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Adverse Childhood Experiences in Children with Autism Spectrum Disorder

Daniel W Hoover, PhD^{1,2} and Joan Kaufman, PhD^{1,2}

¹Center for Child and Family Traumatic Stress, Kennedy Krieger Institute, Baltimore, MD

²Department of Psychiatry and Behavioral Sciences, Johns Hopkins School of Medicine, Baltimore, MD

Abstract

Purpose of Review—Recent years have shown an uptick in studies assessing bullying and other adverse childhood experiences (ACEs) in children with autism spectrum disorder (ASD). This paper reviews extant findings, and points to gaps in the literature.

Recent Findings—Children with ASD are bullied by peers at a rate 3-4 times that of non-disabled peers with negative impacts on academic functioning and mental health symptoms, including increased risk for suicidality. Children with ASD are also at enhanced risk for ACEs, particularly parental divorce and income insufficiency, and as observed in the general population, children with ASD who experience an increased number of ACEs are at elevated risk for comorbid psychiatric and medical health problems. Children with ASD with an elevated number of ACEs also experience a delay in diagnosis and treatment initiation. There is no evidence of increased risk of child maltreatment within the ASD population.

Summary—As bullying and other adverse experiences are common and associated with deleterious outcomes in children with ASD, there is a need for additional research on intervention strategies to prevent and mitigate the impact of these experiences. Ongoing work on the assessment of trauma experiences and PTSD symptoms in children on the spectrum is also needed.

Keywords

autism spectrum disorders; bullying; adverse childhood experiences (ACEs)

Introduction

Autism Spectrum Disorder (ASD) is a neurodevelopmental disability characterized by impaired communication, social reciprocity and rigid, repetitive behaviors [1]. The disorder is increasingly diagnosed, with an estimated 1 in 68 children affected [2]. This paper reviews recent studies examining the rates of bullying, adverse childhood experiences (ACEs), and reports of maltreatment among children with ASD, issues of differential diagnosis with

Corresponding Author. Daniel W. Hoover, PhD, Center for Child and Family Traumatic Stress, Kennedy Krieger Institute, 1750 E. Fairmount Ave., Baltimore, MD., 21231; hooverd@kennedykrieger.org.

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reactive attachment disorder, and suggest future directions in the assessment and treatment of children with ASD exposed to trauma and other childhood adversities.

Types of Adverse Experiences Reported in Children with ASD

Bullying

Children with ASD are bullied more often than peers with other disabilities, their own non-disabled siblings [3, 4], and those with intellectual disabilities alone [5]. In an international review of 17 studies of school bullying, Maiano et al. [6]* reported children with ASD are bullied at a rate three-times that of typically developing children. Physical, verbal, and relational school bullying (e.g., trying to hurt a peer and/or that peer's standing within a particular peer group) were reported in 33%, 50%, and 31% of ASD students, respectively. Bullying occurs both in and outside of special education settings but is more likely in mainstream classrooms and unstructured areas such as the school bus. In addition, children with limited social supports and less parent involvement are at greatest risk for bullying [7]*.

In our clinical experience, incidents of physical victimization can be severe, and in extreme cases result in the need for emergency treatment medical care. Subsets of children that we see in our clinic have developed Posttraumatic Stress Disorder (PTSD) secondary to these assaults. The prevalence of PTSD in ASD populations, however, has been little studied, with only two out of 86 studies assessing anxiety disorders in children with ASD including an assessment of PTSD [8].

Peer victimization of children with ASD has been shown to have serious negative impacts on children's academic and social functioning [9]*. Mayes et al [10] also found ASD youth who were teased were three times more likely than non-teased ASD youth to report suicidal ideation or to make a suicide attempt. While youth with ASD are most often the victims of bullying, they have also been reported to become perpetrators of bullying violence [11].

Anti-bullying interventions have proliferated in recent years with a recent meta-analysis of 14 randomized controlled trials involving over 30,000 students demonstrating these interventions have moderate effects on reducing peer victimization rates in the schools [12]*. None of these broad interventions, however have focused on children with ASD. To date there has only been one small (N=3) pilot anti-bullying intervention investigated with youth with ASD [13]. The pilot study suggests peer networks are a promising strategy for increasing youth's social interactions and reducing rates of bullying victimization of secondary students with ASD, but more work is needed in this area.

Adverse Childhood Experiences (ACEs)

Adults in the general population who report a range of adverse experiences in childhood have been shown to have poorer long-term health and mental health outcomes [14]. ACE are non-specific risk factors for multiple psychiatric disorders, and several health risk behaviors, including smoking, overeating, and excessive alcohol and drug use. Above and beyond the effect of these health risk behaviors, ACE have been found to predict a multitude of medical health problems later in life, including: ischemic heart disease, stroke, respiratory problems, diabetes, and even cancer. In general, exposure to 4 or more ACEs is an established

threshold for poor health, while those with 1-3 adverse experiences do not fare as well as those with none.

Several investigators have examined the number and effects of ACEs on children with ASD by analyzing data from the 2011-2012 U.S. National Survey of Children's Health (N=95,677) [15]. Figure 1 lists the ACEs questions included in this survey. Children with ASD were found to have experienced more ACEs than healthy control (HC) peers, with increased rates of the following ACEs reported: income insufficiency (ASD=40%, HC=23%), parental divorce (ASD=28%, HC=20%), neighborhood violence (ASD=11%, HC=8%), and household mental health (ASD=18%, HC=7%) and/or substance use (ASD=14%, HC=10%) problems. Children with ASD were also twice as likely as the healthy control peers to have experienced 4 or more ACEs (10.2% vs. 5.1%).

The effects of ACEs on timing of ASD diagnoses and receipt of therapies were also measured using data from the 2011–2012 National Survey of Children's Health [16]. Compared to children without ACEs, the adjusted effects of 1–2 and 3 ACEs resulted in prolonged time to diagnoses, with children with no, 1-2, and 3 or more ACEs diagnosed at a mean age of 4.3, 5.2, and 5.7 years respectively. Report of 1–2 and 3 ACEs were also associated with a 22% and 27% increase in the median age of entry into services. As early and sustained intervention for children with ASD is associated with the best prognosis, the delay in diagnosis and initiation of treatment interventions associated with the presence of ACEs is clinically meaningful [17].

The effects of ACEs on comorbid psychiatric and medical health problems were also assessed using data from the 2011–2012 National Survey of Children's Health [18]*. Consistent with research in the field with non-developmental disability populations, among children with ASD, an increased number of ACEs was associated with elevated risk for depression, anxiety, and a number of medical health problems.

Little research has been conducted to date in examining rates of ACE in ASD clinical samples, and interventions to address ACE and mitigate their negative effects have yet to be evaluated.

Child Maltreatment

In a large-scale study (N=9,536) that linked child protective services (CPS) data with school data to determine rates of children with ASD who were referred to CPS due to suspicions of abuse and neglect, children with ASD were found to comprise 1.7% of the referrals [19]*. This rate is consistent with the population prevalence for ASD and suggests children with ASD are not over-represented in the CPS system. A population-based record-linkage study of all children born in Western Australia between 1990 and 2010 (N=524,534) reported similar results, with youth with ASD having the same risk for allegations of maltreatment as children without disabilities.

In a sample of youth with ASD who were admitted to psychiatric hospitals (N=350), Brenner and colleagues [20]* found that 28% of the youth were reported to have experienced maltreatment by caregivers. This rate is about half the rate reported for

psychiatrically hospitalized youth overall [21], again suggesting that ASD is not associated with an increased risk for child maltreatment.

The inpatient youth with ASD and reports of child maltreatment experienced typical trauma-related symptoms, including intrusive thoughts, distressing memories, irritability, and depressive affect, however, only 7% met full diagnostic criteria for PTSD [20]*. Rates of PTSD among youth with ASD have also been assessed in two outpatient cohorts. One study (N=94) reported no children with comorbid PTSD [22], and the other study (N=69) reported 17% of the children with ASD met diagnostic criteria for PTSD [23]. This latter study is the only investigation to utilize child and parent report of PTSD symptoms; the other studies relied exclusively on parent report which may have contributed to the low rate of diagnosis in these studies.

There are no published assessment tools designed specifically to assess trauma experiences and symptoms in children with ASD. Particularly lacking at this point are well-validated self-report measures that would be appealing, engaging, able to hold children's attention, and present material through more than one modality (e.g., visual, auditory, touch) to allow accessibility by individuals at different functional levels. We are currently developing an interactive app that can be used with children on the spectrum that appears to be promising in assessing trauma experiences and symptoms in children with ASD with borderline and higher IQs. Ongoing work on the assessment of trauma experiences and PTSD symptoms in children on the spectrum is needed.

Differential Diagnosis with Reactive Attachment Disorder

DSM-5 and ICD-10 diagnostic criteria for Reactive Attachment Disorder (RAD) rule out the diagnosis in cases where ASD is present. Autism is seen as qualitatively different from RAD and differentially diagnosed based on ASD-related restricted interests and ritualized behavior and marked social communications deficits [24]. Recent studies, however, show that children can meet diagnostic criteria for both disorders [10, 25], and a significant subset of children with histories of institutional rearing and severe neglect present with what has been termed 'quasi-autism,' core autism features that resolve by age eleven in a quarter of the children with this diagnostic designation [26]. It is hypothesized that ASD and or quasi-autism clinical presentations may be overrepresented in samples of children adopted following neglect, abuse, or placement disruption due to prenatal, genetic and family risk factors.

In a recent study with 58 children with autism and no known history of maltreatment and 67 children with RAD [27], the two groups could not be distinguished on most of the features of the inhibited subtype of RAD. Both groups avoided eye contact (RAD: 58%; ASD: 66%), displayed frozen watchfulness (RAD: 18%, ASD: 12%), and displayed unpredictable behavior upon reunion with their caregiver (RAD: 18%, ASD: 12%). The children in the RAD group, however, were more likely to show hypervigilance (RAD: 39%, ASD: 19%). Children with RAD and ASD, however, differed significantly on all the core features of disinhibited attachment disorder, including: cuddliness with strangers (RAD: 45%, ASD: 14%), indiscriminate adult relationships (RAD: 55%, ASD: 10%), comfort seeking from

strangers (RAD: 20%, ASD: 0%), minimal referencing of the caregiver (RAD: 48%, ASD: 28%), and attention seeking behaviors (RAD: 76%, ASD: 26%).

Thus, the extant literature suggests that ASD and attachment disorders are not mutually exclusive, and can be differentiated based on child and family history, developmental status, the presence or absence of cardinal ASD features, and the presence or absence of hypervigilance and disinhibited attachment symptoms.

Cognitive Behavioral Treatment

Trauma-Focused Cognitive Behavior Therapy (TF-CBT) is the psychotherapeutic intervention with the strongest empirical support for PTSD and other trauma-related symptoms in children and adolescents [28]. Cognitive behavioral therapy (CBT) has recently been adapted for treating comorbid anxiety disorders in ASD, with a randomized controlled trial of its effectiveness currently underway [29]*. In a meta-analysis of CBT treatment studies for affective disorders with children on the autism spectrum, Weston and colleagues [30] found small to medium effect size ($g = 0.24$) on self-report measures, a significant medium effect size ($g = 0.66$) for informant-report measures, and a significant medium effect size ($g=0.73$) for clinician-report measures of depression. We have developed adaptations for using TF-CBT with children with ASD and comorbid trauma-related psychopathology [31, 32], but to date there have been no controlled studies of TF-CBT in this population.

Conclusions and Clinical Implications

Children with ASD are bullied by peers at a rate 3-4 times that of non-disabled peers with negative impacts on academic functioning and mental health symptoms, including increased risk for suicidality. Children with ASD are also at enhanced risk for ACES, particularly parental divorce and income insufficiency, and as observed in the general population, children with ASD who experience an increased number of ACES are at elevated risk for comorbid psychiatric and medical health problems. There is no evidence of increased risk of child maltreatment within the ASD population.

It is recommended that a thorough assessment of adverse childhood experiences and other potentially traumatic events be integrated in clinical evaluations of children with ASD [33]*. The assessment and treatment of children with ASD exposed to trauma and other forms of adversity remains practically un-addressed in the literature. Going forward, it will be crucial to establish sensitive measures for detecting exposure and responses to trauma in order to inform both research and clinical practice.

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Key Points

- Children with ASD are bullied at a rate 3-4 times that of non-disabled youth, with bullying associated with negative effects on children's academic functioning and mental health, including an increased risk for suicidality.
- Adverse Childhood Experiences (ACEs) are reported more frequently by families of children with autism, particularly experiences of parental divorce and income insufficiency.
- Extant studies do not show increased risk of child maltreatment in the ASD population.
- ACE exposure is associated with increased risk of comorbid mental health and medical problems, and later diagnosis and initiation of treatment in youth with ASD.

Adverse Childhood Experiences (ACEs)

1. Childhood income insufficiency- “hard to get by” on income
2. Child lived with a parent who got divorced/separated after he/she was born
3. Child lived with parent who died
4. Child lived with parent who served time in jail after he/she was born
5. Child saw parents hit, kick, slap, punch or beat each other up
6. Child was a victim of violence or witnessed violence in his/her neighborhood
7. Child lived with anyone who was mentally ill or suicidal, or severely depressed for more than a couple of weeks
8. Child lived with anyone who had a problem with alcohol or drugs
9. Child was ever treated or judged unfairly because of his/her race or ethnic group

Figure 1. Adverse Childhood Experiences (ACE) Questions

The figure above depicts the items included in the ACE survey of the National Survey of Children’s Health and discussed in the text. Data from source: National Center for Health Statistics, Maternal and Child Health Bureau. National Survey of Children’s Health. Data Resource Center for Child and Adolescent Health, 2011/12. Available from: <http://www.childhealthdata.org/learn/NSCH>.