

CARING FOR ALL: INSIDE RESPITE WORKERS' CHOICES WHEN SUPPORTING KIDS WITH DISABILITIES

Respite Workers (RW) are caregivers who support children with intellectual disabilities (ID) when their parents need a break.

Kids with ID often feel pain in their body, and sometimes have difficulty expressing their pain to caregivers.



PURPOSE

To understand what influences the ways RW:

assess
(understand)
pain

manage
(treat) pain

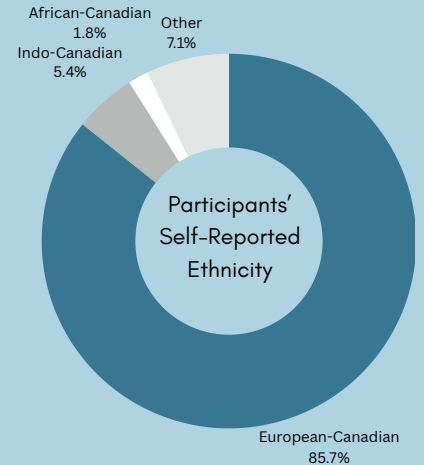
respond to
pain

while supporting children with ID.

PARTICIPANTS

The present study recruited 46 female participants and 10 male participants, for a total of 56 RW. All participants were over the age of 18.

Participants had a lot of experience in caregiving, as they were recruited from children's respite care organizations.



Objectives were to understand:
1. factors RW consider during pain assessment
2. if verbal ability changes ways of assessing pain
3. actions RW would take in response to pain

RW were asked to read and respond to 6 online case studies (vignettes):

- unintentional injury (*fall*), painful medical procedure (*insulin injection, flu shot*), chronic pain (*arthritis, headache*), and an unknown source of pain

Procedure - After reading each vignette, RW were asked to:

- (1) list 3 things they thought about when assessing pain, and (2) describe what they would do to support a child in that situation
- 1/2 of vignettes showed a child who did not communicate verbally

METHODS

RESULTS

Objective #1

When assessing pain, RW most often considered the child's pain expression/response, and the child's pain history/knowledge.

Objective #2

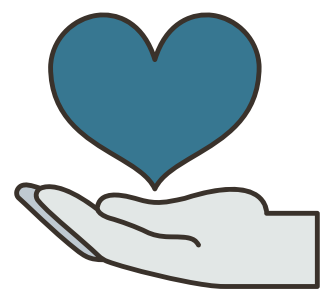
Whether a child communicated verbally didn't seem to impact how RW assessed their pain.

Objective #3

Most common RW actions in response to pain: *assessment* - observation or child self report; *management*: psychological strategies (e.g., distraction).

KEY TAKEAWAYS

- Factors informing pain assessment did not depend on child's ability to verbally communicate.
- No "one-size-fits-all" way of assessing and managing pain
 - the best approaches depend on the situation



WHY IS THIS IMPORTANT?

Understanding the factors that influence RW approaches to pain will:



reduce the risk of experienced pain among children while being supported by RW



lead to better support strategies and education for RW



improve children's overall quality of life

Genik, L. M., McMurtry, C. M., & Breau, L. M. (2017). Caring for children with intellectual disabilities part 2: Detailed analyses of factors involved in respite workers' reported assessment and care decisions. *Research in Developmental Disabilities, 63*, 1-10.

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