Assessment and Management of Pain in Children who have Cognitive Impairments and are Nonverbal: A Survey of Support Workers' Beliefs
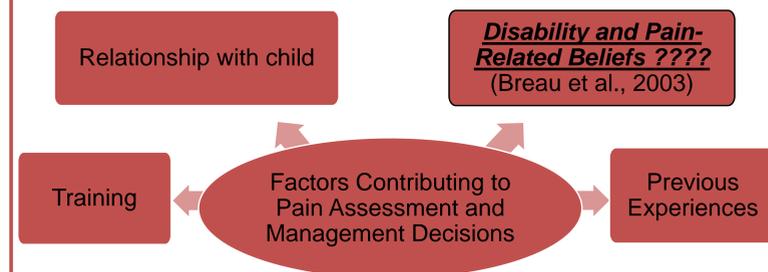
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Introduction

• Children with cognitive impairments (CI) commonly experience everyday pain and are often incapable of providing accurate self-reports of their pain (Stallard et al., 2001; Dubois et al., 2010).

Pain experienced by this population is often assessed and managed by caregivers.

Relationship with child

Disability and Pain-Related Beliefs ???? (Breau et al., 2003)

Training

Factors Contributing to Pain Assessment and Management Decisions

Previous Experiences

• Previous research has focused on beliefs of primary caregivers (i.e., parents) and professionals. Children with cognitive impairments who are nonverbal (CI/NV) often receive care from numerous caregivers (Shelton & Witt, 2011).

It is important to investigate perceptions of secondary caregivers.

Objective 1: Compare disability and pain-related beliefs of respite workers with those who have little to no experience with target population (undergraduates)

H1a: Presence of more positive disability-related beliefs in respite workers (RW) versus undergraduates (UG)

RW ⬆ UG ⬇

H1b: A difference in participants' reports of children's ability to sense pain across CI levels (i.e., mild, moderate, severe) when compared to children without CI.

Objective 2: Determine whether an individual's beliefs and demographic information are related to pain assessment and care decisions for children with CI/NV

H2a: Care decisions made in response to vignettes related to participants' pain and disability-related beliefs.

H2b: Care decisions in response to vignettes related to participants' demographic information.

Pain Beliefs (H2a)

Care Decisions

Demographic Information (H2b)

Disability-Related Beliefs (H2a)
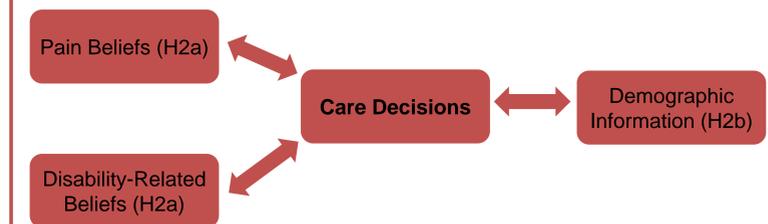
H2c: Care decisions predicted by both pain/disability-related beliefs and participant demographic information.

Participants

Participants: *not all participants answered all demographic questions	Students (N = 217)	Respite Workers (N = 56)
Age (years)	• Range: 19 - 31 • M = 19.63 • SD = 1.733	• Range: 18 - 67 • M = 33.37 • SD = 14.41
Sex	• 41 Male (19%) • 175 Female (81%)	• 10 Male (17.9%) • 46 Female (82.1%)
Ethnicity • % European-Canadian/White	• 173 (79.7%)	• 48 (85.7%)
Frequency of Interaction with CI/NV • Never/Rarely • Occasionally/Often/ Very Often	• 200 (92.2%) • 17 (7.8%)	• 2 (3.6%) • 54 (96.4%)
Level of Education • University Degree (In Progress)	• 208 (95.9%)	• 21 (37.5%)
Intensity of Involvement with CI/NV • 0 (Not at all involved) – 5 • 6 – 10 (Highly involved)	• 200 (92.2%) • 17 (7.8%)	• 10 (17.9%) • 45 (80.4%)
Intensity of Involvement with Adults with CI • 0 (Not at all involved) – 5 • 6 – 10 (Highly involved)	• 204 (94.1%) • 13 (5.9%)	• 28 (50.0%) • 27 (48.2%)
Pain Training • Yes	• 5 (2.3%)	• 7 (12.5%)

Methods

Procedure: Online survey using LimeSurvey (30 minutes); part of a larger study
1) *Demographic questions* (e.g., education, frequency of interaction with children with CI/NV)
2) *6 situational vignettes [3 adapted (Shinde & Symons, 2007); 3 new]*
   • Vignettes manipulated pain source and whether or not the child communicates verbally; in present study only nonverbal vignettes were examined collapsing across pain source.
   • For each vignette, participants answered questions about child's pain intensity (0 = no pain, 10 = very high pain intensity) and need for assistance (i.e., medical and other forms of attention; 0 = no attention necessary, 10 = emergency medical/significant attention necessary).
3) *Mental Retardation Attitudes Inventory – Revised (MRAI-R; Antonak & Harth, 1994)*
   • 29-item inventory (4-point Likert scale); measures <u>attitudes towards people with disabilities</u>
4) *Pain Opinion Questionnaire (POQ; Breau et al., 2003)*
   • 15 items measuring respondent <u>beliefs regarding pain experience</u> in typically developing children versus children with CI. Present study focused on what % of children with CI are less sensitive to pain than children without CI for the pain sensation facet on the POQ for each level of CI severity .
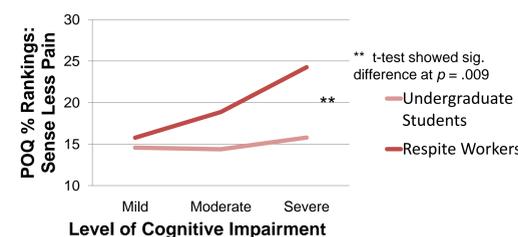
Sample Vignette:

"Taylor is a 10-year-old child who receives respite care. Taylor has a cognitive impairment and is (<u>verbal/nonverbal</u>). Taylor suffers from <u>occasional headaches</u> 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."

Results: Objective 1 – POQ and MRAI-R

H1a: *Difference in MRAI total scores.*
$t(267) = 4.72, p < .001$
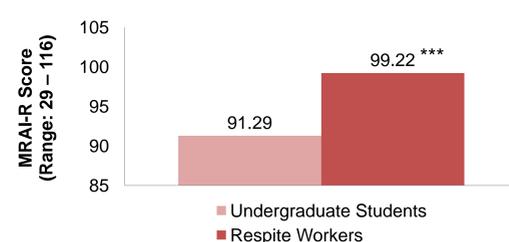
H1b: *Interaction of level of CI and participant group for POQ rankings, $F(1.61, 417.98) = 3.43, p = .043$.*

MRAI-R Score (Range: 29 – 116): Undergraduate Students 91.29; Respite Workers 99.22 ***

POQ % Rankings: Sense Less Pain, by Level of Cognitive Impairment (Mild, Moderate, Severe): Undergraduate Students, Respite Workers. ** t-test showed sig. difference at p = .009

Results: Objective 2 – Care Decisions

H2a: *Care Decisions, Pain and Disability-Related Beliefs*

	1	2	3	4	5	6	7
1. MRAI-R Score	--						
2. POQ Mild CI	-.220**	--					
3. POQ Moderate CI	-.126*	.702**	--				
4. POQ Severe CI	-.137*	.371**	.547**	--			
5. Pain intensity rating	.082	.031	.010	-.042	--		
6. Medical attention rating	-.194**	.226**	.137*	.082	.520**	--	
7. Other attention rating	.151*	-.078	-.089	-.005	.428**	.273**	--

*= $p < .05$; ** = $p < .01$

Note: Variables 2,3 and 4 represent participant % ratings on the POQ (i.e., % of children with CI are less sensitive to pain than children without CI).

H2b: *Care Decisions and Demographic Information.* Analogous series of correlations testing whether care decisions were related to frequency of interaction with CI/NV, involvement caring for children with CI/NV, involvement caring for adults with CI, education and pain training.

H2b Care Decisions: Need for other attention ↔ Intensity of Involvement with CI/NV $r = .123, p = .045$

H2c: *Part 1 - Regression predicting need for medical attention:* pain intensity and need for other attention (block 1), $F(2, 247) = 50.38$, $p < .001$, entered MRAI-R and POQ responses for mild and moderate CI (block 2), $F(5, 247) = 29.22, p < .001$.
1) MRAI-R scores significantly predicted ratings for need for medical attention β = -.197, t(242) = -3.76, p < .001.
2) POQ ratings for mild CI significantly predicted ratings for need for medical attention : β = .200, t(242) = 2.75, p = .006.
Part 2 - Regression predicting need for other attention: pain intensity and need for medical attention (block 1), $F(2, 254) = 27.14$, $p < .001$, entered MRAI-R (block 2), $F(3, 254) = 20.30, p < .001$, entered level of involvement with CI/NV (block 3), $F(4, 254) = 15.35, p < .001$.
1) MRAI-R scores significantly predicted ratings for need for other attention: β = .140, $t(251) = 2.37, p = .018$.
2) Level of involvement with CI/NV did not significantly predict ratings for need for other attention (n.s.).

Discussion

• Respite workers have more positive disability-related beliefs than students, offering further support for past research regarding beliefs of professionals versus students (Au & Man, 2006). Interaction/ and experience with CI may contribute to this.

• Respite workers believed that a higher percentage of children with severe CI sensed less pain than children without CI. This is in contrast to research suggesting children with CI experience pain but express it differently (Dubois et al., 2010). Previous experiences may impact views; respite workers may also be missing pain cues.

• Regressions suggested that individuals' a priori disability-related beliefs can impact care decisions for children with CI/NV, supporting Craig's (2009) Social Communication Model of Pain.

• Limitations: age differences may have impacted the results (e.g., generational factors such as acceptance of disabilities within society); samples may not have been representative; MRAI-R was an older scale; responses to vignettes may not translate to actions

• Future research: continue to learn about the impact of beliefs on care decisions; investigate whether development of educational interventions improves pain assessment and management abilities.