

# EVIDENCE-BASED PRACTICE IN ACTION

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## Pain Assessment in Nonverbal Children with Severe Cognitive Impairments: The Individualized Numeric Rating Scale (INRS)

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Children's Hospital Boston began a major pain assessment and management initiative 3 years ago: Pain assessment and management are considered one of the institution's primary standards of care. The initiative included State of the Science meetings with internationally renowned nursing pain researchers and clinicians. These meetings generated nursing staff interest in specific applications of what is known about pain; how evidence-based knowledge can be used to ask population-specific clinical questions; and how an evidence-based approach can be applied to systematically develop, implement, and assess interventions that suit a population's clinical needs. This article is an example of an evidence-based pain assessment project at Children's Hospital Boston that focused on nonverbal children with cognitive impairments. After developing a clinical question, the authors did a literature review and a benchmarking analysis of best practice. The pilot of an adapted, existing pain assessment tool is described in this article.

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**P**AIN IS A PERSONAL, subjective experience. We cannot see pain in others but we can observe how a person responds to the experience of pain. Self-report is the best method of assessing pain. Many validated self-report tools are available to help children and adults communicate their pain intensity. Patients unable to self-report pain must rely on others to recognize that they are in pain, assess the source of their pain, and then manage their pain accordingly. Until recently, pain assessment tools have not been available for children who are unable to report their pain because of severe cognitive impairments and communication difficulties.

Accurate pain assessment is the first step in effective pain management. It is especially important in nonverbal children with severe cognitive impairments. These children often (1) have medical conditions that cause pain, (2) require procedures and medical interventions that are painful, (3) need frequent hospitalization and are cared for by clinicians who may not know them well, and (4) are not able to express their pain verbally.

Children with severe cognitive impairments express pain differently depending on their mobility, developmental level, clinical condition, ability to vocalize, and learned behavior based on their car-

giver's response to their expression of pain (LaChapelle, 1999). On admission to the hospital, nurses traditionally ask parents (or their principal caregivers) about their child's usual pain behaviors and then informally pass this evolving knowledge from shift to shift. Because of the variation in the expression of pain in nonverbal children with severe cognitive impairments, a pain tool that facilitates systematic collection and documentation of the parents' knowledge of their child's pain expression is highly desirable.

### FOCUSED CLINICAL QUESTION

For nonverbal children with significant cognitive impairments, what pain assessment tool best uses the parent's knowledge of their child's pain expression?

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## THE SEARCH FOR BEST RESEARCH EVIDENCE

Medline was searched in several ways. First, we combined two search terms, "pain" and "nonverbal," and limited citations to those published in the past 10 years in English, involving human studies, in all child age groups. This resulted in 12 articles. Whereas most articles discussed pain assessment in preverbal children, one citation authored by McGrath addressed our clinical question. On review of search terms used in the McGrath article, we redesigned our search strategy. In our second search we combined two search terms, "pain measurement/mt [methods]" and "nonverbal," again limiting our search to those citations published in the past 10 years in English, involving human subjects, in children 6 to 12 years of age. This resulted in three articles, which included the McGrath citation. We then searched "McGrath PJ" (author) using the same limits, with "validation studies" and located an additional two studies. The three articles were reviewed and the reference lists were checked for any additional relevant citations.

Stallard, Williams, Lenton, and Velleman (2001) reviewed 2-week pain diaries of parents of 34 patients with severe cognitive impairments. Parents documented the severity and duration of their child's pain five times a day. Seventy-four percent of parents in the study observed that their children had pain at least 1 day in a 2-week period, with moderate to severe pain being experienced by 68% of patients. Despite these findings, none of the 34 patients received any medications for pain.

An important breakthrough in the assessment of pain in noncommunicating patients has been the creation of the Noncommunicating Children's Pain Checklist (NCCPC; Breau, Camfield, McGrath, Rosmus, & Finley, 2001; Breau, McGrath, Camfield, Rosmus, & Finley, 2000). Caregivers of nonverbal cognitively impaired individuals were interviewed and asked to recall typical pain behaviors in this population. The interview data then was used to create a 30-item checklist of common pain behaviors in noncommunicating patients. These behaviors then were classified into seven categories of behaviors: vocal, eating/sleeping, social/personality, facial expression of pain, activity, body/limbs, and physiologic (McGrath, Rosmus, Campbell, & Hennigar, 1998).

The latest version of the NCCPC Postoperative version (PV) (Breau, Finley, McGrath, & Camfield, 2002) contains 27 items classified into six subscales. The eating/sleeping category was eliminated to avoid false-positive results in the postop-

erative patient. To validate the NCCPC for postoperative pain, caregivers, researchers, and nurses observed cognitively impaired patients for 10 minutes before and after surgery and then rated each of the 27 behaviors as being observed: 0, not at all; 1, just a little; 2, fairly often; and 3, very often. Scores for all items were summed to create total scores. Caregivers, researchers, and nurses also rated the intensity of the children's pain during the same observation periods using a 100-mm visual analog scale. As expected, the NCCPC-PV scores were higher after surgery (indicating more pain) and did not differ by observer. Interestingly, the NCCPC-PV scores correlated with the visual analog scale ratings provided by caregivers and researchers but not with those of nurses. These results were explained by the methodology in that separate nurses completed the NCCPC-PV before and after surgery and that nurses, because of time constraints, were not provided training in common behaviors that may indicate pain in children with severe cognitive impairments.

## EVALUATION OF THE EVIDENCE

These studies are a major breakthrough in developing a formal pain tool for noncommunicating children. However, the current length of the checklist (27 items) and the time required to observe the patients (10 min) makes it cumbersome for clinicians. A tool used in daily clinical practice: (1) should be sensitive to individual differences in expressing pain, (2) be brief and easily scored by clinicians, (3) require minimal training to complete, and (4) be psychometrically sound. In addition, we were looking for a tool that collected and documented parent's knowledge of their child's individual behaviors.

## THE SEARCH FOR THE BEST CLINICAL PRACTICE

In September 2000, we invited three internationally renowned Nurse Researchers in pediatric pain (M. Broome, L. Franck, B. Stevens) to lead a 2-day colloquium on the current state of the art of pediatric pain assessment. Our goal was to identify the best pediatric pain assessment tools for use throughout Children's Hospital, Boston. During this meeting, the validity, reliability, and practicality of all pediatric pain assessment tools were reviewed systematically. The need for a practical pain assessment tool for nonverbal children with significant developmental delays was identified but, given the lack of existing data, a formal rec-

ommendation for an instrument in this population felt premature.

The Individualized Numeric Rating Scale (INRS) is an adaptation of the numeric rating scale that asks parents (and/or caregivers) to identify an individual patient's typical pain behavior and asks them to stratify that behavior on a scale from 0 to 10. It was developed by one of the authors (M.A.Q.C.) to help intensive care nurses observe, consistently document, and communicate the unique pain behaviors of intubated nonverbal critically ill children after major surgical procedures. Staff nurses outside the intensive care unit were introduced to the INRS during the pain colloquium and, through a consensus process, agreed to try using the instrument.

Currently, the need to use the INRS is determined on hospital admission. Nurses complete a Pain History and Initial Assessment then select the INRS if the patient is older than 3 years of age and cognitively dysmature. Parents are then given a blank INRS (see Figure 1) with a list of prompts to help them describe their child's common pain behaviors. Nurses then ask the parent to recall a time when they knew their child had pain whether from past surgeries, painful procedures, and/or experiences. Parents are then asked to describe those behaviors and link them with a number from 0 to 10 with 0 being no pain and 10 being the worst imaginable pain. To help parents recall past pain behaviors, nurses can use the face, legs, activity, cry, and consolability (FLACC) acronym (Merkel,

Figure One: Parent INRS Instructions

The following scale will help us assess and manage your child's pain.

**Directions:**

1. Think about your child's past painful events. How does your child act when in mild pain, moderate pain, or severe pain?
2. In the diagram below, write in your child's typical pain behaviors on the line that corresponds to its pain intensity where 0 = no pain and 10 = worst possible pain.
3. When describing your child's pain, think about changes in:
  1. Facial expression  
Squinting eyes, frowning, distorted face, grinds teeth, thrusts tongue
  2. Leg or general body movements  
Tense, gestures (more or less) or touches part of body that hurts
  3. Activity, or social interaction  
Not cooperative, cranky, irritable, unhappy; Not moving, less active, quiet or more active, fidgety,
  4. Cry or vocalization  
Moaning, whimpering, crying, yelling
  5. Consolability  
Less interaction, seeks comfort or physical closeness, difficult to distract/satisfy
  6. Other changes: Tears, sweating, holds breath, gasping

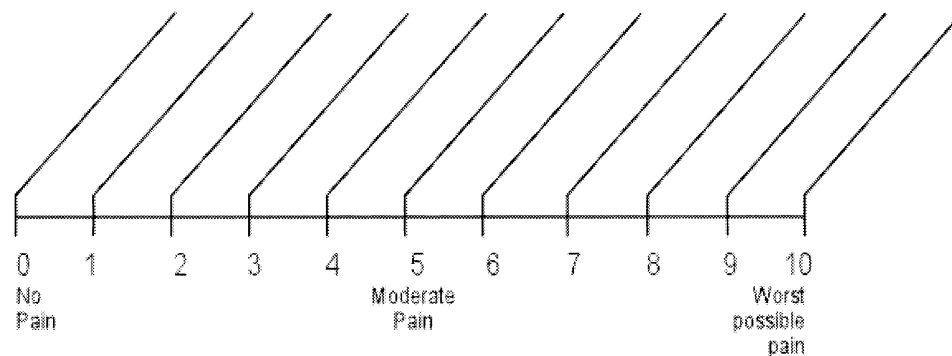


Figure 1. Parent INRS instructions.

Voepel-Lewis, Shayevitz, & Malviya, 1997) and pain adjectives adapted from McGrath et al. (1998). The FLACC is a behavioral measure of pediatric pain intensity initially studied in patients aged 2 months to 7 years. When the parent understands the task they complete the INRS (Figure 2). If the parent is unable to read, write, and/or communicate in English, the nurse completes the INRS with the parent and, if necessary, an interpreter.

As nurses provide care for the hospitalized patient, they also can add pain descriptions to the INRS to create an assessment tool that communicates the patient's personal expression of pain. Pain assessment and the INRS descriptors are discussed during change of shift report and used to establish an informal interrater reliability (agreement between the observers) on the individual patient's pain assessment between nursing shifts.

### IMPLICATION FOR PRACTICE

Since our initial pain assessment planning Colloquium in 2000, the INRS has been used as the pain assessment tool for many acutely ill patients with cognitive impairments on the general inpatient units. This simple adaptation to the established NRS works very well in a clinical setting. It allows for individualization of the assessment of pain based on the parent's knowledge of their child. It is congruent to family-centered care by

using the parents' knowledge of their children to help the health care team assess and manage their child's pain. It helps to establish a partnership between nurses and parents in caring for the patient.

Informally, the response from parents has been extremely positive. The INRS requires little time and training to complete. Parents are reassured that clinicians will use this tool to assess pain, especially when the parent is not able to be present. Many parents have requested a copy of the INRS for the home care nurses or other caregivers.

The INRS enables clinicians to quickly assess and evaluate pain management in cognitively impaired patients. We created an INRS sticker so that the tool could be placed easily in any aspect of the patient's medical record and/or kept at the patient's bedside. The original tool becomes part of the patient's medical record so that there is permanent documentation describing an individual's pain across the care continuum.

### NEXT STEPS

The INRS is a useful tool to assess and communicate pain in children with cognitive impairments. The psychometrics of this instrument have yet to be evaluated. The accuracy of the tool is dependent on the parents' and nurse's

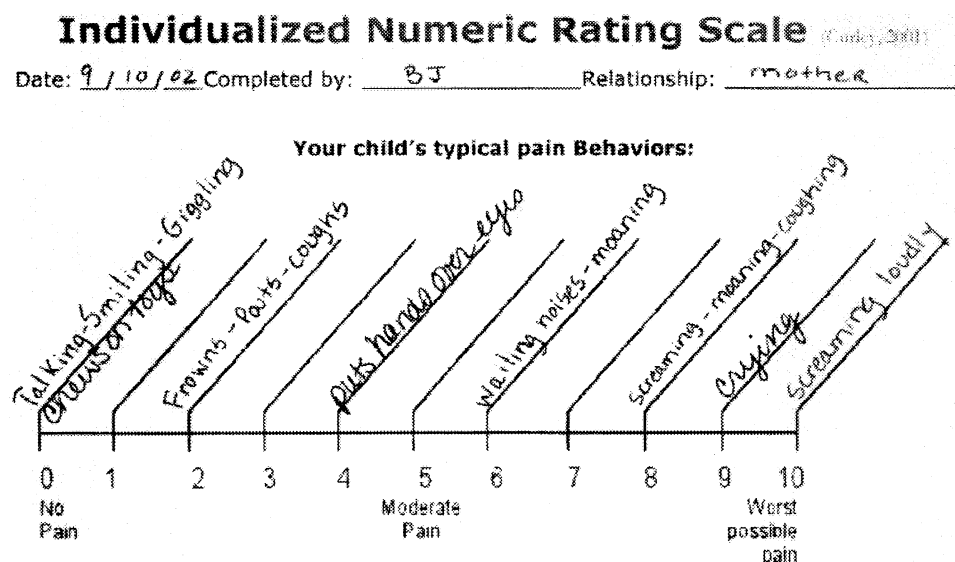


Figure 2. Case example: Timmy, a 5 year old with cerebral palsy, severe cognitive impairment, hypotonia, and history of poor motility is admitted to the intensive care unit after surgical repair of a midgut cecal volvulus. His postoperative course is complicated by cellulitis and acute respiratory failure requiring prolonged endotracheal intubation and mechanical ventilation. Intensive care unit nurses worked with Timmy's mother to create an INRS for Timmy and, over time, nurses noted additional observations. The INRS was used during shift report to assess, communicate, and manage Timmy's level of comfort. When Timmy was transferred from the intensive care unit, the general surgical unit nurses continued using Timmy's INRS to assess pain and efficacy of treatments.

ability to observe a child's response to pain and clearly describe the behavior on paper. However, the INRS is an improvement on current practice and can be used to assess and communicate pain

in a population that does not have a practical and validated pain assessment measure. It is easy to use and consistent with the basic tenants of family-centered care.

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## ERRATUM

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In "Creating a Halo Traction Wheelchair Resource Manual: Using the EBP Approach" by Rachel DiFazio, RN, CPNP (*Journal of Pediatric Nursing* 18:148-52, 2003), the following contributors to the article should have been acknowledged:

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