

Comparative Mortality of Persons With Mental Retardation in California 1980-1999

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The authors studied mortality rates of persons who had mental retardation (MR) but no physical disability, using the extensive California Department of Developmental Services database. The data provide mortality rates by age, gender and severity of mental retardation. Data on 748,651 person-years from 72,727 subjects over age 5 during 1980-1999 were studied. The excess mortality due to MR was much less than previously thought, a finding that may have underwriting implications.

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It has been estimated that 3% of the US population meets the American Association of Mental Deficiency (AAMD) definition¹ of mental retardation (MR).² Approximately 90% of these persons have mild MR [intelligence quotient (IQ) in the range 55-69], while 7% have moderate MR (IQ 40-54) and 3% severe or profound MR (IQ <40).²

Persons with MR are much more likely than the general population to have motor dysfunction and other problems. Previous research on the effect of MR on mortality did not adjust for these.³ Our aim was to estimate the increase in mortality due to MR in persons without serious motor dysfunction. To our knowledge, this has not previously been attempted.

SUBJECTS STUDIED

The database of the California Department of Developmental Services is compiled from

annual client development evaluation reports⁴ (CDERs) on over 235,000 persons with developmental disabilities. The reliability of CDER items has been assessed previously and judged satisfactory.⁵⁻⁸

The authors identified 158,794 persons over the age of 5 with a specified level of MR, as indicated by a separate item on the CDER. Persons with Down syndrome were excluded, as this condition is degenerative; it is associated with rapidly increasing mortality after age 40.⁹ Also excluded were persons with any physical disability, as it is well known that reduced mobility is strongly associated with increased mortality.¹⁰⁻¹⁷ This was accomplished by selecting only those persons who met the following 6 criteria: (1) assumes and maintains sitting position independently, (2) uses fingers independently of each other, (3) fully extends arms, (4) stands well alone and balances well for at least 5 minutes, (5) walks well alone for at least 20 feet and balances

Table 1. Demographic Characteristics of 72,727 Persons With Mental Retardation and No Physical Disability in the 1980–1999 Registry of the California Department of Developmental Services

Category	Distribution
Sex	
Male	56%
Female	44%
Ethnicity	
White	48%
Hispanic	24%
Black	14%
Other	14%
Age at first evaluation	
5–14	28%
15–29	50%
30–44	17%
45–59	5%
60+	1%
Mental retardation level	
Mild	64%
Moderate	26%
Severe	8%
Profound	2%

well, and (6) moves up and down stairs without the need for a handrail. The resulting population was 72,727 persons.

Demographic characteristics are summarized in Table 1. The figures given are percentages. As may be seen, the majority of the subjects in this study were young, white and had mild mental retardation. As the California database includes only persons receiving services from the state (eg, board and care,

physical therapy, medical care), our sample is heavily weighted to the more severely mentally retarded as compared to the general population. For example, 10% of our population had severe or profound MR compared to 3% of those with MR in the general population.

FOLLOW-UP

The CDER database was matched to annual California mortality data from the California Department of Health Services, Bureau of Vital Statistics.¹⁸ Each person's exposure period started with their first CDER evaluation. The end of the person's exposure period was taken at the earliest of (a) their date of death, (b) the end of the study period, December 31, 1999, or (c) 3 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 sex and age intervals. The method yielded a total of 748,651 person-years and 2445 deaths.

RESULTS

The 1992 U.S. Abridged Life Table¹⁹ provided the expected mortality rates (q') shown in Tables 2 and 3. The 1992 table was used because it represented the approximate midpoint of the exposure time in the study pe-

Table 2. Comparative Mortality Rates for Persons With Mild or Moderate Mental Retardation

Attained Age (years)	Exposure Patient-years E	Number of Deaths		Mortality Ratio 100 d/d'	Mean Annual Mortality Rate per 1,000		
		Observed d	Expected* d'		Observed q	Expected q'	Excess q-q'
5–29	399,898	623	355.9	175%	1.6	0.9	0.7
30–44	185,717	652	379.3	172%	3.5	2.0	1.5
45+	67,306	759	597.2	127%	11.3	8.9	2.4
All	652,920	2,034	1,332.4	153%	3.1	2.0	1.1

* Basis of expected deaths: 1992 US Life Table rates for males and females.

Table 3. Comparative Mortality Rates for Persons With Severe or Profound Mental Retardation

Attained Age (years)	Exposure Patient-years E	Number of Deaths		Mortality Ratio 100 d/d'	Mean Annual Mortality Rate per 1,000		
		Observed d	Expected* d'		Observed q	Expected q'	Excess q-q'
5-29	46,855	130	49.3	263%	2.8	1.1	1.7
30-44	36,539	169	80.8	209%	4.6	2.2	2.4
45+	12,337	112	70.8	158%	9.1	5.7	3.3
All	95,731	411	200.9	205%	4.3	2.1	2.2

* Basis of expected deaths: 1992 US Life Table rates for males and females.

riod. The expected number of deaths was computed separately by sex as the product of the quinquennial age-specific mortality rate and exposure time. As the excess death rates (EDRs) were comparable for males and females, the results were summed over sex.

The overall mortality in each table was higher than for the California general population, with a mortality ratio for mild/moderate MR of 153% and for severe/profound MR of 205%. The combined group had a mortality ratio of 159%. It should be noted that these overall figures reflect the age distribution of the population. Most of the exposure time was contributed by the youngest age group, who also have the largest mortality ratio.

As has been found previously for other chronic disabilities,^{20,21} the mortality ratio tends to decrease with age and the EDR to increase.

There was some indication that persons who lived in their own homes were subject to a smaller excess than those who lived in community care or long-term care facilities. This may, however, have been due to the latter having other medical conditions and/or behavior problems. There was no indication of a secular (time) trend in mortality.

A detailed study of the causes of excess mortality is beyond the scope of the present paper. The authors did find, however, that as in the general population, externally caused deaths (eg, accidents, homicide, drowning) were more common in males than in females. They also found that the proportion of exter-

nally caused deaths was larger in the mild/moderate group than in the severe/profound.

DISCUSSION

The population considered here appears to be the largest group with MR to be studied with respect to long-term, risk-adjusted mortality.

The overall mortality ratio of 159% may be misleading, as it is inordinately weighted to the young and the more severely retarded. Despite this, it is smaller than previously published figures. As shown in Tables 2 and 3, the mortality ratios for ages 45 and older are only 127% for mild/moderate MR and 158% for severe/profound. The associated annual EDRs are 2.4 and 3.3 per 1000, respectively.

Lew and Gajewski,²² extracting from a study in Holland,²³ reported mortality ratios of 182% for males and 242% for females. Brackenridge and Elder²⁴ cite results from the 1983 Medical Impairment Study,²⁵ which yielded an overall mortality ratio of 203%. Based on this and other sources, they give rating guidelines equivalent to mortality ratios of 200% to 250% for persons with mild or moderate MR.

The reason for the disparity may be that previous studies did not control for the degree of physical disability or the presence of persons with Down syndrome, the latter representing a large portion of those with MR.

The results of Tables 2 and 3 can be used to construct life tables, and thus life expect-

tancies or median survival times. It should be emphasized that these rates reflect only the excess mortality due to MR, and not that due to frequently concomitant medical conditions and/or physical disabilities.

Given that the EDRs (and mortality ratios) are much smaller than previously thought, life policies may have been overpriced by insurance company underwriters, while underpriced by structured settlement underwriters.

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