

# HOW MUCH DOES IT HURT? FACTORS CONTRIBUTING TO RESPITE PROVIDERS' PAIN INTENSITY RATINGS FOR CHILDREN WITH INTELLECTUAL DISABILITIES

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## Introduction

### Pain in Children with Intellectual Disabilities:

- Often inadequately managed (Chen-Lim et al., 2012)
- Assessment and management are difficult (Chen-Lim et al., 2012)
- Caregivers play an important role in assessment and management (Breau et al., 2003)
- Previous research on *primary* caregivers and pain assessment / management BUT children with intellectual disabilities often receive care from other caregivers (Shelton & Witt, 2011)

### OBJECTIVE:

To investigate factors contributing to respite workers' pain intensity ratings for children with intellectual disabilities

## Participants

Table 1. Selected participant demographics

	Respite Workers (N = 54)
Age (years)	<ul style="list-style-type: none"> <li>• Mean: 33.76</li> <li>• Range: 18 - 67</li> </ul>
Sex	<ul style="list-style-type: none"> <li>• 9 M (16.7%), 45 F (83.3%)</li> </ul>
Ethnicity	<ul style="list-style-type: none"> <li>• European Canadian/White</li> <li>• 46 (85.2%)</li> </ul>

## Procedure

- As part of a larger study, participants read six vignettes about children with ID manipulating pain source (chronic, acute, unspecified)
  - Rated child's pain [0-10 (10= "very high pain intensity")]
  - Listed the first factor considered when rating pain

### Sample Vignette:

"Taylor is a 10-year-old child who receives respite care. Taylor has a cognitive impairment and is (*verbal/nonverbal*). Taylor suffers from occasional headaches which develop suddenly and last for a few hours at a time. When experiencing a headache, Taylor usually squinches his/her eyes and whimpers. Taylor also becomes withdrawn from others. While getting ready for bed with her/his respite provider, Taylor stops what she/he is doing and begins to groan. Taylor also appears restless and uninterested in completing his/her bedtime routine."

Table 2. Twelve coding categories developed inductively and deductively from participant responses. Two coders completed coding; discrepancy decisions were made in consultation with both coders and a primary researcher.

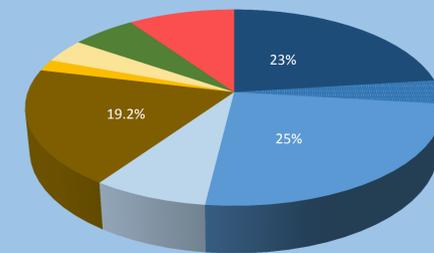
Coding Category Name	Examples
Pain Behaviour/Expression/Response	
• Physical/Nonverbal Behavior	
• 1. Presence of	• Facial expressions
• 2. Absence of	• No squinting
• Verbal/Vocal Behavior	
• 3. Presence of	• Screaming
• 4. Absence of	• No whimpering
• 5. Other – Pain Behavior / Expression/Response	• Child's behavior
Child History/Knowledge	
• 6. Pain History/Knowledge	• Experiences headaches
• 7. General History/Knowledge	• Child's age
• 8. Other History/Knowledge	• History
9. Environmental/Situational Context	• Crowded pool
10. Considerations of Other (alternate) Explanations of Behavior	• May just be tired or anxious
11. Consideration of Specific Pain Source and/or the Severity of This	• The child fell
12. Other (Unrelated/Unclear)	• Consequences

## Results

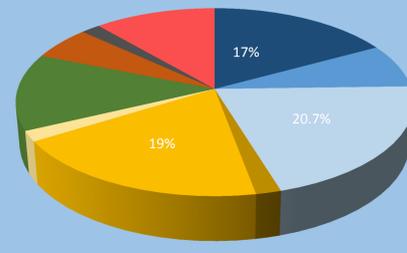
### Pie Chart Legend:

Pain behavior/Expression/Response (All Blue)	Child History (Gold/Yellow)
Physical/Nonverbal – presence of (1)	Pain History (6)
Physical/Nonverbal – absence of (2)	General History (7)
Verbal/Vocal – presence of (3)	Other History (8)
Verbal/Vocal – absence of (4)	Other Alternate Explanation (10 - Orange)
Other – Pain Behavior (5)	Specific Pain Source (11 - Grey)
Environment/Situation (9 - Green)	Other Unrelated/Unclear (12 - Pink)

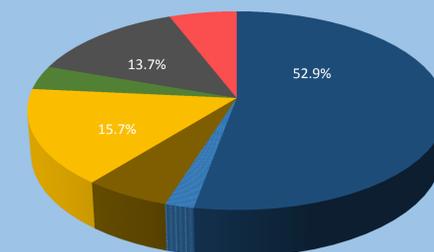
Headache  
(% agreement: 79.7%; n = 52)



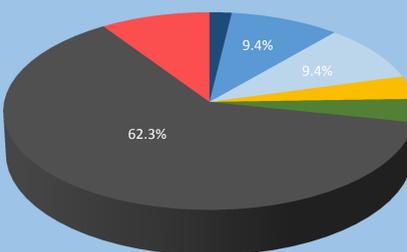
Unspecified  
(% agreement: 76%; n = 53)



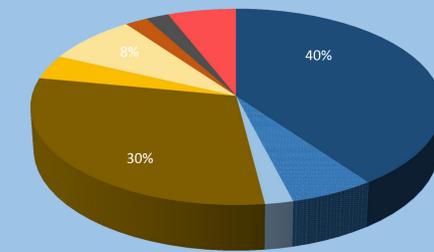
Flu Shot  
(% agreement: 88.9%; n = 51)



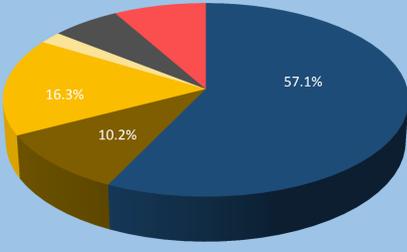
Falling Down  
(% agreement: 94.4%; n = 50)



Arthritis  
(% agreement: 83.3%; n = 50)



Insulin Shot  
(% agreement: 96.3%; n = 49)



Note: The percentage values for the top three factors considered are labelled on the pie charts above.

## Discussion

- Respite workers consider many factors in pain assessment → these may vary depending on pain source
- Child behavior (especially presence of behaviour) and history were commonly considered. This is similar to previous research about factors considered by nurses (Hamers et al., 1994; Hamers et al., 1996)
- For acute accidental pain, respite workers placed more emphasis on the painful event. What role do beliefs regarding a painful event play in pain ratings?
- Ensuring that respite workers have accurate information about (1) unique behavioral expressions of pain by children with ID and (2) the child's history is important