ORIGINAL ARTICLE

Comparative Mortality of Persons with Autism in California, 1980–1996
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Abstract: The authors studied mortality rates of persons with autism, using the extensive California developmental disabilities registry. There was an overall mortality ratio (MR) of 213%. The MR for females (490%) was strikingly higher than for males (167%). The excess mortality rate (EDR) increased with age, while the mortality ratio (MR) decreased with age. Persons with autism are suject to increased mortality risk, as summarized in the provided tables.

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Introduction
Autism is a syndrome characterized by a qualitative impairment in the development of reciprocal social skills and in imaginative activities such as play.[1,2] The repertoire of activities and interests is often restricted and is frequently stereotypical and repetitive. Autism is usually associated with mental retardation as measured on IQ tests. In addition, comprehension of meaning of language, the production of speech, and reciprocal communication are impaired. Finally, alterations in posture, movement, response to sensory stimuli, and patterns of eating, drinking, and sleep are frequently disturbed.

Knowledge about autism is limited in many areas including its causes, prognosis, treatment, associated medical and psychiatric illnesses, and causes or timing of death.[3] In particular, there are limited opportunities to conduct population-based epidemiological research on these issues.

The large data base of the California Department of Developmental Services provides information on 11,347 subjects with autism during a 1980-1996 study period. This appears to be much the largest population of autistic persons ever studied. In this article we report on mortality rates in persons with autism by age and sex, and compare to the general population. Such information may be useful for medical directors and others concerned with quantifying mortality risks.

Subjects Studied
The database compiled and managed by the California Department of Developmental Services comprises annual Client Development Evaluation Reports[4] (CDER's) on 182,263 persons with developmental disabilities. These reports are prepared by regional centers throughout the state, and include information upon entry and changes in medical, social, and living conditions. The reliability of CDER items has been assessed previously and judged satisfactory.[5,6] Autism was assessed by

an evaluation team contracted by the California Department of Developmental Services as part of initial work-up for receiving services. Two CDER items were used to identify subjects: level and severity. The inter-item reliability exceeded 0.999.[9] Data for each sex have been analyzed by quinquennial age groups beginning at age 5 and ending at age 70-75.

Demographic and other characteristics are summarized in Table 1 for the 11,347 persons with autism in the registry during the 1980-1996 observation period. The figures given are percentage of the total. Males predominated over females, 74% to 26%, as is common among persons with autism.[3] Most persons were white (54%). As found by others,[1,2] a substantial proportion (33%) were not mentally retarded. The majority (74%) lived in their own (or parents) homes.

Associated physical or functional disability was uncommon in these persons, so that the basis for their requiring state services was primarily for cognitive and interpersonal development. For example, 35% did not enter into one-to-one interaction with peers (friends, classmates, co-workers, etc.). By contrast, only 7% were unable to walk 20 feet unassisted. We judged that the most interesting group to compare with the general population is that of persons with autism but without severe physical disabilities. To this end we excluded the non-ambulatory individuals from the life table analyses that follow.

Follow-up

The CDER data base was matched to annual California mortality data published by the California Department of Health Services, Bureau of Vital Statistics. Each person's exposure period was from their first CDER to the earlier of (a) their date of death, (b) the end of the study period, December 31, 1995, or (c) three years from their last CDER. This last condition was included to avoid the possible bias introduced by persons who could have moved from the state, and thus would have a hiatus in their CDER evaluations. Deaths were counted only if they occurred within the exposure period. The total exposure time was allocated to the appropriate attained age intervals. Causes of death were available as ICD-9 codes (International Classification of Diseases, 9th revision).[10]

Results

The 1992 U.S. Abridged Life Table was used to derive the expected mortality rates (q') for the male and female populations, shown in Tables 2 and 3, respectively. The Tables indicate that the excess mortality rate increases with age, and that the MR decreases with age. Based upon previous research in cerebral palsy,[11] we expected that the logarithm of the mortality ratio would decrease linearly with age. This appeared to be roughly the case. The age at which mortality rates become similar to those in the general population is, however, considerably larger than the 90 years observed for cerebral palsy.

Table 4 gives the life expectancies for males and females with autism, with comparison to the U.S. general population. The data were not sufficient to estimate all age- and sex-specific mortality rates (for example, age 85; see Tables 2 & 3). Therefore, we modeled the rates from age 10 onwards based upon the linear relationship between the natural log of the mortality ratio and age.

It may be seen that life expectancy in autism is reduced by 6.1 years and by 12.3 years at age 5 for males and females, respectively. The disparities diminish to only 3.5 and 4.2 at age 60.

Discussion

The population considered here appears to be much the largest group of persons with autism ever studied. It consists of all autistic persons who received services from the state of California. Such services are an entitlement in California, and it is likely that the great majority of persons needing extensive services would avail themselves, and thus be in the data base. No doubt the study under-represents those with milder forms of autism, as they are less likely to seek services from the state.

Previously Gillberg[12] had speculated that persons with autism may be subject to excess mortality, and cited the need for detailed longitudinal follow-up data. Not finding any research to the contrary, Holmes[13] suggested that adults with autism have an approximately normal lifespan. The present work is the first systematic study of the issue. As we have seen, there is an excess mortality and a corresponding reduction in life expectancy.

The MR's for males were strikingly lower than for females. The former was 167% (95% confidence interval, 145% to 192%), while the latter was 490% (95% confidence interval, 384% to 596%). The disparity was highly statistically significant, and relatively consistent across age groups. The reasons for this are not apparent to us, and the issue merits further investigation.

The California data base also contains information on comorbidity, causes of death, as well as on longitudinal changes in cognitive and communicative skills. It is, for example, possible to assess the chances that a child with a given level of functioning will acquire various skills over the next 15 years. We hope to report on these issues subsequently.

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Table 1

Demographic, mental retardation, and disability characteristics of 11,347 persons with autism in the 1980-1996 registry of the California Department of Developmental Services

Category	Distribution
Gender	
Male	74%
Female	26
Ethnicity	
White	54%
Black	14
Asian	5
Hispanic	15
Other	12
Age at first CDER	
5–9 years	50%
10–14	15
15–19	14
20–24	9
25–34	8
35+	4
Mental Retardation	
None	33%
Mild	19
Moderate	18
Severe	16
Profound	14
Other/Unknown	2
One-to-One interaction with peers	
Does not enter into interaction	35%
Enters into interaction only when others initiate	38
Initiates interaction in familiar or previously successful situations	21
Initiates interaction in both familiar and unfamiliar situations or settings	7
Ambulation	
Does not walk	3%
Intermediate levels	4
Walks unassisted	93
Crawling & standing	
Does not crawl, creep, or scoot	2%
Intermediate levels	6
Stands	92
Severity of autism	
Mild	20%
Moderate	43
Severe	19
Unknown	18
Residence	
Own home	71%
Group home	14
State hospital	13
Other	2

Table 2

Comparative mortality of males with autism.

Attained Age (years)	Exposure Patient-years	Number of deaths		Mortality Ratio	Mean Annual Mortality Rate per 1,000		
		Observed	Expected*		Observed	Expected	Excess
	E	d	d'	100d/d'	q	q'	q-q'
5	12257	11	2.93	376%	0.9	0.2	0.7
10	10546	11	8.12	135%	1.0	0.8	0.3
15	10204	23	12.45	185%	2.3	1.2	1.0
20	10413	28	16.60	169%	2.7	1.6	1.1
25	8900	22	15.83	139%	2.5	1.8	0.7
30	6017	31	13.50	230%	5.2	2.2	2.9
35	3523	14	10.04	139%	4.0	2.9	1.1
40	1831	10	6.60	151%	5.5	3.6	1.9
45	866	3	4.20	71%	3.5	4.9	-1.4
50	407	4	2.95	135%	9.8	7.3	2.6
55	217	3	2.51	120%	13.8	11.6	2.3
60	118	2	2.15	93%	16.9	18.2	-1.3
65	55	4	1.52	263%	73.2	27.8	45.4
all	65355	166	99.41	167%	2.5	1.5	1.0

*Basis of expected deaths: 1992 U.S. Life Table rates for males.

Table 3

Comparative mortality of females with autism.

Attained Age (years)	Exposure Patient-years	Number of deaths		Mortality Ratio	Mean Annual Mortality Rate per 1,000		
		Observed	Expected*		Observed	Expected	Excess
	E	d	d'	100d/d'	q	q'	q-q'
5	3078	6	0.52	1163%	1.9	0.2	1.8
10	3353	11	0.60	1824%	3.3	0.2	3.1
15	3575	9	1.57	573%	2.5	0.4	2.1
20	3651	7	1.83	383%	1.9	0.5	1.4
25	3112	13	1.94	669%	4.2	0.6	3.6
30	2290	13	1.92	678%	5.7	0.8	4.8
35	1491	7	1.76	397%	4.7	1.2	3.5
40	872	6	1.46	412%	6.9	1.7	5.2
45	499	1	1.27	79%	2.0	2.5	-0.5
50	249	1	1.04	96%	4.0	4.2	-0.2
55	116	3	0.77	387%	25.9	6.7	19.2
60	60	3	0.63	477%	49.6	10.4	39.2
65	46	1	0.73	138%	21.8	15.8	6.0
70	29	1	0.71	141%	34.2	24.3	9.9
all	22422	82	16.75	490%	3.7	0.7	2.9

*Basis of expected deaths: 1992 U.S. Life Table rates for females.

Table 4

Life expectancies for persons with autism, with comparison to the general population (source: 1992 U.S. Life tables[14]). The mortality rates ages 10 and above were modeled using the data from Tables 2 and 3.

age	males mortality rate/1000	males life expectancy autism	males life expectancy u.s. males	females mortality rate/1000	females life expectancy autism	females life expectancy u.s. females
5	0.9	62.0	68.1	1.9	62.5	74.8
10	1.3	57.3	63.2	1.8	58.1	69.9
15	2.1	52.6	58.3	3.8	53.6	65.0
20	2.7	48.2	53.7	3.8	49.6	50.1
25	3.0	43.8	49.1	4.0	45.4	55.2
30	3.7	39.4	44.5	4.7	41.3	50.4
35	4.7	35.1	40.0	5.7	37.2	45.4
40	5.8	30.9	35.5	6.9	33.2	40.9
45	7.8	26.7	31.1	9.1	29.3	36.2
50	11.5	22.6	26.8	12.8	25.6	31.6
55	18.2	18.8	22.7	17.7	22.1	27.2
60	28.3	15.4	18.9	23.8	18.9	23.1
65	42.8	12.3	15.4	31.2	16.0	19.2
70	62.8	9.7	12.4	41.3	13.2	15.5
75	94.0	7.3	9.6	54.7	10.7	12.2
80	145.9	5.3	7.2	78.6	8.3	9.2
85	278.6	3.6	5.3	164.5	6.1	6.6