

# Study the Need of Pharmaceutical Care for Pain in Children with Autism Spectrum Disorder

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## ABSTRACT

**Background:** A heterogeneous neuropsychiatric disorder called autism spectrum disorder (ASD) is frequently accompanied by significant behavioral disorders that might vary significantly in how they react to pain. It is primarily unknown how to quantify pain in people with ASD. An effective pain evaluation in this population will ultimately lead to more effective pharmaceutical pain management strategies. **Aim:** The current study aims to identify the need for pharmaceutical care in children with ASD by evaluating their pain and correlating the autism score with the pain score. **Materials and Methods:** In total, 73 ASD children between the ages of 3 and 14 were enrolled in this study. The pain was evaluated using the non-communicating children's pain checklist-revised (NCCPC-R). The statistical analysis was carried out with the aid of Microsoft Excel. **Results:** The mean age of participating children is  $6.3 \pm 3.25$  years (mean  $\pm$  standard deviation) in this male population is dominating. The total score of NCCPC-R of more than 6 was 93.2% of the children indicating pain. The degree of pain is directly proportional to the degree of autism. **Conclusion:** Most children reported pain scores were greater than average, indicating that they could require pharmaceutical care to control their discomfort. It is strongly advised to conduct additional research using this technique's multicenter prospective use in real-world settings with observations of "real-life" pain events.

**Keywords:** Autism spectrum disorder, Autistic disorder, Pain, Pharmaceutical services  
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## INTRODUCTION

According to the International Society for the Study of Pain (IASP), pain is "a disagreeable sensory and emotional experience related to, or similar to, existing or potential tissue injury." The pain that persisted for at least 3 months is typically regarded as chronic pain. IASP concedes that those who are unable to express their pain vocally may nevertheless be experiencing it. This group may include individuals who co-morbidly have an intellectual impairment (ID) and autism spectrum disorder (ASD).<sup>[1]</sup>

According to the Diagnostic and Statistical Manual of Mental Disorders, ASD is a neurodevelopmental condition marked by persistent challenges with social interaction and communication as well as constrained, repetitive patterns of behavior or interest.<sup>[2]</sup>

The Centers for Disease Control and Prevention (CDC) conducts research on the prevalence of ASDs (CDC). According to the CDC, 1 in 44 American children has been given an autistic spectrum disorder diagnosis as of 2021. One in every 100 kids will have an autistic spectrum disorder diagnosis in 2022. Autism prevalence speculations in India are 11,914 annually.<sup>[3]</sup> In fact, this cohort is more likely to experience pain because of troublesome activities, such as self-harming behavior, and a higher chance of unintentional injury. In addition to having ASD or ID, some people also have co-occurring neurological, musculoskeletal, or gastrointestinal conditions that could cause pain.<sup>[4,5]</sup>

Only a few researches have examined the incidence and implications of pain in people with ASD. According to carer studies, 15–50% of adults with intellectual disabilities report experiencing everyday pain. Those with intellectual disabilities who experience pain struggle to fully participate in day services, which have a detrimental impact on their quality of life, sleep, and emotional health.<sup>[6-9]</sup>

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Children with ASD exhibited a greater incidence (15.6%) compared to children without ASD (8.2%) in a recent survey on the prevalence of pain (based on parental reports), in a representative sample of children in the United States. Furthermore, children with ASD and developmental comorbidities had the highest rate of pain (19.9%). The authors proposed several explanations for the increased occurrence of pain, including underlying sensory sensitivity, comorbidity of illnesses, including cerebral palsy and gastrointestinal disorders, and more frequent medical procedures.<sup>[10]</sup>

Self-report measures are not always available or practical for use with people with ID and ASD, despite the fact that they are the "gold standard" in the assessment of pain. Furthermore, it has been observed that people with ASD-ID often show their

suffering in “atypical” ways, such as sobbing, impatience, poor mood, reduced activity, hunger changes, and self-injurious conduct (such as head banging and biting).<sup>[11-13]</sup> As a result, pain is commonly misdiagnosed and poorly managed in people who have communication problems.<sup>[14]</sup> Research on therapies for those with more severe cognitive deficits and other complicated presentations, such as ASD, is constantly needed to manage their pain effectively.<sup>[15]</sup>

There has been little research done on how to assess pain in people with ASDs. At the same time, this population has had great difficulty using conventional pain evaluation measures because of the underlying deficiencies of ASD. Accurate pain evaluation is essential to providing high-quality care when children with ASD are exposed to a medical setting.

There is not much research on pain in autism. Communication problems and the widespread perception that people with autism have lessened pain sensitivity are two factors contributing to the difficulties in measuring pain in children. According to studies, the most crucial step in managing pain is identifying it. The Non-Communicating Children's Pain Checklist-Revised (NCCPC-R) scale may need to be adapted for children with ASD or any kind of cognitive disability since they may express pain differently. To gauge a child's level of pain who is unable to communicate, this checklist is employed. The NCCPC-Revised form takes 2 h (roughly 120 min) to complete and consists of 30 items that assess a child's vocal, social, and facial; activities; body and limb movements; physiological status; and eating and sleeping patterns. The observer, a parent or carer, evaluated the child during this time.

The current study aims to identify the need for pharmaceutical care in children with ASD by evaluating their pain with the NCCPC-R scale and correlating the autism score from the Indian Scale for Assessment of Autism (ISAA) with the pain score (NCCPC-R).

## MATERIALS AND METHODS

The present study was conducted in the department of pediatrics and neonatology in a multispecialty hospital in Coimbatore, located in Tamil Nadu, India. The ethical approval was obtained from the Ethical Committee of the institution with approval number EC/AP/1008/02/2023 dated February 14, 2023. The study was conducted for 3 months, from December 2022 to February 2023. Children were included in the study after obtaining written, signed consent from the children's parents/caregivers after explaining the nature of the study. The existence of ASD is scored according to ISAA.

In this study, we included children between the ages of 3 and 14 years, both gender with a clinical diagnosis of autism and parents/caregivers who can answer the questionnaire in Tamil or English language and willing to participate. We excluded children with any co-morbidity condition such as epilepsy, sleeping disorders, attention-deficit hyperactivity disorder, anxiety, depression, and bipolar disorder; children who had any surgery or major interventions; and who are not willing to participate in this study.

This study included about 102 children. The enrollment of children was done based on inclusion criteria. All the demographic data and autism score details were collected from the patient's record. NCCPC-R<sup>[16]</sup> was used to assess the pain in this study. The

NCCPC-Revised form takes 2 h (roughly 120 min) to complete and consists of 30 items that assess a child's vocal, social, and facial; activities; body and limb movements; physiological status; and eating and sleeping patterns. The observer, a parent or carer, evaluated the child during this time; a total score of 7 or more indicates that a child has pain and total score of 6 or less indicates that a child does not have pain. Due to practical challenges, we were able to take only 73 children's data. The observational survey data were collected in the data collection form. After that, the data were processed and analyzed.

## Statistical Analysis

Descriptive analysis of mean, standard deviation (SD), and percentages was used to quantify pain and types of expression of pain commonly among children with ASD by Microsoft Excel.

## RESULTS

A total of 73 parents/caregivers participated in this study. Families' sociodemographic characteristics of the children are presented

**Table 1:** Families' sociodemographic characteristics

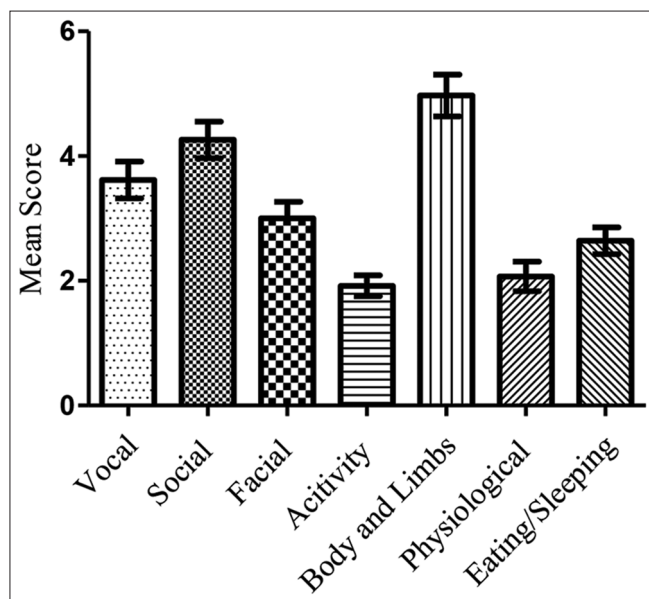
Parent/caregivers mean age	34.8±6.78 years
Male	24.5%
Female	75.5%
Education level	
Mother (%)	
Primary education	16.9
Secondary education	49.3
Higher education	33.8
Father (%)	
Primary education	5.4
Secondary education	24.7
Higher education	69.9
Socioeconomic status (%)	
Low	22.8
Middle	73.1
Higher	4.1
Residence (%)	
Village	66.3
Town	33.7
Employment status	
Mother (%)	
Full time	12.8
Part time	26.3
Unemployed	60.9
Father (%)	
Full time	89.9
Part time	6.9
Unemployed	3.2

**Table 2:** The characteristics of children with autism spectrum disorders

Mean age	6.3±3.25 years
Male	67.9%
Female	32.1%
Autism score (Indian Scale for Assessment of Autism) (%)	
Mild autism (70–106)	56.9
Moderate autism (107–153)	54.3
Severe autism (>153)	2.6
Education (%)	
Ordinary school	33.9
Special school	66.1

in Table 1. The mean age of parents/caregivers who participated in this study was  $34.8 \pm 6.78$  years (Mean  $\pm$  SD). Female parents/caregivers are the majority compared to male participants. Almost half of the mothers completed their secondary education level at the same time; nearly 70% of the fathers completed their higher education levels. The majorities of the families were from the middle-income range and lived in the village. The majority of the mothers were unemployed at the same time and majority of the fathers were full-time employees.

The characteristics of children with ASDs are presented in Table 2. The mean age of participating children was  $6.3 \pm 3.25$  years (mean  $\pm$  SD), in which male population were dominating. Only 2.6% of children came under severe autism. Mild and moderate autism children were almost equally participated in the study. The majority of the children studied in special education schools.



**Figure 1:** The graphical representation of the domain scores

**Table 3:** Total score of non-communicating children's pain checklist-revised (n=73)

6 or less	6.8%
7 or more	93.2%

**Table 4:** Comparison of autism score with mean total score of NCCPC-R (n=73)

Autism score	Mean total NCCPC-R score
Mild autism (70–106)	17.8 $\pm$ 4.9
Moderate autism (107–153)	34.3 $\pm$ 6.9
Severe autism (>153)	56.7 $\pm$ 3.3

NCCPC-R: Non-communicating children's pain checklist-revised

The total score of NCCPC-R for all the participating children (n = 73) is presented in Table 3. Only 6.8% of children scored 6 or less which means that children did not have pain. The remaining children (93.2%) reported with pain.

The comparison of the degree of autism and the mean total NCCPC-R score is presented in Table 4. It indicates that the degree of pain was directly proportional to the degree of autism.

The domain-wise comparison of the NCCPC-R score is presented in Table 5. The lowest score was for the activity domain and the highest score was for the body and limb domain. The social domain comes under the second-highest score. Vocal, facial, eating/sleeping, and physiological domain had decreasing order of scores, respectively. The graphical representation of the domain score is presented in Figure 1.

## DISCUSSIONS

The term "autism spectrum disorders" (ASDs) refers to the combination of Asperger syndrome, and pervasive developmental disorder not otherwise defined. ASD, which affects five times more boys than girls, has been found in roughly 1 in 88 children, according to the CDC. Other developmental, psychiatric, neurological, chromosomal, and genetic illnesses frequently co-occur with ASDs.

In addition to environmental difficulties, autistic patients frequently sense pain differently and may convey their perception of pain differently from non-autistic patients. Children with ASD have a higher risk of acquiring chronic pain than children in the general population, especially if they also exhibit atypical or hypersensitivities, according to the research.<sup>[17]</sup> Children with ASD are probably more prone to experience the negative effects of chronic pain, such as increased rates of depression and poorer quality of life. It is crucial to manage chronic pain in children with ASD due to the possibility of increased functional impairment; nevertheless, difficulties arise due to typical ASD features and a lack of specialized guidelines.

There is a dearth of research on the relationship between chronic pain and ASD; therefore, more investigation is needed. This includes examining sensory anomalies in chronic pain and the treatment of comorbid chronic pain and ASD.

The objective of the present study was to explore the mutual influence of children's pain and degree of autism on pharmaceutical care perception in children with ASD. From the sociodemographical data of the participated children in our study, the average age is consistent with previous studies, and similarly, the percentage of male children was consistent with previous studies. However, children in the most previous studies were diagnosed with a wide range of disorders leading to cognitive impairment, while all our children suffered from ASDs which are more frequent among males.<sup>[18-22]</sup>

Almost 93.2% of children in our study reported that they had experienced pain. While checking the severity of the pain, it

**Table 5:** Mean score with standard deviation in each domain

Parameters	Vocal (n=73)	Social (n=73)	Facial (n=73)	Activity (n=73)	Body and Limbs (n=73)	Physiological (n=73)	Eating/sleeping (n=73)
Minimum	0.0	0.0	0.0	0.0	0.0	0.0	0.0
Median	3.000	4.000	3.000	2.000	4.000	2.000	3.000
Maximum	11.00	11.00	9.000	4.000	11.00	9.000	7.000
Mean	3.616	4.260	3.000	1.918	4.973	2.068	2.644
Standard deviation	2.526	2.495	2.267	1.431	2.862	2.030	1.836

is directly linked to the degree of autism. That means the higher autism score children reported higher pain scores. Subdomain analysis showed that there is a difference in each domain score, indicating that the way of expressing pain is unique in each child. They have a diverse range of expressions to show their pain.

It is clearly indicating that there is a need for pharmaceutical managing protocol to effectively handle chronic and acute pain situations in ASD children. There is a possibility that people with ASD would experience more severe functional impairment as a result of improper pain management. This may be due to undiagnosed pain in ASD children needing more effective interventions to identify their pain. Hence, clinical professionals need to be made more aware of pharmaceutical pain management in ASD children.

## CONCLUSION

According to our research, the NCCPC-R tool appears to be a reliable method for assessing pain in children with ASD. Our research led us to the conclusion that the degree of autism is directly proportional to pain. Most children reported pain scores that were greater than average, indicating that they could require pharmaceutical care to control their discomfort. It is strongly advised to conduct additional research using this technique's multicenter prospective use in real-world settings with observations of "real-life" pain events.

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