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

Aims

To explore parental involvement in the child's acute pain care and establish ways in which parental preferences for involvement in their child's care can be identified, facilitated and enhanced by nurses.

Background

Despite growing evidence supporting effective acute pain management in children and the availability of national and international practice guidelines, children still experience acute pain. Involving parents in their child's pain care has been identified as being a central tenet of pain management in children.

Design and methods

A qualitative study using an ethnographical approach with nonparticipant observation and follow up semi-structured interviews was undertaken. Nurses (n=14), parents (n=41), grandparents (n=2), other relative (n=1) and children (n=30) participated. The framework approach underpinned data analysis. Consolidated criteria for reporting qualitative research (COREQ) enabled comprehensive reporting of the study.

Results

Three concepts emerged from the data: 'parents as advocates for their child', 'nurses promoting involvement and partnership' and 'nurses unintentionally preventing involvement and partnership'. Variations in the way parents were involved in their child's pain care were identified. Despite family-centred care being the dominant model of involving families in their child's care, evidence of this being implemented was limited. Parents attempted to advocate effective pain care for their child, whether or not they were supported by nurses.

Conclusions

Parental involvement in their child's acute pain care can improve the child's pain experience, reduce parental anxiety and increase parents' satisfaction in care. Nurses aspired to involve parents in pain care, but did not always enact this in practice.

Relevance for practice

Children deserve optimum pain care, which includes parental involvement. Parental involvement underpinned by the principles of family-centred care was poorly implemented. Parents attempted to be involved and advocate for their child's pain care whether or not they were supported by nurses. An alternative approach for supporting parents to advocate in their child's acute pain care is offered, the "Partnership in Pain Care Model".

Introduction

Recognition that untreated acute pain is a significant risk to the health and wellbeing of children has in recent years led to a proliferation of national and international child specific pain management guidelines. Untreated pain contributes to the morbidity and mortality in surgical trauma (Verghese & Hannallah, 2010). For children requiring acute care, and their parents, pain is a significant concern (Edmonds & Twycross 2018). Children and parent concerns are not unfounded, as we know from the literature that children are still experiencing unnecessary pain while in hospital (Shrestha-Ranjit & Manias, 2010; Birnie, et al., 2014; Simons, 2015; Walther-Larsen, et al., 2017). Although, pain management strategies such as pharmacological interventions are crucial in the management of acute pain, involving parents in their child's pain care has been identified as a central tenet of pain management in children (Royal College of Nursing, 2009; American Academy of Pediatrics Committee, 2001). Some studies have explored parental involvement in a child or neonate's pain care in specialised environments, or as part of a wider exploration of pain experiences for children (Simons & Roberson 2002; Franck et al, 2012). However, no studies have been identified that have specifically focused on parental involvement in their child's pain care in acute hospital wards, where there is a high probability of children's experiencing acute pain. Therefore, little is known about how nurses work in partnership with parents to care for the child experiencing acute pain in children's wards.

Parental presence and involvement can be beneficial for both children and parents, across all aspects of pain care from assessment to providing pain care, and can impact positively on the child's acute pain experience in hospital (Lim, Mackey, Liam & He, 2011). Parental presence has been found to have both preventative and therapeutic effects, such as reducing children's pain experiences, decreasing the length of hospital stay and enabling more effective use of staff time (Diaz-Caneja, Gledhill, Weaver, Nadal & Garralda, 2005; Twycross & Collins, 2013). In addition, pain care is a significant concern for parents when their child is admitted to hospital. Benefits of participating in pain care for parents have been attributed to reducing feelings of helplessness when their child is acutely ill (Franck, Oulton & Bruce, 2012).

The implementation of parental involvement in their child's pain care must be supported by a robust framework that supports parents to work in partnership with nurses and other health professionals. Philosophies and models of care have evolved to support children's nurses to adopt a collaborative approach to working with children, young people and families, the most acclaimed being family-centred care (Smith, Swallow & Coyne, 2015). Family-centred care is widely advocated as a philosophy to underpin the care of children and families within the UK and the United States of America (USA). The Institute for Family-Centred Care (IFCC) was established in the USA to develop strategies to facilitate a family-centred care approach. Nine elements of family-centred care were identified as a framework for embedding family-centred care into practice (Shelton, Jepson & Johnson, 1987), which emphasised recognising the family as a constant in the child's life and promoting collaborative working between parents and healthcare professionals. While family-centred care is claimed to be ubiquitous (Shields, 2015), poor understanding of how it can be effectively implemented into practice and lack of

empirical evidence supporting better outcomes for the child and family render the concept as idealistic (Uniacke, Browne & Shields, 2018; Shields et al., 2012).

Background

Despite an abundance of literature related to other aspects of acute pain care in children, such as assessment (Royal College of Nursing 2009; Dürango, Åkeson, Jonsson, Nilsson, & Åkeson, 2017) and interventions (Shrestha-Ranjit & Manias, 2010), less is known about how nurses work in partnership with parents to involve them in their child's acute pain care (Jaakola, Mervi, Kaarianen & Palkki, 2013). This is compounded by the differences in how parents and nurses understand and perceive involvement and partnership working, which is highlighted in the wider literature and contributes to the variations in implementing parental involvement in practice (Vázquez Sellán, Sellán Soto, & Díaz Martínez, 2017; Uniacke et al., 2018). Parental involvement is a component of family-centred care and occurs at the nurse-led end of the family-centred care practice continuum (Smith, Coleman & Bradshaw, 2010). Despite family-centred care being espoused as an ideal philosophy to support nurses and parents working together, it is challenging to embed into practice (Coyne et al., 2013; Smith, Swallow & Coyne, 2015). Furthermore, growing concern about lack of a shared understanding of family-centred care (Al-Motlaq, et al., 2018) and its usefulness to guide practice ensue (Uniacke et al., 2018).

A range of activities are identified by nurses as central to parents' involvement in pain care, such as parents participating in specific non-pharmacological interventions, such as comforting and re-positioning the child, staying with the child in hospital and being present for procedures (Lim 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 (Kristensson-Hallstrom & Elander, 1994). A study exploring parental involvement in the child pain care on a cardiac unit has suggested that parents perceived it is their role to advocate on behalf of the child when pain is not well controlled (Simons & Roberson, 2002). However, and in contrast, parents also report pain in acute health conditions is to be expected and accepted (Twycross & Finley, 2013). Trends of unrelieved pain in children have been highlighted (Shrestha-Ranjit & Manias, 2010); one study found 58% of children experienced severe pain and 24% moderate pain (Twycross & Collis, 2013), while similarly, Shrestha-Ranjit & Manias (2010) found in their retrospective audit that on average, 75% of children experienced some degree of pain in hospital and 50% had moderate to severe pain. If nurses develop 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, et al., 2013; Simons & Roberson, 2002; Twycross & Finley, 2013).

Effective communication between parents and nurses is central to promoting parental involvement in pain care (Simons & Roberson, 2002) but does not always occur in clinical practice (Polkki, Pietila, Vehvilainen-Julkunen, Laukkala & Ryhanen, 2002; Simons et al., 2001). There is often an unspoken assumption that parents know what is expected of them without nurses clarifying or negotiating their role. Parents are not routinely invited or supported to be actively involved in their child's pain care and therefore become passive participants (Simons et al., 2001). Furthermore, lack of involvement in care was not questioned by many parents,

suggesting the balance of power for care decisions is firmly within the domain of the nurse. Parents report being stressed by lack of information, involvement and support, leading to parents' feelings of helplessness (Polkki et al., 2002), and frustration (Simons et al., 2001). Being more involved in care resulted in less anxiety for parents and gave them 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 (Tallon, Kendal & Snider, 2015).

In order to be involved in care nurses must recognise that parents are reliant on them to provide relevant information, support and facilitate involvement in care. Research has found that nurses' knowledge about children's pain care needs to improve to enable them to support parents' involvement in pain care (Simons & Roberson, 2002; Twycross & Collins, 2013). However, overemphasis on education solely as the key to improving pain care is misleading because even when nurses have theoretical knowledge, it is not always applied to practice (Czarnecki et al., 2011). Involving parents in pain care requires nurses to understand the principles of family-centred care, and be proficient in identifying practical ways of involving parents in every day care (Smith et al., 2015) that is integrated with pain care knowledge (Twycross & Collins, 2013).

In summary, the international literature on parental involvement in children's pain care in general children's wards indicates that little is known about how involved parents are in their child's acute pain care and whether family-centred care described in health policy is implemented in practice. This is a significant limitation in the current research literature that the study reported in this article aims to address.

Although "pain management" is usually used to describe pain related care activities, this implies a hierarchical approach and a focus on assessment and treatment intervention. In this study we conceptualise "pain care" as a term to describe a broader application including the way nurses and parents can work in partnership in caring for a child's acute pain.

The aim of this study was to explore parental involvement in the child's acute pain care. The specific objectives were:

1. To observe and analyse the interactions and experiences of the child, parent and nurse in the child's pain care in acute care settings
2. Examine the extent to which parents are partners and are involved in their child's pain care;
3. Identify 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 pain care can be identified, facilitated and enhanced.

The main author (female), an academic undertook the study as part of the Professional Doctorate, supported by three female supervisors with PhD's.

Methods

Methodology

An ethnographical approach was chosen because exploring and understanding complex interactions between nurses and parents is best achieved by capturing nurse-parent interactions in the “field” and was congruent with meeting the study aim and objectives. (Spradley, 1980). The “field” in this study was an acute children’s ward. Understanding the interactions between participants as they occurred was crucial to represent practice and the reality for the participants (Lambert & Loiselle, 2008). At the macro level, parental involvement in a child’s care in hospital has evolved over the last century and is shaped predominantly by changing societal views of children, and a greater recognition of children’s agency (Department of Health, 2010; Ministry of Health 1959). However, at the micro level, the realities of the parent, child and nurse interactions and the relationships formed are linked and influence parental involvement in care. 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.

Sample

The study was set in two District General Hospitals, from one National Health Service (NHS) Trust, in the North of England. The sites were selected as they provided care to children receiving potentially painful interventions for a range of medical and surgical conditions. Site one was a 26 bedded children’s ward, caring for children aged from the age of one day to 16 years of age. Site two was an 11 bedded inpatient unit admitting infants and children from four months to 16 years of age.

A purposive sample of 30 family dyads (children and their parent/carer(s)), and 14 nurses providing care on the study observation days, were invited to participate. All children receiving inpatient care that was likely to include pain care on the days of observed practice were eligible to participate. However, families being cared for in single rooms/areas were excluded as the observation was considered to be too intrusive. Children being cared for without the presence of their parents were also excluded.

Data collection tools

Data were collected by nonparticipant observation and follow up semi-structured interviews, over a four-week period (weekdays between 08.00-17.00). Nurse and child/parent pain care interactions were observed by the researcher (JV) sitting in an unobtrusive position in the inpatient bays on the wards. Hand written field notes were recorded as encounters took place highlighting specific pain care interactions or absence of pain care interactions, where they would be expected to take place.

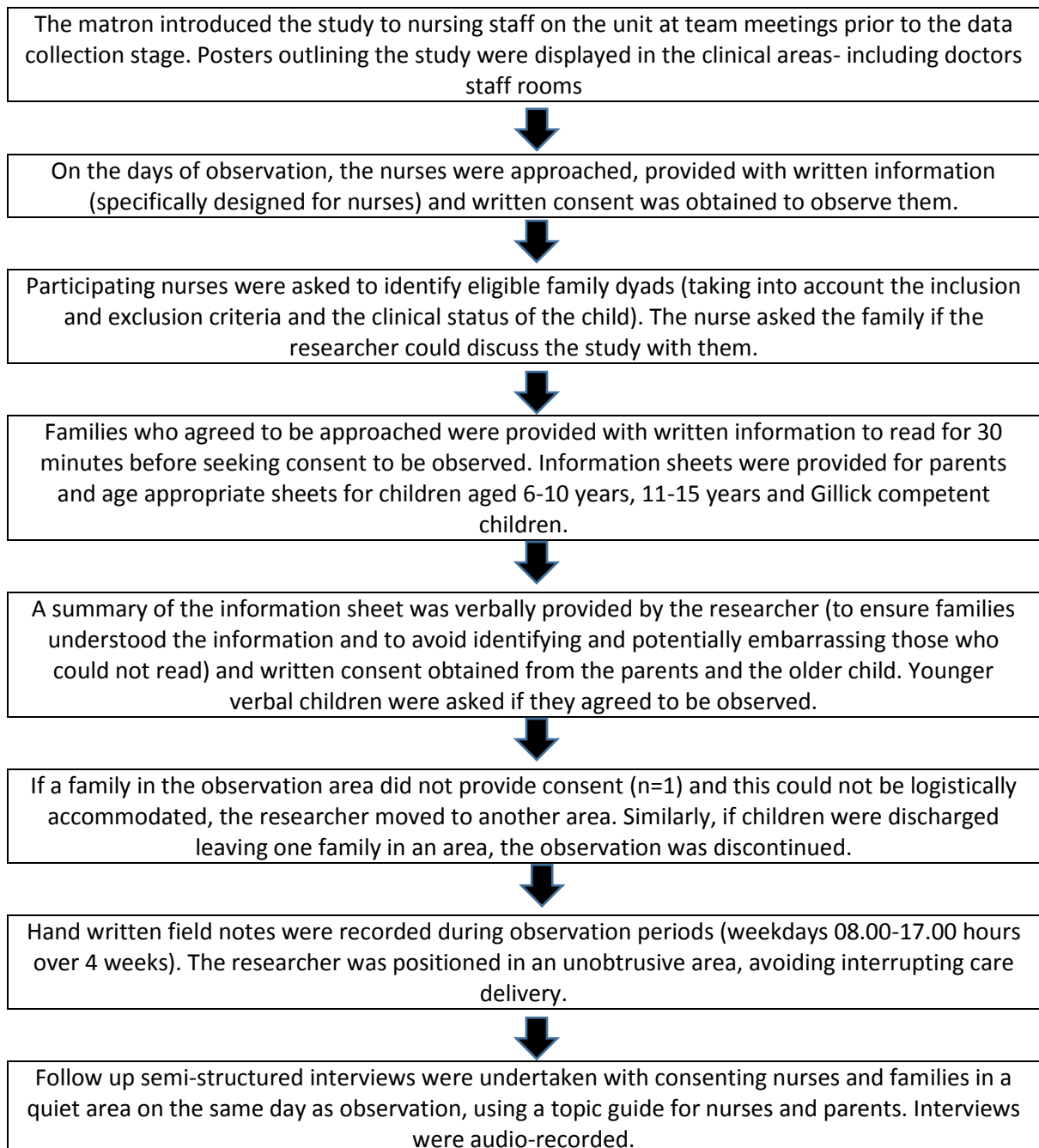
Follow up semi-structured interviews with nurses and parents were undertaken separately by one researcher (JV) to explore participant perceptions and thoughts about episodes of care observed and lasted 30-75 minutes. Interviews were audio-recorded. The topic guide for the interview schedule was focused around exploring the interactions that were observed and eliciting parents’ experiences of their child’s pain care and the extent to which they were or wanted to be involved in care. The

guide also sought to examine nurses' views of involvement of parents in pain care and their interpretation of family-centred care.

Procedure

The procedure is outlined in Figure 1.

Figure 1



Data analysis

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”. To ensure a full account of the observations were represented, extracts from field notes were also included in the data. The process of one researcher (JV) transcribing the field notes and interviews assisted in becoming fully immersed and familiar with the data. It was not possible to return transcripts to families as their home details were not collected and as the average length of stay in an acute children’s ward is one to two days, they would have been discharged before transcripts could be returned for participant review.

The framework approach underpinned data analysis because it enabled the data to be explored systematically, and across the observational and interview data sets. The processes were iterative and involved forward and backward movement across the stages of data management, descriptive accounts and explanatory accounts. The framework approach strengthened the rigour and credibility of the findings (Ritchie, Spencer & O’Connor, 2003) and enhanced transparency across the analytical stages, outlined in Figure 2. The analysis was based on the whole data set, rather than selective interpretations of the data, to ensure the findings represent the reality of what was observed and participants’ perceptions to increase the trustworthiness and transferability of the findings (Spencer, Ritchie, O’Connor, & Morrell, 2014).

Figure 2- framework approach

Stages	Actions
Data management	<ol style="list-style-type: none"> 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 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. 5. The coding index was used as 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.
Descriptive accounts	<ol style="list-style-type: none"> 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.
Explanatory accounts	<ol style="list-style-type: none"> 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. 3. Conceptualising the data enabled explanations of the phenomena to emerge (how and why questions as presented in the discussion). 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 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.

Data were analysed by one researcher (JV). However, monthly meetings with research supervisors were used to discuss and critically evaluate each stage of the analysis to develop a shared understanding of the data, development and refinement of themes and to challenge assumption in order to minimise unintentional bias (Burnard, Gill, Stewart, Treasure & Chadwick, 2008).

Criteria to demonstrate rigour in qualitative studies have been developed to reflect different philosophical position and purpose (Noble & Smith, 2015). To enhance the integrity of this study Guba & Lincoln's (1994) five criteria for establishing rigour in qualitative research was used: credibility; dependability; confirmability; authenticity and transferability. Additionally, to overcome challenges to rigour in reporting qualitative studies, the use of COREQ composed of a 32-item checklist (Supplementary File 1), provided a framework for explicit and comprehensive reporting (Tong, Sainsbury & Craig, 2007). Reviewing the study based on research team and reflexivity, study design and data analysis, the key domains of this checklist, enabled the researcher to identify and report important aspects of the study. Reflexivity was particularly pertinent to adopting an ethnographic approach, as the way researchers acknowledge their role in constructing and interpreting the data can be a threat to trustworthiness. Therefore, the main researcher used reflexivity as a way of minimising bias in all stages of the research. Table 1 outlines the measures undertaken to enhance rigour.

Table 1

Credibility	<p>The credibility of study findings depends on the integrity and trustworthiness of the research methods adopted and ways in which bias were minimised. 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. Sustained periods of observation enabled prolonged immersion in the environment and exposure to real life encounters and interactions in real time. Follow up interviews enabled triangulation of methods to corroborate observational data. The use of the framework approach contributed to credibility during data interpretation and analysis. Peer debriefing of data analysis took place, whereby debates with colleagues helped to 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.</p>
Dependability	<p>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.</p> <p>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” (Spradley 1980). Accurate recording of field notes and a clear audit trail of decisions made during analysis using the framework approach contributed to dependability.</p>
Confirmability	<p>Confirmability exists when credibility, transferability and dependability have been established (Farley & McLafferty, 2003). By acknowledging researcher bias, ethnographers aim to present participant accounts and views accurately, by minimising the impact of the values of the researcher. This was achieved by recording and presenting detailed descriptions of participant accounts in the findings. COREQ for reporting the study enhanced rigour and encompassed the domains of research team and reflexivity, study design and data analysis which underpin this framework for reporting (Tong, Sainsbury & Craig, 2007). Reflexivity, one of the COREQ domains, a key consideration in ethnographic studies also contributed to confirmability.</p>
Authenticity	<p>Authenticity is concerned with ensuring that the range of participant realities are represented (Lincoln & Guba, 1985). Presenting verbatim accounts aims to truly encapsulate the participant perspectives, with data collected in a truly authentic environment.</p>
Transferability	<p>Transferability refers to how well the findings are applicable to a similar setting or groups (Lincoln & Guba, 1985). 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. The selected sites represent a typical District General Hospital environment providing care to a diverse population. 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</p>
Reflexivity	<p>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. Furthermore, having insider knowledge can create intrinsic tensions in the “field”, which were acknowledged and reconciled through reflexivity. Meticulous note taking and recording of decisions during data analysis contributed to the integrity of the data which were discussed at each stage with all researchers. Epistemological reflexivity also helped to clarify the motivation for the study while ensuring the selected approach met the study aims (Mahon & McPherson, 2014).</p>

Ethical approval

Ethical approval was gained from the University Research Ethics Panel, the NHS Research Committee (Health Research Authority- NRES Committee Yorkshire and Humber- Leeds West. REC Reference 11/YH/0445) and the site specific Research and Development Units. The main ethical considerations related to ensuring consent was informed, accessing children and families in an NHS acute environment and ensuring care was not disrupted. Informed consent was gained from all participants and took into account the age ranges of the children and the stressful environment. Information was provided specifically for nurses and parents, leaflets were designed to cover the following age groups; 6-10 years, 11-15 years and Gillick competent young people. Outlining how potential safeguarding issues or poor practice would be managed was an additional key consideration agreed with nurse managers and nurse participants in advance of the study. Establishing a reporting strategy for managing unsafe practice is crucial for research involving particularly vulnerable participants such as sick children in hospital (Skene, 2012). This enabled all participants to be clear that if unsafe care was observed the researcher, as a children's nurse and Nursing and Midwifery Council registrant, would be professionally obliged to act and report. It was necessary on one occasion to report a child whose condition deteriorated when no member of staff was present to a nurse and during one interview a parent reported an incident that required investigation.

Findings

Participants

Eighty-eight participants were recruited to the study and included: mothers (n=27), fathers (n=14), grandparents (n=2), another relative (n=1) across 30 families, children (30) and nurses (n=14). Children were admitted for a range of medical and surgical conditions that required pain care. The age of children in the study ranged from 14 months to 15 years of age. Nurses were all qualified children's nurses with a range of experience from junior nurses to senior nurses and children's nurse advanced practitioners. One parent declined to participate stating that she had been repeatedly 'observed' by junior doctors. Posters were displayed in a range of locations to provide information about the study to health professionals and other family members who might be present on the ward during observation. It was not possible to inform everyone of the study due to the nature of the acute environment, as people entered the ward transiently and without notice. However, when there was an opportunity, and away from direct care delivery, as many people as possible were informed the study was taking place by JV or the nurses on the ward.

Three broad concepts and associated themes were identified; parents as advocates for their child; nurses promoting parental involvement and partnership and nurses unintentionally preventing parental involvement and partnership, and are presented in Figure 3. The conceptual model reflected the different ways in which nurses promoted or prevented involvement of parents in their child's pain care and the ways in which parents advocated for their child's pain care. Nurses appeared to move across the partnership continuum depending on the child's clinical status and the way parents engaged with their child's care. For example, little evidence of promoting partnership in relation to pain care was observed or discussed where the child had a medical condition, compared to children requiring or who had undergone

surgical procedures. However, it was observed that parents attempted to act as advocates for their child regardless of whether nurses promoted or prevented involvement, but was more overt when parents perceived that their child's pain care needs were not met.

Concept 1: Parents as advocates for their child

A dominant feature to emerge from both interview and observation data related to parents attempting to be an advocate for their child's pain care. The categories 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'. Being an advocate for their child was linked to parents' satisfaction with involvement, which appeared to drive parents' advocacy role. Parental satisfaction with involvement in their child's pain care was variable, 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:

'Erm, no, I felt it was ok.. 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 mum/ dad?

However, other 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 or persistently highlighting their dissatisfaction with pain care:

Henry's mother and paternal grandparents approached me [researcher] 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

In an attempt to be more involved, parents appeared to use their knowledge of their child and previous knowledge of pain care to initiate pain care. 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:

'I did, erm, we knew that the physios were coming about half past one, so we, me and the nurse had discussed that probably more appropriate to have something before the physios came to sort of take the edge off... Erm, I went to remind the nurse. Well we know that because, erm, my niece, his cousin, broke her femur.' Family 18, Fred aged 8 years, interview mum/ dad?

Other parents who were not satisfied with their child's pain care were hesitant or 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 managed in a timely manner;

'I just did not want to be fussing, but I knew ...she was getting tetchy so I knew it was due, and no-one was coming... so, I might have 'hummed' and 'arhd' 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 mum/ dad?

'...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 mum/ dad?

Many parents wanted greater involvement in their child's pain care but required support from nurses to do so. Parents often suggested the ways in which they could be more involved, but were reluctant to ask for support. Whereas, other parents expressed frustration with hospital procedures and practices that did not ensure their child's pain care needs were met, such as inadequate prescriptions for analgesia, for example:

'I would be happy to be more involved. 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'. Family 25, Amy 2 years, 10 months, interview mum/ dad?

'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 mum/ dad?

However, in contrast nurses' highlighted that some parents did not seek assistance or support if their child was experiencing pain, as illustrated here:

'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

Concept 2: Nurses promoting involvement and partnership

Despite the findings indicating variability in how nurses involved parents in their child's pain care, there were occasions where nurses did facilitate parental involvement in care. Involvement was described by nurses as listening to parents and valuing their contribution. Nurses' accounts revealed that they recognised the importance of listening to parents about their child's experience of pain:

'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

'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

Nurses recognised that parents could contribute to care. However, nurses' views of parents' contribution to pain care appeared to be influenced by a range of factors such as how knowledgeable they perceived parents were. For example, parents were viewed as knowledgeable if they worked in a healthcare setting.

'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

At times nurses were observed to discuss the child's pain with the child and family and check understanding, asking specifically what helped with the child's pain. This occurred more in surgical care areas and was largely absent in areas where children were admitted with medical conditions.

Concept 3: Nurses unintentionally preventing involvement and partnership

While nurses were observed to listen to parents' views of their child's pain, listening to parents was primarily related to eliciting their views about their child's current pain experience to inform nurses' decisions, rather than actively encouraging parental participation in care decisions:

'the best person to ask about the child is their parent, they know their child and if they think something is wrong... try and decide if I think, erm, pain relief is needed. You're the one that's deciding on medications and prescribing them.' Nurse 8, Karen, interview

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:

'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

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 extract highlights 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 then you can have those discussions after...if somebody's anxious, it's, they often don't take information on board...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

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 their 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

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:

'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 ...and that can feel a bit ooh, you know, I'd better watch what I say here... 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, linking with parent advocacy, 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

When parents reported that their child was experiencing pain, “being seen” to be responding and implementing pain care was highlighted by nurses:

‘Especially if the child is crying and they think “have they had anything given” ... 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 ...are they believing you that there is nothing else and the drugs that they've had?.'

Nurse 2, Lorraine, interview

Nurses found it difficult to articulate family-centred care and indicated a range of differing views on how this was reflected in practice:

'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

Although nurses aspired to family-centred care, they were not observed to overtly discuss with parents how they could be involved in their child's pain care. Nurses did not refer to attributes central to family-centred care, such as negotiation, empowerment, participation or partnership when describing involving parents in care. Rather, nurses described family-centred care in practical terms, such as being given

a choice about being present during procedures. Furthermore, being able to stay with the child was often the response when asked about how nurses promoted 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

Similarly, nurses described that providing information was related to family involvement in pain care:

'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 providing information about pain care, particularly analgesia, was a dominant feature of both nurses' and parents' accounts and observations. Parents often referred to being provided with information.

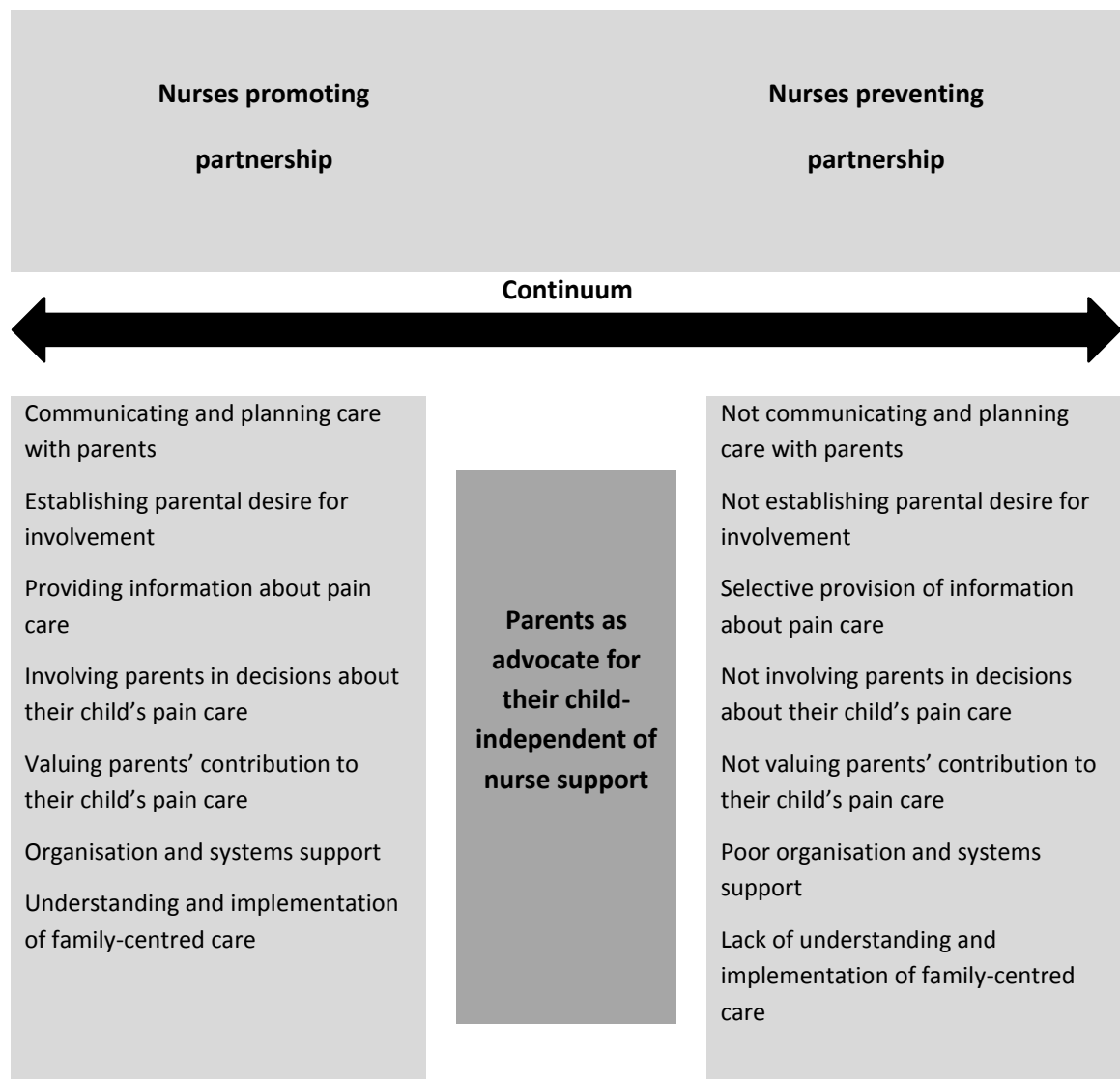
'Erm, yes, it was really helpful actually, erm, the nurses went through everything, sort of with as well, erm, ... what was going to be happening and things like that, so that helped.' Family 15, Sebastian aged 5 years, interview

However, when asked about how they became actively involved in care, one parent highlighted that parents may need to vocalise their concerns:

'she spent too long arguing the toss really...erm, with me about how things are prescribed. It makes no odds, it still needs to be prescribed by somebody...so there wasn't any warning of it building up, erm, so then they had to react rather than proactively keep him pain free. Is it down, I suppose, a lot to how, not the right word, bolshy the parent is, you know, do you know what I mean' Family 18, Fred aged 8 years, interview.

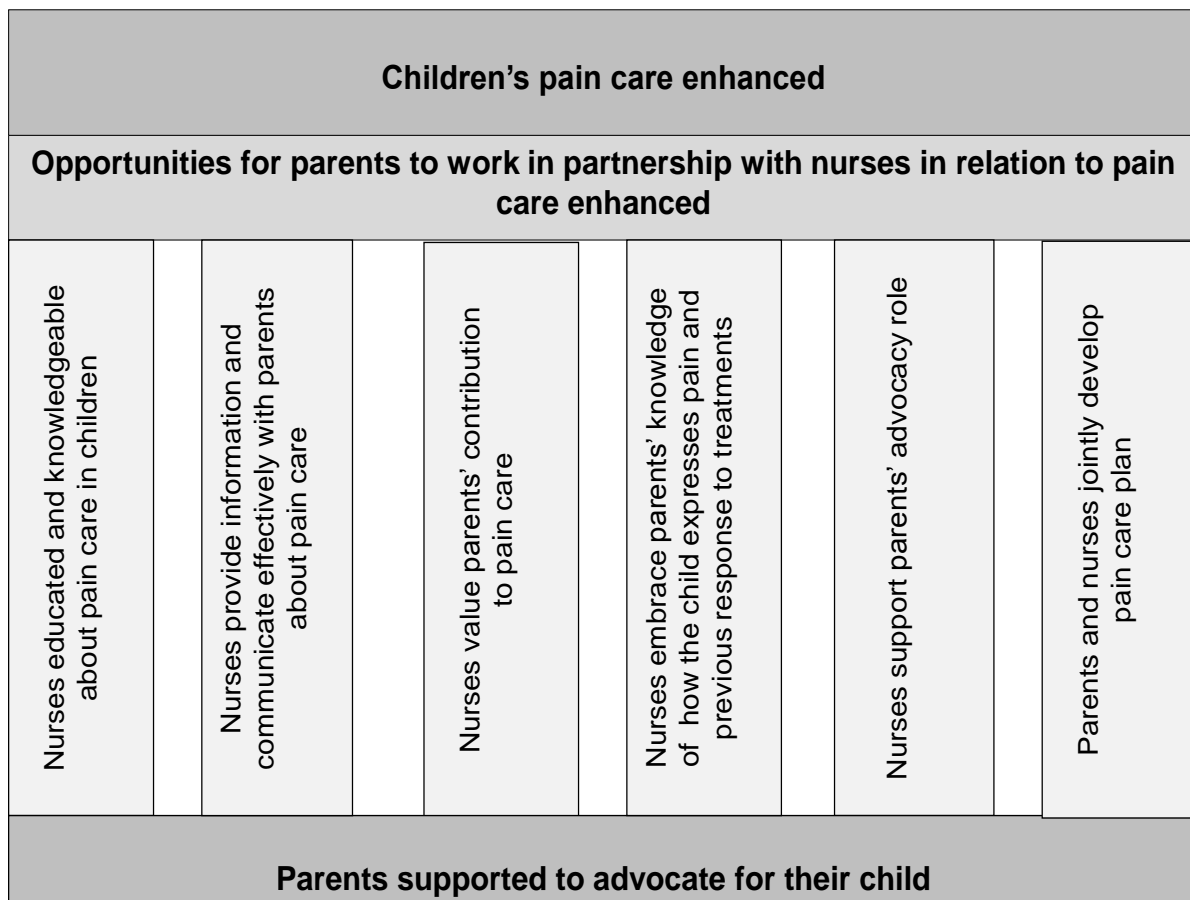
Exploring these concepts in relation to participant observation and interview data during analysis has revealed parents' needs for involvement and a better understanding of how partnership working in relation to pain care can be enacted in practice. The conceptual framework presented in Figure 3 brings together the themes and illustrating the relationship highlights the ways in which nurses promoted or prevented partnership working, and how parents advocate for their child's pain care.

Figure 3: Conceptual Model: promoting or preventing partnership working



The final stage of the Framework approach, if appropriate, involves making connections between the themes, and expanding existing knowledge (Spencer et al., 2014). The *'Pillars of Partnership in Pain Care Model'* presented in Figure 4, developed from the findings, offers a new framework to support nurses to work in partnership with parents with the emphasis developing parents to be proactive advocates for their child's pain care, rather than parents attempting to do this in isolation. The model represents the dynamic relationship between parents as advocate for their child and identifies the specific support that can be provided by nurses to achieve this.

Figure 4 *"Pillars of Partnership in Pain Care Model"*



Discussion

This study offers a unique insight into parental involvement in a child's acute pain care in general children's wards. As far as we are aware, this is the first study to identify the significant finding of the dominant role of parents as advocates in their child's pain care whether or not supported by nurses. The study found that nurses do not consistently involve parents in their child's pain care or implement family-centred care as a framework to support involvement. Despite this, parents who perceived that they had not been involved in care or they were not satisfied with pain care were prompted to speak out in an attempt to advocate for their child's pain care, highlighting the gap between the support parents require to be involved in their child's pain care and what nurses provide. We know that nurses want to support

parental involvement (Diaz et al., 2005; Smith & Kendal, 2018), but to date there appears to be lack a clear and coherent framework to underpin the implementation of the support required. The *'Pillars of Partnership in Pain Care Model'* offer an evidence-based framework to guide practice.

Findings from this study highlighted that nurses engaged in activities that either promoted or hindered parents to be involved in their child's pain care, ranging from exclusion to active collaboration. Engaging with parents by sharing information, valuing parent knowledge of their child, embracing and building on parent knowledge of pain care and communicating in an equal partnership to establish parent expectations of involvement can promote partnership working (Smith et al., 2015; Smith & Kendal, 2018). While some elements of each of these aspects of care were evident with nurses valuing parents' prior knowledge and knowledge of the child, this did not occur consistently. Lack of communication and information provision and poor negotiation of roles resulted in missed opportunities for nurses to work in partnership with parents, which is reflected in the wider literature (Shields, 2015).

Nurses are in a position of power and control in acute healthcare environments (Gibson, Britten & Lynch, 2012). In contrast, parents are not in a strong position to negotiate with professionals as they usually lack the knowledge and experience that healthcare professionals have, and if not invited to collaborate in care and care decisions the opportunity for contribution can be limited (Hill, Knafl & Santacroce 2017). Nurses in this study tentatively invited parents to be involved by seeking their views on their child's pain, but did not usually acknowledge parents' contribution or follow this up with inviting parents to be involved in decision about care. Failure to effectively clarify and negotiate roles has been well documented and a key factor to the lack of effective implementation of family-centred care (Coyne, Murphy, Costello, O'Neill & Donnellan, 2013; Lim et al., 2011). This was apparent in our study as nurses made decisions about pain care without parent involvement suggesting a lack of negotiation and unequal power balance between parents and nurses.

Being an advocate for their child's pain care emerged as a dominant finding of the study and was linked to satisfaction with pain care, with those parents who were less satisfied being more determined to be involved in care and subsequently taking on a more prominent advocacy role. Driven by a desire to ensure their child's pain care needs were met, as featured in this and other studies, parents used their knowledge of their child and previous experience of pain care to raise concerns when they perceived their child's pain care was suboptimal (Jaakola et al., 2013). In highlighting poor care, parents can be described as a "voice for the child" (Holm et al., 2003, p. 305). Although related to pain assessment, self-report is claimed to be the "gold standard" approach (Royal College Nursing, 2009). As children may not be able to communicate or "self-report" their pain care experience due to age, illness or developmental stage, perhaps the gold standard is for parents to speak up in behalf of their child, across all aspects of pain care. However, parents' ability to speak up to ensure their child's pain care needs are met can be facilitated or hindered by a range of factors. Facilitating parents' advocacy role can be enhanced by nurses eliciting parents' opinions and involving parents in care decisions (Coyne et al., 2013; Ford, Davenport, Meier & McRee, 2011).

Nurses have the most contact with families in acute hospital care and are therefore 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 (Manworran, 2007; International Association for the Study of Pain, 2018). However, findings from this study mirrored the literature in that several factors hinder parents' ability to undertake an advocacy role. Parents lack of medical and institutional knowledge and experience, coupled with poor communication and ill-defined negotiation of role boundaries can marginalise parent's ability to advocate for their child. Nurses are in a position to share and provide information to parents to address the knowledge deficit, but do not consistently do so, therefore rendering parents vulnerable in the relationship and reliant on nurses to provide relevant information (Twycross & Collins, 2013). Parents coming into acute care areas with their child are often uncertain what is going to happen, anxious and worried and can be overwhelmed by the situation and environment (Smith et al., 2013).

Despite the barriers outlined, a key and unique finding from our study highlighted is that when parents were dissatisfied with pain care, or their level of involvement, they often attempted to undertake a participatory role based on their desire to advocate for their child, whether or not they were supported by nurses. If as the study shows, parents are attempting to advocate whether or not they are supported by nurses, it would seem reasonable that the aim would be to promote partnership working and involvement by supporting them to do so. Nurses did not appear to recognise the importance of their role in supporting parents' position as an advocate for their child. However, the move towards supporting parents to advocate for the child is complex and could encounter the same problems that occur with implementing family-centred care, such as poor communication between professionals and parents, and issues of control and power. While professional elitism and subject specific knowledge (Gibson et al., 2012), often associated with inhibiting partnership working is claimed to be diminishing, our findings suggest the shift towards a greater parental advocacy role remains challenging for nurses. Nurses claimed that they wanted to work families in partnership, but appeared to lack the confidence to enact this, especially when parents were more knowledgeable, therefore unintentionally creating barriers. If nurses are to reduce barriers when working with families, they need to work in partnership with parents as equals. Equal partnership requires nurses 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. Without partnership working, parents will continue to independently advocate for their child, potentially creating conflict and poor relationship building between parents and nurses. Coaching 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 (Shields, 2015).

Family-centred care as an approach to involve parents in their child's pain care was not effectively implemented, as reflected in other research, and remains espoused (Coyne et al., 2013; Smith et al., 2015). The 'Pillars of Partnership in Pain Care Model' (Figure 4) is proposed as an alternative approach for children's nurses to adopt to enhance and support partnership working with parents. The model is based on the premise that partnership working can be enriched by parents being supported to advocate for their child to ensure that their pain care is effective. The model "pillars" are aimed to identify ways nurses can help, rather than hinder parents to improve the child's pain care. As illustrated in the model, to enable nurses to effectively communicate and provide information to parents, they would require

detailed knowledge of pain care and the ability to clearly articulate this to parents (Bettle, Latimer, Fernandez & Hughes, 2018). By establishing parents' requirements for information, as this would vary based on prior experience and knowledge, nurses can personalise the information to meet the individual needs. Implementing the model would require nurses to value parent contribution without feeling threatened, which can be challenging for nurses. Embracing parental knowledge can enhance the experience for all. The parent would feel valued and involved and the nurse can learn from parents' experience and perspectives of care. Once these elements have been addressed, the nurse and parents can work in conjunction to develop a pain care plan to implement together with parents leading the process (Ford et al., 2011). While there are similarities to the concepts of the family-centred care continuum, this model aims to shift the focus from a nurse focussed to a parent focussed model, effectively putting parents "in the driving seat". Parents' desire and ability to be involved will inevitably vary between parents and at different times throughout the child's illness trajectory (Lim et al., 2011). 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 being excluded from participating in care.

No other study has specifically explored parental involvement in pain care in an acute care area in a General Hospital setting using an ethnographical approach. This study highlights that issues raised in the literature relating to involvement of parents in care, underpinned by the espoused family-centred care approach, extend to pain care. Little progress has been made in relation to how nurses involve parents in their child's acute pain care in partnership. This study enhances our understanding of how nurses prevent parental involvement but more importantly explores how nurses could harness the contribution of parents' as willing and often determined advocates for their child's pain care.

Methodological considerations

Although a strong ethical code has underpinned this study, this may have resulted in some potential limitations. Not all interactions could be captured simultaneously, reducing the scope of the data. A larger sample in a wider range of setting could have enhanced the 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. The confirmation that family-centred care is espoused rather than enacted effectively in relation to pain care, has created tension in relation to exploring parental involvement based on the conceptual framework of family-centred care.

Relevance to practice

Children and parents benefit from parental involvement in the child's pain care. Nurses are in a position to support involvement. Family-centred care as a framework to promote involvement is poorly understood and implemented in relation to pain care. Parents attempted to advocate for their child's pain care whether or not they are supported by nurses. An alternative approach for supporting parents to advocate in their child's acute pain care is offered, the "Partnership in Pain Care Model".

Conclusion

Parents want to be involved in their child's pain care, but are not being supported by nurses to work in partnership in their child's pain care in acute hospital settings. Whether supported by nurses or not, parents are attempting to advocate for their child, drive involvement and potentially partnership working. Nurses claim to want to work with parents in the child's pain care and aspire to family-centred care as an approach, but do not always implement this effectively in practice. The Pillars of Partnership in Pain Care Model offers a way forward to overcome barriers to promoting parental involvement and partnership, by promoting nurse support for parent advocacy.

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Impact statement

- Children and parents benefit from parental involvement in the child's acute pain care
- Family-centred care as a framework to promote involvement is poorly understood and implemented in relation to pain care.
- Parents attempted to advocate for their child's pain care whether or not they are supported by nurses. An alternative approach for supporting parents to advocate in their child's acute pain care is offered, the "Partnership in Pain Care Model".