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“Doctor, I think my baby is in pain”: the assessment of infants’ pain by health professionals

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It was not that long ago that some health professionals did not believe infants could feel pain. Infants were not always given analgesics in the postsurgical period and sometimes during the surgery itself. Pain was not recognized as an important treatable symptom, and therefore was rarely assessed. It was only during the 1980’s that clinicians and researchers started to measure the impact of pain assessment and treatment in infants.1 Despite these research advances, it took years before pain assessment and treatment in infants became generalized, and unfortunately, they are not yet universal today in the medical world.

Parents, on the other hand, have known for ages that their young children can suffer pain. The article by Elias et al.,2 in this issue of the Jornal de Pediatria, illustrates well this disagreement between parents and health professionals. The most interesting finding of this study, performed in a non-acute pain situation, is that the agreement between parents and health professional was better in extreme situations, where pain was obviously present or absent, and decisions about treatments were not in doubt. It is in that gray zone of moderate pain that the disagreement was the most important, the zone where a few points higher or lower on the visual analogue scale (VAS) will make a difference between using an analgesic medication or not. Of this disagreement, only 10% could be explained by factors inherent to babies, leaving a large proportion of the difference of opinion to factors related to the person assessing the pain and to the context surrounding the assessment. This is not surprising, in a situation where the pain is not what the infant says, but what the parent or health professional says.

Disagreement between parents and health care professionals has been shown in the past for infants and toddlers,3 but also between health professionals4 and between children and parents.5 Using a VAS as a global pain assessment score by proxy may increase the risk of disagreement. The VAS is an observational scale in which each observer uses a collection of behavioral cues, which they interpret in the context of their own experience. In particular, the meaning of the anchor

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“worst pain imaginable” will vary from person to person. However, with a single observer, the VAS scale should have good consistency and not vary tremendously over time. Many multidimensional neonatal pain scales have been published in the past decade; few however, have been validated extensively, including the psychometric properties of reliability, validity, feasibility and clinical utility (see reviews by Stevens et al. and Hummel et al.). Most of them, with exception of the EDIN, have only been tested with brief procedural pain, and therefore their use is not appropriate in a chronic pain situation. To ensure adequate pain management of infants and to avoid as much subjectivity as possible, pain assessment by some method should be used regularly and systematically, and not only “as needed” when a health care professional thinks a child might be in pain. Many health centers are now considering pain as the “fifth vital sign.” This can only become true if, as for any other vital sign, a clinically significant change in pain intensity noted in the infant’s chart is translated into an appropriate action to relieve the pain and identify its cause.

Parents and health care professionals may also differ in their concern and distress about an infant’s pain. Frank et al. have shown that parents want information about their child’s pain and its management, and also want to be involved in their child’s pain care. In this study carried out in England, it was demonstrated that parental stress was predicted by parents’ estimation of their infant’s worst pain, their non-satisfaction with the information received on pain and their worries about pain and its management. Parents are experts on their child, and the importance of this knowledge should not be underestimated. A disagreement in pain intensity assessment between health care professional and parents can become a good opportunity to open the discussion about a child’s pain. This exchange of crucial information between parents and professionals can help improve pain assessment and treatment for this child and others.

While Elias et al. looked at agreement in a broad form, the phenomenon of pain underestimation has been well described in the literature. Pain overestimation seems to happen far less frequently, and usually when a patient reports no or very low level of pain. Why this bias toward underestimation? Prkachin described this issue as a lack of a “mental dipstick” that the health care providers could use to assess the patient’s consciousness and capture his current state. The observers are looking for cues in the behavior and context of the person suffering; access to those cues is often limited, and this limited information can bias the pain evaluation toward a lower score. The more limited this access to information is, the more severe the underestimation can be. This phenomenon puts some vulnerable populations at high risk of having their pain underestimated, including children who are nonverbal because of young age, cognitive impairment, or sedation. Obviously, other factors are involved in the observer’s pain assessment, as represented in the Prkachin & Craig model.

What make the Elias study so important is the fact that it looks at the parent-professional dyad, and not the patient-professional dyad, as with most studies published to date.

It is not clear as yet what the long-term effects on infants of this pain assessment disagreement are, in particular if it is the more common pain-underestimation. What is clear, though, is that neonates exposed to repeated pain early in life develop sensitization. This sensitization is even more significant in premature infants or newborns who have surgery during the neonatal period. To prevent sensitization to pain, good pain prevention, assessment, and treatment are crucial.

Examples of pain assessment guidelines have been published. Ideally, guidelines have to be adapted to each care center and to particular health care teams to be accepted, used, and efficient. Many obstacles might appear on the road to good pain assessment and will require energy and commitment from dedicated health care workers to be overcome. Lack of training and time, and a perceived unwillingness to change practice, have been identified as the main obstacles to changing pain assessment practice in pediatrics. The continuous support of a multidisciplinary pain team and collaboration with “local champions” can help sustain new pain assessment practices.

How can we apply Elias’s findings to a busy neonatology practice? The most important message is certainly to assess pain regularly, using well-validated pain scales with good clinical utility. Unless involved in research on the topic, one only needs to become familiar with one or two pain scales, and to use them systematically for every patient. We also need to remember the importance of the phenomenon of pain underestimation. Any of us may be guilty of this; it is most important that we pay attention to our attitudes, values, and beliefs about pain when we assess another person’s pain. Lastly, we should never forget to include and trust the parents as key team players in their infant care team. Their goals are similar to ours.

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