

How do children with autism spectrum disorders express pain? A comparison with developmentally delayed and typically developing children

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ABSTRACT

There is a lack of knowledge about pain reactions in children with autism spectrum disorders (ASD), who have often been considered as insensitive to pain. The objective of this study was to describe the facial, behavioral and physiological reactions of children with ASD during venipuncture and to compare them to the reactions of children with an intellectual disability and nonimpaired control children. We also examined the relation between developmental age and pain reactions. The sample included 35 children with ASD, 32 children with an intellectual disability, and 36 nonimpaired children. The children were videotaped during venipuncture and their heart rate was recorded. Facial reactions were assessed using the Child Facial Coding System (CFCS) and behavioral reactions were scored using the Noncommunicating Children's Pain Checklist (NCCPC). A linear mixed-effects model showed that children's reactions increased between baseline and venipuncture and decreased between the end of venipuncture and the recovery period. There was no significant difference between groups regarding the amount of facial, behavioral and physiological reactions. However, behavioral reactions seemed to remain high in children with ASD after the end of the venipuncture, in contrast with children in the 2 other groups. Moreover, we observed a significant decrease in pain expression with age in nonimpaired children, but no such effect was found regarding children with ASD. The data reveal that children with ASD displayed a significant pain reaction in this situation and tend to recover more slowly after the painful experience. Improvement in pain assessment and management in this population is necessary.

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1. Introduction

Autism spectrum disorders (ASD) are severe and lifelong neurodevelopmental disorders characterized by impairments in socialization and communication, as well as a pattern of repetitive behaviors and interests [28]. Like other children, children with autism and developmental disorders inevitably experience pain in their everyday life, but they might be confronted with painful situations more frequently because of challenging behaviors (eg, agitation, self-injury) and medical issues (gastrointestinal tract problems, epilepsy) that are common in this population

[2,3,12,16]. For these reasons, it is crucially important to better identify and treat pain in this population.

There are few studies about pain expression in children with autism (see [8] for a review). Tordjman et al. [26,27] observed a decreased behavioral reactivity in children with autism during venipuncture, but the 5-point tool they used to assess behavioral reactivity (paradoxical, absent, hypo-, normal, hyperreactivity) was global and was based on the observer's judgment, which might explain the low behavioral reactivity in their study. Their results also showed an increase in physiological reactions (heart rate and plasma β -endorphin level) during venipuncture and the presence of self-injurious behaviors immediately after a painful experience. The authors interpreted those results as a different mode of pain expression rather than insensitivity to pain. Nader et al. [22] compared pain reactivity in a group of 21 children with autism and a nonimpaired comparison group comprising 22

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children during venipuncture. Using the Child Facial Coding System (CFCS) [7], they showed that children with autism displayed a significant facial reaction to venipuncture and that facial reactions were even stronger during needle injection than in the comparison group. It must be noted that both procedures differed (children with autism were bundled and children in the control group were not) and that the purpose of venipuncture was different in the 2 groups (injection for children with autism, blood collection for the control group of nonimpaired children), calling for caution when considering differences between the groups. Despite this, the results are important because this study was the first to show a significant behavioral reaction in response to a painful stimulus in children with autism.

Another important issue regarding pain in children with ASD is the impact of the children's clinical characteristics, especially their psychological development. Some studies showed that, in children with an intellectual disability, pain reactivity was influenced by the level of psychological development [9,10,18]. Results showed that children with a mild or moderate intellectual disability had similar pain reactions to typically developing but younger children, whereas children who were more severely disabled had more unusual reactions such as self-aggressive behaviors, withdrawal, etc. There are no such studies describing children's reactions according to their psychological development in children with ASD.

The purpose of the present study was to describe the behavioral and physiological reactions of children with ASD during venipuncture, and to compare them to the reactions of children with intellectual disabilities and typically developing children. A secondary objective was to determine whether reactions to the painful stimulus varied according to the level of psychological development in the 3 groups of children.

2. Methods

2.1. Participants

Participants were recruited in 4 pediatric and care units in Montpellier and Marseille. All children had a venipuncture for the purpose of a routine blood collection (eg, genetic or metabolic tests) and not for the purpose of the study. Inclusion criteria for children with ASD were being aged between 3 and 8 years, and having an ASD diagnosis according to ICD-10 [28] or a score of 7 or more on the Autism Diagnostic Observation Schedule–Revised (ADOS-R) [19] and the clinical judgment of an experienced

multidisciplinary team. Inclusion criteria for children in the intellectual disability group were being aged between 3 and 8 years, having a diagnosis of intellectual disability according to ICD-10 [28], a score of <70 on the Vineland scale [25], and an absence of an ASD diagnosis. Children in the control group were matched to children in the ASD and intellectual disability groups on the basis of developmental age measured at the Vineland scale using age intervals. Because children with ASD had developmental delays, children in the control group had to be aged between 18 months and 6 years. We ensured that they did not have a developmental disability through a short parental interview (including questions about school level, communication and daily living skills). The local human subjects protection committee approved the research protocol and parents provided informed consent for all children.

Thirty-five children with ASD were recruited, 29 boys and 6 girls, with a median age of 58 months (interquartile range [IQR] 47–76). On the Vineland scale [25], the median developmental age, calculated on the basis of the Vineland composite standard score, was 32 months (IQR 26–44) (Table 1).

Thirty-two children with an intellectual disability were recruited, 19 boys and 13 girls, with a median age of 56 months (IQR 46–69). On the Vineland scale, the median developmental age was 35 months (IQR 24–47).

Thirty-six children without developmental disability were recruited, 27 boys and 9 girls, with a median age of 44 months (IQR 25–59). Children in this group did not have an intellectual disability and had a venipuncture for either an acute health problem (eg, diarrhea) or a stabilized chronic disease that did not require many medical examinations at the time (eg, cystic fibrosis).

2.2. Procedure

On the day of the venipuncture, the children were videotaped and their heart rate was recorded. The use of a topical anesthetic (EMLA cream) or inhaled nitrous oxide and oxygen (N₂O/O₂) was recorded. Heart rate was measured via a sensor placed on the top of the finger, linked to a monitor that recorded the changes of values. Recordings began a few minutes before the venipuncture for a baseline period until 1 min after the end of it for a recovery period. The procedure lasted between 50 and 250 s (mean 110, SD 63). Because of this variability in duration, only the first 50 s of the venipuncture was used in the analyses. In order to study pain reactions over time [14,22], five 10-s periods were defined: baseline (30 to 20 s before needle insertion), needle 1 (10 s

Table 1
Summary information across groups.

Participants' characteristics	ASD (n = 35)		Intellectual disability (n = 32)		Control (n = 36)		P value ^a
	n	%	n	%	n	%	
Gender							
Male	29	83	19	59	27	75	NS
Female	6	17	13	41	9	25	
Children who had a venipuncture during last 6 months	4	11	7	22	18	50	.001 ^b
Children who had been hospitalized before	13	38.2	19	61.3	21	58.3	NS
Local anesthesia/sedation during venipuncture							
EMLA	16	46	12	38	24	67	.06
N ₂ O/O ₂	1	7	1	3	7	19	.1
EMLA and/or N ₂ O/O ₂	18	49	13	41	28	81	.008 ^c
	Median	IQR	Median	IQR	Median	IQR	P value ^d
Chronological age, months	58	47–76	56	46–69	44	25–59	<.0001 ^b
Developmental age, months	32	26–44	35	24–47	44	25–59	NS

ASD, autism spectrum disorders; IQR, interquartile range.

^a Chi-square test.

^b ASD different from control.

^c Intellectual disability different from control.

^d Kruskal-Wallis significance test.

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