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Original Reports

Chronic Pain in Hospitalized Infants: Health Professionals' Perspectives

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Abstract: Potentially significant numbers of infants hospitalized in Neonatal Intensive Care Units (NICUs) and Pediatric Intensive Care Units (PICUs) experience chronic pain. However, the phenomenon of chronic pain in infancy has neither been defined nor described adequately by researchers. To stimulate and focus further work in the area, the purpose of this study was to explore expert opinions on definitional and assessment parameters of infant chronic pain. Forty-five health care professionals, with a median of 17 years of clinical experience, were recruited from 4 tertiary-level, university-affiliated institutions. Individual (n = 24) and group (n = 21) interviews were conducted by trained interviewers. Qualitative data were analyzed using a standard descriptive method. Health care professionals were able to offer preliminary definitions of chronic pain in infants. The most contentious definitional issue was whether iatrogenically prolonged pain (pain induced and maintained by medical procedures) should be considered chronic pain. Possible indicators for chronic pain included inability to settle, social withdrawal, constant grimacing, tense body, hypo- or hyper-reactions to acute pain, and dysregulated sleep or feeding patterns. These indicators differed significantly from those traditionally used to measure acute pain.

Perspective: Despite infants' established capacity to physiologically experience chronic pain, no current definitions exist that are wholly applicable to infancy. By exploring the definitional parameters and potential assessment cues of infant chronic pain, this study provides a foundation for improving pain measurement and management in infants with chronic pain.

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A recent consensus statement acknowledges that infants can experience chronic pain.³ However, there is no clear definition for chronic pain in

infants, nor are there validated assessment scales. As a result, long-term pain may be inadequately managed in a vulnerable population. In older children and adults, chronic pain has been defined as pain without apparent biological value that has simply persisted or persisted beyond expected tissue healing time.² Temporal delineations of "healing time" have been debated,⁶ as some suggest that pain could be considered chronic even if it lasts less than 1 month,¹⁵ whereas some offer definitions that stipulate pain should persist for 3 months⁸ or 6 months⁹ to be considered chronic.

Most of these timelines have the potential to systematically exclude the neonate and young infant simply

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because they have not lived long enough to fit these temporal criteria. Moreover, the concept of "normal healing time" in very young infants is poorly understood, especially in preterm neonates, in whom the gestational age of fetal viability continues to transition downward. Given the lack of a clear definition of chronic pain in infants and the considerable variability in how chronic pain is defined even in adults, it is not surprising that there is little research exploring potential assessment indicators for infant chronic pain.

A review of the literature produced 4 papers on pain beyond acute that could provide potential cues for infant chronic pain (Table 1).^{1,4,5,7,17} Although all of these researchers list potential indicators for "prolonged" or "persistent" pain in infants, there is a pronounced lack of agreement among them, particularly in the roles of physiological indicators, observation time periods, the role of cry, and type of facial expression. These inconsistencies are partly owing to the lack of consensus regarding when to use the terms "persistent," "prolonged," or "chronic" pain. Before one can properly assess and treat chronic pain in infants, a clearer articulation of a definition and key indicators for assessing chronic pain must be established.^{7,14,16}

Infants in Neonatal Intensive Care Units (NICUs) and Pediatric Intensive Care Units (PICUs) undergo many medical procedures that expose them to pain for long periods and are a population who may also suffer from chronically painful conditions (such as epidermolysis bullosa). Accordingly, clinical experts with these infants are an appropriate population to target in an exploratory study of how to best define chronic pain in infancy. Because prolonged pain is known to have both immediate and long-term consequences, it is crucial to understand this phenomenon more clearly. The contribution of experienced NICU clinicians is critical to the conceptualization of chronic pain in infancy. This descriptive exploratory study aims to elicit the opinions of highly experienced clinicians on the breadth of parameters that could be used to define and assess chronic pain in infancy.

Materials and Methods

Study Population

A primary selection recruitment strategy (researchers were aware of which specific individuals of a particular group would have the requisite knowledge to provide an informed response) was used to provide information-rich cases for in-depth study of this largely unexplored phenomenon (Morse, 1991). A purposeful sample (participants in our sample were selected for their level of clinical experience with infants) of 45 expert clinicians was recruited from 3 tertiary-level NICUs and 1 PICU in 3 university-affiliated hospitals in central Canada. Participants were recruited over a 10-month period spanning 2005 to 2006. Participants were considered clinical experts and were invited to participate if they (1) had a minimum of 10 years of professional experience caring for infants in an NICU or PICU setting (on 1 unit a lower boundary of 5 years was accepted as there were no clini-

cians within a particular profession that met this criterion); (2) worked more than 19 hours per week; and (3) spoke English. An attempt was made to select as broad a sample as possible in terms of profession, educational preparation, and practice site. In total, the sample consisted of 26 nurses (58%), 7 neonatologists (16%), 7 respiratory therapists (16%), 2 pharmacists (4%), and 1 of each from the following disciplines (6% total): occupational therapy, physical therapy, and nutritional science. Preliminary data analysis occurred concomitantly with data collection, and saturation (when no new information is added to the data pool by subsequent participants) was used as the criterion to determine the end of recruitment. The median level of experience for the sample was approximately 17 years (Fig 1), 77% of the sample was female, and 85% were between 36 and 55 years of age (9% were younger and 6% were older).

Procedure

The study protocol was approved by research ethics boards at the participating hospitals and universities. Eligible participants were identified, using the inclusion criteria, by nurse managers (not otherwise involved in the study) on each of the participating units. All approached health care professionals agreed to participate and provided informed consent.

Participants were interviewed either individually or in groups. Two interview modalities (individual and group) were used to maximize the numbers of eligible staff that could participate during the study period. Twenty-one participants (47%) were interviewed in a group format, whereas 24 participants (53%) were interviewed individually. All participants answered every posed question, and no one declined to comment during any part of the interview. Interviews were conducted by the lead author and 2 of her doctoral-level clinical psychology graduate students (S.A. and L.D.). All interviews were audiotaped, transcribed verbatim, and then double-checked for accuracy by a second transcriber.

Semi-structured Interviews

The structure of the interview guide was based on previously conducted work by the co-investigators^{10,11} to maximize idea generation from participants. Health care professionals were asked to describe an infant or a group of infants that they cared for that may fit into 1 of the following categories: (a) infants in pain for longer than expected given their medical status, (b) infants in pain for a longer period of time given what would be considered normal healing times for a particular procedure or procedures, and (c) infants in pain that lasted for a long period of time. After they had provided a clinical example, participants were asked if they thought that the infant may have had "chronic pain" and to justify their rationale. This 2-level sequencing of questions formed the basis for our analysis on opinions defining chronic pain. Respondents were also asked open-ended questions about (a) potential indicators of infant chronic pain and (b) potential medical conditions and situations that would characterize chronic pain in infants.

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