



Caring for children with intellectual disabilities part 1: Experience with the population, pain-related beliefs, and care decisions



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ABSTRACT

Some children with intellectual disabilities (ID): experience pain more frequently than children without ID, express their pain differently, and are incapable of providing self-reports. No research has examined disability and pain-related beliefs of respite workers (RW) and their relations to pain assessment and management decisions for children with ID.

Objectives: (1) compare disability and pain-related beliefs between RW and a sample with little experience in ID; (2) determine whether individuals' beliefs and personal characteristics are related to pain assessment and management decisions.

Participants: Fifty-six RW (aged: 18–67 years, $M_{age} = 33.37$, 46 female) and 141 emerging adults (aged: 18–31 years, $M_{age} = 19.67$, 137 female).

Procedure/measures: In an online survey, participants responded to six vignettes depicting pain in children with ID, and completed measures of pain and disability-related beliefs.

Results/discussion: Compared to those without experience, RW held more positive disability-related beliefs, $t(192) = 4.23$, $p < 0.001$. Participants' pain-related beliefs (e.g., sensitivity to pain) differed depending on severity of the child's ID and participant group. Participants' pain-related beliefs predicted care decisions. Results provide initial insight into RW pain-related beliefs about children with ID, and a basic understanding of the relations among pain beliefs, personal characteristics and pain-related decisions.

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What this paper adds?

Pain is prevalent throughout childhood. Children with intellectual disabilities (ID) are particularly at risk because they may: experience pain more frequently than children without ID, express their pain differently, and be incapable of providing pain self-reports. Further, unmanaged pain can impact these children's quality of life (e.g., through decreased ability to use adaptive functioning skills). Despite many of these children receiving respite care, no research has examined disability and pain-related beliefs of respite workers (RW) and their caregiving implications. This novel research is the first to provide

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insight into RW disability and pain-related beliefs, compare these beliefs to an inexperienced emerging adult population, and investigate the role these factors may play in RW pain-related decision making.

Compared to emerging adults, respite workers held more positive disability-related beliefs; however, respite workers also endorsed inaccurate beliefs including the notion that a larger percentage of children with more severe ID are less sensitive to pain and have a higher emotional reaction to pain. As children's ID severity increased, both participant groups believed that a higher percentage of these children were less able to sense pain, had higher emotional and behavioral reactions to pain, had a decreased ability to communicate their pain, and experienced less pain overall (i.e., prevalence of pain). Some pain-related beliefs predicted participants' care decisions.

Future research directions include the development of educational programming for respite workers to provide them with accurate pain assessment and management-related information and strategies that they can use when supporting children with ID.

1. Introduction

For many children with intellectual disabilities (ID),¹ painful experiences are more common than in 'typically developing' children due to factors such as an increased prevalence of health problems, injuries, and need for medical procedures (Breau & Burkitt, 2009; Dubois, Capdevila, Bringuier, & Pry, 2010). Effective pain assessment and management for children with ID is important, not only because relief from pain is a human right, but also because it negatively impacts other areas of their lives such as adaptive functioning (e.g., motor skills, daily living, communication; Breau, Camfield, McGrath, & Finley, 2007; Brennan, Carr, & Cousins, 2007).

Many children with ID cannot provide accurate self-reports of their pain (Dubois et al., 2010; Stallard, Williams, Lenton, & Velleman, 2001). Thus, their pain is commonly assessed and managed by caregivers. Craig's (2009) Social Communication Model of Pain suggests that there are numerous interpersonal (e.g., situational context, type of relationship between individuals) and intrapersonal (e.g., personal history, level of knowledge) factors which interact and contribute to an individual's pain experience and expression as well as observers' assessments of an individual's pain/decisions of whether to intervene. Differences in how individuals communicate their pain impact responses from others. For example, caregivers may have preconceived ideas about how children should respond to painful experiences; behaviors deviating from this may not be recognized as potential pain indicators, and thus adequate care may not be provided.

To some degree, research has investigated the abilities of professionals and primary caregivers to effectively assess and manage pain in children with ID. For example, parents generally provide accurate estimates of their children's pain when using structured pain assessment tools (Voepel-Lewis, Malviya, & Tait, 2005), and their reports may be useful to assist professionals in assessment. Further, professionals have expressed difficulty in assessing pain even when one knows a child well (Oberlander & O'Donnell, 2001), and research suggests that secondary caregivers with more experience may be better at detecting pain (Shinde & Symons, 2007). The manner in which caregivers' beliefs² and attitudes may impact the decisions they make has also been investigated. Breau, MacLaren, McGrath, Camfield, and Finley (2003) found that primary caregivers believed children's pain sensation increased as a function of severity of a child's ID. In their discussion, Breau, MacLaren, McGrath et al. (2003) Breau, Camfield, MacLaren, McGrath, and Finley (2003) suggested that beliefs held by caregivers could impact the level and type of care provided to these children when experiencing pain.

The majority of research regarding pain assessment and management of children with ID has focused on pain in medical settings (Malviya et al., 2001; Messmer, Nader, & Craig, 2008; Voepel-Lewis et al., 2005). Research investigating everyday pain in children with ID is also critical, as this type of pain is highly prevalent, potentially even more common than in typically developing children (Breau, Camfield, McGrath, & Finley, 2003; Stallard et al., 2001). When focusing on pain in everyday settings, a critical issue is that children with ID often receive care from non-primary caregivers in order to alleviate some of the stress placed on the family (Shelton & Witt, 2011). Indeed, respite care provides an opportunity for primary caregivers of children with disabilities (including ID) to take a break from the demands of raising a child with special needs (Shelton & Witt, 2011), and is a service that continues to grow for families in need (Chan & Sigafos, 2000). Though previous pain assessment research has focused on both professionals and primary caregivers (e.g., Breau, MacLaren, McGrath et al., 2003; Voepel-Lewis et al., 2005), no research has examined the beliefs of respite care providers. When children receive support from respite workers, primary caregivers may not be available to assist in identifying when their child is in pain and to what degree. Further, respite workers may hold different beliefs than healthcare providers, close family members, or individuals who do not have experience with children with ID. It is important that research focuses on disability and pain-related beliefs of these respite workers, and how these may impact their assessment and care decisions. Exploring the differences between beliefs of respite workers and others (e.g., those without experience with children with ID), can help us to understand whether beliefs may emerge as a result of direct experience.

¹ For the purpose of this study, children with intellectual disabilities are those children who receive a diagnosis prior to turning 18 years of age and express both lower levels of overall intellectual functioning and limitations in adaptive behavior (e.g., social skills; AAMR, 2002).

² Note that in other pain-related publications to date, beliefs and attitudes have been regarded as two separate entities without indicating the difference between these terms (e.g., Breau, MacLaren, McGrath et al., 2003). Throughout the remainder of this paper beliefs and attitudes will be referred to collectively as "beliefs".

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