

## **Persistent pain in neonates: challenges in assessment without the aid of a clinical tool**

Elaine M Boyle PhD, Joanna Bradshaw RN<sup>1</sup> and Kathryn I Blake MB ChB<sup>1</sup>

Department of Health Sciences, University of Leicester and <sup>1</sup>Neonatal Unit, University Hospitals, Coventry and Warwickshire NHS Trust

### **Corresponding Author:**

Elaine M Boyle

Senior Lecturer in Neonatal Medicine

University of Leicester

Department of Health Sciences

22-28 Princess Road West

Leicester LE1 6TP

Email: [eb124@leicester.ac.uk](mailto:eb124@leicester.ac.uk)

Tel 0116 252 5447

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### **Key Notes:**

- No accepted definition exists for persistent pain in neonates; assessment tools are few; strategies used by staff and parents in assessing babies' pain have not been explored.
- Professionals use diverse methods and terminology when assessing pain, and perceive greater difficulty than do parents observing their own baby
- There is a need for terminology that facilitates communication between professionals and enhances identification and targeted management of different types of neonatal pain.

## **ABSTRACT**

**Aim:** Evaluation of comfort and pain in neonates is important for management. Specific signs of persistent pain in neonates remain undefined; few validated clinical tools assess persistent pain. We sought to determine (i) difficulty perceived by staff and parents in assessing comfort/persistent pain in babies, (ii) strategies employed when no clinical tool is used (iii) variation between clinicians' assessments.

**Methods:** Parent and staff questionnaires addressed difficulty in assessing pain/comfort in neonates and strategies used in making assessments.

**Results:** 47/50 (94%) parents and 83/91 (91%) staff participated. 50% of staff reported it was moderately/very difficult to assess persistent pain, and 13% very easy. 75% of parents found it moderately/very easy and 23% difficult to assess their baby's comfort. 15% of parents thought staff found pain assessment difficult. Staff described 94 different factors indicative of comfort and 139 factors of persistent pain. Terminology differed widely and was often non-specific. 67% of staff described forming a 'general impression'.

**Conclusion:** Pain assessment is challenging for staff. Most parents feel confident in assessing their babies' comfort, but may overestimate the ease with which staff can do so. Indicators of persistent pain/comfort are poorly defined; staff use differing, subjective assessments, which may complicate communication between carers.

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### **INTRODUCTION**

Pain assessment is an important part of care in the neonatal intensive care unit (NICU), and can help to achieve appropriate and timely pain management. Simple environmental measures such as containment or facilitated tuck are useful in managing pain in a newborn baby. Pharmacological treatments, when necessary, include sucrose, paracetamol or opiates, dependent on severity. The importance of identifying and appropriately managing pain is demonstrated by the fact that both increased exposure to neonatal pain and opiate administration have been shown to have adverse short- and long-term effects on neurodevelopment(1)

Most pain research in neonates has centred upon acute pain associated with tissue damage. There are now many validated clinical tools to assess acute procedural pain in pre-verbal infants(2) although utilization of these in clinical practice is variable(3-5). In contrast, the concept of persistent pain in newborn infants has received less attention from researchers(6, 7). There is no accepted definition of 'persistent pain', also variously referred to as 'chronic', 'ongoing' or 'prolonged' pain. Pain definitions in adults often include a stated duration, and so are inappropriate for neonates. In articulate individuals, subjective assessment and self-report contextualize the perception of pain, but this is not possible in pre-verbal infants. It has been suggested that persistent pain in neonates may be considered as that resulting from inflammatory conditions, therapeutic interventions such as mechanical ventilation, or repeated procedures. It has also been defined as pain persisting for longer than would normally be expected following a particular painful stimulus(7). However, clear and specific

signs of persistent pain in neonates remain undefined, although a framework for defining terminology for pain in the newborn has recently been proposed, albeit with a limited evidence base(8).

Although it is recognized as an important entity, only a small number of validated clinical tools attempt to assess persistent pain(9-11) and these have not been universally adopted into clinical practice(12). In the clinical environment, a baby's condition is often considered in terms of 'comfort', which is similarly subjective and difficult to measure without self-report, but has been defined as "a state of physical ease and freedom from pain or constraint"(13). Nevertheless, despite challenges in definition, the evaluation of a baby's ongoing comfort and identification of pain during neonatal intensive care is of major concern for both parents and staff (14-16).

Measurement of pain in neonates is challenging, given the lack of self-report and limited behavioural repertoire. Without universally accepted objective tools it is inevitable that nursing and medical staff use subjective measures to assess levels of pain or comfort in sick and preterm neonates. We sought to determine (i) the level of difficulty perceived by staff and parents in assessing comfort in babies, (ii) strategies used by NICU staff on a day-to-day basis to assess levels of comfort and persistent pain in neonates in the absence of a clinical tool and (iii) to what degree these strategies were similar or variable between individuals.

## **METHODS**

A questionnaire study was carried out in a single NICU in the United Kingdom, in which there was no routine use of a validated pain assessment tool, and clinical judgement during routine care guided decisions about the need for analgesia. All medical staff, nursing staff, and parents whose babies were being cared for on the NICU were eligible to participate with no exclusion criteria. Participants were given information about the study that clarified the

definition of persistent pain used in the study as “pain that is not associated with an invasive procedure”. All participants receiving the questionnaire were able to speak and read English; questionnaires were administered and completed by staff and parents within a one month period. Semi-structured questionnaires, containing forced choice answers and options for free text, were developed for both parents and staff. These were revised prior to administration according to feedback from professionals with experience of neonatal care and parents who were not involved in the study.

Parents were asked to report the level of difficulty they experienced in assessing comfort in their own baby and the level of difficulty they believed that staff experienced in the assessment of their baby (four choices ranging from “very easy” to “very difficult”, or “don’t know”); how important they regarded management of persistent pain to be (five choices ranging from “not at all important” to “very important”); and whether they thought their baby’s comfort was being regularly assessed. A similarly designed questionnaire for nursing and medical staff asked about the degree of difficulty that they experienced in assessing babies’ comfort and persistent pain; whether they believed that watching a baby’s behaviours was helpful to assess comfort and persistent pain; and how important they regarded management of persistent pain to be. In addition, members of staff were also asked to suggest, using free text, which specific factors they believed to be valuable indicators of either comfort or persistent pain in babies. All participants received a verbal explanation and written information about the study prior to receiving the questionnaire and completed the questionnaire anonymously. Receipt of the completed questionnaire by research staff was regarded as implied consent to participate. The West Midlands Research Ethics Committee gave approval for the study.

### **Data analysis**

Two researchers (EMB and JB) independently reviewed all returned questionnaires. For forced choice answers, proportions of participants selecting each answer were recorded.

Free text results identifying indicators of comfort or persistent pain were coded and categorized according to similar emerging themes. This categorization was aided by discussion groups comprising members of staff to explore and confirm understanding where terminology was unusual, or if there was any lack of clarity. For each indicator, the number of staff who reported using this indicator in day-to-day practice was recorded.

## **RESULTS**

### **Staff Questionnaire**

84/91 (92.3%) staff completed and returned the questionnaire. All participating staff rated the management of persistent pain as a very important part of neonatal care. 50% of staff reported that it was either moderately difficult or very difficult for them to determine whether a baby was comfortable or had persistent pain; only 13% reported that they found it very easy.

### **Parent Questionnaire**

47/50 (94%) parents completed and returned the questionnaire. Of these, 62% had spent 3-6 days, 23% 7-14 days and 15% had spent more than 14 days with their baby on the neonatal unit prior to completion of the questionnaire. All parents who returned questionnaires reported that they regarded the management of persistent pain as a very important part of their baby's care. 75% of parents indicated that they found it either very easy or moderately easy to determine whether their own baby was comfortable; 23% said it was difficult for them. More than 75% of parents thought that their baby's pain/comfort levels were regularly assessed during the neonatal stay. Only 15% of the parents thought that staff experienced difficulty in assess babies' comfort (Table 1).

**<< Table 1 >>**

**Indicators used by staff to assess pain and comfort**

Using free text, staff identified a total of 94 factors that they thought were indicative of a baby's comfort and 139 factors that they believed indicated persistent pain. Terminology differed widely between members of staff and many of the indicators suggested were non-specific. However, there was considerable overlap in themes and most indicators fell into the following broad groups: (i) physiological indicators; (ii) facial expression; (iii) body posture and movements; (iv) response to handling; (v) sleep patterns; and (vi) subjective opinion. Table 2 shows details of these indicators and the proportion of staff stating that they used each of them in their own clinical practice. Most members of staff reported using a combination of indicators to determine a baby's status with respect to comfort and pain, but different individuals used different combinations. 67% of staff also described the importance of simply forming a general impression of a baby's comfort to support their interpretation of clinical indicators.

#### **<< Table 2 >>**

## **DISCUSSION**

In this study, we have demonstrated marked diversity in the way in which pain and comfort are assessed on a day-to-day basis by nursing and medical staff caring for preterm and sick neonates in a NICU setting. We have also shown that medical and nursing professionals perceive greater difficulty in identifying comfort and pain than do parents observing their own baby. To our knowledge, no other study to date has explored the way in which nurses and doctors approach this challenge in everyday practice, given the limited guidance available and lack of consensus.

A strength of our study was the high response rates from both staff and parents, enabling us to obtain a comprehensive representation of views from a wide range of participants. The main limitation was that the study was conducted in a single neonatal centre, meaning that staff may have received similar training in pain assessment and management. However,

among those participating, there was a range of past experience of neonatal care in different settings and it is unlikely that all were trained in a completely standardised way. For this reason, we believe that our results are likely to be generalizable to other similar units. A further limitation is our failure to ask parents about indicators of comfort or pain that they felt were important. This would have allowed comparison between staff and parent perceptions but, at the time of study design, it was felt that demanding such detailed consideration of their baby's potential or actual pain might be unduly distressing.

Identification and assessment of persistent pain in neonates is acknowledged to be more challenging than the evaluation of acute pain(6, 7, 11). There is no accepted gold standard measure and, although a small number of assessment tools have now been developed(9-11), none has been universally adopted into clinical practice. Nevertheless, despite limited understanding about definitions and signs of persistent pain, decisions are needed, every day and in every NICU, with respect to administration of analgesia or other comfort measures. A recent study in 18 European countries showed assessments of continuous pain occurred in less than one third of NICU admissions; only around 10% received daily routine assessments(12). In the 66 UK units included in this study, reported rates of pain assessments were 40% to 60% for ventilated, and 30% for spontaneously breathing infants. Use of local guidelines and pain assessment tools varied considerably between units, as did the proportion of ventilated infants receiving pain assessments(17). However, more than 80% of ventilated, and a small proportion of non-ventilated babies received analgesic or sedative medications, suggesting that either formal or subjective evaluations may have guided this therapy. Although our work may be less relevant for centres where a formal pain scale is in use, surveys have consistently shown that many NICUs worldwide have chosen not to use available scales in routine clinical practice (3-5, 18-20).

Our questionnaire responses highlighted a large number of indicators reported to be used by staff for assessment of comfort and persistent pain. There was substantial diversity in the



choice of terminology and descriptions, although there were similarities and areas of overlap, allowing distillation of the information into discrete categories. Information obtained during discussion groups indicated that different individuals used different terms to express similar concepts. Whilst the range of terminologies was understood and recognised by many, there was limited consensus about which terms were most appropriate. The use of diverse terminology is likely to introduce confusion and misunderstanding, which may be particularly important when responsibility for care is being handed from one professional to another.

The clinical acceptability of any tool requires that it has face validity and can be readily used by professionals. In a recent review, Van Dijk and Tibboel proposed a checklist of behavioural signs associated with well-being or prolonged pain in neonates and infants, based on their own research and published literature(21). A number of items appear both in this checklist and in our responses from clinicians. Using such indicators, one might expect that it would be possible to define common, acceptable, and easily comprehended terminology. However, a recent Delphi Survey(7) attempting to achieve consensus in defining chronic pain in neonates was unable to identify a range of specific indicators for the diagnosis of chronic pain, and it generated wide-ranging statements about definition and aetiology. The report concluded that signs may be non-specific and differ between babies, and may therefore not be amenable to assessment using current tools. Our findings are in line with these concepts, but also suggest that differing perceptions between assessors may be difficult to reconcile, increasing the challenge further.

## **Conclusions**

Members of staff involved in the care of sick and preterm infants perceive that assessment of comfort or persistent pain in neonates is challenging. Highly subjective and non-specific assessments appear to be common and staff use widely disparate terminology to assess comfort and persistent pain in the NICU. Without standardised and validated means of assessing and quantifying pain, communication between staff and with parents is difficult.

This may threaten effective continuity of care with respect to pain management. Further research should be directed towards more objective means of detecting persistent pain in the newborn; techniques such as electroencephalography, near infra-red spectroscopy or neurological imaging may prove useful in future(22). However, until such techniques have been fully evaluated and are feasible for bedside use, there is a pressing need to develop terminology that facilitates and enhances communication in the clinical environment. This includes clarifying potential sources of persistent pain and developing terminology to allow better description of type and severity of pain and improve targeting of appropriate treatments, as suggested in the recently proposed framework(8). Parents report greater confidence in assessing their own babies and may overestimate the ease with which staff can make such assessments. Their experiences and perceptions may prove valuable in guiding development of new clinical assessment tools.

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### **Abbreviations**

NICU – neonatal intensive care unit

**Conflicts of Interest:** None declared

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