Pain Assessment of Children with Autism Spectrum Disorders

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Objectives

- Identify and discuss clinical challenges of assessing and managing postoperative pain of children with ASD.
- Understand the experience of postoperative pain from the point of view of children with ASD.
Introduction

- Pain assessment of individuals with Autism Spectrum Disorders (ASD) is largely unexplored. However, the core deficits of ASD significantly interfere with this population’s ability to effectively utilize traditional pain assessment tools (e.g. FACES self report scales).
- When children with ASD encounter the health care environment, accurate pain assessment is crucial to providing quality care.
- Individuals with ASD reveal a spectrum of concerns limiting effective communication and social participation. Recognizing emotions through facial expressions and body language can be particularly difficult when a child has ASD.
- This social communication deficit may explain why children with ASD seem to demonstrate less outward reaction to pain or pleasure.
Aims

- Describe how children with ASD understand and communicate about pain. Specifically to:
  - Identify a vocabulary familiar to this population that holds meaning with respect to describing pain.
  - Understand common frames of reference for pain among individuals with ASD.
Methods

- Qualitative, descriptive study design using semi-structured interviews including interactive, electronic technology to enhance communication.

- Interviews were between 10-25 minutes in length.

- One or both parents were present for 38 interviews
Subject Eligibility

- Subjects included children with an ASD experiencing acute pain following a surgical procedure at a large urban tertiary children’s hospital.

- Eligibility criteria:
  - English speaking
  - Ages 6 -17 yrs.
  - Verbal communication skills (commensurate minimally of a typical 6 year old)
D #19, male, age 8
Pain Location

Use of iPad Body outline drawing
Interview Format

- Questions included asking the child what words they use to talk about their pain, ways they communicate pain, and what helps to make their pain better.

- Using the outline of a body on the iPad, children were asked to draw their pain onto the image.

- Faces of children with a variety of emotions were displayed on the iPad and subjects were asked if the child pictured had pain/hurt.

- Pain assessment tools used included the Poker Chip Tool, Wong/Baker Faces Scale and a Numeric Rating scale.
ID #26, male, age 12
Drawing of his pain
Demographics (N = 40)

- **Age (years):** M= 11.75, median = 11.5, S.D, 3.36, Range 6-17
- **Gender:** Male, 34(85 %)
- **Race:** White, 29 (72.5%) African American, 3 (7.5%) Hispanic, 2 (5 %) Other, 6 (15 %)

**Social Responsiveness Scale (SRS) T Score**
- Severe ≥ 76, n=26 (65%)
  - Mild to Moderate (60 -75), n=10 (24%)
  - Normal Range (≤ 59), n=4 (10%)
- **Post-operative Interview Day:**
  - M= 1.05 days (range 0-7), median 0.5 days, S.D, 1.7 days

**Autism Spectrum Diagnosis**
- Autism 13 (32.5%)
- Aspergers 14 (35 %)
- PDD 13 (32.5%)

**Surgery Type:**
- Orthopedic 17 (42.5%)
- GI related 10 (25%)
- Ear/Nose/Throat 10 (25%)
- General Surgery 2 (5 %)
- Plastic surgery 2 (5 %)
- Neurosurgery 1 (2.5%)
Qualitative Analysis Themes/Exemplar Quote

- **Understanding Pain/Hurt: Child Communication**
  - “It’s {the pain} like as if I came back from battle… although in real life I didn’t go to war.” (ID#40)
  - “When something hurts me I stay real quiet with it.” (ID#29)

- **Understanding Pain/Hurt: Parent As Interpreter**
  - “Tell my Mom” “My mom understands my pain and what I mean”. (ID#15)
  - “He definitely has the vocabulary for it... but he doesn’t make the connections sometimes. Putting it [coping skills] into practice is a little harder.” (Dad of ID#14)

- **What helps to make pain better?**
  - “I was doing a word search to get my mind off it {pain}… ‘cause sometimes the medicine helps but you need other things as well.” (ID#4)
  - “Leave it alone, don’t mess with it, don’t touch… and it will feel better.” (ID#6)
Understanding Pain/Hurt: Child Communication

- Showing where it hurt; point to location on self, mark on iPad or paper body outline drawing. Usually discussed first in each interview.

- Scale/Pain assessment tools; No one tool was preferred. Most children identified extremes of highest or lowest when using any of the scales offered (e.g. number, face, or poker chip scales) to describe pain.

- Child pain descriptors could be very sophisticated "excruciating", “annoying”, “frustrated”, “twisting”

- Words matter; e.g. using the word “hurt” rather than “pain”. Each child had preferred words for pain.

- Children were reluctant to, and did not want to dwell on discussing their pain.

- Change in “usual” behavior may help, but expressions often not “typical” pain cues.
Parents/Caregivers as interpreters of child's "pain words" and behaviors help to clarify both the verbal and behavioral communication of the child.

Historically, parents had to learn that pain behaviors could be subtle changes or atypical behaviors e.g. "restless, not them self", "child had broken leg and we didn't know except to see she didn't use it".

Check with parents about words for pain. Most frequently used: "hurt", "pain", "cry"

Parents can help recognize/interpret pain behaviors and intervene especially when a child unable to self-regulate or effectively communicate their pain.
Words Used to Describe Pain

- Hurt
- Pain
- Cry
- Sad
- Scream
- Sore
- Owie
What helps to make pain better?

- Parent presence
- Distraction from pain; extremely helpful, children worked hard to not talk about pain, changed conversation to other interests. For some, it was difficult to hold attention to topic.
- What is acceptable to do when in pain? Crying is ok, Children said: sleep, cry, tell someone, try to think and do something else, take medicine.
- Subjects expressed creative and thoughtful ideas about methods to decrease their pain.
Non-pharmacologic Methods to Treat Pain

- Distraction (e.g. play games)
- Sleep/Nap
- Elevate limb on pillow or position for comfort
- Warm Bath or heat pad
- Other ideas: breathe, “Don't Touch”, imagine, rub back, wait
Additional Quotes

- Asked what are best ways to understand pain in kids? said” Don’t ask them all the time, it makes them mad. But check in to make sure they are ok.” (ID# 7)

- “I was actually screaming before, when I did it [broke arm], I was screaming so loud someone from like 200 meters could hear me.” (ID#5)

- When you are home and something hurts, you tell your Mom? “I point to it, show her”. (ID #9) I “take a nap” to cope with pain; try to relax when it hurts “every time I move”... it hurts worst. (ID #9)

- [When]“I have a problem with my stomach. So I’ll either rock back and forth, forward and back, or I just rock side to side or play technology to get it off my mind.” (ID #15)

- “My grooving” (moving fingers/hands in front of face). (ID#20)

- “I usually tell mommy when it hurts, she can take me to the doctor and give me some medicine… and I do a word search to get my mind off it”.(ID#4)
Preferred Pain Scale

- Wong Baker FACES scale
- Location: draw, point to area, not use scale
- Unable to grasp
- Visual Analog Scale
- Liked all or no preference
- Poker Chip Tool
- Describe with words, not numbers
Discussion

- Consider using a *seriating task as a screen* for choosing a pain assessment scale.
- Important to individualize care; **find effective words** and tools to understand and treat pain for children with ASD.
- Parent communication and involvement is a **key finding**. Interview analysis supports the idea that parents can tell when their child is in pain and that children depend on their parents to help.
- **Ask what helps** decrease the hurt, what has worked in the past and incorporate into plan of care.
- **Words matter**; need to establish what word (s) the child uses for pain and use that word(s). Describing pain was preferred to using numbers by many of the subjects.
Most subjects were able to tell about their pain and how it feels using a variety of tools. For those who could not, parents interpreted subject behaviors and communicated methods to intervene to manage pain.

Locating the pain (either on themselves or using iPad image of a human outline) was used by each child to describe their pain.

Facial expressions, body language often did not match pain scores or descriptors, therefore relying on observation for pain assessment may result in under-treatment.

26 (65%) of subjects scored in the severe range of the SRS, with another 10 (24%) in the moderate range indicating subjects have clinically significant problems with everyday social interactions, many severe.
Publications:


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