

PFA Tips

Pain Management and Autism

Sensory stimulation can be perceived very differently in people with autism spectrum disorder. It is common for children to be averse to certain types of taste, texture, and flavors. How they perceive pain, however, is not very well understood. Some people believe that people with autism may have a decreased sense of pain, but pain can manifest in different ways. Identifying and managing pain can be challenging for both healthcare providers and parents.

Methods to assess pain

Assessing pain in children can often be a challenge for providers and parents. For older children, the number pain scale is typically used with 0 representing no pain and 10 being the worst pain imaginable. The faces pain scale allows children to choose a face – images range from happy to crying – that shows how their pain is making them feel. For children who are nonverbal, the FLACC score is often utilized. This method looks at Facial expression, Leg positioning, Activity level, Crying and Consolability. This pain scale requires more time but can reliably assess pain responses in neurotypical individuals.

People with ASD or intellectual disability, or any type of cognitive impairment may express pain in other ways and may require a customized FLACC scale. This would incorporate individualized pain behaviors which is more reliable in detecting pain in individuals with cognitive impairment. Again, this would require additional time and understanding of the scale.

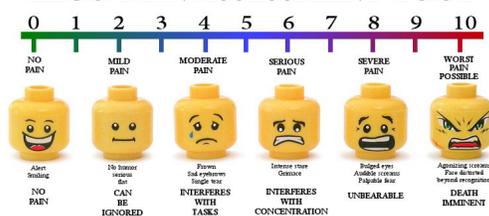


Research on autism and pain

Not much research has been done on the topic of autism and pain, partly due to the challenges of assessing pain in children with communication difficulty and partly due to the common belief that people with autism have decreased sensitivity to pain or a high pain threshold. Studies conducted with people with high-functioning ASD tend to use a pain scale of 0-10. On this scale, patients tend to respond with lower numbers, but other methods of rating pain have shown varying results. Some studies have used observations of providers or parents, which also tended to show decreased sensitivity to pain in children with autism.

Some case studies have found that when asked their pain score, verbal individuals with ASD respond with low scores, but when asked how much discomfort they have, the score tends to be higher.

LEGO PAIN ASSESSMENT TOOL



How does pain manifest in children with autism?

Children with ASD may not express pain in typical ways – crying, moaning, or withdrawing from a painful stimulus – and therefore may often be labeled as less sensitive to pain. Several case studies have shown that though children may not show these typical signs or may not react to pain in the moment, they still have physiologic reactions and behavioral reactions. Even with no obvious reaction to a painful stimulus, they may start breathing fast or their heart rate may increase. They may have increased stimming behaviors, aggression, or anxiety after the painful incident. Individuals with ASD also tend to show behavior changes for longer after the painful incident than neurotypical children or children with intellectual disabilities.

| FLACC Scale | 0 | 1 | 2 |
|------------------------|---|---|---|
| 1 Face | No particular expression or smile. | Occasional grimace or frown, withdrawn, disinterested. | Frequent to constant frown, clenched jaw, quivering chin. |
| 2 Legs | Normal position or relaxed. | Uneasy, restless, tense. | Kicking, or legs drawn up. |
| 3 Activity | Lying quietly, normal position, moves easily. | Squirming, shifting back and forth, tense. | Arched, rigid or jerking. |
| 4 Cry | No crying (awake or asleep). | Moans or whimpers; occasional complaint. | Crying steadily, screams or sobs, frequent complaints. |
| 5 Consolability | Content, relaxed. | Reassured by occasional touching, hugging or being talked to, distractible. | Difficult to console or comfort. |

Other studies have challenged the idea that people with autism experience less pain. These studies found that pain is expressed differently among those with autism. One study comparing children with autism, children with intellectual disabilities, and neurotypical children showed that both behavioral changes and physiologic changes (i.e. heart rate) were higher with pain, but face scores did not vary among the groups.

continued on back



When assessing for pain in a nonverbal child with ASD, close attention should be paid to increased aggression, self-injurious behaviors, stimming, or any behavior that is not typical for that child. If they are acting unlike themselves, look for a possible source of discomfort or pain that may be present or was present in the near past. In a more verbal child, asking if they have pain or if something hurts may not accurately reflect what they are feeling. Using words such as “discomfort”, “uncomfortable”, or “anxiety” may better approximate the level of pain they are in.

What can I do about my child's pain?

If a source of pain can be identified, treating that pain is of utmost importance. Treatment would be the same as for any other child—analgesics such as Tylenol or ibuprofen, ice, or heat (if tolerated), and rest. Parents and providers should be wary of hidden injuries that the patient may not be able to communicate about, such as a fracture or insect bite.

If the source of pain cannot be identified or you are unsure of the severity of the injury/illness, always err on the side of caution and have a physician assess your child. They should do a full skin exam to look for scratches, bites, rashes, or other injuries. If an injury is suspected to a limb, x-rays may be needed to rule out a fracture. If no clear injury or illness can be identified, parents and providers should

look for other possible medical causes for the behavior changes, like abdominal pain, headache, or urinary tract infection.

For pain management during painful or stress-inducing medical procedures, like a blood draw, there are several techniques that can be used. Non-pharmacologic (medication) methods are preferred. Every child may respond differently to these techniques, so some trial and error may be necessary to determine the best method for your child.

- **Distraction:** If your child has a preferred activity, engaging them in this activity during the procedure may significantly reduce their focus on pain. This could include watching a show, blowing bubbles, deep breaths, playing with a toy, or calming movements such as a parent rocking them.

- **Sensory distractions:** There are several items that can be used to distract a child's senses from the painful stimulus. A vibrating device or ice placed on the area of a blood draw or lumbar puncture can reduce the pain signal sent to the brain.

- **Topical pain control:** There are a few topical medications that can be used to reduce pain sensation. A cooling spray at the site of the procedure is quick and easy. A numbing gel or cream can also be applied 20-30 minutes prior to the procedure, which has been shown to be an effective way to manage pain during IV sticks. However, this has not been

shown to reduce anxiety or fear during procedures.

- **Deep pressure:** Firm pressure, through squeezing or a tight hug, has been shown to significantly decrease anxiety and stress in individuals with autism. This method can also be used during medical procedures to decrease discomfort. Every child is different though, so deep pressure may be too much sensory stimulation for some.

Medications can also be used to control pain, as well as anxiety, during medical procedures. Pre-medication with acetaminophen or ibuprofen may be helpful in reducing pain. For extremely painful procedures, an opioid may also be reasonable, per a physician's assessment. Anti-anxiety medications may be helpful in reducing not only anxiety but also pain as they are typically slightly sedating. If you feel it is right for your child, discuss these options with your physician.

When it comes to pain management in autism, remember these key points:

- Always rule out pain when atypical behaviors occur or when certain behaviors increase.
- Children are all different, whether in how their pain manifests or in what strategies work best to control their pain.
- There are lots of non-medication options to help manage pain and anxiety during medical procedures.

Additional Resources

Visual Support for Hospital and Doctor Visits (includes the graphics shown in this article)

<https://pathfindersforautism.org/articles/healthcare/visual-supports-for-hospital-visits/>

PFA Tips: Going to the Hospital

<https://pathfindersforautism.org/articles/healthcare/pfa-tips-going-to-the-hospital/>

PFA Tips: At the Doctor's Office

<https://pathfindersforautism.org/articles/healthcare/pfa-tips-at-the-doctors-office/>

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