



Caring for children with intellectual disabilities part 2: Detailed analyses of factors involved in respite workers' reported assessment and care decisions[☆]



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ABSTRACT

Respite workers (RW) commonly care for children with intellectual disabilities (ID), and pain is common for these children. Little is known about factors which inform RW pain assessment and management-related decisions.

Objectives: To describe/determine the following in response to a series of pain-related scenarios (e.g., headache, falling): (1) factors considered important by RW when assessing children with ID's pain; (2) whether children's verbal ability impacts pain assessment factors considered; (3) RW assessment and management approach.

Participants: Fifty-six RW (18–67 years, $M_{age} = 33.37$, 46 female).

Procedure/measures: In an online survey, participants read and responded to six vignettes manipulating child verbal ability (verbal, nonverbal) and pain source.

Results: The factors most frequently considered when assessing pain were child behavior (range: 20–57.4%), and history (e.g., pain, general; 3.7–38.9%). Factors did not vary by child's verbal ability. RW indicated varied assessment and management-related actions (range: 1–11) for each scenario.

Discussion: Findings suggest: a) factors informing pain assessment did not depend on whether or not the child was verbal and b) a degree of flexibility in RW response to pain across situations. While these findings are encouraging, ensuring RW have adequate pain assessment and management knowledge specific to children with ID is critical.

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What This Paper Adds?

Children with intellectual disabilities (ID) are vulnerable to experiencing unmanaged pain due to increased risk of pain and difficulties in self-report. This study is the first to examine pain assessment and management-related decisions by

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respite workers who support children with ID. Understanding respite workers' approaches to pain in this population is critical because these children often rely on caregivers to assess and manage their pain. Systematic vignette methodology was used to gather respite worker responses to a number of different pain-related scenarios.

Results demonstrated that respite workers are flexible in their approach to assessing pain in children with ID. The child's behavior and history were commonly considered. Respite workers also reported a number of actions they would take in response to each scenario, many of which are supported by research literature. The most commonly reported action involved using psychological pain management strategies, while the least common actions were consulting resources (children's care profiles) and reporting the incidents to caregivers. A child's ability to communicate verbally did not appear to impact respite workers' pain assessment or management.

Building from Part One of this manuscript (Genik et al., revision submitted), the current findings provide insight into the types of pain assessment and management strategies that RW are (a) aware of and (b) likely to apply across pain-related scenarios. The results can inform future intervention/educational efforts (e.g., which information may be most useful to help educate respite workers about pain in children with ID).

1. Introduction

Pain may be more common among children with intellectual disabilities (ID; Breau & Burkitt, 2009), and has the potential to negatively impact various aspects of these children's lives including adaptive functioning (Breau, Camfield, McGrath, & Finley, 2007). Thus, effective pain assessment and management are crucial. However, pain assessment for children with ID is particularly challenging. These children may provide inaccurate self-reports if they do not understand or have the necessary skills to participate in self-report activities (Fanurik, Koh, Harrison, Conrad, & Tomerun, 1998); thus, caregivers are often asked to assist with pain assessment. Many children with ID, particularly those who do not communicate verbally, demonstrate atypical behaviors when expressing their pain (Dubois, Capdevila, Bringuier, & Pry, 2009). Yet, it is these types of behaviors that caregivers would need to use to determine whether or not a child is in pain and in need of pain management.

There are a number of pain management strategies that have been found to effectively reduce children's pain. These may be categorized into four main domains: psychological (e.g., distraction; Birnie et al., 2015; Palermo, Eccleston, Lewandowski, Williams, & Morley, 2010; Riddell et al., 2015), physical (e.g., applying ice; Taddio, Shah et al., 2015), pharmacological (i.e., using medication; Taddio & Oberlander, 2006) and process/procedural (e.g., providing simultaneous injections; Taddio, Shah et al., 2015). While some research related to pharmacological pain management has been conducted (Taddio & Oberlander, 2006), much research related to non-pharmacological pain management in children appears to exclude children with ID.

There has been some investigation of pain assessment and management of children with ID in health care settings (e.g., Breau & Burkitt, 2009; Malviya et al., 2001) and with parents (e.g., Carter, McArthur, & Cunliffe, 2002; Davies, 2010). However, investigation of secondary caregivers' pain assessment and management of these children is very limited. This is concerning, as children with ID frequently receive care from a number of different people when they are not with their parents (e.g., schools, respite care, camp). Respite care in particular is a growing service for families who have children with ID (Chan & Sigafos, 2000). These services allow families temporary relief from the demands of raising a child with special needs, often while also meeting the child's unique needs (e.g., social development, personal care; Neufeld, Query, & Drummond, 2001). Respite care may be provided in or out of the child's home and may take many forms (e.g., summer camps, residential treatment centres, day programs; Canadian Healthcare Association, 2012; Neufeld et al., 2001) for differing time periods (e.g., day long respite, week long respite). When receiving respite services, the parents of a child with ID may not be available to help these secondary caregivers assess whether the child is in pain and in need of treatment.

Respite workers may hold pain-related beliefs contrary to current knowledge about pain in children with ID (Genik, McMurtry, & Breau, revision submitted). A minority of respite workers seems to receive formal pain-related training (Genik et al., revision submitted); furthermore, this training is not specific to children with ID, and often comes from health care related school programs, or other experiences outside of respite workers' employment positions. A more detailed understanding of factors (e.g., child behavior, pain history) that respite workers consider in their responses in a pain context and the impact of child functioning on these considerations is important. These factors could impact respite workers' pain assessment and management decisions, resulting behaviors, and in turn, a child's overall quality of life. For example, pain-related beliefs about children with ID's general ability to sense pain may predict individuals' likelihood of providing medical attention to a specific child with ID experiencing pain (Genik et al., revision submitted). Similarly, understanding what actions respite workers take when a child with ID may be in pain can help us to understand how they presently care for these children. The pain assessment and management-related information described above can inform training programs and help to ensure that respite workers are aware of factors to consider and appropriate pain assessment and management strategies.

1.1. Objectives

Using a series of written vignettes, the objectives of the current study were: (1) to describe the factors (e.g., child behavior) considered by respite workers when assessing different types/sources of pain in children with ID; (2) to explore whether assessment factors vary depending on the child's verbal ability (verbal versus nonverbal); and (3) to describe the types

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