



Parental assessment of pain coping in individuals with intellectual and developmental disabilities

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ABSTRACT

Pain coping is thought to be the most significant behavioural contribution to the adjustment to pain. Little is known about how those with intellectual and developmental disabilities (IDD) cope with pain. We describe parental reported coping styles and how coping relates to individual factors. Seventy-seven caregivers of children and adults with IDD reported on coping styles using the Pediatric Pain Coping Inventory (PPCI), pain behaviour using the Non-Communicating Children's Pain Checklist—Revised (NCCPC-R), illness-related interactions using the Illness Behaviour Encouragement Scale (IBES) and past pain experience using the Structured Pain Questionnaire. Scores were compared across mental ages and interactions between pain coping and the other factors were explored. A Multivariate Analysis of Variance (MANOVA) by mental age group ('≤4 years', '5–11 years' and '≥12 years') revealed that those in the '5–11 years' mental age group used more coping styles than those in the '≤4 years' mental age group, and those in the '≥12 years' group used more cognitively demanding coping styles than the other two groups ($F_{(10,130)} = 2.68, p = .005$). Seeking Social Support ($r = .39, p = .001$) and Catastrophizing/Helplessness ($r = .33, p < .01$) coping styles were significantly related to a greater display of pain behaviour. Those with younger mental ages, who Seek Social Support or Catastrophize, also displayed more pain behaviour, which may be an attempt to seek external resources when pain is beyond their ability to deal with independently.

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1. Introduction

While research has increased our ability to assess pain in people with intellectual and developmental disabilities (IDD), aspects of the multidimensional pain experience, such as coping, have been relatively neglected. Pain coping is considered one of the most significant behavioural contributions to outcomes, functioning, and adjustment in both children and adults (Boothby, Thorn, Stroud, & Jensen, 1999; Hermann, Hohmeister, Zohsel, & Ebinger, 2007).

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1.1. Pain coping styles

Specific pain coping styles have become apparent through research with typical children (Bennett-Branson & Craig, 1993; Pillai Riddell, Badali, & Craig, 2004; Thastum, Herlin, & Zachariae, 2005). These studies demonstrate that active strategies such as Distraction, Cognitive Self-Instruction, and Problem Solving are considered optimal and may be the most helpful in the management of pain. Passive strategies include Catastrophizing/Helplessness and Seeking Social Support, and are thought to be disadvantageous because they increase the negative consequences associated with pain (Bennett-Branson & Craig, 1993; Piira, Hayes, Goodenough, & von Baeyer, 2006).

The way typical children cope with pain changes as they develop into adulthood (Van Cleve et al., 2004). Younger children will attempt different methods of coping until something works or until they have exhausted their resources. Older children use fewer strategies and tend to use more cognitively demanding coping styles, such as positive self-statements (Lynch, Kashikar-Zuck, Goldschneider, & Jones, 2007). There seems to be no differences in the coping strategies used by young boys compared to young girls; however, adolescent females use significantly more types of coping strategies than adolescent males. Adolescent males tend to use more distraction techniques and adolescent females tend to Seek Social Support in order to cope (Van Cleve et al., 2004).

1.2. Pain coping specific to individuals with IDD

Two studies have examined pain coping in individuals with IDD; both focussed on children. Fanurik, Koh, Schmitz, Harrison, and Conrad (1999) asked parents about their child's coping during a past needle stick and found that individuals with mild to moderate impairment showed more coping behaviours than individuals with severe or profound impairment. Zabalia and Duchaux (2007) used the Pediatric Pain Coping Inventory (PPCI; Varni et al., 1996) to ask children with IDD how they coped with pain. The authors concluded that children with IDD were more likely than typically developing children to Seek Social Support. Zabalia and Duchaux (2007) suggested that this may be because Seeking Social Support is more adaptive for these children when they may not have the mental ability to use more cognitively demanding coping strategies.

1.3. Specific aims

This study explores the coping behaviours of children and adults with IDD. To be inclusive of non-verbal individuals we utilized parent/caregiver reports. Parent report of their child's pain has been shown to be accurate (Spagrud et al., 2008), suggesting their report of pain coping is likely also accurate.

1.4. Hypotheses

First, we expected individuals with IDD would use multiple coping styles and would favour Social Support Seeking, based on Zabalia and Duchaux's (2007) finding that individuals with IDD may Seek Social Support more frequently. Second, we expected coping styles would vary depending on mental age but not chronological age. Although, Lynch et al. (2007) and Van Cleve et al. (2004) found that chronological age was associated with changes in coping style for typically developing children, mental age and not chronological age is indicative of cognitive ability for individuals with IDD. Further, Fanurik et al. (1999) found that individuals with IDD who had greater cognitive ability were reported to cope better with pain. Third, we expected those who use passive coping styles (i.e. Catastrophizing/Helplessness, Seeking Social Support) would typically show more overt pain behaviour as scored on the Non-Communicating Children's Pain Checklist-Revised (NCCPC-R; Breau, McGrath, Camfield, & Finley, 2002). This was expected because (1) typical children who use passive coping styles have a more negative pain experience (Varni et al., 1996), which could lead to more pain behaviour and (2) Seeking Social Support and Catastrophizing necessitate communicating that one has pain, including non-verbal actions (Craig, 2009). Finally, we expected that individuals with more prior pain experience would use more active coping styles because, like typical children, individuals with IDD may learn to cope more effectively with more experience (Van Cleve et al., 2004).

2. Materials and methods

2.1. Participants and data collection

Participants were 78 primary caregivers (parent/step-parent/guardian) of individuals diagnosed with IDD. The caregivers completed all measures and provided informed consent. The individuals with IDD had all taken part in previous studies lead by one of the authors in which their diagnosis of an IDD was confirmed through review of medical records or testing. Thus, this information was not collected as part of this study, with the exception of one question regarding caregiver's estimate of the individual's current mental age. All individuals with IDD had a chronological age greater than 3 years, due to limitations in confirming a diagnosis of IDD below this age in previous studies. This study was approved by the hospital's Research Ethics Board.

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