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Everyday expressions of pain in children with and without autism spectrum disorder

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ABSTRACT

Background: Anecdotal reports from parents suggest that their children with autism spectrum disorder (ASD) may have diminished pain experiences and expressions. In contrast, objective measures of pain have been used to document typical and enhanced expressions of pain in response to noxious stimuli (e.g., blood draw) among children with autism. The purpose of this study was to compare non-biased parental ratings of pain among children with and without ASD.
Method: As an everyday measure of pain, parents completed The Non-Communicating Children's Pain Checklist (NCCPC-R) across two time windows (i.e., 2 h and 1 week) for 31 children with ASD and 19 children without ASD.
Results: There were no significant group differences in everyday expressions of pain between children with and without ASD. However, in general, increased autism symptomology severity was associated with decreased parental ratings of pain expressions.
Conclusion: These results continue to support a framework where children with ASD may have typical pain sensitivity, however, their expressions of pain may differ based on where individuals lie on the autism spectrum.

1. Introduction

Individuals with autism spectrum disorder (ASD) are often described as having an increased tolerance for pain. "Apparent indifference to pain/temperature" is provided as a symptom of ASD in the Diagnostic and Statistical Manual on Mental Disorders-5 (American Psychiatric Association, 2013). Additionally, previous descriptions of associated features of ASD included "a high threshold for pain" (American Psychiatric Association, 2000) and "ignoring pain" (American Psychiatric Association, 1987). Many of the documented reports of increased pain tolerance in this population are from anecdotal reports from caregivers (e.g., Bursch, Ingman, Vitti, Hyman, & Zelter, 2004; Militerni et al., 2000) or case studies (Allely, 2013). The belief that children with ASD do not feel pain may bias caregivers when seeking treatment options. This is especially concerning, as children with ASD are likely to have comorbid conditions such as gastrointestinal and seizure disorders, which

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may require frequent medical care (Ellerbeck, Smith, & Courtemanche, 2015). Accurate assessment of pain is necessary to provide appropriate intervention.

In contrast to anecdotal reports, when using a more objective measure of pain, like facial coding systems or behavioral rating scales (e.g., Non-Communicating Children's Pain Checklist (NCCPC)) (Breau, McGrath, Camfield, Rosmus, & Finley, 2000; McGrath, Rosmus, Camfield, Cmapbell, & Hennigar 1998), researchers have documented that children with ASD displayed painful reactions to noxious stimuli (e.g., venipuncture, dental procedures) (Daughters, Palermo, & Koh, 2007; Nader, Oberlander, Chambers, & Craig, 2004; Tordjman et al., 2009). For example, Nader et al. (2004) reported that children with ASD had significant painful reactions to a blood draw procedure. The painful reactions displayed by the children with ASD were similar to (or enhanced) the typical controls. Tordjman et al. (2009) also reported that individuals with ASD had enhanced physiological and biological stress responses (e.g., heart-rate and endorphin levels) during a similar procedure when compared to children without ASD. Results from these studies suggest that individuals with ASD may not have blunted pain sensitivity.

There have been fewer evaluations of everyday expressions of pain in individuals with ASD. Many of the prior studies examining painful reactions in individuals with ASD have used procedures that involve measuring pain-related behaviors before, during, and after the presentation of a clear stimulus. Using this type of methodology may produce more reliable measures of pain among a variety of populations. Generalizing the results of these studies to everyday expressions of pain should be done with caution (Allely, 2013; Nader et al., 2004). Identifying pain in the absence of a clear stimulus may prove to be much more difficult. The purpose of the present study was to measure everyday expressions of pain in young children with and without ASD to assess differences in the frequency and types of pain-related behavior displayed by these two populations. An additional purpose was to assess if the severity of autism symptoms was related to the frequency of pain-related behaviors reported by parents.

2. Method

2.1. Recruitment

The study was conducted at a university-based child development center that conducts evaluations of children and adolescents at risk for autism and other developmental disabilities, as is described elsewhere (Courtemanche, Black, & Reese, 2016). Families who met eligibility requirements (i.e., child under the age of seven, family spoke English, and physician referral to be evaluated for ASD) were sent information about the study. Interested families provided informed consent and either returned the rating scale on the day of their child's appointment or completed the scale at their home and returned it at a later date in the mail. Forty-two percent of interested families returned the completed rating scale.

2.2. Dependent measures

2.2.1. Pain

The Non-communicating Children's Pain Checklist-Revised (NCCPC-R) was used to measure everyday expressions of pain (Breau, McGrath, Camfield, & Finley, 2002). The NCCPC-R has seven categories of non-verbal pain-related behavior (e.g., facial, vocal, and social) with a total of 30 items (e.g., furrowed brow). Each item is rated on a 4-point scale regarding the frequency of each behavior ranging from not at all (0) to very often (3). The scale is intended for children, ages 3–18 years, who have communicative difficulties and can be completed by parents or caregivers with no training. Scores of seven or higher in a two hour window indicate the presence of pain. The NCCPC-R has excellent psychometric properties. The NCCPC-R has been shown to be valid and reliable when used by parents in natural settings (Breau et al., 2000), and discriminted between pain and non-pain episodes in children with cognitive impairments (Breau et al., 2002). Ratings on the NCCPC-R also were internally consistent, consistent over time, and discriminated pain from more general distress (Breau et al., 2000, 2002). For this study, the scale was de-identified to minimize the influence of any potential perceptions that parents may have had about ASD and pain. Parents were asked to retrospectively rate each item on the NCCPC-R during the last 2 h and over the last week.

2.2.2. Diagnostic evaluation measures

Children were referred to the center for a wide variety of developmental concerns (e.g., communication, behavior, and learning) including evaluations for ASD. Interdisciplinary diagnostic teams included a licensed psychologist, developmental pediatrician, one additional discipline (e.g., speech-language pathology) and student trainees. Because the data were collected over two years, some children were diagnosed using the DSM-IV-TR (APA, 2000) and some children were diagnosed using the DSM-5 (APA, 2013). Diagnostic teams used information from several instruments when making a diagnosis of ASD including:

2.2.3. Autism diagnostic observation schedule 2nd edition (ADOS-2)

The ADOS-2 (Lord, Rutter, DiLavore, Risi, & Gothman, 2012) is a semi-structured assessment that presents a number of play-based activities, which allow for the assessment of communicative behavior, social interaction and play, and the frequency and severity of restricted and repetitive behaviors. The ADOS-2 also provides a comparison score used to