Ten lessons from 10 years of research into parental involvement in infant pain management

This article explores the past 10 years of research into the involvement of parents in the management of their infant's pain on the neonatal unit. It uses this clinical evidence to explore current practices on neonatal units, providing recommendations to bridge the gap between theory and practice.

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Key points

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1. Parents worry that their infants will suffer short- and long-term consequences from experiencing pain in the neonatal unit.
2. Nurses are vital in ensuring that parents are educated in techniques of how to recognise, assess and manage their infant's pain to address these worries.
3. Improving the culture of pain management and awareness as a unit will help nurses to achieve this goal.

Parents of infants receiving treatment in the neonatal unit worry that their infant will experience pain[1]. Research on parental stressors in the neonatal unit has shown that pain, along with the loss of the parental role, is of major concern to parents[2]. These stressors are associated with higher stress levels in parents, which may in turn impact upon healthy attachment and bonding with their infant in the neonatal unit, which is vital for the long-term development of the infant[3]. At three years post-discharge mothers recalled their infant's suffering as one of the most stressful experiences in the neonatal unit[4]. Studies have also indicated that the more involvement parents have in their infant's pain management in the neonatal unit, the more empowered they are to manage their infant's pain following discharge.

A randomised control trial by Franck et al in 2011 piloted a pain information booklet and instruction on infant comforting techniques[5]. The results highlighted a small positive effect on parents perceived role attainment. Interestingly, it was also noted that by simply implementing the intervention, the frequency of pain assessment documentation increased. This would indicate that greater attention to parents' information and participation needs regarding their infant's comfort, led nurses to improve their infant pain care practices.

Parental understanding of pain management

The understanding of parents about their infant's pain management varies. In one study, 30% of parents did not know if their infant had received pain medication[12]. Some parents thought that their infant had received medication when their medical records reported none (15%), whereas others thought that their infant had received no pain medication when in fact they had (3%). Parents were not routinely shown ways to detect pain in their infant, but despite this they developed their own measures to determine whether their infant was experiencing pain, including noticing crying and facial expressions[6]. Interestingly, parents in a study by Gale et al in 2004 perceived a mismatch between parents' perception of their infant's pain level and those of staff, leading to concern that staff would not respond appropriately[7]. Staff must therefore ensure that both they themselves and the parents are aware of the correct identification of pain and its subsequent management, using a valid and reliable tool.

Being able to recognise that their infant was in pain caused the parents distress, particularly during what they perceived to be painful procedures (such as eye examinations and lumbar punctures). In Gale et al's qualitative exploration of parents' perceptions of their infant's pain, parents reported that the decision of whether to stay and comfort the infant or leave due to the distress the infant's pain would cause them, resulted in much anxiety[7]. Thus some parents do not necessarily want to be present during all interventions; however to determine this, neonatal staff need to have discussed their preferences and asked the question of how much involvement they would like. In 2011 Franck et al found that less than 25% of parents in both the control and intervention groups trialling a pain assessment and management tool were asked by clinical staff for their preferences

of whether to stay during painful procedures[5].

The nature of parental concerns about their infant's pain from the 10 years of research is summarised below:

- Recognition of pain: Is my baby in pain now? How do I recognise my baby's pain?
- Relief from pain: Will staff recognise my baby is in pain and comfort them if I am not here?
- Presence during painful procedures: I want to comfort my baby but I find it too stressful.
- Long-term outcomes of pain: How will pain affect my baby's future development?

The role of the neonatal nurse

Neonatal nurses play a vital role in facilitating parents to be active partners in care for their infants on the neonatal unit. They have been at the forefront of research into family-centred care (FCC) on the neonatal unit, promoting the principles that optimal health outcomes for the infant will only be achieved if families are fully involved in providing emotional, social and developmental support for their children[8]. Recent research has found, however, that this concept is not always adhered to and the implementation of FCC may be sporadic[9-10]. The implications for parents is that their concerns around their infant's pain may not always be recognised by neonatal nurses, limiting parents' opportunities to participate in comforting their infants and adding to parents' stress.

Recent guidelines and recommendations have recognised the vital role that parents have in managing their infant's pain. For example, the Toolkit for High Quality Neonatal Services[11] highlighted that:

"parents are encouraged and supported to participate in their baby's care at the earliest opportunity, including regular skin-to-skin care, providing comforting touch and comfort holding, particularly during painful procedures" (principle 3.5).

In order to participate in their infant's care, however, parents need to be supported to recognise when their infants are distressed, and provided with opportunities to learn the measures that they can take to provide comfort to their infant. For some parents, verbal information from the neonatal healthcare professional may not be enough to achieve this at such an emotionally demanding time. The Poppy Report, which explored FCC in all neonatal units within the UK, highlighted that while parents were very satisfied with overall care that staff provided in terms of support, as few as 30% of parents received written information relating to how to recognise and manage their infant's pain[9]. This was further highlighted in the 2011 survey of family care in neonatal units by Bliss and the Picker Institute, which found that only 40% of parents received any kind of written information about their infant's stay in the neonatal unit[10].

Clinical recommendations

There is a growing body of research in the past 10 years to determine how parents perceive their infant's pain, helping to develop an understanding of how healthcare professionals can empower parents to become involved in the assessment and management of their infant's pain[1,5-7,12]. Recommendations have been made for clinical practice; however the theory-practice gap remains, as recent research has shown[5,12]. The main findings from this research suggest that simple improvements in neonatal nursing practice may have far reaching implications for the alleviation of parental stress about their infant's pain. The following three sections provide recommendations for making changes to the clinical environment to improve the experiences of families:

1. Evaluating current practice

It is important to provide information about infant pain and its assessment and treatment to parents in an understandable way (verbal and written formats). If neonatal health professionals are to empower parents, they must themselves be competent and confident in their ability to assess and manage an infant's pain. There must also be an open culture of the recognition of infant pain within the neonatal unit. This may be facilitated by improved education and training, and the implementation of a valid and reliable infant pain assessment tool. Unit evaluation should include the following questions:

1. Does the unit have an infant pain assessment tool?
2. Is this tool used routinely for all infants?
3. Is there any training or are there updates on new findings in infant pain research?
4. What resources are available for parents in the unit?

Neonatal nurses will require on-going education and updates if they are to be effective role models for parents in providing pain assessment and management techniques. Study days and educational tools may facilitate a continuous learning environment for all neonatal health professionals.

Regarding information available for parents on the unit, some parents may find written information helpful, for others a visual tool may be more useful. Posters on the unit which highlight ways in which parents can recognise their infant's pain and the strategies they can employ to comfort their infant can be very effective. This may help to empower parents to bond and participate in the care of their infant, asserting their parental role.

2. Communicating with parents

Parents have many concerns about their infants pain, from whether they should be present for painful procedures to understanding the pain medication which their infants may be receiving[6-7]. The following questions should be considered when determining how staff actively involve parents in the assessment and management of their infants' pain:

- When is pain assessment and management discussed with the infant's parents/carers?
- Are parents asked how much involvement they would like in their infant's comfort care?
- How are parents supported to become involved?
- Do parents get the opportunity to document their concerns/comments?

3. Working together

Neonatal nurses need to work effectively with each other to ensure that there is continuity for the infant and parents in how the infants' pain is assessed and managed. This includes careful documentation of the use of pain tools, parents' concerns and comfort measures to be used. Individualised infant pain plans will facilitate staff to do this. This will then facilitate effective partnership with the parents, to allow for their input into the care planning and assessment of their infant. Despite the lack of written information and shared knowledge around pain management, parents are often satisfied with their infant's pain care and the ability of staff to manage this[5]. Studies have also repeatedly found that through simply asking parents questions about their desired level of involvement in pain

management, nurses have become more aware of the issues surrounding infant pain and documentation and provision of information has increased[1-5].

The following questions about practices on the neonatal unit need to be considered by staff members:

- Do staff routinely discuss an infant's pain profile on ward rounds?
- Do parents get the opportunity to document and discuss their concerns/comments?
- Do staff work with parents to determine a pain care plan for the infant taking into consideration plans for when parents are not present?
- Do staff have individualised infant pain plans to facilitate continuity of care with staff and parents?

Summary

Recent research into parental involvement in the assessment and management of their infant's pain has highlighted clinical questions which can be used as a driver to improve practice in neonatal units. Using these recommendations as prompts will help neonatal nurses to empower parents to assert their parental role and feel more confident in bonding with their infant, providing an optimal start to the infant's ongoing developmental care. Using the research on which to base practice will also ensure that the theory practice gap can significantly reduce, allowing neonatal nurses to stay at the forefront of building the evidence to underpin and drive forward best practice in infant pain management. To do this it is worth considering the following 10 lessons from 10 years of research:

1. Choose an appropriate pain tool
2. Educate staff on the unit
3. Develop resources for parents – written, posters, research
4. Choose appropriate timing
5. Talk to parents
6. Teach parents how to assess
7. Teach parents how to comfort
8. Document
9. Discuss in the ward round
10. Evaluate

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