

New research identifies priorities in identifying pain in nonverbal children with medical complexity

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Pain is a frequent problem for children with complex medical conditions -but many of them are unable to communicate their pain verbally. For these children, nurses face a challenging task in assessing and determining the cause of pain, according to a study in the August issue of the *American Journal of Nursing*.

"While most kids can be in and out of the primary care provider's office in under an hour for an ear infection, children with complex needs stay in the hospital for a week just to find the ear infection," comments lead author Brenna L. Quinn, Ph.D., RN, NCSN, CNE, of the Solomont School of Nursing, University of Massachusetts Lowell. "Identifying pain early so teams may get to work finding and addressing the source is essential in avoiding long hospital stays, family stress, poking and prodding, or even surgery and death."

'When Pain Assessment Is Inadequate, These Children Suffer Unnecessarily'

The two-year study examined the symptoms, diagnostic testing, and nursing assessment of pain in children who have profound intellectual and developmental disability and are completely dependent on caregivers or medical devices (such as feeding tubes) for their care.

The study included 46 patients seen at a children's hospital Complex

Care Service with a chief concern of pain. The patients ranged from infants to young adults; the average age was 13 years. Most had several chronic conditions, most commonly seizure disorders and cerebral palsy; all were unable to verbally communicate their pain—where they were hurting, how much pain they were experiencing, or whether they were in pain at all.

The most common symptoms prompting parents or caregivers to seek medical care for their child were [abdominal pain](#) or distention (bloating), irritability, or other signs of pain. In some cases, the parents said that their child was just "not acting like herself [or himself]." The patients underwent an average of five diagnostic tests, most commonly X-rays; and were evaluated by an average of four specialty services while in the hospital.

The most common diagnoses were infections, including urinary tract infections (30 percent of children); constipation (20 percent); and increased seizure activity related to low levels of antiepileptic medications (13 percent). After other conditions were ruled out, a diagnosis of [chronic pain](#) was made in 22 percent of patients. Across diagnostic groups, symptoms were similar, including irritability, feeding intolerance, mental status changes, and vomiting.

While in the hospital, the children underwent more than 3,300 pain assessments—an average of seven assessments per patient per day. Since the children couldn't communicate their pain, the nurses used a number of assessment tools based on observable pain behaviors (facial expressions, crying, etc).

Although they represent a small percentage of hospitalizations, medically complex children use a high proportion of healthcare services. "Like all patients, nonverbal children with medical complexity require a balance of standardized and individualized care," Dr. Quinn and coauthors write.

Based on their findings, they make recommendations for pain evaluation in this group of patients, including:

- Eliciting the parents' or caregivers' knowledge of the child. As in previous studies, the results suggest that parents are often able to identify behavior changes suggesting that their children are in pain.
- Assessing the presence of pain, even when the child appears to be sleeping or when there are indications of a change in mental status.
- Using [pain assessment](#) tools matched to the patient's cognitive abilities, incorporating behavior assessments and input from parents.
- Being alert for potentially life-threatening sources of pain—while also not overlooking more common problems like infections or constipation.

The researchers emphasize the need for further studies of [pain symptoms](#), evaluation, and diagnosis in children with complex medical conditions, especially those who cannot communicate their pain verbally. Dr. Quinn and coauthors conclude, "When pain assessment is inadequate or lacking, these [children](#) suffer unnecessarily." The researchers are working to develop a tool to aid in comprehensive, efficient assessment of common causes of [pain](#) in this vulnerable group of [patients](#).

More information: Brenna L. Quinn et al. CE, *AJN, American Journal of Nursing* (2018). [DOI: 10.1097/01.NAJ.0000544137.55887.5a](https://doi.org/10.1097/01.NAJ.0000544137.55887.5a)

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