

Injury Mortality in Individuals With Autism

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Objectives. To examine epidemiological patterns of injury fatalities in individuals with a diagnosis of autism.

Methods. We identified individuals with a diagnosis of autism who died between 1999 and 2014 by screening causes of death in the multiple cause-of-death data files in the National Vital Statistics System based on the *International Classification of Diseases, 10th Revision*, code F84.0. We used the general US population as the reference to calculate proportionate mortality ratios (PMRs) and 95% confidence intervals (CIs).

Results. During the study period, 1367 deaths (1043 males and 324 females) in individuals with autism were recorded in the United States. The mean age at death for individuals with autism was 36.2 years (SD = 20.9 years), compared with 72.0 years (SD = 19.2 years) for the general population. Of the deaths in individuals with autism, 381 (27.9%) were attributed to injury (PMR = 2.93; 95% CI = 2.64, 3.24), with suffocation (n = 90; PMR = 31.93; 95% CI = 25.69, 39.24) being the leading cause of injury mortality, followed by asphyxiation (n = 78; PMR = 13.50; 95% CI = 10.68, 16.85) and drowning (n = 74; PMR = 39.89; 95% CI = 31.34, 50.06).

Conclusions. Individuals with autism appear to be at substantially heightened risk for death from injury. (*Am J Public Health.* 2017;107:791–793. doi:10.2105/AJPH.2017.303696)

Autism spectrum disorder is a developmental disability that can cause significant social communication and behavioral challenges.¹ Patterns of impairment in social interactions and communication and restricted, repetitive, and stereotyped behaviors may emerge in early childhood, usually between age 2 and 3 years, and last throughout adulthood.^{1–4} Examples of such maladaptive behaviors include self-harm and forms of aggression with various degrees of severity.^{5,6}

The reported prevalence of autism spectrum disorder has increased markedly in the past 2 decades.⁷ The estimated prevalence of autism spectrum disorder from the Autism and Developmental Disabilities Network was 1 in 68 children aged 8 years, and this rate has more than doubled between 2000 and 2012.⁷ The disorder is about 4 times as common in males as in females.² Prevalence tends to be higher among non-Hispanic White children and among children of highly educated parents.²

Excess mortality has been reported in the autism spectrum disorder population. Previous studies have suggested that the risk of

premature death is 2- to 10-fold higher in the autism spectrum disorder population than in the general population, particularly among females.^{8–10} However, autism spectrum disorder alone rarely causes death. Thus, factors contributing to the excess mortality are likely related to comorbid conditions, such as schizophrenia, attention-deficit/hyperactivity disorder, epilepsy, and depression.^{11,12} Aside from the natural disease causes of death, autistic individuals appear to be at heightened risk for death from unintentional and intentional injuries.^{8–10}

Previous studies were limited by small numbers of deaths and to select age groups and geographic locations. The purpose of this study was to document the epidemiological patterns of injury fatalities in

individuals with a recorded diagnosis of childhood autism in the United States from 1999 through 2014.

METHODS

Data for this study came from the multiple cause-of-death data files in the National Vital Statistics System from 1999 to 2014. The multiple cause-of-death data files are a census of death certificates in the United States and contain information about the causes of death and demographic characteristics. During the 16-year study period, a total of 39 524 849 deaths were recorded in the National Vital Statistics System. We identified decedents with a diagnosis of autism by screening the causes of death and conditions contributing to the death in the multiple cause-of-death data files based on the *International Classification of Diseases, 10th Revision (ICD-10)*,¹³ code F84.0 (designated for autism or autistic disorder). Up to 20 ICD-10 codes could be entered into the death certificate, with the first code being the underlying cause of death and other codes being contributory causes of death. Injury causes were identified by ICD-10 codes S00 to Y99. For death certificates that did not list any injury as the underlying cause of death, the first injury code listed as the condition contributing to the death was used as the injury cause in the analysis.

We used the general US population as the reference to calculate proportionate mortality ratios (PMRs) and 95% confidence intervals (CIs) for specific causes of death, assuming that the mortality data followed a Poisson distribution. We used PMRs

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instead of standardized mortality ratios because population data for those with autism were unavailable.

RESULTS

During 1999 through 2014, a total of 1367 deaths (1043 males and 324 females) in individuals with a diagnosis of autism were recorded in the United States. The annual number of decedents with a diagnosis of autism was 27 (accounting for 0.001% of all deaths) in 1999, which increased to 184 (0.007% of all deaths) in 2014. The mean age at death for individuals with autism was 36.2 years (SD = 20.9 years; median = 34.0 years), whereas the mean age at death for the general population was 72.0 years (SD = 19.2 years; median = 77.0 years).

Of all the recorded deaths in individuals with autism, 381 (27.9%) were attributed to injury. Of the 381 injury fatalities in individuals with a diagnosis of autism, 40.4% occurred in homes or residential institutions. The mean age of injury deaths in individuals with autism was 29.1 years (SD = 19.0 years; median = 26.0 years) compared with 54.7 years (SD = 24.6 years; median = 54.0 years) in the general population.

When adjusted for age, sex, and calendar year, autism was associated with a significantly increased proportionate mortality from unintentional injury (PMR = 2.93; 95% CI = 2.64, 3.24; Table 1). The excess proportionate mortality from unintentional injury was particularly pronounced in autistic children younger than 15 years (PMR = 41.87; 95% CI = 34.33, 50.59). The most common injury cause of death in

individuals with a diagnosis of autism was suffocation (n = 90), followed by asphyxiation (n = 78) and drowning (n = 74; Table 1). These 3 injury causes were each associated with substantially heightened proportionate mortality in both sexes (Table 1).

DISCUSSION

Although previous research has reported increased mortality in individuals with autism, injury mortality in the autism spectrum disorder population is understudied. We examined national mortality data and found that individuals with a diagnosis of autism died on average 35.8 years younger than individuals in the general population. For deaths caused by injury, the difference was almost as striking. We also found that the annual number of recorded deaths for individuals with a diagnosis of autism has risen nearly 7 times from 1999 to 2014. This number has likely increased because of the increasing prevalence of autism resulting from improved detection and diagnosis of the condition and changes in the diagnostic criteria. Despite the marked increase in the annual number of deaths occurring in individuals with autism, autism-related deaths still may be severely underreported, particularly deaths from intentional injury such as assaults, homicide, and suicide.

We also found that deaths in individuals with autism were nearly 3 times as likely as were deaths in the general population to be caused by unintentional injury. The excess risk of unintentional injury associated with autism was particularly high for children younger than 15 years and for 3 specific causes: drowning, suffocation, and

asphyxiation. Together, these 3 causes accounted for 79.4% of the total injury mortality in children with autism.

This study had several notable limitations. First, in the absence of population data on autism, we were unable to calculate the death rates and cause-specific standardized mortality ratios. Instead, we relied on proportionate mortality analysis to explore the relative burden of injury mortality in individuals with autism. In proportionate mortality analysis, a cause-specific PMR is influenced by changes in the number of deaths from the specific cause or the number of deaths from all other causes. Consequently, the heightened PMR from injury observed in individuals with autism may not necessarily measure the excess risk of injury mortality in individuals with autism as compared with the general population. Second, our study was limited to death certificate data. The accuracy of data on death certificates filed by medical examiners and coroners varies with the cause of death and the types of disease. Therefore, autism as a contributing cause of death is likely underreported.

PUBLIC HEALTH IMPLICATIONS

Findings from this study indicate that individuals with a diagnosis of autism appear to be at substantially heightened risk for death from unintentional injury, particularly for children younger than 15 years. Because suffocation, asphyxiation, and drowning are the leading injury causes of death for individuals with autism, prevention programs specifically targeting these risks must be developed and implemented. Given the exceptionally heightened risk of drowning

TABLE 1—Age-Adjusted Proportionate Mortality Ratios (PMRs) and 95% Confidence Intervals (CIs), by Cause of Death, for Individuals With a Diagnosis of Autism, by Sex: United States, 1999–2014

Cause of Death	Males			Females			Total		
	Observed	Expected	PMR (95% CI)	Observed	Expected	PMR (95% CI)	Observed	Expected	PMR (95% CI)
Injury	296	82.97	3.57 (3.17, 4.00)	85	47.12	1.80 (1.44, 2.23)	381	130.08	2.93 (2.64, 3.24)
Asphyxiation	60	3.04	19.73 (15.07, 25.38)	18	2.74	6.58 (3.90, 10.34)	78	5.78	13.50 (10.68, 16.85)
Drowning	57	1.47	38.66 (29.30, 50.05)	17	0.38	44.68 (26.07, 71.18)	74	1.85	39.89 (31.34, 50.06)
Suffocation	67	1.56	42.82 (33.20, 54.35)	23	1.25	18.34 (11.64, 27.43)	90	2.82	31.93 (25.69, 39.24)
Other	112	75.49	1.48 (1.22, 1.79)	27	56.43	0.42 (0.32, 0.48)	139	131.91	1.05 (0.89, 1.24)
All other causes of death (excluding injury)	747	572.59	1.30 (1.21, 1.40)	239	633.62	0.38 (0.33, 0.43)	986	1206.21	0.82 (0.77, 0.87)

for children with autism, clinicians, parents, and social workers should help provide swimming lessons to these children as soon as the diagnosis is made. **AJPH**

CONTRIBUTORS

J. Guan performed the literature review and data analysis and participated in the drafting and revision of the article. G. Li designed the study, supervised the statistical analysis, interpreted the data, and participated in the drafting and revision of the article. Both authors approved the final version of the article.

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HUMAN PARTICIPANT PROTECTION

This study meets the criteria for the Protection of Human Subjects exemption 4 (research involving preexisting data) of the US Code of Federal Regulations (45 CFR 46.101). The study was deemed exempt from review by the institutional review board's Administrative Review Committee at Columbia University Medical Center.

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