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# International Family Nursing Conference August 2015



# Tokenism or true partnership: parental involvement in the child's acute pain care

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#### Background



#### **Key concepts:**

- Pain care;
- Parental involvement;
- Family centre care;
- Preferences for involvement.

# Involving parents in pain care includes:

- Providing a pain history;
- Contributing to assessment of the child's pain;
- Be involved in decisions about interventions;
- Monitoring the child's pain and the effectiveness of interventions;
- Continuing pain care at home.







### Aim and objectives



#### Aim:

To explore parental involvement in the child's acute pain care.

#### **Objectives:**

- Describe interactions and experiences of the child, parent and nurse in the child's pain care in acute care settings;
- Examine extent to which parents/main carers are partners and are involved in their child's care;
- Identify factors which may influence parental involvement in their child's pain care;
- Explore ways parental preferences for involvement in their child's care can be identified, facilitated and enhanced.







#### Theoretical framework



#### Family centred care: A practice continuum

"Family centred care is an approach to the planning, delivery and evaluation of healthcare that is governed by mutually beneficial partnerships between healthcare providers, patients and families" (Shields et al 2006, p. 1318)

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







### Study design and methods



- Qualitative ethnographic approach
- Study setting was 2 district general hospitals:
  - 44 families observed/5 interviewed
  - 4 nurses observed/ 4 interviewed
- Data collection included non-participant observation with follow up semi-structured interviews with nurses and parents/childen
- Framework approach underpinned data analysis: (Ritchie & Lewis, 2003)







## Findings



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



# Concept 1Parents as advocates for their child

- Satisfaction with involvement in pain care
- Expectations of involvement in pain care
- Parents initiating pain care
- Ensuring that their child's pain care needs are met
- Knowledge of child informs care







#### Concept 1: extract



• 'I did explain it to them and I'm, probably because I was a little bit stressed anyway, weren't I, I said well I'll go and get him some more of my own if you can't get the doctors up to give it and she was trying to explain to me, well 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. Erm, that, I think that's just the nature of the injury. 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 (how parents could be more involved)? Family 18, Fred aged 8 years, interview.







#### Satisfaction with care and involvement



SATISFIED WITH LEVEL OF INVOLVEMENT	SATISFIED WITH OVERALL LEVEL OF INVOLVEMENT DESPITE OCCASSIONAL LACK OF INVOLVEMENT		DISSATISFIED WITH LEVEL OF INVOLVEMENT	
Satisfied with pain care	Overall satisfied with pain care, despite occasional dissatisfaction with care		Dissatisfied with pain care	
No concerns voiced	Voiced concerns	No concerns voice	Voiced concerns	No concerns voice

# Concept 2Nurses promoting involvement and partnership



- . Communicating and planning pain care with parents
- . Providing information about pain care
- . Involving parents in decisions about pain care
- . Valuing parents' contribution to their child's pain care
- . Organisation and systems support
- Understanding and implementation of family-centred care







#### Concept 2 extract



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







## Concept 3-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 familycentred care







#### Concept 3 extract



'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







#### **Future directions**



- Pillars of partnership in care model
- Evaluation of model
- Include children in similar study to enhance child perspective





#### The Pillars of Partnership in Care Model



#### Children's pain care enhanced

### Opportunities for parents to work in partnership with nurses in relation to pain care enhanced

Nurses educated and knowledgeable about pain care in children communicate effectively with parents about pain care to pain care to pain care to pain care to pain care how the child expresses pain and previous response to treatments

Nurses support parents advocacy role

Parents and nurses jointly develop pain care plan

Parents supported to advocate for their child

#### Who has the first question?



#### Thank you for listening

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