

## Brief Report: Judging Pain Intensity in Children with Autism Undergoing Venepuncture: The Influence of Facial Activity

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**Abstract** The biasing effect of pain sensitivity information and the impact of facial activity on observers' judgements of pain intensity of children with autism were examined. Observers received information that pain experience in children with autism is either the same as, more intense than, or less intense than children without autism. After viewing six video clips of children with autism undergoing venepuncture, observers estimated pain intensity using a visual analogue scale. Facial activity as coded by Chambers et al. (Child Facial Action Coding System Revised Manual, 1996) had a significant impact on observers' estimates of pain intensity; pain sensitivity information did not. These results have important implications for the assessment and management of pain in children with autism.

**Keywords** Autism · Pain · Facial expression · Observer report · Biasing information

Children inevitably experience pain as part of their everyday lives (McGrath and McAlpine 1993), and they often must depend on caregivers for relief from pain. It is important, therefore, for caregivers to be able to accurately interpret children's expression of pain in order to provide appropriate care. Unfortunately, accurate pain assessment can be a challenging task, especially in children with autism. The language impairments that characterize this population pose a significant barrier to communicating their pain to others (Nader et al. 2004). As well, there is a

belief that children with autism are less sensitive to pain than the average child, and this may bias observers' interpretation of pain signals in these children. Caregivers may discount or deny signals of distress in children who cannot clearly express their pain (Walco et al. 1994), especially if it is believed that the child does not feel pain. It is important, therefore, to understand the behaviours observers can use to assess pain in children with autism, and to understand the potential bias of pain sensitivity information on judgements of pain in these children.

The sociocommunicative model of pain was developed by Craig et al. (1996) to help explain how pain in children is experienced, expressed, and interpreted by others. According to the model, the communication of pain begins with the child's experience of pain (1) this experience influences the encoding of pain expressions by the child, (2) these pain expressions are broadcast to observers, who then can decode the child's pain, (3) and potentially take action to alleviate the child's pain (4) this model can be used to help understand pain in children with autism. The model takes into account that there are many ways that a child can encode their pain experience. Because the substantial impairment in verbal and nonverbal language functions in children with autism impose a significant barrier to pain communication, observers must rely on other modes of communication in order to decode the child's pain.

Facial activity has been found to be a major determinant of observers' judgements of pain in infants (Hadjistavropoulos et al. 1994), children (Breau et al. 2001), and adults with cognitive impairments (LaChapelle et al. 1999). Nader et al. (2004) examined the facial pain reactions of children with autism undergoing venepuncture and compared them to children without autism undergoing a similar procedure. As well, the researchers compared parents'

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report of pain in their children to the objectively coded facial activity of the children. They found that the children with autism displayed significant facial pain reactions, and these reactions were comparable to the children without autism. However, there was no relationship between parental reports of pain and the observed pain responses in children with autism. Nader et al. (2004) suggests that the widespread reports of pain insensitivity or indifference in children with autism may cause parents to be uncertain about the pain experience of their children, and could explain the discordance between parental report of pain and observed behaviours of the children with autism.

Another potential barrier to assessing pain in children with autism is the prevailing belief, frequently based on anecdotal observation or clinical impression, that pain insensitivity is a common feature of children with autism (e.g. American Psychiatric Association 2000). The belief that children with autism are insensitive to pain may bias observers' judgements of pain in these children. Prkachin et al. (1983) examined the impact of pain-relevant information on judgements of the pain conveyed in facial expressions and found that the information participants were given regarding the pain sensitivity of the people they observed biased the participants' evaluations of pain. The findings of this study support the idea that perceptions of pain in children with autism could potentially be influenced by the belief that children with autism are insensitive to pain.

The present study had two objectives: (1) to examine the influence of information about the pain experience of children with autism on observers' judgement of pain intensity in children with autism, and (2) to examine the impact of facial activity on observers' judgement of pain intensity in children with autism.

Our first hypothesis was that the three groups would rate the pain intensity of the children with autism in accordance with the information they received. Specifically, we expected that participants who received information about potential pain hypersensitivity in children with autism would give the highest pain intensity ratings, participants who received information that children with autism experience pain no differently than other children would give moderate ratings of pain, and participants who received information about potential pain insensitivity in children with autism would give the lowest pain intensity ratings.

Our second hypothesis was that observers who received information that children with autism experience pain no differently from children without autism would give pain intensity ratings that were ranked in accordance with rankings from an objective measure of facial pain activity (CFCS, Chambers et al. 1996). Specifically, children who receive lower scores on the CFCS are expected to be rated as experiencing a lower intensity of pain, and children who

receive higher scores on the CFCS are expected to be rated as experiencing a higher intensity of pain. Observers who had been influenced by biasing information about the pain experience of children with autism were expected to give pain intensity ratings that were not ranked in accordance with an objective measure of facial pain activity.

## Methods

### Participants

Twenty-seven undergraduate psychology students who had no previous experience with children with autism were recruited at the University of British Columbia. The sample consisted of 23 females and four males, with a mean age of 20.11 years ( $SD = 6.6$ ). Nineteen of the participants identified themselves as Caucasian, seven participants identified themselves as Asian, and one identified him/herself as "other". None of the participants identified themselves as parents.

The video clips of children with autism undergoing venepuncture were obtained from a previous study (Nader et al. 2004), and were used with permission of the parents of the children. Inclusion criteria for the children with autism in Nader et al. (2004) study were (a) a score of 30 or more on the Childhood Autism Rating Scale (CARS, Schopler et al. 1998); (b) a score of 6 or more on the DSM-IV diagnostic criteria; and (c) clinical judgement by a paediatrician, psychiatrist, or registered psychologist experienced in the field of pervasive developmental disorders. The sample of children with autism used for the current study consisted of four boys and two girls between the age of three and seven. The clips consisted of the 10 s immediately preceding the injection, and the 10 s immediately after needle insertion.

### Procedure

Participants were randomly assigned to one of the three groups. Group A consisted of seven participants, and group B and group C consisted of 10 participants. Each group read a two-page booklet with information taken from *Children with autism: A parent's guide* describing features of autism (Powers 1989). Embedded in the general account was a description of the pain experience of children with autism. This information differed for each group, saying either (a) "Children with autism appear to respond to pain in the same way that children without autism do"; (b) "Children with autism also appear to respond to pain differently than children without autism. In particular, they seem to have a low tolerance for pain and appear to feel

pain more than other children. This has been termed ‘pain hypersensitivity’ and has recently been documented in research on children with autism”; or (c) “Children with autism also appear to respond to pain differently than children without autism. In particular, they seem to have a high tolerance for pain and don’t appear to feel pain as much as other children. This has been termed ‘pain insensitivity’ and has recently been documented in research on children with autism.”

After reading the booklet, participants watched six video clips of children with autism undergoing venepuncture. The video clips had been previously coded for facial activity using the Child Facial Coding System (CFCS, Chambers et al. 1996). The CFCS is a facial coding system designed to assess children’s pain experiences. The frequency and intensity of thirteen explicitly defined facial actions (e.g. brow lower, eye squeeze, nose wrinkle) are coded by a trained CFCS coder using stop-frame and slow-motion video editing equipment. The CFCS score for each child is obtained by calculating the average of the individual facial action unit scores. The CFCS has been shown to be a reliable and valid measure of pain in children (Gilbert et al. 1999).

After each video clip, participants rated the pain intensity of the child on a visual analogue scale (VAS), a 100-mm horizontal line anchored on the left by “no pain” and on the right by “worst possible pain.” Participants placed a mark on the line to indicate how much pain they thought the child was feeling. The VAS is a valid measure for assessing pain intensity (Jensen and Karoly 2001).

After watching the video clips and rating the pain intensity of each child, participants completed a manipulation check consisting of 10 questions assessing how closely they had read the information booklet about autism, including a question to assess whether they could recognize what information they had read about the pain experience of children with autism. All participants in this study answered this question correctly.

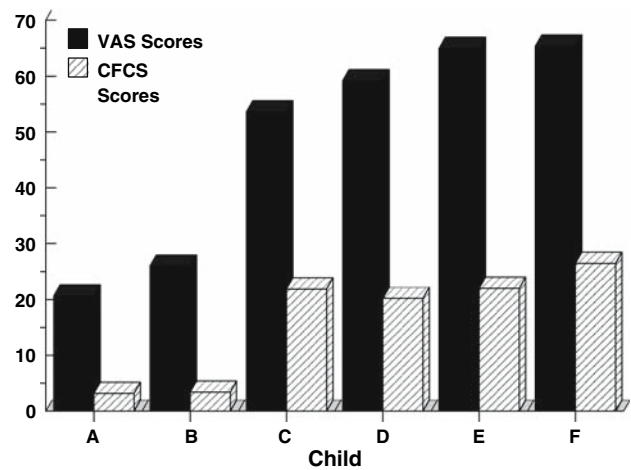
## Results

A 3 (group)  $\times$  6 (child) analysis of variance (ANOVA) with repeated measures was used to determine if there were significant differences in VAS pain ratings across any of the children and between the subject groups. There was no significant interaction between child and group,  $F(10, 27) = 1.42, p > .05$ . There was no significant main effect in VAS ratings between the groups,  $F(2, 27) = 0.95, p > .05$ . However, there was a significant main effect in VAS ratings, combined from all groups, across the children,  $F(5, 27) = 38.54, p < .001$ .

Mean VAS scores were calculated for each child to determine the order of pain intensity ratings (see Table 1).

**Table 1** Mean VAS score and CFCS score for each child

Child	VAS score ( <i>SD</i> )	CFCS score
A	20.63 (16.85)	3.20
B	25.96 (19.52)	3.40
C	53.59 (20.53)	21.90
D	59.15 (21.28)	20.22
E	64.96 (20.57)	22.00
F	65.37 (20.81)	26.50



**Fig. 1** Mean pain intensity (VAS) scores and facial activity (CFCS) scores for each child

Mean pain intensity scores on the VAS were compared to the average facial pain activity scores from the CFCS. A Spearman rank order correlation indicated that the order of VAS ratings were highly correlated with the order of the CFCS scores ( $r_s = .943, p < .01$ ). Children who received lower scores on the CFCS were judged to be experiencing a lower intensity of pain, and children who received higher scores on the CFCS were judged to be experiencing a higher intensity of pain (see Table 1 and Fig. 1).

## Discussion

This study found that observers’ ratings of pain in children with autism were not influenced by information regarding the pain experience of children with autism. This is in contrast to the view that parents’ ratings of pain in their children with autism may be distorted due to misinformation about pain insensitivity in their children. This study also found that facial activity had an impact on observers’ estimates of pain in children with autism, regardless of the information the observer received about the pain experience of children with autism. This stands in contrast to the previous finding that parents’ ratings of pain in their

children with autism do not correspond with an objective measure of facial pain activity (Nader et al. 2004).

The fact that observers in this study were influenced by the facial pain activity of the children with autism indicates that the children's experience of pain is communicated, at least in part, through their facial activity. It also suggests that observers are capable of, and do use, facial activity as one basis for estimating pain in children with autism. This is consistent with previous research done with infants (Hadjistavropoulos et al. 1994), children (Breau et al. 2001), and adults with cognitive impairments (LaChapelle et al. 1999). The finding that observers may be able to decode pain information from facial activity is important because children with autism frequently lack the skills to express their pain verbally and this could put them at risk for substandard health care.

A few limitations of this study should be noted. One problem was that the power for the between group analysis was very small due to the sample size of the groups ( $n = 7, 10$  and  $10$ ). The impact of our manipulation on the observers' ratings of pain intensity would have had to be quite substantial for it to have been apparent in a sample of this size. Although all participants in this study correctly answered the manipulation check, it is still possible that our manipulation was not strong enough.

This study examined pain intensity based on an acute pain reaction to a specific medical procedure. Care should be taken in generalizing the results of this study to observations of everyday pain or chronic pain in children with autism. It is also important to acknowledge that the experiences of children with autism occur along a spectrum of severity, and the experience and expression of pain may differ along the spectrum.

The current study offers preliminary findings on the decoding of facial expression and the effect of biasing information on the ability of observers to receive pain information from children with autism. More research is needed to understand how observers decode the pain experience of children with autism. As well, future research should continue to explore the potentially biasing effect of pain sensitivity information of observers' estimates of pain in children with autism. Future research should also examine observers' estimates of pain in different settings and with different types of pain. It is important to understand how different types of pain in different settings are perceived in order to acceptably manage pain in children with autism.

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