything differently to what you would normally do. If you are asked to be interviewed and agree to this, this will take place in a private area and it will be like a conversation or chat with only a couple of questions. The interview will be tape recorded. It is anticipated that it will not take longer than 30 minutes.

What if my child is too young to agree to be involved?

If your child is too young to be involved in consenting for themselves, we will ask you to consent on their behalf.

If your child is unable to read or understand the written the information and consent form, but old enough to say whether they want to be involved, I will explain it to them and ask for their permission.

If your child is old enough to understand the full information about the study, they will be able to consent for themselves.

In all circumstances if you or your child do not want to be involved, this will be respected and will not affect your care in any way.

What will happen to the study results?

The results will be included in the thesis for the Professional Doctorate which will be stored in the university library on completion. They will also be available in the university repository. It is also anticipated that the results will be published in journal articles and may be presented at conferences, so that the findings can be used in practice. The aim of the study is to explore what influences parents/main carers being involved in their child's pain care. It is hoped by identifying this, that it will lead to ways of improving this.

Your identity will not be disclosed in any circumstances.

What if you are worried or something goes wrong?

Although, I will not be doing anything other than look at you and those around you and talk to you, if you have any concerns please contact me and I will do my best to answer your questions. Alternatively, you can contact the Director of Centre for Health and Social Care Research, Professor Annie Topping on 01484 473 974 or a.e.topping@hud.ac.uk.

My contact details

Jackie Vasey

University of Huddersfield

j.vasey@hud.ac.uk

Thank you for taking the time to read this information sheet.

Appendix 11: Participant information leaflet- Nurse

"Tokenism or true partnership: An observational study of nurse's involvement of parents/main carers in their child's acute pain care, within the culture of family-centred care".

Research participant Information sheet (nurse)

Dear colleague

You are being invited to take part in a research study. Your participation in this research is voluntary and will not affect your job whatever your decision. You may withdraw from the study at any time without giving a reason. Before you decide, it is important for you to understand why the research is being done and what it will involve. This information sheet explains the purpose and potential value of the study and how you may be able to contribute. If anything is unclear or you would like further information then please contact me on the details provided at the end of this sheet. Please take time to read through this information and decide whether or not you wish to take part.

What is the purpose of this research study?

I am a children's nurse who currently teaches child nursing at the local university and I am undertaking a professional doctorate. As part of this doctorate I am undertaking research about parental involvement in a child's pain care in your area. Research is a way of finding

answers to questions and I want to find out about how families are involved in their child's pain care. Pain care includes assessment, interventions and evaluation. The research involves observing nurses and families, and where possible talking to/interviewing nurses and families after the observation. Involvement is entirely voluntary. I am asking you to be involved as you will be on duty when I am doing one of my observational sessions.

What permission have I got for this research?

I have gained all appropriate ethical permissions. I have the approval from the university, NHS and local trust research and development department. I also have the approval of your clinical manager.

What will I be doing?

I will be sitting in a position where I can observe a number of families and the nurse or nurses when they interact with parents. This is planned to be in the assessment area and in a "bay" where a number of families will be present. It is not intended to observe a single family as this would be too intrusive. I will be taking notes throughout the observation.

I will ask if you are willing to talk to me about your experiences following the period of observation. You can choose to be observed and not agree to the interview if you wish. However, this would provide an opportunity to enhance the research and explain why you interacted with families in a particular way that cannot be uncovered by observation. Interviews will be informal and more like a discussion/chat and will be audio-taped.

It is not anticipated that I will be intervening at any point. In the very unlikely event where the child is deemed at risk, I will be obliged under the NMC Code of Conduct (2008) to intervene or report my observations.

Will your confidentiality be maintained?

Your identity will not be disclosed on any documents- you will be completely anonymous.

Do you have to take part in this research?

It is your choice. You can say no if you wish. If you agree, you will be asked to sign a consent form.

If you agree to take part what do you need to do?

You will not be expected to do anything differently to what you would normally do in your usual day to day practice.

What will happen to the study results?

The results will be included in the thesis for the Professional Doctorate which will be stored in the university library on completion. They will also be available in the university repository. It is also anticipated that the results will be published in journal articles and may be presented at conferences, so that the findings can be used in practice. The aim of the study is to explore what influences parents/main carers being involved in their child's pain care. It is hoped by identifying this, that it will lead to ways of improving this.

Your identity will not be disclosed in any circumstances.

What if you are worried or something goes wrong?

Although, I will not be doing anything other than look at you and those around you and talk to you, if you have any concerns please contact me and I will do my best to answer your questions. Alternatively, you can contact the Director of Centre for Health and Social Care Research, Professor Annie Topping on 01484 473 974 or a.e.topping@hud.ac.uk.

My contact details

Jackie Vasey

University of Huddersfield

j.vasey@hud.ac.uk

Thank you for taking the time to read this information sheet.

Appendix 12: Consent form

University of HUDDERSFIELD

Research Informed Consent Form

Please initial box

1. I confirm that I have read and understand the information sheet for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

2. I understand that my participation is voluntary and that I am free to withdraw from the observation at any time, without giving any reason, without it having a direct impact on my (my child's) care ☐

3. I understand that my participation is voluntary and that I am free to withdraw from being interviewed at any time, without giving any reason, without it having a direct impact on my (my child's) care ☐

4. I consent to being observed ☐

5. I consent to being interviewed ☐

6. I give permission for my interview to be audio tape recorded ☐

7. I understand that the recorded data and audio tapes may be looked at by individuals from the research supervision team at the University of Huddersfield or by regulatory authorities. ☐

8. I understand that the recorded data and audio tapes will be kept in secure storage at the University of Huddersfield ☐

9. I understand that all final data will be safely destroyed within 5 years of the completed and accepted study ☐

10. I understand that the anonymised data may be used for journal publications, public dissemination, through conferences for example and in teaching materials ☐

---------- ---------- --------- ----------

Participant name Date Signature

---------- ---------- --------- ----------

Researcher Date Signature

Appendix 13 Field note template- adapted from Walford (2009)

<table>
<tr>
<td>Page number

Date

Time started

Time finished

Site

Description of location</td>
<td>Diagram of ward area layout- seating position/bed positions</td>
<td>Nurses present
1
2
3
4
5
6

Families present- Child anonymised name/age/diagnosis
1
2
3
4
5
6</td>
</tr>
<tr>
<td colspan="2">Field notes (include time of each interaction)</td>
<td>Reflection/thoughts</td>
</tr>
</table>

Appendix 14: Interview schedule- parent

Guidance notes

1. Preparation

   Ensure private room, with enough space for parent (s) and child. Comfortable chairs with no desk between interviewer and participants. Chairs should be fairly close together- but not too close. Child should not be separated from the parent unless they choose to move around. Bring toys into the room for the child to play with (involve play staff if required), which may allow parents to speak more easily. Speak to parents first to gain the child's trust, unless child attempts to become involved at the beginning. Depending on the age of the child- ask question 5. Younger children may be asked broader questions about what is it is like being in hospital- question 6. Preverbal children will obviously not be asked any questions, but will be made to feel part of the discussion, by communicating with them generally in age appropriate language and play

2. Introduction

   - Welcome/ Ice breaker
   - Outline aim of interview
   - Explain again that interview will be taped
   - Explain again that the interview can be stopped at any time

   Open questions about what is like being on the ward.

   If the parent/child does not talk about specific topic, obliquely introduce following topics:

3. Questions-

   Question 1

   What is your understanding of the term "pain care?"

   Question 2

   Tell me about your child's pain care.

   Question 3

   Tell me about how much you were involved in your child's pain care.

   Question 4

   Tell me about how much you wanted to be involved in your child's pain care.

   Question 5- older children

   Ask older children to talk about what their parents have said and about their experiences on the ward.

Question 6- younger children

Ask what it is like being on the ward

4. Close with thank you and opportunity to ask questions about what will happen to data on tape etc.

Appendix 15: Interview schedule- nurse

Guidance notes

1. Ensure private room, with enough space for nurse and interviewer. Comfortable chairs with no desk between interviewer and participant. Chairs should be fairly close together- but not too close
2. Introduction
    - Welcome/ Ice breaker
    - Outline aim of interview
    - Explain again that interview will be taped
    - Explain again that the interview can be stopped at any time
3. Questions

    Open questions about what is like working on the ward.

    If the nurse does not talk about specific topic, obliquely introduce following topics:

    Question 1

    What is your understanding of the term "pain care?"

    Question 2

    Tell me about your ideas about family-centred care.

    Question 3

    Tell me about pain care and family-centred care.

    Question 4

    Thinking about the care you have given today to the observed families, tell me about any aspects of care, where family-centred care in relation to pain care featured.

4. Close with thank you and opportunity to ask questions about what will happen to data on tape etc.

Appendix 16: Application of the framework approach (adapted from Spencer et al., 2003).

Stages	Actions
Data management	1. All interviews were transcribed verbatim and sentences, paragraphs or phases inputted directly into an excel spreadsheet (one page per participant). 2. Field notes were transcribed and inputted directly into an excel spreadsheet (one page per day of observation) 2. Each sentence, paragraph or phrase of participant accounts (in vivo accounts) were reviewed and summarised, reviewed again and a label attached to form initial categories from 2 parent and 2 nurse interviews (Figure 5) 3. Initial categories with direct links to extracts were constantly re-read to ensure they represented the original data. 4. Initial categories were grouped together in a list of initial categories to form an initial coding index (Figure 6). 5. The coding index was used a s a guide to code the observation field notes and remaining interview transcripts (3) with new categories added as new insights emerged. 5. Printed versions of the initial coding indexes enabled each category to be cut out and arranged and re-arranged to assist with making links between categories to develop initial themes. This enabled the initial categories to be sorted and re-sorted into related groups. 6. Initial themes were reviewed constantly and initial categories regrouped electronically by "cut and pasting" as ideas developed and insights emerged (Figure 7).
Descriptive accounts	1. Labelling/tagging of data by initial theme continued into this stage as repeated exposure to the original data resulted in greater familiarisation and refinement of categories and initial themes. 2. Data was constantly reviewed and re-ordered until a clear picture of the way nurses involved parents in pain care emerged 3. Associations and links between themes enabled the development of abstract concepts. 4. Refined final themes were developed as data were analysed for illuminating descriptions of parent involvement in their child's pain care (Figure 8).
Explanatory accounts	1. Final themes were synthesised as relationship between themes emerged, which were grouped into concepts. 2. Constant refinement of themes resulted in the development of a conceptual framework, by identification of core concepts (Figure 9). 3. Conceptualising the data enabled explanations of the phenomena to emerge (how and why questions as presented in the discussion of the findings). 4. A typology was established between parental involvement in their child's pain care and satisfaction with pain care. 5. Final themes and concepts were applied to wider theory/policy strategies, presented in the study conclusion

The analytical hierarchy is an iterative process whereby movement through the interconnected stages enables a transparent audit trail from original data to findings with clear links between stages of the analysis.