



# Complex Child E-Magazine

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## The Crisis in Pain Control for Children who are Complex, Non-Verbal, or Cognitively Impaired

by Susan Agrawal

A previously healthy thirty-year-old lawyer is wheeled into the Emergency Department with horrible abdominal pain. He is moaning and vomiting. Ultimately, he is diagnosed with pancreatitis, an extraordinarily painful inflammation of the pancreas, and given IV fluids and IV narcotic pain medication. He recovers uneventfully in three days and is discharged home with no further complications.

A child with multiple medical issues who is non-verbal but uses a communicator has been screaming in agony continuously for the past week. Using her communicator, she has stated her stomach and back hurt. She is also vomiting and has a distended abdomen. Ultimately, she is diagnosed with pancreatitis, admitted to the hospital, and given regular Tylenol and IV fluids. She continues to scream on the second day after diagnosis despite the Tylenol, leading her doctors to evaluate her for ear infections, broken bones, and a urinary tract infection since they cannot understand why she is still screaming. She develops severe hypersensitivity in her gastrointestinal tract in part due to uncontrolled pain, and is fully dependent on IV nutrition, in a Palliative Care program, and on methadone due to severe pain two years after diagnosis.

While the two cases are clearly different, they illustrate a common problem in medicine today: the lack of adequate pain control for children, especially children with complex medical issues who are unable to verbalize their discomfort due to physical, cognitive, or behavioral impairments. Both cases described above are cases of pancreatitis, and almost all recommendations for treating this condition include using narcotics for pain relief when pain is present. The educated, verbal, and healthy adult received the appropriate treatment of strong narcotic pain medication, while the child received nothing but Tylenol.

The fact that this child was denied appropriate pain relief despite repeated requests on the part of the family is truly a tragedy. Why was pain medicine denied? The doctors did not believe her pain was severe based on her behavior and lab values, even though she clearly exhibited signs of pain, including screaming, an elevated heart rate, very high blood pressure readings, and a complete inability to sleep. Her doctors thought she was screaming in part because she was neurologically impaired and had no way to communicate, and not because she was in pain. In addition, they were concerned that side effects from pain medication might worsen her respiratory state or further aggravate

her underlying gastrointestinal problems, and used this as another reason to deny pain medication.

Why do doctors not recognize pain in children who are non-verbal, complex, or cognitively impaired? Here are just a few of the reasons:

**Some doctors still do not believe children feel pain as acutely as adults, and pain is particularly underestimated in children with disabilities.** A study of newborns in the NICU is shocking.<sup>1</sup> In newborns with high risk of neurological impairment, doctors and nurses perceived reduced pain as compared to unimpaired infants. Even though most of the babies with neurological impairments were likely to receive more procedures and have more complications, doctors and nurses did not judge them to be in more pain.

Unfortunately, studies have shown that about 22% of children with cerebral palsy and similar conditions experience pain fairly often or every day, and the more physically impaired the child, the more pain was reported.<sup>2</sup> In one study, none of the children who experienced pain, including 67% of children with moderate to severe pain episodes, received any treatment for pain.

**Doctors believe that children with neurological impairments cry because their brains are injured and not because they are in pain, even when the child has good reason to be in pain.** The study on newborns cited earlier discusses how many doctors and nurses believe that children with neurological impairments do not perceive as much pain, but respond to pain more.<sup>3</sup> In other words, these doctors believe the sensation of pain in a child with neurological problems is often impaired, but the response to pain may be out of proportion. Some healthcare professionals seem to hold onto the belief that children with significant impairments have reduced pain perception, even when they are faced with clear displays of pain behaviors. While it would be simple to blame healthcare professionals for holding inappropriate beliefs, another study demonstrated similar beliefs in caregivers of children with cognitive impairments. Parents believed their children experienced less pain than other children of the same age and that children with mild-moderate impairments over-reacted to pain.<sup>4</sup>

The expression “neuro-crying” is often used to describe the irritable infant. For quite some time, doctors have operated on the assumption that infants and toddlers with neurological impairments are unable to process the world around them and become exceptionally irritable simply because of their neurological impairment. Studies such as a 2007 study on neuro-irritability published in *Pediatrics* have begun to doubt this assumption.<sup>5</sup> The authors posit that visceral pain and hypersensitivity within the gastrointestinal tracts of young babies may cause them significant pain, and dramatic results were seen in behavior and development with the introduction of a pain medication used to treat neuropathic pain, Neurontin (Gabapentin).

**Most doctors have difficulty assessing pain in children who are unable to talk or gesture, especially when the child is cognitively impaired or severely physically disabled.** The study on newborns mentioned earlier states that doctors and nurses are

particularly poor at identifying signals of pain in newborns.<sup>6</sup> Facial expressions and bodily postures suggesting pain are often missed, and without the perception of pain, there cannot be any control of pain. The same lack of pain recognition is likely to occur in children with disabilities.

Certain children with cognitive or behavioral impairments may not demonstrate typical responses to pain, while abnormal behaviors common in children with disabilities (such as grunting or grimacing) may be inappropriately associated with pain.<sup>7</sup> It is also difficult for these children to express the severity of their pain, as well as the location of their pain. While multiple pain scales for toddlers and those with cognitive impairments exist, most rely on some sort of self-report, such as pointing or choosing, that may not be possible for many children with disabilities.<sup>8</sup> Similarly, pain scales for infants have the expectation that the infant will cry and move normally in response to pain, which may not be the case for some children with severe physical or cognitive impairments. Measurement of physiological parameters, such as heart rate, respiratory rate, and blood pressure, is used in children who are critically ill, though these measures may not be appropriate for some medically complex children whose vital signs fluctuate on a daily basis.

**Sadly, a subset of doctors exists who do not believe children with significant cognitive or physical impairments are worth their time and effort, and subsequently treat them as if they are less than human.** These doctors may not take the time to assess and treat pain or may believe that children with neurological disorders are too impaired to even sense pain. In either case, children are left to suffer unnecessarily.

What can be done about this crisis? Here are some general suggestions for improving pain management for children with complex medical issues or disabilities.

**Be an advocate.** Parents know what is typical and atypical behavior for their children, and if a parent believes his child is in pain, he must advocate continuously for pain control. Parents also may need to reconsider their own beliefs about pain perception in their children as these may exaggerate or underestimate pain. If pain is identified, it may take trips to several different doctors or programs, and may unfortunately take time, sometimes even months or years, to treat. Keep advocating until your child is treated appropriately.

**Doctors need to trust caregivers.** Parents and other caregivers are almost never “drug-seekers” and need to be trusted to assess the level of their child’s pain. As a parent or caregiver, you know your child best and can recognize subtle signs of pain that doctors may miss in your child. Doctors need to learn to listen to a caregiver when she indicates that her child is in pain. Caregivers also need to try to provide doctors with a “key” to decoding their child’s pain behaviors (see attached pain checklist). For example, if a child indicates pain by flapping her hands and sticking her tongue out, it is important to communicate that exact mechanism to the doctors and nurses caring for your child.

**Children must be given opportunities to communicate their pain.** The child in the case study above may not have been tested for pancreatitis if she had not used her communicator to tell her parents that her stomach and back hurt. While she was unable to communicate the exact location and severity of her pain, her communicator allowed her to indicate that she was in pain and the general area of the pain. Even children with cognitive impairments and severe physical disabilities may be able to communicate if they are provided with the correct equipment. All types of communication, including verbal language, facial and bodily expression, sign language, augmented communication, and other types of communication, should be offered to a child to help him communicate his pain.

**Pain must be assessed in ALL children with disabilities or complex medical issues.** Pain is often overlooked or accepted in children with disabilities, even though studies show a great percentage of children struggle with severe pain. All children should be assessed for pain and treated appropriately.

**A combination of scales and techniques must be used to assess pain.** No one technique for assessing pain will work for every child. If a child is offered a pain scale that requires her to choose a face (happy, troubled, crying, etc.) and she cannot point or gesture, another scale must be chosen. Multiple methods of assessment, including parent report, child self-report if possible, vital signs, body language, and other techniques, must be used in combination to assess the child's pain.

**Novel treatments for pain with fewer side effects must be researched and approved for children.** Many children are denied adequate pain control because doctors worry about how pain medication may affect other issues, such as breathing problems or seizures. In some cases, tough choices must be made. Treating pain may cause side effects that then must be treated with other medications or technologies. We all need to advocate for the development and implementation of more pain control options, including complementary methods such as massage and acupuncture, as well as traditional pain medications with fewer side effects.

In addition, the following tips may be helpful for families trying to get help for their children who are suffering in pain:

- ❑ **Visit a doctor who specializes in Pain Management.** These doctors have much more experience treating pain and may have more aggressive approaches to treating pain.
- ❑ **Consider Palliative Care for children with life-threatening illnesses.** Many families have been unable to get adequate pain management until the child began a Palliative Care program. For children with life-threatening illnesses, even if death is far off and curative treatments are being tried, a Palliative Care program may be the only way to get adequate and aggressive pain management.
- ❑ **Even if pain cannot be located, it may be useful to try treating for pain.** Sometimes a source for pain cannot be located. In this case, it is often useful to try treating for pain using a safe medication such as Motrin or Tylenol to see what

happens. In children with significant neurological impairments, often trying a neuropathic or visceral pain medication such as Neurontin may be helpful, even without a clear pain source.

Children with disabilities and complex medical issues are suffering needlessly due to inadequate pain management. Many children have suffered with pain for years and years, despite repeated pleas by their families for pain medication. As human beings, we must recognize that allowing any child, disabled or not, to suffer in pain violates the fundamental morals of our society. It is time for ALL children to receive the pain medication they need to live in dignity and enjoy a good quality of life without pain.

## Checklist for Pain<sup>9</sup>

### Vocal

- Moaning, whining, whimpering
- Crying
- Screaming/yelling
- A specific sound or word for pain

### Eating/Sleeping

- Eating less, uninterested in food
- Increase in sleep
- Decrease in sleep

### Social

- Not cooperating, cranky, irritable, unhappy
- Less interaction with others, withdrawn
- Seeking comfort or physical closeness
- Being difficult to distract, not able to satisfy or pacify

### Facial

- Furrowed brow
- Change in eyes, including squinching eyes, eyes wide open, eyes frowning
- Turning down of mouth, not smiling
- Lips puckering up, tight, pouting or quivering
- Clenching or grinding teeth, chewing or thrusting tongue out

### Activity

- Not moving, less active, quiet
- Jumping around, agitated, fidgety

### Body/Limb

- Stiff, spastic, tense, rigid
- Gesturing to or touching part of body that hurts
- Protecting, favoring, or guarding part of the body that hurts

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<sup>1</sup> Lynn M. Breau, *et al.* “Judgments of Pain in the Neonatal Intensive Care Setting: A Survey of Direct Care Staffs' Perceptions of Pain in Infants at Risk for Neurological Impairment.” *The Clinical Journal of Pain* 2006;22(2):122-9.

<sup>2</sup> Christine M. Houlihan, *et al.* “Bodily pain and health-related quality of life in children with cerebral palsy.” *Developmental Medicine & Child Neurology* 2004;46(5):305–10.

<sup>3</sup> Breau (2006), 127-8.

<sup>4</sup> Breau, *et al.* “Caregivers' Beliefs Regarding Pain in Children With Cognitive Impairment: Relation Between Pain Sensation and Reaction Increases With Severity of Impairment.” *The Clinical Journal of Pain* 2003;19(6):335-44.

<sup>5</sup> Julie M. Hauer, *et al.* “Gabapentin Successfully Manages Chronic Unexplained Irritability in Children With Severe Neurologic Impairment.” *Pediatrics* 2007;119:519-22.

<sup>6</sup> Breau (2006), 127.

<sup>7</sup> Houlihan, 305–6; P. Stallard, *et al.* “Pain in cognitively impaired, non-communicating children.” *Archives of Disease in Childhood* 2001;85(6):460-2.

<sup>8</sup> For an overview of pain scales, see Linda S. Franck, *et al.* “Pain assessment in infants and children.” *Pediatric Clinics of North America* 2000;47(3):487-512.

<sup>9</sup> From Breau, *et al.* “Psychometric properties of the non-communicating children's pain checklist-revised.” *Pain* 2002;99(1-2):349-57.