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Causes of Death in Autism

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The objective of this study was to determine which causes of death are more frequent in persons with autism, and by how much, compared with the general population. Subjects were 13,111 ambulatory Californians with autism, followed between 1983 and 1997. The units of study were person-years, each linked to the subject's age, sex, and cause of death (if any) for the specific year. Observed numbers of cause-specific deaths were compared with numbers expected according to general population mortality rates. Standardized mortality rates (SMRs) were computed for each mental retardation level. Elevated death rates were observed for several causes, including seizures and accidents such as suffocation and drowning; elevated mortality due to respiratory disease was observed among persons with severe mental retardation. Overall, excess mortality was especially marked for persons with severe mental retardation, but life expectancy is reduced even for persons who are fully ambulatory and who have only mild mental retardation.

KEY WORDS: Autism; PDD; cause of death; life expectancy; mental retardation level; mortality; standardized mortality ratio.

INTRODUCTION

The life expectancy of persons with autism is of interest to parents, health professionals, and service providers concerned with these patients' lifetime needs. Mortality information that includes the causes of death can influence care and treatment strategies. Such information is also important in biomedical studies of post-mortem brain tissue and helps provide a complete bio-behavioral profile of the brain donor.

A recent report on comparative mortality in California (Shavelle & Strauss, 1998) confirmed the speculation of Gillberg (1991) that persons with autism have reduced life expectancy. Data from the extensive California developmental disabilities registry, with 11,347 autistic individuals, clearly showed that persons with autism are subject to increased mortality risk, with an overall mortality ratio of 213% (mortality ratio, MR, is observed deaths compared with expected deaths converted to a percentage). The MR for females (490%) was notably higher than that for males (167%). The life expectancy of a 5-year-old in that cohort was reduced by 6.1 years for boys and 12.3 years for girls.

The present study, supported by the East Bay Chapter of the Autism Society of America, California, was designed to determine the reasons for this large increase in mortality by investigating which causes of death are elevated, by how much, and how the results depend on type or severity of autism.

METHODS

Subjects were selected from a computerized database of 168,461 persons who received any services from the California Department of Developmental Services between January 1983 and December 1997. Services include medical treatment, occupational or physical therapy, and board and care. According to the California Welfare and Institutions Code, Section 4512,

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eligible individuals are mentally retarded or have ". . . a disabling condition found to be closely related to mental retardation or to require treatment similar to that required for mentally retarded individuals, but shall not include other handicapping conditions that are solely physical in nature."

All subjects are evaluated approximately annually, using the Client Development Evaluation Report (CDER, 1978). This instrument contains some 200 psychological, medical, functional, behavioral, and cognitive items. The reliability of the functional items has been assessed previously and judged satisfactory (Harris *et al.*, 1982; Arias *et al.*, 1983; Widaman, 1984; Widaman *et al.*, 1985). The Diagnostic Information section of the CDER contains information on mental retardation, cerebral palsy, autism, epilepsy/seizure disorder, and other types of developmental disabilities and mental disorders. The CDER has data fields for the date of determination of disability; ICD-9 (Autism International Classification of Diseases, Ninth Revision) etiology codes were added in 1988.

From this database, we selected the 13,111 persons with clinically diagnosed autism who also met the following criteria:

i. Without concomitant etiology of Down syndrome (ICD-9 758.1), cerebral palsy, severe tuberous sclerosis (ICD-9 759.5), or Rett syndrome (ICD-9 299.8).
ii. Could walk well alone at least 20 feet, and balance well. We included this condition to focus on persons with no substantial motor impairment. Increased mortality risk is well known in persons with developmental disabilities and motor impairment (Strauss *et al.*, 1998a; 1998b; Strauss & Shavelle, 1999; Strauss *et al.*, 1999) and even in the sedentary general population (Paffenbarger *et al.*, 1986, 1993).

Without conditions (i) and (ii), the autism population would have been 13,482 persons (228 deaths). For descriptive purposes, we also extracted CDER data on subjects' histories of seizure activity, aggression, one-to-one interaction with peers, medications, and communication skills.

Mortality information was obtained from annual computer tapes from the State of California (1983-1997). In California it is required that death certificates be filed with the state, and the resulting computer tapes represent the state's official mortality record. Tapes were matched against the California disabilities data on the basis of name, date of birth, and social security number. Of the 13,111 subjects in the study, we identified 202 who died during the study interval.

Causes of death were also obtained from the computer tapes. These were in the form of ICD-9 (1995) codes of 3 to 4 digits. The causes were grouped into 11 categories:

- Cancer (ICD-9 codes 140–239; $n = 21$ deaths)
- Seizures (345,436,780.3; $n = 15$)
- Diseases of the Nervous and Sense Organs (320–389, excluding 345; $n = 10$)
- Circulatory (390–459; $n = 22$)
- Respiratory (460–519; $n = 13$, primarily pneumonia)
- Digestive (520-579; $n = 13$)
- Congenital Anomalies (740–759; $n = 16$)
- Drowning (910; $n = 11$)
- Suffocation (911–913; $n = 8$)
- Other external causes (other codes 800+, excluding drowning and suffocation; $n = 30$, mostly motor vehicle accidents)
- All other causes not previously listed ($n = 43$, including 16 listing autism or mental retardation as the cause and 16 unspecified).

Individual cause of death information on all 202 deceased persons is available from the Authors (Shavelle, Strauss & Pickett, 2001).

Comparison of death rates to the general population was carried out as follows:

1. For each combination of quinquennial age, sex, and cause of death group, we computed mortality rates in the general California population by using the California mortality tapes (State of California, 1988–1997) and data on the California population (State of California, 1988) over the same time period. A mortality rate is roughly defined as the chance of dying in a given year; here the rates were age-, sex- and cause-specific.
2. For persons with autism we computed the exposure time as the total number of person-years at risk of death. This was done separately for every combination of quinquennial age and sex.

   The beginning of the "exposure" period for a given subject was the later of (a) the first CDER, and (b) January 1, 1983. The end of the subject's period at risk was the earliest of (a) the date of death, (b) the end of the study period (December 31, 1997), and (c) 3 years after the date of the subject's last CDER evaluation. This last condition was included to minimize the po-

tential bias due to subjects who may have left California. Deaths of such persons would not be in our records, but because of condition (c), these subjects would also not be counted as being at risk for more than a fairly short period. Migration from California is generally believed to be uncommon because California is the only U.S. state providing services to persons with mental disabilities as entitlement.

3. The mortality rates from step 1 were then applied to the exposure times to give an expected number of deaths due to each cause for each combination of the above factors based on the general population.
4. The actual number of deaths associated with each combination of factors was noted.
5. The ratio of the observed number of deaths to the expected number is a standardized mortality ratio, SMR (Kahn & Sempos, 1989). SMRs were computed for each combination of factors. Also, by summing both observed and expected numbers appropriately, we computed SMRs for combined groups, such as "all persons age 20 or more."
6. The unit of analysis is a person-year, not a person. Thus, one person may contribute several person-years to the "age 0–4" category and several more to the "age 5–9" category.

By using the same source of mortality information when comparing the autism group to the general California population, we attempted to minimize various sources of reporting bias.

RESULTS

Table I shows the breakdown of the 13,111 subjects by age, sex, and other factors. As is common in groups of persons with developmental disabilities, the majority was male, but the male to female sex ratio of 3.9:1 is much higher than that of most other such disabilities.

The overall SMR was 2.4, indicating that on average in this group the mortality was more than double that of the general population. We investigated whether this average concealed differences between subgroups. Table II shows that males had a lower SMR, 1.7, than did females, 5.5, but the age-specific and cause-specific

Table I. Characteristics of the 13111 Subjects at First Evaluation. Figures are Percentages by Column

	Males (n = 10,412)	Females (n 2699)	All (n = 13,111)
Percent Died	1.4	2.2	1.5
Age (years) at first evaluation[a]			
<2	0.4	0.2	0.3
2	9.3	10.4	9.5
3	26.1	24.5	25.8
4	16.8	16.4	16.7
5	9.6	8.6	9.4
6	5.9	4.9	5.7
7	3.4	3.7	3.4
8	2.7	3.3	2.8
9	1.8	2.4	1.9
10–15	7.5	7.6	7.5
15+	16.5	18.1	16.8
Mental retardation level[b]			
None	53.8	44.4	51.9
Mild	18.6	16.9	18.2
Moderate	13.5	14.9	13.8
Severe	9.1	14.3	10.1
Profound	5.0	9.6	5.9
Ethnicity[c]			
White	49.0	52.9	49.8
Black	13.9	11.9	13.5
Hispanic	16.1	16.8	16.2
Asian	6.0	5.1	5.8
Other	15.0	13.3	14.7

(Continued)

Table I. Continued

	Males (n = 10,412)	Females (n = 2699)	All (n = 13,111)
Seizures			
Yes	3.9	5.2	4.2
No	96.1	94.8	95.8
Medications[d]			
Yes	7.8	6.0	7.4
No	92.2	94.0	92.6
Residence			
Own home	82.6	76.1	81.2
Community care facility	10.5	13.0	11.0
Institution	5.4	8.8	6.1
Other	1.5	2.1	1.7
Frequency of self-injurious behavior			
At least daily	8.6	11.4	9.2
Weekly	10.1	13.0	10.7
Monthly	7.4	8.3	7.6
Not more than 3 times per year	7.4	8.6	7.6
Rarely or never	66.5	58.7	64.9
Repetitive body movements			
Occur continuously without cessation during waking hours	4.6	5.5	4.8
Occur continuously, but person can be distracted from the behavior	15.2	17.6	15.7
Sometimes, daily	31.7	31.0	31.5
Only under conditions of excitement or stress	19.4	18.6	19.3
None	29.2	27.3	28.8
Auditory perception			
Does not react to sounds	1.5	1.8	1.6
Demonstrates startle response to loud sounds	1.6	2.2	1.7
Turns head or eyes towards sound source	4.6	5.2	4.7
Responds differently to voices	5.8	6.4	5.9
Responds differently to different voices	17.5	18.6	17.7
Recognizes different words	22.3	20.9	22.2
Can differentiate similar words	46.8	44.9	46.4
Receptive language			
Does not understand speech	4.0	5.9	4.4
Understands simple words	21.7	23.2	22.0
Understands simple phrases or instructions	48.6	47.2	48.3
Understands meaning of simple conversation	20.9	19.6	20.7
Understands complex conversation	4.7	4.1	4.6
Expressive language			
Makes no sound	3.3	5.2	3.7
Babbles but says no words	26.2	24.8	25.9
Says simple words	25.5	25.9	25.6
Says two-word sentences	12.3	12.3	12.3
Says sentences of three or more words	18.5	19.5	18.7
Carries on basic conversation	10.8	9.5	10.5
Carries on complex conversation	3.4	2.8	3.3

[a] The study period began in 1983. Some subjects had prior evaluations that were not considered.

[b] Mild mental retardation is defined as an IQ (±5) of 55–70, moderate 40–55, severe 25–40, and profound below 25.

[c] The ethnic distribution for all persons, all ages, in the state of California in 1990 was: white, 57%; black, 7%; hispanic, 26%; asian, 9% and native american, 1%.

[d] Taking least one of the following types of medications: antipsychotic, antidepressant, antianxiety, sedative/hypnotic, stimulant, or other psychotropic drug.

Table II. Standardized Mortality Ratios (SMRs) by Age and Sex

Ages (years)	Males	Females	Overall
2–5	2.3	3.0	2.4
5–10	3.5	16.8	5.4
10–20	2.3	9.2	3.0
20+	1.7	5.3	2.1
All	1.7	5.5	2.4

patterns were similar, and so the sexes were combined in subsequent analyses.

For persons with no or mild mental retardation the SMR was 1.4, compared with 3.1 for those with moderate, severe, or profound mental retardation. No other dichotomy yielded such a sharp contrast, and we therefore stratified our analysis into these two groups.

Table III shows SMRs for those with no or mild mental retardation, by age group and cause. The SMR of 22.6 for seizures is highly significant. SMRs are also higher than the general population for circulatory diseases (2.3), congenital anomalies (2.0), cancer (1.9), and nervous and sensory diseases (4.8). Among the external causes of death, drowning (3.9) and suffocation (5.7) have large SMRs, whereas the remaining causes such as homicides and other accidents are, in fact, less likely to occur (SMR = 0.8).

Table IV shows SMRs for those with moderate, severe, or profound mental retardation, by age and cause. Almost all causes of death are elevated by comparison with the general population, and the SMRs are for the most part substantially higher than in Table III. The SMR for seizures (36.9) is again striking. As with the less mentally impaired group, drowning (13.7) and suffocation (51.4) are increased, whereas other external causes are decreased (0.6).

DISCUSSION

The aim of this study was to expand on the initial report of excess mortality in the California autism population (Strauss & Shavelle, 1998) by exploring the cause of the death. We excluded the nonambulatory population, a group known to have a very high mortality rate; even so, subjects had higher mortality than

Table III. Standardized Mortality Ratios (SMRs): No or Mild Mental Retardation Only[1]

Cause of Death (ICD-9 Codes)	Age Group (years)				All Ages
	2–5	5–10	10–20	20+	
Cancer			3.8	1.6	1.9
(140–239)	(0)	(1)	(2)	(3)	(6)
Seizures				33.1	22.6
(345,436,780.3)	(0)	(0)	(0)	(4)	(4)
Nervous and Sense			15.9		4.8
(320–389, excluding 345)	(0)	(1)	(3)	(0)	(4)
Circulatory				2.2	2.3
(390–459, excluding 436)	(0)	(0)	(1)	(4)	(5)
Respiratory					1.3
(460–519)	(0)	(0)	(0)	(1)	(1)
Digestive					1.2
(520–579)	(0)	(0)	(0)	(1)	(1)
Congenital Anomalies					2.0
(740–759)	(0)	(1)	(1)	(1)	(3)
All other causes		8.7		0.4	1.0
(<800)	(0)	(3)	(1)	(2)	(6)
Drowning	5.0	14.1			3.9
(910)	(1)	(2)	(0)	(0)	(3)
Suffocation					5.7
(911)	(0)	(1)	(0)	(0)	(1)
All other causes	3.1	2.6	0.6	0.6	0.8
(≥800)	(2)	(3)	(3)	(7)	(15)
All Causes	1.6	4.0	1.5	1.0	1.4
	(3)	(12)	(11)	(23)	(49)

[1] The observed number of deaths is shown beneath each in parentheses. Age-specific SMRs are not given if the observed number is less than 2.

Table IV. Standardized Mortality Ratios (SMRs): Moderate, Severe, or Profound Mental Retardation Only[1]

Cause of Death (ICD-9 Codes)	Age Group (years) 2–5	5–10	10–20	20+	All Ages
Cancer			6.2	2.4	2.9
(140–239)	(1)	(0)	(3)	(11)	(15)
Seizures				38.0	36.9
(345,436,780.3)	(0)	(0)	(1)	(10)	(11)
Nervous and Sense			12.0	4.1	6.2
(320–389, excluding 345)	(0)	(1)	(2)	(3)	(6)
Circulatory				3.7	3.8
(390–459, excluding 436)	(0)	(0)	(1)	(16)	(17)
Respiratory			24.5	9.4	10.8
(460–519)	(0)	(0)	(3)	(9)	(12)
Digestive			40.8	5.9	7.5
(520–579)	(0)	(1)	(2)	(9)	(12)
Congenital Anomalies			11.1	8.7	9.4
(740–759)	(0)	(1)	(4)	(8)	(13)
All other causes			15.0	3.3	3.8
(<800)	(0)	(1)	(6)	(30)	(37)
Drowning		90.6	11.3	8.5	13.7
(910)	(0)	(3)	(2)	(3)	(8)
Suffocation			110.2	23.4	51.4
(911)	(1)	(0)	(4)	(2)	(7)
All other causes			0.8	0.6	0.6
(≥800)	(0)	(1)	(4)	(10)	(15)
All Causes	10.2	11.3	4.4	2.7	3.1
	(2)	(8)	(32)	(111)	(153)

[1] The observed number of deaths is shown beneath each in parentheses. Age-specific SMRs are not given if the observed number is less than 2.

expected in the general population after adjustment for age and sex.

Because medical records on cause of death were not generally available, we worked with computer codes and death certificates. It should be noted that the cause-specific SMRs reported here are conservative, as in the 16% of cases in which we were unable to determine the cause. Although these sources are frequently used in large epidemiologic studies, their limitations are well-known (Lilienfeld & Lilienfeld, 1980). Resulting bias may have been reduced, however, because the same source (California mortality computer tapes) was used for the causes of death of both the subjects with autism and the reference California population.

In the no or mild mental retardation group, deaths by seizures, nervous system dysfunction, drowning, and suffocation were all more than three times higher than would be expected in the general population. For the more severely retarded subjects, all categories of cause of death except cancer and "all other causes ≥800" were more than three times higher. External causes of death excluding drowning and suffocation, which were analyzed separately, were actually lower than expected. This is largely because the general population death rate from injuries climbs rapidly in the teen years, whereas many teenagers with autism may lack the same opportunities for risky behavior.

Overall, children between 5 and 10 years of age had the highest SMRs, especially girls, with an SMR of 16.8. Further research is needed on why some causes are elevated, and on the male/female/age differences. Future studies might also examine medical records and death certificates. The present study reflects a 15-year period ending in 1997. Given the large increase in autism intakes into the California system from the first to the second half of the last decade (148%, unpublished data), a follow-up through 2000 should provide further information on the younger age groups.

State databases and individual records are extremely important in obtaining the numbers necessary to examine cause of death, or other characteristics of interest in autism. For instance, the prevalence of epilepsy for all ages in this study was 4.2%. This figure is at the lower end of the range of seizure frequency

(4%–60%) reported in various studies. The CDER contains fields for eight seizure types, the frequencies for each, the condition impact, and whether the person takes anticonvulsant medication. Further data mining could assess age, level of cognitive function, and type and degree of language dysfunction pertinent to epilepsy (Tuchman, 2000). The potential of these data sources is immense and work should continue to improve the accuracy and consistency of the autism data in all states.

The prerequisite for accuracy of data is equally true for mortality reporting. In the present study, a review of ICD-9 codes for the 202 deaths showed many instances of ill-defined causes of death. For example, 3 deaths were coded 299 (infantile autism); 13 coded 318 or 319 (moderate mental retardation or mental retardation, not otherwise specified); and 16 were coded 799 (unspecified causes). It is estimated that sudden unexplained deaths (SUD) claims over 4000 persons between the ages of 1 and 22 each year in the United States (Ackerman *et al.*, 2001). Ackerman and colleagues (1999, 2001) used post-mortem "molecular" tissue autopsies to link a KVLQT1 gene defect with fatal cardiac arrhythmias associated with one form of inherited long QT (LQT) syndrome and swimming-triggered cardiac events. Another autosomal-dominant LQT gene, HERG, is located on chromosome 7q35-36 (Wang *et al.*, 1998).

Deaths due to drowning and epilepsy are common in the California autism population and deserve further forensic study as does the possibility of "acquired" LQT syndrome from various medications. De Ponti and colleagues (2001) have called for a consensus to organize information on QT prolongation and the occurrence of torsades de pointes, polymorphic ventricular tachycardia thought to be initiated by early after-depolarizations in the cardiac Purkinje system (Chiang & Roden, 2000), with use of non-antiarrhythmic drugs.

Looking strictly at patient populations with epilepsy, the rate of sudden, unexpected, and unexplained death in epilepsy (SUDEP) exceeds the expected rate of sudden death in the general population by nearly 24-fold (Ficker *et al.* 1998; Annegers & Coan, 1999). The incidence and risk of SUD and SUDEP will be fully ascertained only with careful post-mortem examination and complete death narratives.

The information from this study is relevant to the Autism Tissue Program (ATP), which recruits brain donors for biomedical research, as it reveals age-trends in the number and causes of death. Without these data, one would not know if a given group of brain tissue cases was representative of deaths in the autism population or simply an unusual sample. For example, the 23 donations through June 2001, 43% of which were from donors under 15 years of age, may now be viewed as fairly typical. The causes of death were: seizures (6, two of these in the SUDEP category), drowning (5), external injury such as auto trauma (4), congestive heart failure (2), hyperthermia (1), infection (1), gastrointestinal bleeding and seizure disorder (1), anoxia (1), sepsis from infected bowel (1), cardiac arrest, SUD (1). Nevertheless, each donor represents one or more potential subsets of autism characteristics or co-morbidity that must be taken into account in brain tissue research. Hyperthermia was associated with at least 3 deaths and, in 2 of these, neuroleptic malignant syndrome was thought to contribute to the cause of death (Andreassen & Pedersen, 2000; Kahn & Farver, 2000).

The annual monetary cost of autism in the United States is estimated at roughly $26 billion (Maltby, 2000), but the impact of higher mortality is an incalculable emotional cost to families. The Autism Society of America (ASA) Foundation, together with the Autism Coalition for Research and Education, is currently funding a study addressing autism aging, morbidity, and mortality. We hope that this initial study on causes of death in autism will improve prevention, care, and planning for this patient population.

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