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Injury Treatment among Children with Autism or Pervasive Developmental Disorder

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Abstract This study examined the differences in the frequency and type of injury for children with autism and pervasive developmental disorder (PDD) compared with typically developing peers, when both groups are insured by Medicaid. The relative rate (RR) of emergency/hospital treatment of injury for children with autism or PDD compared to controls was 1.20 [95% Confidence Interval (CI) 1.04–1.39] after controlling for age and gender. Children with autism or PDD had a higher rate for head, face, and neck injuries (RR 1.47, 95% CI 1.13–1.90) and lower rate for sprains and strains (RR 0.54, 95% CI 0.32–0.91). Treatment for poisoning was 7.6 times as frequent, and self-inflicted injury was also 7.6 times as frequent for children with autism or PDD.

Keywords Autism · Injury · Epidemiology · IDC9 codes · E-codes

Introduction

Children with autism and pervasive developmental disorders (PDD) have challenges related to their environment which could put them at risk for injuries. Their risk might differ from children without autism in terms of frequency and type of injury but there has been little evidence available to evaluate their injury pattern. There is one article on causes of death in autism that identifies seizures, circulatory disease, congenital anomalies, cancer and nervous system diseases as having higher standardized mortality ratios (SMRs) compared to the general population. Overall the SMR is higher for males compared to females with autism and the only external causes (E-codes) of death with larger SMRs for those with autism were drowning and suffocation (Shavelle et al. 2001; Pickett et al. 2006). There are no data on treatment of injury requiring emergency department or hospital admission for children with autism.

PDD include autistic disorder, Asperger disorder, childhood disintegrative disorder, and Rett disorder, with autism the most prevalent diagnosis (Dalton et al. 2004). PDD is most notably characterized by a qualitative impairment in communication and in reciprocal interactions. There is a body of literature on self-injurious and other challenging behaviors for children with autism, but this is not presented in terms of injury risk (McClintock et al. 2003; Murphy et al. 2005).

Injuries in children are a leading cause of death and disability. In 2003 the overall all cause nonfatal injury rate for children 1–17 years in the US was 1.19 per 100,000 (America's Children in Brief 2006). Disparities in injury prevalence based on disability has been studied for children with mental retardation (MR) and the results indicate a higher proportion of children and adolescents with MR were injured compared to children without this disability (Dunne et al. 1993; Sherrard et al. 2002; Braden et al. 2003; Slayter et al 2006).

We were able to use administrative data from Medicaid to describe the injury treatment rates for children insured by Medicaid, using emergency department and hospital

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billing and E-codes for external cause of injury in South Carolina. These data are used to compare relative rates (RR) of treated injury in children with autism compared to children without disability. Administrative data such as Medicaid billing records is an acceptable source of data to make comparisons about hospital and emergency department utilization for children (Iezzoni 2002). In this study we used these data to understand treatment of children's injuries in hospitals and emergency departments. The Medicaid program pays ~39% of all injury-related costs for children in the US (Miller et al. 2000; Hostetler et al. 2005). However since Medicaid coverage varies among the states, despite some core coverage, comparisons need to be cautiously interpreted (Iezzoni and O'Day 2006).

The State of South Carolina Medicaid system provides healthcare coverage to children through a number of mechanisms. Most of these mechanisms require family income to be under 150% of poverty but up to 185% in some cases. Children with disabilities who are determined to require "institutional level care" can receive Medicaid benefits (even if they live at home) through the Tax Equity and Fiscal Responsibility Act (TEFRA) program and most are eligible since there are no limits on the family's income or assets. Only the child's income and assets are considered for TEFRA eligibility. Overall Medicaid programs provide insurance coverage for 31.6% of all children under age 19 in South Carolina. For all emergency room and inpatient charges resulting from injuries in 2003 the proportion of children covered by Medicaid was ~53% for children 1–4 years, 42% for children 5–12 years, and 35% for children 13–17 years.

Managed care penetration is generally low in South Carolina, and only 10% of children covered by Medicaid in 2003, the year for our data, were enrolled in managed care. The managed care Medicaid programs in 2003 had hospital and emergency department carve-outs so only primary care was capitated. Therefore, billing records for hospital and emergency care are an acceptable measure of utilization of these services.

The research question for our inquiry was: Are there differences in the frequency or type of injury treated in hospitals and emergency departments for children insured by Medicaid during 2003 in South Carolina, based on whether the child has autism compared to children with no disability? We also explored the differences in treatment of self-inflicted injury and injury purposely inflicted by others in the two groups of children, after controlling for age and gender. Because the behaviors of autistic children are less responsive to environmental cues we hypothesized these children would be more likely to be treated for injury compared to similar children with no disability. We also hypothesized the treatment of self-inflicted injury and injuries intentionally inflicted by others would be significantly higher in the children and adolescents with autism, after controlling for age and gender. These later hypotheses were based on evidence in the literature and in clinical practice that children with autism are sometimes impulsive, self-stimulating, and frustrating to the caregiver. In some cases this could result in injury.

Methods

We measured injury frequency for 138,111 children who were insured by Medicaid throughout the 12 months of 2003, using both eligibility and claims data obtained from the South Carolina Office of Research and Statistics (ORS). We had access to all the Medicaid Statistical Information System (MSIS) files which are the data submitted by each state to the Center for Medicare and Medicaid Services (CMS), on a quarterly basis. We decided to focus on the more severe injuries which would be captured through hospital admissions and emergency department visits.

Our research more broadly includes children with a number of disabilities: MR, developmental delay, autism, spinal cord injury (SCI), cerebral palsy (CP), hearing loss, and vision loss. We provided the South Carolina ORS with a list of ICD-9 codes for these conditions. ORS then provided us with a file that included all the children with one of these diagnoses in 2003, plus an age-matched file of comparison children, at a 2 to 1 ratio. Thus, the overall file includes records from ~46,000 children with one of these diagnoses, in addition to 92,000 children without any of the disabilities listed above. Of the 46,000 children with one of the disabilities, 1,610 had autism or a PDD. Since there were no children with autism or PDD under 12 months of age we included children ages 12 months to 17 years and 11.9 months, who were Medicaid eligible for all 12 months of 2003.

The data obtained for each child include demographic information (age and gender); monthly eligibility information; and diagnosis (International Classification of Diseases, Ninth Revision, Clinical Modification- ICD-9-CM, World Health Organization, 1999) and dates of admission to the hospital or emergency department. For each record, there is one field for primary diagnosis and eight fields for secondary diagnoses. All the diagnosis codes were used in identifying the children with autism or PDD, and also in defining the treatment of injuries.

Study Subjects

Autism or PDD was identified on the basis of having at least one ICD-9 code: 299.0 for autism, 299.8 for other specified PDD, and 299.9 for unspecified PDD.

The comparison children were the 92,000 children without any of the diagnoses listed above. Children were excluded from both groups if they had an ICD-9 code indicative of CP, SCI, hearing loss, or vision impairment. They were excluded from the comparison group if they had a 315 ICD-9 code for developmental disability (DD) or 317–319 for MR. Children with MR or DD were not excluded from the case group since ~80% of children with autism or pervasive DD have MR or developmental delay (American Psychiatric Association 2000; Greydanus and Pratt 2005; Hertz-Picciotto et al. 2006).

Our analyses focused on comparing the rate of injury treatment of children with autism or PDD to the rate in the comparison group without a disability (including autism, PDD, MR, DD, CP, SCI, hearing loss or vision impairment). However, to ensure that an apparent effect of autism/PDD was not really due to the inclusion of children who also had MR/DD, we also looked at injury diagnoses for two subsets: Children with (1) autism or PDD only, and (2) children with autism or PDD plus MR or DD.

Variables Selected

The outcome of interest was emergency room or hospital admission for treatment for an injury. We identified injuries using the ICD-9-CM codes and the Barell Matrix (ICD-9-CM 1995; Barell et al. 2002). Injury diagnoses in the ICD-9-CM code range of 800 through 995 were selected and grouped using the 5-digit code ranges for the injury categories in the Barell Matrix. The Barell body region by nature of injury diagnosis matrix standardizes data selection, using a two-dimensional array that includes all ICD-9-CM codes describing trauma. We excluded four columns from the matrix because the cell sizes were too small to make meaningful comparisons. The excluded columns were: Amputations, crush injuries, blood vessel injuries, and nerve injuries. We included seven rows of data for each of the remaining injury types. These were: Traumatic brain injury, other head, face, and neck, torso, upper, lower and other and unspecified. Spinal cord injuries were excluded because, given their rare occurrence yet typical lifelong duration, we anticipated that the majority of diagnoses would be for prevalent (pre-existing) rather than incident (new) occurrences.

We focused the analysis on the number of episodes of emergency room or hospital care for children with autism compared to children without this disability. Each episode of care was defined as an emergency room visit or hospitalization, with an ICD-9 code indicative of injury, on a given day. Hospital treatment on consecutive days was considered a single episode of care. If a child had an emergency room and hospital care on the same day, the visits were regarded to be only one episode of care.

We counted the total number of injury related episodes of care for each child. The total number of injury treatment episodes for any cause was counted as one outcome. For this overall rate, only one count per episode was included. For example, if a child experienced a leg fracture and a traumatic brain injury during the same episode of care, this counted as only one episode of injury in the overall rate.

We also counted the number of episodes for each specific type or location of injury, according to the Barell Matrix. Each type or location of injury was counted independently such that a count was given for a specific type or location of injury if the ICD-9 codes for that type or location of injury were found in an episode of care. For this outcome, the hypothetical child who experienced both a leg fracture and a traumatic brain injury on the same day would be counted in the outcome group for both leg fracture and TBI.

Poisson regression was used to model the rate of any injury and each specific type or location of injuries. The RR for children with autism versus children without any disability and the 95% Wald confidence intervals for the RR were obtained from the model, adjusting for age and gender. The interpretation would be that the rate of emergency department or hospital treatment for a specific type/location of injury, or any injury among children with autism is XX times the rate among children without disability, adjusting for age and gender. The GENMOD procedure in SAS 9.1 (SAS Institute Inc., Cary, NC, USA) was used to fit the Poisson regression models that provide the RR and 95% confidence interval for this RR.

We also created a binary variable indicating whether a child received hospital or emergency room treatment for any injury during year 2003. This step was added to help insure that any increase in the occurrence of injury treatment was not due simply to prolonged treatment in children with autism/PDD but, rather, was more likely to represent a difference in the rate of injury occurrence. Logistic regression models (LOGISTIC procedure, SAS 9.1, SAS Institute Inc.) were fitted on those binary variables, adjusting for age and gender.

Additionally, we used ICD-9 E-codes to identify the external cause of injury. We grouped the E-codes according to the categories established by the National Vital Statistics Reports (Murphy 2000). Poisson regression was run on rates of each of the specific external causes, adjusting for age and gender. The rates of self-injury (ICD-9: 950–959) and injury purposely inflicted by others (ICD-9: 960–969) were also counted, and Poisson regression was run modeling the rates controlling for age and gender.

Results

Descriptive statistics for the children with autism and the control group are presented in Table 1. Children with

Table 1 Characteristics of children diagnosed with autism and pervasive developmental disorders and children with no disability, in South Carolina medicaid 2003

	Autism (*N* = 1,610)		Not disabled (*N* = 91,571)	
	n	%	*n*	%
Age				
1–4 years	223	13.9	14,762	16.1
5–12 years	1,002	62.2	57,995	63.3
13–18 years	385	23.9	18,814	20.5
Gender				
Male	1,301	80.8	45,908	50.1
Female	309	19.2	45,663	49.9

autism were disproportionately male (81%) in keeping with the profile of autism. Because the injury experience of boys differs from that of girls and the experience if different for each age, we controlled for gender in our analyses.

Overall, for the 138,111 children 1–18 years of age insured by Medicaid there were 226 children with autism or PDD and 1,384 children with autism or PDD and DD or MR. The proportion of our sample with autism or PDD was 1.17 per 100 children. The diagnosis of autism (ICD-9 299.0) was present for 1,383 (86%) of the children in our case group. Since some physicians use PDD to describe children with autism we included these codes in our case definition. The remaining 227 (14%) children assigned as cases had a diagnosis of other specified PDD (ICD-9 299.8, 209 children) and unspecified PDD (ICD-9 299.9, 15 children) or both of these codes (three children) (Table 2).

Seven percent of controls and 9% of children with autism received emergency room or hospital treatment for injury at least once during the year. Table 3 depicts the crude numbers and rates of injury episodes in the groups by location and by injury type. The number and rate of any injury treatment is also included in the table. Children with autism or PDD had a 0.11 rate of injury treatment compared to 0.09 rate of injury treatment for children with autism or PDD and MR or DD.

Autism appears to be associated with higher rates of emergency room or hospital treatment for a substantial number of injury types. These include traumatic brain injury, other head, face, and neck injuries, upper body and unspecified injuries, fractures, internal injuries and open wounds, contusions and burns. These are unadjusted rates that could result from having a higher proportion of boys or a different distribution of age in the case group. Rather than stratifying by age and gender we controlled for these factors using Poisson Regression.

Table 4 shows the results of Poisson regression modeling of the rate of treatment for each injury category, controlling for age and gender.

Children with autism had statistically significantly higher adjusted rates of injury treatment for head, face, and neck injuries (other than traumatic brain injury) (RR 1.47; $P = 0.004$). Children with autism had a statistically significantly lower rate for injuries that result in sprains and strains (RR 0.54; $P = 0.02$). Overall, the rate of receiving emergency room or hospital treatment for any injury was elevated in children with autism (RR 1.20; $P = 0.02$).

We also used logistic regression to model the odds of injury for children with autism compared to those with no disability, controlling for age and sex. The result was an Odds Ratio of 1.21 [95% Confidence Interval (CI) 1.02–1.44]. The similarity of the logistic regression and the Poisson regression reinforced the results.

We looked at external causes of injury and found that the rate ratios were not statistically different from 1.0 with one exception: For poisoning we found that children with autism or PDD and MR or DD had a rate that is 7.6 times as high compared with similar children without autism (Rate Ratio 7.59, 95% CI 3.76–15.30), controlling for age and gender (Table 5).

We explored the intentional injuries to determine if self-injury or harm by others was more common in children with autism. The RR of injury intentionally inflicted by others including homicide (E960–E969) was not statistically significantly different for children with autism compared to those without disability (RR = 1.79, 95% CI 0.79–4.07), controlling for age and gender. For

Table 2 Diagnoses for children in the case group, *N* = 1,610

Diagnosis	ICD9 diagnostic code	*n*	% = *n*/1,610
Autism	299.0	1,241	77.1
Other specified pervasive developmental disorder	299.8	209	13.0
Unspecified pervasive developmental disorder	299.9	15	0.9
Children with combined disorders	299.0 + 299.8	113	7.0
	299.0 + 299.9	27	1.7
	299.8 + 299.9	3	0.2
	299.0 + 299.8 + 299.9	2	0.1

Table 3 Frequency of injury location and type, using a modified Barrel Injury Matrix, stratified by group

Category	Autism (N = 1,610)		No disability (N = 91,571)	
	Count	Rate[a]	Count	Rate[a]
Body location				
Traumatic brain injury	2	0.12	87	0.10
Other head, face, and neck	60	3.73	2,123	2.32
Vertebral column injury	0	0.00	275	0.30
Torso	8	0.50	510	0.56
Upper	55	3.42	2,659	2.90
Lower	38	2.36	2,213	2.42
Other and unspecified	10	0.62	372	0.41
Type of injury				
Fracture	26	1.61	1,054	1.15
Dislocation	1	0.06	136	0.15
Sprains and strains	14	0.87	1,392	1.52
Internal	2	0.12	97	0.11
Open wound	43	2.67	1,804	1.97
Contusion/superficial	64	3.98	2,738	2.99
Burns	7	0.43	275	0.30
Any injury treatment	181	11.24	7,855	8.58

The Barrel Injury Matrix was modified to exclude amputations, blood vessels, crush, nerves, and spinal cord injury

[a] Rate is rate per 100 children, which equals 100 times the frequency count divided by total number of children in the group

Table 4 Poisson regression for the relative rate of injury by body location and type of injury

	RR[a]	95% CI		χ^2	P-value
Body location					
Other head, face, and neck	**1.47**	**1.13**	**1.90**	8.51	**0.00**
Upper	1.03	0.79	1.35	0.05	0.83
Lower	0.90	0.65	1.24	0.46	0.50
Other and unspecified	1.52	0.81	2.86	1.69	0.19
Type of injury					
Fracture	1.20	0.81	1.77	0.83	0.36
Sprains and strains	**0.54**	**0.32**	**0.91**	5.26	**0.02**
Open wound	1.15	0.85	1.55	0.79	0.38
Contusion/superficial	1.24	0.97	1.59	2.93	0.09
Any injury treatment	**1.20**	**1.04**	**1.39**	5.84	**0.02**

Bold indicates statistical significance at $P < 0.05$

[a] Relative Rate of injury treatment in emergency room and hospital comparing children with autism versus children without disability, controlling for age and gender

self-inflicted injury or suicide attempt (E950–959) the RR was statistically significant higher among children with autism compared to those without disability after controlling for age and gender (RR 7.62, 95% CI 1.65–35.21, P = 0.009).

Finally, we re-analyzed the associations between autism and PDD and injury treatment using the two subsets of children: (1) those with autism or PDD alone (n = 226), and (2) those with autism or PDD and MR or DD (n = 1,384). The overall injury treatment rate for children with autism or PDD alone was statistically significantly different from the rate for children with no disability (RR 1.75, 95% CI 1.28–2.40). The injury treatment rate for children with autism or PDD and MR or DD was marginally significant (RR 1.10, 95% CI 0.94–1.30). The children with autism or PDD alone had two and a half times the rate of treatment for injuries of the upper limbs compared to children without disability (RR 2.53, 95% CI 1.64–3.89) and three times the rate of treatment for fractures compared to children without disability (RR 3.01, 95% CI 1.61–5.62). This same group of 226 children with autism or PDD had a marginally significant higher rate of being treated for injuries resulting from being cut or pierced (RR 2.59, 95% CI 0.97–6.95). Children with autism or PDD and MR or DD had 40% higher rates of treatment for head, face, and neck injuries compared to children without disability (RR 1.46, 95% CI 1.11–1.92). Another finding was the relative risk of poisoning among

Table 5 Top categories of external cause of injury (E code group)

External cause	Autism (N = 1,611)			No disability (N = 91,571)			Relative rate[a]	
	Count	Rate[b]	Order	Count	Rate[a]	Order	Autism versus no disability	95% CI
Falls	34	2.11	**1**	1,528	1.67	1	1.21	(0.86, 1.70)
Other	32	1.99	**2**	1,377	1.50	2	1.23	(0.86, 1.75)
Struck by/against	24	1.49	**3**	1,242	1.36	3	0.91	(0.61, 1.36)
Cut/pierce	10	0.62	**5**	497	0.54	4	0.96	(0.51, 1.80)
Motor vehicle, all	6	0.37	**7**	458	0.50	5	0.76	(0.34, 1.71)
Natural/environmental	11	0.68	**4**	402	0.44	6	1.45	(0.79, 2.64)
Bicycle	2	0.12	**9**	242	0.26	7	0.41	(0.10, 1.65)
Fire/hot object/substance	3	0.19	**8**	93	0.10	8	1.96	(0.62, 6.24)
Poisoning	9	0.56	**6**	85	0.09	9	**7.59**	**(3.76, 15.30)**

There were only nine causes of injury for the children with autism therefore we limited the comparison to these. Bold indicates statistical significance at $P < 0.05$

[a] Relative Rate of injury treatment due to specific comparing children with autism versus children without disability, controlling for age and gender

[b] Rate is rate per 100 children, which equals 100 times the frequency count divided by total number of children in the group

children with autism or PDD and MR or DD was 8.57 (95% CI 4.25–17.29).

Discussion

Autism is a neuro-developmental syndrome with a biological/genetic basis and behavioral definition. Current theories of autism suggest that sensory integration is atypical and this impacts the development of the perceptual system (Bertone et al. 2005). The symptoms of autism include disorders of social interaction, communication, and imagination and the positive symptoms include repetitive behaviors and interests. These symptoms are consistent with our study findings that children with autism were 7.6-fold more likely to have self-injurious behavior. Both self-inflicted injuries and poisoning are consistent with the behavioral patterns associated with autism, since the child might be less likely to perceive the risk, more impulsive in his/her pursuits, and more likely to engage in repetitious behaviors that could be self-injurious (Matson and Nebel-Schwaim 2006; Brinkley et al. 2006).

The fact that the E-codes 950–958 include both self-injury and suicide attempts in each code is a substantial problem for interpretation, e.g., E950: Suicide and self-inflicted poisoning by solid or liquid substances, E951: Suicide and self-inflicted poisoning by gases in domestic use. For people with autism and other disabilities (including psychoses and other developmental disabilities) it is extremely important to distinguish self-injury from suicide, although it is often difficult for a clinician to assess intent. We believe this distinction should be considered in subsequent E-code versions.

The RR of injury intentionally inflicted by others, including homicide attempts, were not statistically significantly elevated for children with autism (RR 1.79, 95% CI 0.79–4.07) but this could be the result of small sample size. Children with disabilities are considered a vulnerable group and frustration with their care could result in harm. We believe this analysis should be repeated using a larger dataset.

Results of our study support our primary hypothesis that children with autism would have higher rates of emergency department and hospital admission compared to children without autism. They in fact were 20% more likely to have treated injuries in the hospital setting. The ranking of the top three external cause of injury is the same for the children with autism and those without disability. Even the findings of reduced risk are consistent with our knowledge of behaviors associated with autism. Children with autism were at significantly lower risk for sprains and strains (RR 0.54). This is consistent with the behavioral profile of children with autism since they are expected to be less likely to compete in organized sports or group play which might precipitate sprains and strains.

This study was conducted using computerized Medicaid reimbursement files and thus the results might not generalize to children with autism who are insured by other payers. South Carolina is an excellent state to use Medicaid data since the penetration of managed care has been extremely low and these plans have carve-outs that allow fee for service hospital and emergency department billing. Nonetheless Iezzoni (2002) has pointed out the concerns about the questionable accuracy of using billing codes to determine disability status. Thus, we cannot be sure we captured all children insured by Medicaid with autism or

PDD during the year of our study. Further, since children with disabilities can qualify for Medicaid coverage based on different financial criteria than children without a disability, there may be some socioeconomic differences between the children with autism and the comparison children. In fact, we explored the coverage of the children in our study and found 80% of the children with autism or PDD and 2% of the children in the comparison group had TEFRA coverage. Given this Medicaid coverage data we can assume a larger proportion of the comparison children qualified on the basis of poverty or near poverty status. Thus, if lower income is related to increased rates of injury treatment, this effect would be in the opposite direction from the association that we observed.

The limitation of using administrative data means we can only describe the treated prevalence of injury, not the actual injury occurrence. And we are only looking at emergency department and inpatient admissions, not outpatient visits, so the results could only be generalized to more severe injuries that require a higher level of care. In addition we did not have enough data to analyze some types of injury. We did not model any data when the cell counts are below 10, because of the questionable validity of modeling such rare outcomes. Thus we did not model traumatic brain injury, vertebral column injuries, torso injuries, dislocations, internal injuries, and burns. Another limitation was the age range available for study. There were no children less than 12 months of age with a diagnosis of autism and we decided to report children up to age 18 because most of the Medicaid eligibility categories end at age 18. Finally the study was conducted in South Carolina, and since each state has different income and need-based eligibility this could limit generalizability.

The external validity of these analyses is strengthened by our relatively low late of missingness in the E-codes. This is unusual in state data and directly results from a legislative mandate in 1992 to include E-codes in all hospital data. For the total of 8,036 hospital/ER injury encounters 23% were missing E codes. The proportion of missingness was very similar for the groups of children: 23% for the controls, 28% for autism or PDD only, and 28% for children with autism or PDD and MR or DD.

This study should be replicated in other states and using other insurers. Nonetheless, it provides evidence for professionals and families who understand the risks associated with autism and need data to support services that could reduce the RR of injury occurrence. These data provide evidence that risk reduction should focus on positive behavior support that reduce self-injury and both behavioral and environmental strategies that reduce exposure to poisons.

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