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Brief Report: Prevalence of Self-injurious Behaviors among Children with Autism Spectrum Disorder—A Population-Based Study

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Abstract

Self-injurious behaviors (SIB) have been reported in more than 30 % of children with an autism spectrum disorder (ASD) in clinic-based studies. This study estimated the prevalence of SIB in a large population-based sample of children with ASD in the United States. A total of 8065 children who met the surveillance case definition for ASD in the Autism and Developmental Disabilities Monitoring (ADDM) Network during the 2000, 2006, and 2008 surveillance years were included.

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Disclaimer The findings and conclusions in this report are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention.

Authors Contribution Dr. Soke developed the initial proposal of the study, analyzed the data, and wrote the first manuscript. Drs. DiGuiseppi, Rosenberg, Robinson, Hamman, and Fingerlin participated in developing the initial proposal of the study and reviewed the manuscript. Drs. Lee, Carpenter, Durkin, and Wiggins reviewed the manuscript.

Compliance with Ethical Standards

Ethical Approval All procedures performed in studies involving human participants were in accordance with ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. This study is a secondary data analysis of unidentified data previously collected in a surveillance system. Therefore, formal consent is not required.

Conflict of interest All authors reported no conflicts of interest.

The presence of SIB was reported from available health and/or educational records by an expert clinician in ADDM Network. SIB prevalence averaged 27.7 % across all sites and surveillance years, with some variation between sites. Clinicians should inquire about SIB during assessments of children with ASD.

Keywords

Self-injurious behaviors; Autism; Autism spectrum disorder; Prevalence; Challenging behaviors

Introduction

Autism spectrum disorder (ASD) is characterized by deficits in social communication and the presence of restricted and repetitive patterns of behaviors, interests, and activities (APA 2013). Among 8-year-old children living in selected areas of the United States, one in 68 has ASD based on the most recent data from the Autism and Developmental Disabilities Monitoring (ADDM) Network (CDC 2016). In addition to the core symptoms of ASD, associated conditions and behaviors, such as abnormalities in sensory processing (hypo or hypersensitivity), self-injurious behaviors (SIB) have been reported (Baghdadli et al. 2003; Duerden et al. 2012; McTierman et al. 2011; Murphy et al. 2009; Rattaz et al. 2015; Richards et al. 2012).

Self-injurious behaviors are diverse, often highly repetitive and rhythmic types of behaviors that occur without an apparent intent of willful self-harm and result in physical harm (Fee and Matson 1992). Common types of SIB in ASD include-head banging, hair pulling, arm biting, eye poking, and skin scratching (Minshawi et al. 2014a; Weiss 2002) and a few studies have found that those with ASD engage in specific topographies of SIB compared to those with other developmental disabilities, including Down Syndrome and Fragile X Syndrome (Buono et al. 2010; Richards et al. 2012). Behavioral and pharmacologic interventions have yielded positive results in some cases of SIB (Matson and LoVullo 2008; Minshawi et al. 2014b). SIB are a particularly serious type of challenging behaviors because of the potentially serious health consequences that may result. Those who engage in SIB are at high risk for injuries (e.g., lacerations, contusions, fractures, concussions) that may lead to hospitalization or even death (Guinchat et al. 2015; Iannuzzi et al. 2015; Kalb et al. 2012; Mandell 2008). In their study, Kalb et al. (2012) reported that externalizing behaviors, such as severe behaviors, including aggression and SIB were the leading cause of emergency room visits among children with ASD. Further, the consequences of SIB go beyond the affected person. The entire family and other caregivers can also be affected (Kalb et al. 2012; LeCavalier et al. 2006). Among children with developmental disabilities, the societal costs of providing services to children with SIB are higher compared to those without SIB (Devine 2014).

Though numerous population-based studies have examined the prevalence of SIB in children with developmental disabilities, data specific to ASD are lacking. Available estimates of the prevalence of SIB in ASD come primarily from clinic-based studies, mostly done outside of the United States. These studies have reported prevalence of 30 % or higher (e.g., Ando and

Yoshimura 1979; Baghdadli et al. 2003; Duerden et al. 2012; Lance et al. 2014; McTierman et al. 2011; Murphy et al. 2009; Rattaz et al. 2015; Richards et al. 2012). These studies may have oversampled children with more challenging behaviors as well as other impairments, since parents of such children are more likely to seek services and treatments (Bickel et al. 2015; Mandell et al. 2005). Because significant associations have been reported between severity of ASD and the presence of SIB (Baghdadli et al. 2003; Rattaz et al. 2015), the prevalence of SIB reported in clinic-based studies could be different than the prevalence in a more diverse population of persons with ASD. Further, most of the above studies reported the prevalence of SIB in a much older sample (i.e. age of participants greater than 8 years) and this can also affect the prevalence, since SIB has been associated with increased age (Duerden et al. 2012). Data from large population-based studies with a younger sample are needed to provide valid estimates of SIB in ASD in order to determine the burden of SIB and inform clinical practice, resource allocation and policy development. Therefore, we used ADDM Network data in the United States to assess the prevalence of SIB in a large and diverse sample of children with ASD.

Methods

Study Design

This descriptive study examined data from a population-based, multisite surveillance system for ASD and was approved by the ADDM Network data sharing committee.

Sample

We included 8-year-old children who lived in selected areas of the United States and met the surveillance case definition for ASD in the ADDM Network during the 2000, 2006, and 2008 surveillance years (CDC 2007, 2009, 2012). Though the 2002 and 2004 data were available, we excluded these two surveillance years because of differences in the methodology used for data collection that led to incomplete data on SIB. More recent ADDM data were not available at the time this study was conducted. The ADDM Network is a record-based, multiple source surveillance system for ASD and other developmental disabilities started by the Centers for Disease Control and Prevention (CDC) in 2000, involving multiple sites in the United States. Participating sites change periodically, based on a competitive application process. Details of the ADDM methodology have been published by others (CDC 2009, 2014, 2016; Rice et al. 2010, 2007; Sell et al. 2012; Wiggins et al. 2012). In brief, available health records from providers serving children with developmental disabilities (all sites) and educational records from children receiving special education services (some sites) of 8-year-old children living in ADDM catchment areas during each surveillance year were first screened for trigger words that indicate social impairments potentially associated with ASD, such as ‘child likes to play alone’ or ‘poor eye contact;’ the presence of a diagnosis of ASD from a community provider; or eligibility of special education services under ASD. If any of these conditions are met, these records were systematically abstracted verbatim and compiled in a composite record for each child. This summary record was reviewed at each site by research reliable clinicians with expertise in the diagnosis of ASD to determine if the child met the surveillance case definition for ASD, based on a coding algorithm from the ASD diagnostic criteria in the Diagnostic and

Statistical Manual of Mental Disorders-4th edition-text revision [DSM-IV-TR] (APA 2000). While a previous diagnosis of ASD in the child's records was considered, it was not sufficient for the child to meet the surveillance case definition. Records for each participant who met the surveillance definition were combined with census data (e.g., census tract SES indicators). To assure reliability, all sites were required to adhere to a common protocol; ongoing training and quality control checks were implemented for record abstractors and clinician reviewers. Minimal reliability standards for ASD case status and SIB were 90 and 80 %, respectively (Rice et al. 2007; Sell et al. 2012). Data from available records of all children who met the surveillance definition of ASD in all ADDM Network sites during the three above surveillance years were included in these analyses.

Variables

The outcome (SIB) was determined by the presence in the child's available records of any behaviors that were considered as SIB by the ADDM clinician who reviewed these records to identify children meeting the ADDM Network case definition. SIB were defined as "any self-directed behavior that could cause physical harm or a sign or bodily mark of the act, such as picking fingers until bleeding, sucking fingers until chapped, slapping self in face, head banging, etc." This definition is comparable to those used by others (e.g., Baghdadli et al. 2003;Duerden et al. 2012;Rattaz et al. 2015;Weiss 2002). SIB were categorized as yes (present) or no (not present). Thirteen participants (0.16 %) were excluded because of missing data on SIB. The explanatory variables examined were study site and surveillance year. These variables were complete for all participants.

Data Analysis

The prevalence of SIB among children with ASD during each surveillance year was calculated as the proportion of all children with ASD identified during that study year who had documented SIB in their records. We estimated the overall and site-specific prevalence (point estimates and 95 % confidence interval (CI) during each surveillance year using Poisson distribution with robust error variance (Wolkewitz et al. 2007; Zou 2004). We compared children with and without SIB on sociodemographic characteristics and co-occurring conditions using independent t tests for continuous variables and Chi square tests for categorical variables.

Results

Children from six ADDM Network sites were included in the 2000 surveillance year, 11 sites in the 2006 surveillance year, and 14 sites during the 2008 surveillance year. Across all sites, records of 15,156 children were reviewed. A total of 8065 children (53.21 % of the children whose records were reviewed) were included in these analyses: 1293 children in 2000; 2757 in 2006; and 4015 in 2008 surveillance year.

Unadjusted comparisons of children with ASD with and without SIB are presented in Table 1. Significant differences were noted between the two groups. For example, children with SIB were less likely to be of "other races," and more likely to have had a previous documented diagnosis of ASD, a documented developmental regression, and IQ and

adaptive tests scores ≤70 on a psychometric test. Further, those with SIB were more likely to be identified from health sources, had a high number of evaluations abstracted (proxy for access to services), and lived in census tract within the lowest median income quartile.

The overall prevalence of SIB during each surveillance year and the site-specific prevalences are shown in Table 2. During the 2000, 2006, and 2008 surveillance years, the overall prevalence of SIB in ASD was 27.2 % (95 % CI: 24.8, 29.7); 27.4 % (25.8, 29.1); 28.1 % (26.7, 29.5), respectively. This averaged 27.7 % for all three surveillance years. Variations in the prevalence of SIB were observed between sites in all three surveillance years. For example, the lowest prevalence estimates of SIB were reported in Maryland in 2000 (19.8 %) and 2006 (12.8 %), and in North Carolina in 2008 (19.1 %). The highest prevalence estimates were reported in West Virginia in 2000 (36.5 %), Pennsylvania in 2006 (54.0 %), and Utah in 2008 (42.3 %).

Discussion

The prevalence of SIB in a population-based study of ASD averaged 27.7 % over three surveillance years. These results suggest that SIB in ASD are common and deserve more clinical and research attention.

The estimated overall average prevalence of SIB reported in this study was slightly lower than has been previously reported (Ando and Yoshimura 1979; Baghdadli et al. 2003; Duerden et al. 2012; Rattaz et al. 2015; Richards et al. 2012). This may be due to sampling differences, as these other studies included children enrolled in treatment or research programs. These children are likely to have a more severe presentation of ASD, or cognitive impairments, prompting their parents to access services and treatments in the community (Bickel et al. 2015). Further, because of the associations between SIB and more severe symptoms of ASD (Baghdadli et al. 2003; Rattaz et al. 2015), these children are likely to have SIB documented in their records. In fact, children with ASD and SIB in our sample were more likely to be identified for a review of health records than education records and had a documented ASD diagnosis from the community compared to children without documented SIB. It is also possible that differences in the age of participants between studies may also explain this difference in the prevalence, since most of these past studies included a much older sample compared to the ADDM sample.

The ADDM Network included a considerable proportion (34 %) of children who did not have a documented diagnosis of ASD from a community provider. These children may represent those with fewer ASD impairments or those with limited access to services. Including children with fewer ASD impairments in SIB prevalence estimates may be more reflective of the assessment and intervention needs involving SIB in diverse ASD populations. Even in our large and diverse sample, we found that SIB occurred in more than a quarter of children with ASD, which is slightly higher than the 4–20 % prevalence reported in children with other developmental conditions, such as intellectual disability, language disorders, hearing and vision impairments (Dominick et al. 2007; Emerson et al. 2001; Schroeder et al. 2014). Though differences in the age of participants could affect this comparison, this finding confirms results from the meta-analysis by McClintock et al.

(2003), which reported that the presence of comorbid ASD increased the risk for the occurrence of SIB in those with intellectual disability. Therefore, SIB should be considered during the assessment of those with ASD.

Differences were found between children with and without SIB on a number of sociodemographic and clinical characteristics. Compared to children without documented SIB, those with SIB were more likely to experience developmental regression and had cognitive and adaptive delays. The associations between SIB and delays in cognitive and adaptive behaviors have been reported by others (Ando and Yoshimura 1979; Baghdadli et al. 2003; Duerden et al. 2012). In those with cognitive or adaptive delays, SIB may be used as an alternate way to communicate, or a consequence of frustration because of inability to communicate. Thus, these associations might reflect the challenges children with ASD and limited cognitive or adaptive skills face when interacting with their environment. Though these findings should be re-examined in future large etiologic studies, in light of substantial missing data on cognitive and adaptive skills, interventions that target alternate communication strategies and emotional regulation are particularly important for children with ASD and cognitive or adaptive delays to prevent or reduce the occurrence of SIB. Children with SIB were also more likely to live in a census tract with the lowest median income. As mentioned previously, children with ASD and SIB were more likely to have a previous diagnosis of ASD and to have been identified through the review of health records than children without SIB. They also had significantly more evaluations abstracted. This association with the number of evaluations may be related to the age of child, in addition to the presence of SIB, although contradictory findings have been reported concerning the association between SIB and child's age (Baghdadli et al. 2003; Duerden et al. 2012; Esbensen et al. 2009; Murphy et al. 2009). These results highlight the importance of the availability of evaluations which reflects access to services as an important determinant of whether a child had documented SIB.

We reported variations in the prevalence of SIB between sites. These variations may reflect differences between sites in factors such as level of awareness of SIB in the community and among providers, types of records assessed, availability of services in the community, demographic composition, and possible environmental exposures. A portion of the site variation may also be due to year-to-year variability in the occurrence and/or recognition of SIB among relatively small numbers of children, since there was variation between sites as to which surveillance years they were included. We documented differences based on the types of records (health vs. education), and this may be another factor that could explain site differences, as access to different types of records varied between sites.

This study has several strengths. This is the first study in the United States that used a large population-based sample of children with ASD and included children who had not previously received a clinical diagnosis of ASD. In addition, the presence of SIB was documented by trained expert clinicians in ADDM Network using information from multiple sources and the definition of SIB was similar to that used in past studies. Nevertheless, it also had some limitations. First, though the ADDM Network is the largest network providing population-based data on ASD in the United States, it was not intended to be a representative sample of 8-year-old children with ASD. Thus, these results are more

likely to reflect the prevalence in communities included in the ADDM Network than in the general population of children with ASD. Further, the ADDM Network is a record-based surveillance system and the records reviewed depend on a number of factors, such as access to services, level of training of community providers in the catchment areas, and authorization for ADDM sites to access education records, in addition to health records. It is also possible that not all clinicians in the community documented SIB the same way, as there is no common definition of behaviors that are considered SIB. Therefore, it is likely that providers may have not adequately reported minor types of SIB in the children' records. This could have resulted in an underestimation of the prevalence of SIB in this study. Lastly, because the documentation of SIB depended on review of available records, some children who may have SIB could have been missed because no records were available (e.g., children with only one evaluation completed at younger age, before SIB developed). This may lead to an underestimation of the SIB prevalence.

Conclusion and Public Health Implications

This study demonstrates that SIB are a common phenotypic characteristic among children with ASD and that its prevalence is higher than has been reported in children with other developmental disabilities. SIB have important individual, familial, and societal consequences, including increasing the overall costs of services. Therefore, SIB deserve more clinical and research attention. Clinicians, health care systems, and policy makers can use these results to inform training of clinical and service providers, planning of services, and allocation of funding and resources. Future population-based studies are needed to examine potential risk factors for SIB among children with ASD, which may inform development of prevention strategies targeting these risk factors, or allow earlier detection and provision of tailored interventions to potentially reduce SIB severity. Studies are needed to estimate the prevalence of different types of SIB in ASD, since studies have reported differences in the topography of SIB in ASD compared to other developmental disabilities. Studies are needed to examine regional differences in the prevalence of SIB in more depth in order to identify characteristics that may explain differences between sites. In conclusion, SIB in ASD is an important public health concern that affects many children. Future research is warranted to better understand its potential risk factors and consequences, in order to develop effective and more targeted treatment strategies.

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Table 1

Comparison of children with autism spectrum disorder (ASD) with and without self-injurious behaviors (SIB) from the Autism and Developmental Disabilities Monitoring Network during the 2000, 2006, and 2008 surveillance years

Variable	Total of children with ASD (n = 8065) N (%)	ASD With documented SIB (n = 2234) N (%)	ASD Without documented SIB (n = 5831) N (%)	*p* value*
Gender				
Female	1432 (17.76)	383 (17.14)	1049 (17.99)	0.37
Male	6633 (82.24)	1851 (82.86)	4782 (82.01)	
Race				
Non-hispanic white	4563 (56.58)	1297 (58.06)	3266 (56.01)	**0.01**
Non-hispanic black	1818 (22.54)	525 (23.50)	1293 (22.17)	
Hispanic	940 (11.66)	242 (10.83)	698 (11.97)	
Others	448 (5.55)	99 (4.43)	349 (5.99)	
Missing	296 (3.67)	71 (3.18)	225 (3.86)	
Previous diagnosis of ASD				
Yes	5329 (66.08)	1629 (72.92)	3700 (63.45)	**<0.0001**
No	2736 (33.92)	605 (27.08)	2131 (36.55)	
Age at diagnosis				
Mean (SD)**	4.46 (1.73)	4.26 (1.72)	4.55 (1.72)	**0.0001**
Median household income				
Quartile 1 (Lowest)	2071 (25.68)	671 (30.04)	1400 (24.01)	**<0.0001**
Quartile 2	2208 (27.38)	599 (26.81)	1609 (27.59)	
Quartile 3	1724 (21.38)	451 (20.19)	1273 (21.83)	
Quartile 4 (Highest)	1700 (21.08)	397 (17.77)	1303 (22.35)	
Missing	362 (4.48)	116 (5.19)	246 (4.22)	
Source type				
Education only	2532 (31.39)	488 (21.84)	2045 (35.07)	**<0.0001**
Health only	3209 (37.29)	969 (43.38)	2240 (38.42)	
Both	2324 (28.82)	777 (34.78)	1547 (26.51)	
Number of evaluations abstracted				
Mean (SD)**	5.59 (4.60)	7.33 (5.83)	4.92 (3.83)	**0.0001**
Cognitive ability				
Above intellectually disabled range(IQ > 70)	3613 (44.80)	887 (39.70)	2726 (46.75)	**<0.0001**
Intellectual disability (IQ ≤ 70)	2399 (29.75)	773 (34.60)	1626 (27.89)	
Missing	2053 (25.45)	574 (25.70)	1479 (25.36)	
Adaptive impairment				
No (adaptive score > 70)	1516 (18.80)	393 (17.59)	1123 (19.26)	**<.0001**
Yes (adaptive score ≤ 70)	3061 (37.95)	968 (43.33)	2093 (35.89)	
Missing	3488 (43.25)	873 (39.08)	2615 (44.85)	
Developmental regression				
Yes	1422 (17.63)	496 (22.20)	926 (15.88)	**<.0001**

Variable	Total of children with ASD (n = 8065) N (%)	ASD With documented SIB (n = 2234) N (%)	ASD Without documented SIB (n = 5831) N (%)	*p* value*
No	6643 (83.37)	1738 (77.80)	4905 (84.12)	

p-values are significant at the alpha level of 0.05, which are highlighted in bold
SD standard deviation

*Comparing children with SIB to those without SIB

Table 2

Overall prevalence and prevalence by site of self-injurious behaviors (SIB) by surveillance year among children with autism spectrum disorder (ASD) from the Autism and Developmental Disabilities Monitoring (ADDM) Network during the 2000, 2006, and 2008 surveillance years

Site name	Children with SIB in 2000	Total Children with ASD in 2000	Prevalence and 95 % CI in 2000	Children with SIB in 2006	Total Children with ASD in 2006	Prevalence and 95 % CI in 2006	Children with SIB in 2008	Total children with ASD in 2008	Prevalence and 95 % CI in 2008
Overall	351	1293	27. 2 (24.8, 29.7)	755	2757	27.4 (25.8, 29.1)	1128	4015	28.1 (26.7,29.5)
Alabama	–		–	66	212	31.1 (25.5, 38.0)	53	174	30.5 (24.3, 38.1)
Arizona	66	282	23.5 (18.9, 28.9)	117	504	23.2 (19.8, 27.2)	125	507	24.6 (21.2, 28.7)
Arkansas	–		–			–	17	52	32.7 (22.1, 48.3)
Colorado	–		–	20	54	37.0 (26.2, 52.4)	89	279	32.0 (27.0, 37.9)
Florida	–		–	24	116	20.7 (14.5, 29.5)	47	211	22.3 (17.3, 28.7)
Georgia	71	285	24.9 (20.3, 30.5)	135	474	28.5 (24.7, 32.8)	165	601	27.4 (24.1, 31.3)
Maryland	34	172	19.8 (14.6, 26.7)	31	243	12.8 (9.2, 17.7)	71	336	21.1 (17.2, 26.0)
Missouri	–		–	91	321	28.3 (23.8, 33.7)	113	357	31.6 (27.2, 36.8)
New Jersey	90	295	30.5 (25.7, 36.2)			–	40	145	27.6 (21.2, 36.0)
North Carolina	–		–	55	230	23.9 (18.9, 30.1)	100	525	19.1 (16.0, 22.7)
Pennsylvania	–		–	81	150	54.0 (46.6, 62.6)	95	245	38.7 (33.1, 45.4)
South Carolina	52	155	33.5 (26.9, 41.9)	54	196	27.5 (21.9, 34.6)	100	264	38.0 (32.4, 44.2)
Utah	–		–			–	22	52	42.3 (31.0, 58.1)
West Virginia	38	104	36.5 (28.4, 47.1)			–			–
Wisconsin	–		–	81	257	31.5 (26.3, 37.7)	91	267	34.1 (28.8, 40.3)

CI confidence interval