Pain Assessment & Management in Developmental Disabilities

A REVIEW OF PAIN SCIENCE & DISCUSSION OF BEST PRACTICES IN DEVELOPMENTAL SERVICES

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Objectives

- Define pain
- Review sensation & pain neurophysiology
- Compare pain “experiences”
- Discuss pain in developmental disabilities (DD)
- Review pain assessment
- Discuss interventions
- Examine assumptions

What is Pain?

- Horrible
- Alarming
- Irritating
- Confusing
- Frustrating
- Frightening
- Debitating
- Expensive
- Life-altering
- A curse
- A gift*

- Multi-faceted
- Multi-factorial
- Symptom
- Cause
- Sensation
- Perception
- Stimulus
- Response
- Experience
- Subjective
- Relative
What is Pain?

I.A.S.P. (International Association for the Study of Pain):

“...an unpleasant sensory and emotional experience associated with actual or potential tissue damage or described in terms of such damage.”

Q: Ok, but why does it have to feel so bad?

A: Protection

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For example, if the fire A is close to the foot B, the small particles of fire, which as you know move very swiftly, are able to move as well the part of the skin which they touch on the foot. In this way, by pulling at the little thread cc, which you see attached there, they at the same instant open e, which is the entry for the pore d, which is where this small thread terminates, just as in pulling one end of a cord, you ring a bell which hangs at the other end... Now when the entry of the pore, or the little tube, eh, has been opened, the external spirities flow into it from the cavity F, and through it they are carried partly into the muscles which serve to pull the foot back from the fire, partly into those which serve to turn the eyes and the head to look at it, and partly into those which serve to move the hands forward and to turn the whole body for its defense.”

- Descartes, On Man, 1662

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A (Simple!) Neurophysiology Review

- Nerves (PNS) connect almost every part of the body with the spinal cord and brain (CNS)
- Together, the systems transfer information (sensory, motor, homeostatic etc.) and regulate body function
- Nerve or tract are cells (“neurons”) that work electrically by depolarizing their outer membranes (the “signal”)
A Neurophysiology Review

- Neurons communicate with each other by synapses
- At the terminal end, neurotransmitters are released and these bond to the next cell.
- Most neuro-processes are concerned with inhibition, not activation.

How We Perceive Our Bodies

- Sections of our brains are devoted to processing sensory and motor information about the various parts of our bodies.
- Cortical geographical representation is proportional to area demand complexity.
- Some areas of the body do not have sensory neurons or representation in the brain.

The Autonomic Nervous System

- Regulates visceral (organ) function
- Known as the “Flight or Fight” (Sympathetic) and “Rest and Digest” (Parasympathetic) systems of the body
- Closely tied to the “feelings” areas of the brain (amygdala, insula, thalamus, hypothalamus, etc.)
Appreciate the complexity that is You...

- The human brain has a HUGE number of synapses (connections) and therefore possible actions.
- EACH of your one hundred billion neurons has on average 7,000 synaptic connections to other neurons.
- Adult estimates range from 100-500 trillion synapses.

The Nervous System is Dynamic

- The changing nature of the brain and nervous system is known as neuroplasticity.
- They change throughout our entire lives: killing off neurons, changing their type or function, and growing new ones.
- Triggers for this are stimuli in the neuron’s environment.
- This is learning.

The Neurophysiology of Pain

1. Injury site
   - Nerve receptors in the tissue are triggered mechanically
2. Spinal Cord
   - Signal carried through dorsal root ganglion: may “react”
3. Brainstem
   - Connects to higher-order neurons in reticular formation
4. Thalamus
   - Relay station of the brain
5. Cortex
   - Thinks “Ouch!”
A Model for “Pain Pathways” (Mosby et al.)

Habituation (↑‘Threshold’)
- Brain “gets used” to the pain signal and the recognition of it diminishes:
  - “Fatigue” of the neurons
  - Attention to other inputs (i.e., “jamming” the signal)
  - Conscious override

Sensitization (↓‘Threshold’)
- Brain pays more attention to the painful stimulus, resulting in more pain:
  - Nearby neurons “take up the charge” (so to speak)
  - Body’s internal environment conducive to maintaining stressful conditions
### Pain as a Continuum (I.A.S.P.)

<table>
<thead>
<tr>
<th>Acute</th>
<th>&lt; 1, 3, 6 or 12 months?</th>
<th>Chronic</th>
</tr>
</thead>
<tbody>
<tr>
<td>“Pain attributed to a present ailment or injury.”</td>
<td>“Pain that extends beyond the expected healing time of an injury or in addition to a present disease process.”</td>
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</tbody>
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### Pain Factors

- "How much" pain we feel varies greatly based on:
  - Body tissues affected
  - Sensitivity of nervous system (i.e. "pain threshold")
  - Conflicting tactile stimulation
  - Co-morbid conditions
  - Environment
  - Distractions
  - Mood
  - Stress or Fatigue
  - Perceived importance of body tissues affected
  - Personality
  - Culture
  - Gender
  - Past experience
  - Expectations

(Just to name a few)

### Interpretation of Pain

- Consciously and unconsciously, we interpret our pain:
  - "It feels like a knife in my back."
  - "I have no cartilage left, so my knees are bone on bone."
  - "I have a nagging headache."
  - "The pain in my chest is suffocating."
...therefore, the “Perception” of Pain is:
Possibly indicative of physical damage, BUT...

- Not always proportional to amount of physical damage
  - i.e. stubbed toes, paper-cuts, etc.

- Not always where the location of the damage is
  - i.e. heart attacks, sciatica, etc.

- Not always indicative of physical damage
  - i.e. chronic pain

### Pain in Developmental Disabilities

<table>
<thead>
<tr>
<th>Medical Issues</th>
<th>Assessment Challenges</th>
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</thead>
<tbody>
<tr>
<td>“Secondary” conditions</td>
<td>Confusing co-morbidities</td>
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<tr>
<td>Intestinal conditions</td>
<td>Limited communication</td>
</tr>
<tr>
<td>Circulatory conditions</td>
<td>Limited understanding</td>
</tr>
<tr>
<td>Abnormal muscle tone</td>
<td>Poor “historians” *</td>
</tr>
<tr>
<td>Skeletal deformities</td>
<td>Less medical knowledge</td>
</tr>
<tr>
<td>Mental health issues</td>
<td>Bias or lack of knowledge</td>
</tr>
<tr>
<td>Poly-pharmacy</td>
<td>on part of the examining health professioanl.</td>
</tr>
<tr>
<td>Abuse or self-abuse/SIB</td>
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</table>

### Clinical Practice Recommendations*

1. Obtain self-report
   - Majority of individuals with ID are verbal & can self-report pain using appropriate self-report pain assessment tool.

2. Search for potential causes of pain
   - Prevalence & burden of pain higher than in healthy children, & prevalence of pain in adults with ID higher than in adults without ID.

3. Observe patient behavior
   - Observe facial expressions, vocalizations, body movements, changes in interactions, changes in activity patterns or routines, & mental status. Behavioral observation should occur during activity whenever possible.

4. Proxy report
   - Parents & caregivers may know individual’s typical behavioral response to pain & can identify unique pain behaviors. However, caregivers of children with ID frequently underestimate pain intensity.

5. Analgesic trial
   - Initiate analgesic trial if pain is suspected.

Assessment of Pain

McJunkins, Green, Anand (2010):
- Compared effectiveness of the NCCPC-PV, MOPS, CHEOPS and VAS in cognitively-impaired children aged 3-17
- Parents noted their confidence with identifying "severe" pain but not mild or moderate
- VAS score often "unavailable"

Types of Pain

- What the sensation may tell us about the problem:
  - Somatic – skin, bones, muscles, some joint tissues
    - "Sharp or dull, aching, throbbing, gnawing, etc."
  - Visceral – distention or inflammation of organs
    - "Cramping, gripping, deep pain, pressure, etc."
  - Neuropathic – nervous tissue
    - "Burning, tingling, stinging, shooting, stabbing, shocking, etc."
Understanding of Pain in DD

Beacroft & Dodd (2010):
- Reviewed scientific literature re: DD pain thresholds, health practitioner attitudes and pain recognition in DD.
- Examined pain understanding (by questionnaire) in 40 adults with mild-moderate DD.
- Only 35% reported that they would tell someone if they were in pain.
- Known strategies for management: “pills”, “drink”, “lie down” and “don’t know”.
- Main outcomes: education for individuals, consideration of “alternative therapies” such as Snoezelen and hydrotherapy.

... and what do we do when there are no words?

- Physical Evidence of Issue
  - Expression
  - Vocalization
  - Muscle Tone
- Change in Behaviour
  - Caregiver Report
  - Diagnostic tests

Consequences of Poor Assessment

We know that these challenges lead to:
- Delayed diagnosis of injuries and illnesses
- Increased mortality rate
- Under-medication/management of pain
- Over-medication/management of pain
- Increased secondary effects of conditions
  - i.e. decreased mobility, increased dependence on others, decreased mood, self-efficacy, quality of life, etc.

“Death by Indifference” (2007) - www.mencap.org.uk
A New Policy on Pain at Ongwanada

Pain Interventions & Management Strategies

- Painkillers
- Modalities (heat, cold, massage, etc.)
- Exercise
- Nutrition
- Hydration
- Calming techniques
- Change the environment
- Change the position
- Change the activity

Pain Interventions

Comfort Measures & Behavioural Therapy
Slifer et al. (2011)

- 8 children aged 4-16 with dual diagnosis underwent therapy sessions using distraction, exposure and counter-conditioning techniques to reduce behaviour during mock needle sticks
- All showed significantly reduced negative behaviours (vocalization or aggression) when the same protocols were then used during actual injections
- Implications for individuals requiring life-long unpleasant medical intervention.
Cognitive-Behavioural Therapy

* Lewis, Bell, Gillanders. (2007)

- 32y/o woman with developmental disability and a 16-mth Hx chronic pain (believed to be triggered by an accident; however current symptoms in "well" leg)
- Treated for 4 mths with a program addressing physical, mental and social well-being
- Showed improvements in ratings of pain, depression, anxiety and social activation (GDS, GAS, FAPS, PRCS)
- Remained at baseline for "helplessness"

A Final Word: Pain Assumptions in DD

Counterpoint: why may this individual *NOT* live with pain?
- Higher pain threshold?
- Habituation?
- Impaired sensation?
- Gradual onset of some deformities?
- Other factors?

Pain Assumptions in DD

What may be the dangers of falsely ascribing pain to our clients?
- Over-prescription of medication
- Masks other issues that may need to be addressed
- Discourages examination of other causes of challenging behaviour
- Discourages objective assessment
- Maintains societal misconceptions about appearances and our client's quality of life
Our Pain Management Goal

This year, Ongwanada is moving forward, through direct-care staff education, to create a culture of:

- understanding pain better
- recognizing and interpreting pain better
- managing client pain in a variety of ways that are holistic and client-centered

What is Pain? (O.E.D. this time...)

- pain |pān| noun
  1. a strongly unpleasant bodily sensation such as is produced by illness, injury or other harmful physical contact

- sensation |sen'sā sh ən| noun
  1. the consciousness of perceiving some state or condition of one’s body

- perception |por'sep sh ən| noun
  3. an interpretation of sensation based on one’s understanding 4. the ability of the mind to refer sensory information to an external object as its cause

References


