

Explorando a complexidade do Comportamento Autolesivo no transtorno do espectro do autismo: uma revisão sistemática

Exploring the complexity of Self-Injurious Behavior within autism spectrum disorder: a systematic review

Explorando la complejidad de la Conducta Autolesiva dentro del trastorno del espectro autista: una revisión sistemática

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Resumo

Introdução. O Transtorno do Espectro Autista (TEA) é um dos transtornos do neurodesenvolvimento caracterizado por déficits de comunicação, comportamentos repetitivos, interesses restritos e dificuldades na interação social. Além dessas características, alguns indivíduos com TEA também apresentam comportamentos autolesivos (SIB), que podem ocorrer em diferentes graus de gravidade e são uma preocupação relevante para pais e cuidadores. Objetivo. Explorar a relação entre os comportamentos autolesivos em indivíduos com TEA, realizando uma revisão sistemática baseada em critérios de inclusão e exclusão estabelecidos. Foram analisados artigos que avaliaram comportamentos autolesivos em indivíduos com TEA, abrangendo diferentes faixas etárias e contextos geográficos. Método. Dos 823 artigos identificados, seis atenderam aos critérios de inclusão, com estudos realizados no Reino Unido, Estados Unidos, Canadá e França. Resultados. A pesquisa revelou que os SIB são comuns em indivíduos com TEA, com prevalência observada tanto em crianças quanto em adultos. Fatores como habilidades cognitivas, presença de condições dolorosas e controle comportamental foram associados à gravidade dos comportamentos autolesivos. Não foram encontradas diferenças significativas entre sexo e SIB, e a sensibilidade à dor parece variar entre os indivíduos. Conclusão. Os SIB são comuns no TEA, destacando a importância de intervenções precoces e abordagens terapêuticas para reduzir os impactos a longo prazo e melhorar a qualidade de vida.

Unitermos. Transtorno do Espectro Autista (TEA); Comportamentos autolesivos (SIB); Diagnóstico de TEA; Autolesão; Terapias para TEA

Abstract

Introduction. Autism Spectrum Disorder (ASD) is one of the neurodevelopmental disorders characterized by communication deficits, repetitive behaviors, restricted interests, and difficulties in social interaction. In addition to these characteristics, some individuals with ASD also exhibit self-injurious behaviors (SIB), which can occur in different degrees of severity and are a relevant concern for parents and caregivers. Objective. To explore the relationship between self-injurious behavior in individuals with ASD, performing a systematic review based on established inclusion and exclusion criteria. Articles that evaluated self-injurious behaviors in individuals with ASD were analyzed, covering different age groups and geographic contexts. Method. Out of the 823 articles identified, six met the inclusion criteria, with studies conducted in the United Kingdom, the United States, Canada, and France. Results. Research has revealed that SIB is common in individuals with ASD, and its prevalence is observed in both children and adults. Factors such as cognitive abilities, the presence of painful conditions, and behavioral control were associated with the severity of self-injurious behaviors. No significant differences were found between sex and SIB, and pain sensitivity appears to vary between individuals. Conclusion. SIB is common in ASD, highlighting the importance of early interventions and therapeutic approaches to reduce long-term impacts and improve quality of

Keywords. Autism Spectrum Disorder (ASD); Self-injurious behavior (SIB); Diagnosis of ASD; Self-harm; Therapies for ASD

Resumen

Introducción. El Trastorno del Espectro Autista (TEA) es uno de los trastornos del neurodesarrollo caracterizado por déficits en la comunicación, comportamientos repetitivos, intereses restringidos y dificultades en la interacción social. Además de estas características, algunos individuos con TEA también presentan comportamientos autolesivos (CAL), que pueden ocurrir en diferentes grados de gravedad y son una preocupación relevante para padres y cuidadores. Objetivo. Explorar la relación entre los comportamientos autolesivos en individuos con TEA, realizando una revisión sistemática basada en criterios de inclusión y exclusión establecidos. Se analizaron artículos que evaluaron comportamientos autolesivos en individuos con TEA, abarcando diferentes grupos de edad y contextos geográficos. Método. De los 823 artículos identificados, 6 cumplieron con los criterios de inclusión, con estudios realizados en el Reino Unido, Estados Unidos, Canadá y Francia. Resultados. La investigación reveló que los CAL son comunes en individuos con TEA, con una prevalencia observada tanto en niños como en adultos. Factores como las habilidades cognitivas, la presencia de condiciones dolorosas y el control conductual se asociaron con la gravedad de los comportamientos autolesivos. No se encontraron diferencias significativas entre el sexo y los CAL, y la sensibilidad al dolor parece variar entre individuos. Conclusión. Los CAL son comunes en el TEA, destacando la importancia de intervenciones tempranas y enfoques terapéuticos para reducir los impactos a largo plazo y mejorar la calidad de vida.

Palabras clave. Trastorno del Espectro Autista (TEA); Comportamientos autolesivos (CAL); diagnóstico de TEA; Autolesión; Terapias para TEA

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INTRODUCTION

Although the term "Autism" was first coined in 1911 by Eugen Bleuler, it was Leo Kanner in 1943 who described Autism Spectrum Disorder (ASD), understood as a disorder that affects neurodevelopment, in which its sufferers may

present communication deficits, specific interests' behavior, unusual social interactions, and stereotyped behavior to a greater or lesser degree¹⁻³. Among the characteristics of ASD, the most frequently observed are those related to the interest in socialization^{4,5}. Also, one can have manifestations of intellectual disability⁶, epileptic seizures⁷, impulsive aggressive behaviors, self-harming behavior, and exacerbated sensitivity to sensory stimulation and anxiety⁸.

The Autism Spectrum receives this name precisely accommodates, within because it its heterogeneous complexity, different degrees of etiological and behavioral presentation⁹⁻¹¹. From the childhood of patients with ASD, it is possible to identify the characteristic symptoms of the disorder and, consequently, it is possible to notice how they negatively affect development and lead to inability to socialize and academic impairment. Culminating in the emotional stress caused by the families of these patients, the economic impact is also a factor that must be considered. It is possible to find in the literature descriptions about ASD being the most prevalent in groups of pediatric patients affected in their psychomotor development. The diagnosis, carried out by a multidisciplinary team and with the support of the Diagnostic and Statistical Manual of Mental Disorders - 5th edition (DSM-5), can be made before the age of three, with a ratio of one autistic child for every 150 outside the spectrum. Also, some symptoms and characteristics of ASD are already noticeable at six months of age^{12-16} .

It was observed that, although it affects both men and women, men have a higher prevalence. It is estimated that from 3.5 to 4.0 men can receive a diagnosis of ASD, and one female diagnosis is carried out. Some theories try to explain the difference in how autism can be identified in men and women so that patients receive their diagnosis and how these differences influence the difficulty in completing the diagnosis. In 2018, Ratto et al. recognized that women who have ASD may demonstrate their behavioral patterns differently when compared to men with ASD^{5,17,18}.

The etiology of autism remains unknown, although there is a consensus among researchers: It is a multifactorial and complex condition, and according to data in the literature, it is possible to relate the development of ASD with genetic, environmental, immunological, neurobiological, metabolic, and neuroanatomical factors^{11,19}.

Victor Lotter (1966), when conducting the first epidemiological study on the prevalence of autism in the United Kingdom, showed that 4.1 out of every 10,000 British citizens had autism. Since then, projections about ASD have grown significantly over the years, when considering studies carried out in Europe and the United States, recent statistics show an average prevalence of 100 per 10,000 people with autism^{20,21}.

It can also be evaluated that the increase in the statistical numbers of diagnoses of people with ASD is due to society's perception of autism itself, in addition to the constant evolution and improvement of diagnostic methods

that facilitate the medical approach, the cognitive awakening of society about autism is particularly important for the increasingly precise understanding of this disease and the recognition of the autistic population that, As is already well established, it does not homogeneously present itself, but rather with different characteristics and degrees of intensity within the spectrum¹¹.

It is recognized by science that human beings, like all animals in nature, have an innate system of selfpreservation. This instinct, as pointed out by Charles Darwin (1809 - 1882) in his book "The Origin of Species", helps us to understand how this type of behavior can be essential for the perpetuation of the human species since the act of preserving oneself in the environment allows us the ability to generate viable offspring capable of carrying our genes for generations. However, the impulse preservation can sometimes conflict when an individual assesses themself of an injurious/destructive act; these acts can be described in the literature as non-suicidal selfinjurious behavior (NSSI)^{13,22}. That is an individual who can compromise their physical integrity through acts of violence against himself. NSSI is described as the cause of deliberate physical injury to the body without suicidal intent. They can present themselves in several ways, such as intentionally carving or cutting the skin, scratching the subdermal tissue, burning themselves, hitting or punching objects against themselves to hurt themselves, and inserting objects under the skin^{23,24}.

Self-injury behavior (SIB) is a type of behavior present in children and adults who are within ASD, causing these people significant interferences in their physical and mental health, directly affecting their quality of life. It is also possible to point out the frightening feeling of caregivers and parents when they see their autistic family members inflict severe injuries on themselves that can cause visible injuries. It is important to note that SIB can happen in highly functioning autistic adults and that this type of action is not restricted to only individuals who are on the most severe spectrum of autistic disorder^{25,26}.

Thus, a better understanding of the relationship between SIB within the context of the autism spectrum is essential for us to be able to design new therapeutic approaches so that a better quality of life is provided to individuals with ASD who are affected by self-injury.

METHOD

The central issue addressed by this review was the relationship between self-injury behavior (SIB) in individuals with ASD.

This systematic review followed the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines for conducting and reporting systematic reviews. The protocol of this study was registered in PROSPERO (ID: CRD42024558132).

Search and database strategies

In June 2024, a systematic search approach was used through three databases to identify relevant publications: PubMed, Web of Science, and LILACS. The search strategy combined the following keywords and terms: autism spectrum disorder, pain, and behavior.

Inclusion criteria

Publications should meet the following inclusion criteria: adult individuals or children diagnosed with ASD, presence of SIB, articles published in English, and observational or clinical study. No restrictions on age or date of publication have been applied.

Exclusion criteria

The exclusion criteria were as follows: narrative reviews, systematic reviews or meta-analyses, case series, case reports, and *in vitro* and animal studies.

Study Selection and Data Extraction

Initially, two reviewers (LMDS and LBC) independently analyzed the titles and abstracts of the publications identified in the databases, considering the inclusion criteria recorded in the report. Subsequently, with the assistance of a third reviewer (END), the initial disagreements between the first two reviewers were resolved. Next, a complete reading of all selected publications that met the inclusion criteria was

carried out, and the reasons for exclusion were recorded in dedicated reports.

The following items were extracted from the publications that met the inclusion criteria: primary author, country of origin of the article, number of participants, evaluation structure, age group, results obtained, analysis groups, statistical analyses used, limitations of the research carried out, and funding received.

RESULTS

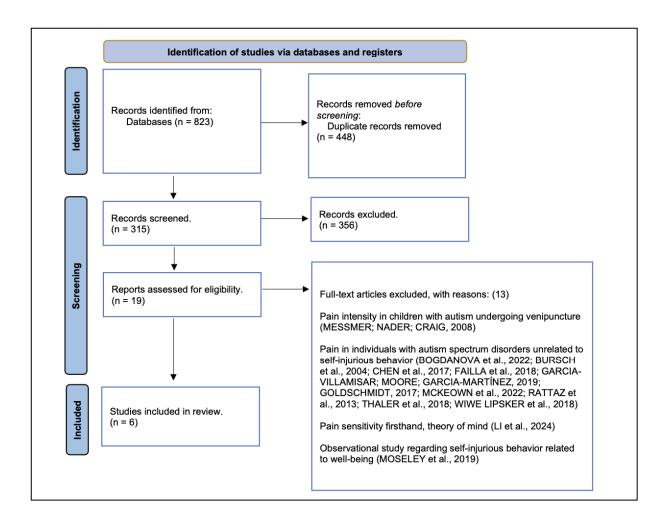
Selection of studies

The database search identified 823 articles, of which 804 were excluded after reviewing titles and abstracts. The full texts of 19 publications were analyzed, and 13 were excluded. In total, six articles were selected for the systematic review. The flowchart presents the details of the search strategy (Figure 1).

Study characteristics

Of the included studies, two were conducted in the United Kingdom^{27,28}, two were conducted in the United States, one in Canada, and one in France. The age range of the participants varied: three studies included pediatric and adult groups, one consisted of adults only, two were pediatric only, and one involved young adults and adults^{29–32} (Tables 1 and 2).

Figure 1. Identification of academic papers collected from the databases for the performance of this systematic review.



A study in the United Kingdom pointed out that 45.7% of participants with SIB were children, while 49.1% were adults. The analysis also showed that males were not associated with SIB; however, lower cognitive ability was correlated with SIB in the adult sample and with severe SIB in the infant sample. In terms of severity, 18% of children and 19.9% of adults had severe SIB²⁸.

 ${\sf Table\ 1.\ Features\ Population,\ Evaluation\ Structure\ and\ Study\ Results.}$

Author and country	N Sample	Evaluation Framework	Age Group	Findings
Richards <i>et al</i> . 2017 ²⁸ (United Kingdom)	N: 515	 Self-Harm, Aggression and Destruction Screening Questionnaire (SAD-SQ). Self-Control Checklist. Challenging Behavior Questionnaire. 	Pediatric and Adult	The presence of health problems was significantly associated with the presence and severity of childhood SIB.
Edelson <i>et al</i> . 2021 ²⁹ (United States)	N: 2327	Two Questionnaires: 1st Diagnostic Checklist Form E – 2; 2nd Developed with the participation of influential researchers in the area.	Pediatric and Adult	Both individuals with ASD had SIB and aggressiveness.
Duerden <i>et al</i> . 2014 ³¹ (Canada)	N: 33	Repetitive Behavior Scale – Revised (RBS-R)	Pediatric and Adult	Twelve of the children who participated in the study reported a high incidence of self-injury, while the remaining 17 children showed low or no self-injury.
Courtemanche <i>et al</i> . 2016 ³⁰ (United States)	N: 31	- Pain Form for Non-Verbal Children – Revised (NCCPC-R). - Inventory of Behavioral Problems (BPI).	Pediatric	NCCPC-R scores did not differ between groups on any 2-hour ratings (p > 0.05) when compared between the three SIB categories. NCCPC-R scores, however, differed between groups during the 1-week assessment.
Rattaz <i>et al</i> . 2018 ³² (France)	N: 102	Aberrant Behavior Checklist (ABC: Aman et al. 1985). Note: The ABC is a 58- item rating scale that measures behavior problems in five domains: irritability, lethargy/withdrawal, stereotypy, hyperactivity, and inappropriate speech.	Young Adult and Adult	Self-injurious behaviors were significantly related to the participants' language and cognitive level and to the CARS score. Gender, sleep or gastrointestinal disorders, and epilepsy were not significantly related to the presence of SIB.
Richards <i>et al</i> . 2016 ²⁷ (United Kingdom)	N: 93	 Demographic questionnaire to collect information on gender, mobility, verbal ability, and diagnosis. Wessex Scale. Humor Interest and Pleasure Questionnaire – Short Form (MIPQ-S). Activity Questionnaire (TAQ). 	Pediatric	SIB behavior was persistent in 77.8% of individuals with ASD over 3 years.

Table 2. Analysis Groups, Study Limitations and Funding.

Author and country	Analysis Groups	Research Limitations	Financing
Richards <i>et al</i> . 2017 ²⁸ (United Kingdom)	Two groups: 1st Children with ASD 2nd, Adults with ASD	Sample size; representativeness of the sample; variables not considered; Biases are possible.	Funded by Autism and Brain Research.
Edelson <i>et al</i> . 2021 ²⁹ (United States)	Four categories: 1st SIB only 2nd Only aggression 3rd SIB + Aggression 4th Neither SIB, nor aggression	All interviewees needed to have access to the Internet. Missing data may have purposely ignored a question.	This study did not receive external funding.
Duerden <i>et al</i> . 2014 ³¹ (Canada)	Scoring System from 0 to 6 0 = No self-injury 1 = Low self-injury < 2 = High incidence of self- injury	The actual causal relationships between injury and brain structures remain uncertain in individuals with ASD due to genetic or environmental factors.	Canadian Health Research Institute, Hospital for Sick Children (EGD) Research Training Competition Grant; Reva Gerstein Fellowship in Pediatric Psychology (EGD).
Courtemanche <i>et al</i> . 2016 ³⁰ (United States)	Self-Injurious Behavior: 1st Children without SIB; 2nd Children with infrequent and/or mild SIB; 3rd, Children with frequent and moderate-severe IBS.	The children presented with a variety of developmental issues, resulting in a lack of gender, age, or IQ matching. In addition, there was an unequal gender distribution among participants.	Donations from the Orange Foundation and the French National Institute of Health.
Rattaz <i>et al</i> . 2018 ³² (France)	Relationship between ASD and IBS 1st Without SIB; 2nd Low SIB; 3rd High SIB.	Although there is potential bias due to non-random recruitment and data reflecting period effects, ASD diagnoses, cognitive level, and language have been confirmed. Variables in the ABC domains reflect parents' reports, not direct observation.	This study did not receive external funding.
Richards <i>et al</i> . 2016 ²⁷ (United Kingdom)	Three groups: 1st Absent Group: no history of SIB; 2nd Transient Group: with a history of SIB, but without presenting self-injurious behavior throughout the study; 3rd with a history of IBS and with self-injurious behavior throughout the study.	Sample size; selection bias; duration of follow-up; individual variability; previous interventions; limitations of assessment instruments; factors not evaluated.	Partial funding from Research Autism and Cerebra; recruitment supported by the National Autistic Society.

In the study conducted in the United States, analyses of sex and age differences showed no significant differences about SIB²⁹. Among the participants, 19.6% were men and 21.2% were women²⁹. In the assessment of self-injurious behavior in Canada, the RBS-R questionnaire (Repetitive Behavior Scale – Revised) was administered to the parents of 29 children and adolescents with ASD³¹. Among the children evaluated, 12 had a high incidence of mutilation (mean=2.31; SD=1.4), while the remaining 17 children demonstrated low (score of 1) or no self-harm³¹.

In another study conducted in the United States, the parents of 51 children (Mean Age=3.94; SD=1.39) answered questionnaires, 43 of them male (84%)³⁰. The results indicated that the presence of ASD was not associated with the observed SIB³⁰. In addition, SIB frequency and severity also showed no correlation with the cognitive level of these children³⁰. In France, a study of 106 young adults with ASD Disorder revealed that, regarding self-injurious behaviors, 19 participants (18%) had a high level of SIB, 17 (16%) had a low level of SIB, while 68 (65%) did not demonstrate any SIB³².

In another study conducted in the UK, participants with ASD were recruited through the National Autistic Society at T1 and invited to participate again three years later at T2²⁷. In total, 190 participants and 68 caregivers of individuals with ASD completed the assessments²⁷. The results revealed no significant differences between the two periods in the

presence or topography of self-harm, indicating that the behavior is persistent and stable over time²⁷.

The most frequent topography of SIB among both groups, children and adults, was hitting oneself with the same part of the body, while the least frequently involved using objects to self-mutilate²⁸. There were no differences between the groups regarding SIB's prevalence, severity or topography. Interestingly, the children had a significantly higher number of specific topographies of self-control, such as clinging to others or clinging to others' clothes, this being the only topography of self-control that involved other people²⁸.

In the study, it was pointed out that lesions in children and adolescents were usually localized to various parts of the body, covering large areas such as the face, hands, arms, and legs³¹. Half (six children) of these children engaged in self-harm daily, and the parents of seven self-injurious children reported low pain reactivity, while three were classified as having high pain reactivity³¹.

Another study revealed that individuals who were self-harmed were significantly more likely to be nonverbal than those who did not self-harm^{27,31}. In addition, it was evidenced that these individuals had lower mood, differences in interest and pleasure, compulsive behaviors, stereotyped behavior, hyperactivity, insistence on sameness, impulsiveness, and characteristics of ASD, such as impairments in social interaction and repetitive behaviors³¹.

DISCUSSION

The prevalence of IBS in individuals with ASD was analyzed and synthesized in this review, aiming to generate a robust estimate of pooled prevalence. While there is evidence associating a range of demographic and behavioral characteristics with SIB at a single time point, there is a paucity of studies investigating these characteristics at multiple time points, as well as persistent self-harm^{34–36}.

A study in the United Kingdom confirmed a high prevalence of SIB in adults and children with ASD, corroborating the model proposed by Oliver and Richards (2015)³³. Data demonstrated that painful physical health conditions and impaired control behaviors contribute significantly to the presence and severity of SIB²⁸. These findings support the idea that SIB is persistent in ASD, with no significant differences between age groups³⁷. Although limited conclusions can be drawn from cross-sectional data, the results demonstrated the significant contribution of painful physical health conditions and behaviors indicative of impaired behavioral control to the presence and severity of SIB and self-restraint in these individuals²⁸.

In the United States, Courtemanche *et al.* (2016)³⁰ showed that the presence of self-injury is not related to developmental level, challenging the idea that pain sensitivity is reduced in individuals with self-injury³⁸. Thus, this study supported a model in which pain sensitivity may be intact in individuals with self-injury, suggesting that pain expressions may be intensified, rather than attenuated, as

indicated in other studies³⁰. In the study carried out by Edelson et al. 2021²⁹ it was shown that 67% of individuals diagnosed with ASD, who participated in their research reported the absence of pain sensations²⁹. An important factor in this study is that when investigating the relationship between SIB and aggressiveness in individuals with ASD, it was observed that not all individuals had SIB or aggressiveness²⁹. Regarding the study by Courtemanche et 2016³⁰, it is worth noting the presence of some limitations, such as the absence of matching by gender, age, IQ, the unequal gender distribution among the participants, predominantly male, and the lack of information on the causal role of pain in the development and maintenance of self-injury, aggression, and stereotypy³⁰.

A Canadian study detailed self-harm in children, with parental reports on the location and duration of the behaviors, and it was observed that many showed low pain reactivity (seven children), while others showed high reactivity (three children), suggesting a complex relationship between pain and SIB³¹. Generally, the sites of the lesions covered large areas of the body, such as on the hands and arms (in four children) and the leg (one child), ranging from six months to more than 100 months in duration³¹. In France, the study revealed that challenging behaviors in adulthood were related to irritability and stereotypy, with self-harm persisting from adolescence to adulthood³². Regarding SIB, no decreases were observed with the transition from adolescence to early adulthood, presenting results like other

studies that did not report such a decrease²⁷. Although some authors have suggested an increased risk of involvement in IBS among adults compared to adolescents, studies on the topic are still scarce²⁶.

In the United Kingdom, the study revealed that selfharm was persistent over three years in 77.8% of those who presented at time 1 $(T1)^{27}$. This finding corroborates data collected in populations with intellectual disabilities, where persistence of self-harm has been reported to be between 71 and 84%^{39,40}. In contrast, in populations with ASD recruited from clinical services, a significant decrease in self-harm was observed over time^{36,41}. These results indicate that self-harm in ASD tends to be persistent and stable over time, suggesting that intervention with younger children may be beneficial since the behavior is unlikely to decrease on its own²⁷. However, it is important to consider the limitations of the study, given that the data presented consisted of a subset, both cross-sectional and longitudinal, of a much larger cohort and that the observations were part of a prospective follow-up study whose objective was to examine the heterogeneity of developmental trajectories among individuals with ASD⁴².

When investigating the variables associated with SIB in ASD, it was observed that gender was not associated with the presence or severity of SIB, corroborating previous research that indicates that being a man, in populations with ASD, does not increase the probability of SIB⁴³⁻⁴⁵. The study conducted by Rattaz *et al.* 2016 also showed no significant

differences between the sexes about SIB severity³². However, other studies suggest that women with ASD may have higher scores in non-suicidal self-injurious behaviors compared to men. This phenomenon can be attributed to the fact that women with ASD often have delays in cognitive development and more pronounced behavioral problems compared to boys with similar disorders^{38,46}.

CONCLUSION

The systematic review highlighted that self-injurious behavior (SIB) is a common and persistent phenomenon among individuals with ASD, with no clear distinction between age groups and gender. Although the severity of SIB is correlated with factors such as cognitive abilities and evident that painful conditions, it is self-injurious manifestations vary widely among individuals. The findings indicate that, in many cases, self-injury tends to be stable over time, suggesting that early interventions are crucial to mitigate the long-term impact of SIB. The persistence of this behavior underscores the need to develop therapeutic approaches that not only treat the symptoms but also improve the quality of life of individuals with ASD and their caregivers and family members.

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