

## ORIGINAL ARTICLE

### Comparative Mortality in Cerebral Palsy Patients in California, 1980-1996

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**Background:** The large database of the California Department of Developmental Services provides a data source for mortality rates in persons with mental retardation by age, sex, severity, cause and associated conditions. This study involves patients with a diagnosis of cerebral palsy.

**Results:** After a table of demographic data, four tables are used to show detailed age-related observed and expected mortality rates for Cerebral Palsy patients by sex and a severity factor that divides the patients into two groups of approximately equal size. The factor used was quadriplegia (all four limbs involved in motor dysfunction). Spasticity was the predominant feature of the motor dysfunction.

**Conclusion:** Excess mortality was moderate in the less severe Cerebral Palsy patients, but was higher in those with quadriplegia (overall EDR — Excess Death Rate — about 6 per 1000 and 16 per 1000, respectively). In less severe cases EDR was higher at ages 1-4 years, then almost constant to age 49, then rose with advancing age. In cases with quadriplegia EDR decreased in childhood and young adults to a relatively stable minimum at ages 25-49, then increased at older ages. There was little sex difference in EDR.

#### Objective of This Abstract

To present age-related comparative mortality rates of patients with Cerebral Palsy in the registry of the California Department of Developmental Services, 1980-1996, by sex and by presence or absence of quadriplegia as a measure of severity.

#### Subjects Studied

The database managed by the State of California Department of Developmental Services utilizes at least annual CDER reports (Client Developmental Evaluation Reports). These reports are prepared by local centers throughout the state, and include reports on entry, change in status, and death, in addition to the regular annual status report. Exposure data and deaths by attained age were used for male and female patients classified by presence or absence of quadriplegia, by attained age, all durations combined. Data on infants under 1 year were excluded. The age groups used were age 1-4 years, quinquennial to 35-39, decennial to 60-69, and 70 up, with summary

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data in four broad age groups. Because Cerebral Palsy is a congenital or perinatal condition (present at birth), mortality results by attained age are equivalent to mortality by lifetime duration, as is true of other conditions such as congenital heart disease or cystic fibrosis.

#### Follow-up

Enumeration in the registry was carried out on July 1, the mid-point of each observation year. A registrant was considered to be at risk in a given year if he or she had at least one CDER in the previous three years, and either died or had at least one CDER in the following three years. This method of counting yielded a total exposure (E) of 367,106 patient-years, an average observation period of 9.6 years. There were 4,885 total deaths observed. As noted above, death records of the California Bureau of Vital Statistics were utilized as well as the CDER death notices.

#### Expected Mortality

Demographic characteristics for the 38,044 Cerebral Palsy patients observed during calendar years 1980 through 1996 are shown in Table 1. As with the general registry population, the Cerebral Palsy group was a predominantly young population, with 53% under age 20, and only 6.5% age 50 and older. The Cerebral Palsy patients were 55% male, and fewer than 54% were white (Hispanic classified as nonwhite). They were nearly equally divided by the severity feature of all four limbs involved (quadriplegia), or fewer than four limbs (non-quadriplegia). This was found to be a more useful feature for distinguishing the group than the severity of motor dysfunction, by which about one third were classified as moderate and one third severe. The most severely disabled patients were the 8.4% who required tube feeding. Nearly one quarter of the patients had no mental retardation, and about 20% had only mild retardation.

These characteristics may be compared with similar ones found in the entire registry population as observed 1986-91 and previously reported.<sup>3,4</sup> Age and sex distribution were similar, but the Cerebral Palsy cases had more with normal intelligence, and at the same time a higher percentage of severe or profound mental retardation. It is likely that there was a statistical association between severe mental and severe physical disability, although some severely disabled Cerebral Palsy patients may have a normal or superior intelligence. Fully 18% of the registry patients were unable to walk at all, but only 2.1% required tube feeding.

#### Expected Mortality

The 1992 U.S. Abridged Life Tables were used to provide mortality rates for the total male and the total female population. A matching  $q'$  rate was found for the central age of each age group. When age groups were combined, expected deaths ( $d'$ ) were calculated as the product of exposure and expected mortality rate:  $d' = (q')(E)$ . The  $d'$  values were then added and the total  $d'$  divided by the total exposure to obtain an aggregate mean annual  $q'$  for the combined age group.

As discussed in this section of the previous Mortality Abstract,<sup>4</sup> the skewed age distribution in this registry results in a major bias for the difference between mean age and the tabular age corresponding to the mean  $q'$  for all ages combined, calculated as just described above. For all male Cerebral Palsy patients the mean age is about 19 years and the tabular age corresponding to the mean  $q'$  of 2.1 per 1000 is 31 years; for the female patients the corresponding ages are 20 and 37 years respectively. These wide disparities are due to concentration of cases at the younger ages, with a long tail in the distribution curve extending to the oldest ages. Attention is focused on the age-specific rates in this Abstract, so there is no need to emphasize comparative mortality for all ages combined, as shown in Table 5. However, if only mean ages were available with no age distribution,  $q'$  and  $d'$  would have been much lower. Mortality ratios would have been greatly overestimated, but the effect on EDR would have been much smaller. The issue is raised here to illustrate the potential error of employing mean age to estimate expected mortality, especially when the age distribution is skewed so markedly, as it is in these patients.

#### Results

Age-related comparative mortality is given for the quadriplegic patients in Table 2 (male) and Table 3 (female). MR values are extremely high up to age 15, and EDRs exceed or are close to 20 per 1000. As would be expected from the lower female expected mortality rates, the MRs are consistently higher in females than in males at the same age. There is little difference in EDR between the sexes. From age 15 to age 50 the MR decreases steadily, and EDR decreases to nearly constant level of about 10 per 1000, in both sexes. In the three oldest age groups, above age 49, EDR tends to increase with advancing age, and the highest EDR, 50 per 1000, is seen in women age 70 and older. MR decrease at a slower pace, with a minimum of about 200% in the oldest age group. Even when EDR is at a minimum, about ages 25 to 49, excess mortality remains at a very

high level, and MR values would be much higher against select mortality instead of population mortality for the expected rates.

Excess mortality is relatively more favorable in the less severe, non-quadruplegic cases (Tables 4 and 5), with a minimum EDR level of about 5 per 1000 in the age range 25-49 years. The age trend is similar to that observed in the more severe cases: highest MR and high EDR under age 15, then a decrease in young adults to a constant EDR while the MR continues to decrease, followed by an increase in EDR at ages 50 and up. The maximum EDR of 32 per 1000 is again in female patients, but in the next to oldest age group, 50-69 years. The minimum MR is about 150% in patients age 70 years and older. This degree of excess mortality is potentially insurable in adults, but it should again be emphasized that MR values would be much higher against insurance select standard mortality rates.

All of these detailed results are summarized in a single Table 6 by condensing them into four broad age groups. Overall results, all ages combined, are also shown. MR values are higher in females than males, but EDR is virtually the same: overall about 6 per 100 in the less severe cases, and about 16 per 1000 in the quadruplegic patients.

### Comment

Although the coding list used by insurance companies for medical conditions now contains a code for Cerebral Palsy, this was not in use in the 1952-1976 experience reported in the inter-company 1983 Medical Impairment Study. A recent statistical report shows a low incidence of only 0.7 per 1000 codes. If Cerebral Palsy is included in the next inter-company Impairment Study, I am not sure if the numbers would be sufficient to permit a meaningful study broken down by sex, age and duration. Hence these results are of importance in devising better underwriting standards for Cerebral Palsy. It is important to realize that much of the excess mortality in

this experience is probably due to severe degrees of physical disability (39.3% of the cerebral palsy patients were unable to walk). It would seem reasonable to accept otherwise normal adults with Cerebral Palsy if they are walking and working, even if they are "quadruplegic." It should be emphasized that the use of this term here has very different implications from the quadriplegia of spinal cord injury, which almost always means total physical disability. In our opinion the best cases with minimal spasticity might be eligible for a low rating or even standard insurance.

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**Table 1**

Demographic and Other Data for 38,044 Cerebral Palsy Patients\* Observed 1980-1996  
in the Registry of the California Department of the Developmentally Disabled

Demographic Factor		Percent	Medical Factor	Percent
<b>Age</b>	1- 9 years+	19.4	<b>Ability to Walk</b>	
	10-19	25.2	Walks easily 20+ feet	35.3
	20-29	20.6	Walking very difficult	12.0
	30-39	17.0	Only with assistance	13.4
	40-49	10.6	Cannot walk 39.3	
	50-59	4.1		
	60-69	2.1	<b>Level of Motor Dysfunction</b>	
	70-79	0.8	Mild	20.5
80 up	0.2	Moderate	32.6	
			Severe	37.2
<b>Sex</b>	Male	54.9	Not specified	9.7
	Female	45.1		
<b>Race</b>	White	56.3	<b>Level of Mental Retardation</b>	
	Hispanic	9.0	None	20.8
	Black	23.0	Mild	20.5
	Other	11.7	Moderate	14.4
			Severe	14.6
		Profound	26.9	
		Not specified	3.0	
<b>Medical Factor</b>			<b>Tube Feeding Required</b>	7.6
Quadriplegic	49.9			
Non-quadriplegic	50.1			

\*Approximately 20% of total registrants, 1980-1996, including infants under 1 year.  
+Infants under 1 year of age were excluded from the cerebral palsy cohort.

**Table 2**

Comparative Mortality of Male Cerebral Palsy Patients with Quadriplegia,  
California Registry of the Developmentally Disabled, 1980-1996

Attained Age (years)	Exposure Patient-Yrs. E	No. of Deaths		Mortality Ratio 100d/d'	Mean Annual Mortality Rate per 1000		
		Observed d	Expected* d'		Observed q	Expected q'	Excess (q-q')
1-4**	14,541	311	6.87	4,500%	21.4	0.5	20.9
5-9	16,071	326	3.84	8,500	20.3	0.2	20.0
10-14	12,361	266	9.52	2,800	21.5	0.8	20.8
15-19	11,662	220	14.23	1,550	18.9	1.2	17.7
20-24	12,113	190	19.31	985	15.7	1.6	14.1
25-29	10,847	129	19.30	670	11.9	1.8	10.1
30-34	9,116	127	20.45	620	13.9	2.2	11.7
35-39	6,693	87	19.08	455	13.0	2.8	10.2
40-49	7,183	110	29.23	375	15.3	4.1	11.2
50-59	2,728	77	24.56	315	28.2	9.0	19.2
60-69	1,010	46	21.27	210	46	22	24
70 up	290	23	12.64	182	79	44	35

\*Basis of expected deaths: 1992 U.S. Life Tables for the total male population.

\*\*Infants under age 1 year excluded.

**Table 3**

Comparative Mortality of Female Patients with Cerebral Palsy, with Quadriplegia,  
California Registry of the Developmentally Disabled, 1980-1996

Attained Age (years)	Exposure Patient-Yrs. E	No. of Deaths		Mortality Ratio 100d/d'	Mean Annual Mortality Rate per 1000		
		Observed d	Expected* d'		Observed q	Expected q'	Excess (q-q')
1-4**	11,253	274	4.34	6,300%	24.4	0.4	24.0
5-9	12,963	265	2.17	12,200	20.4	0.2	20.2
10-14	10,680	201	1.92	10,500	18.8	0.2	18.6
15-19	9,928	187	4.36	4,300	18.8	0.4	18.4
20-24	10,211	144	5.12	2,800	14.1	0.5	13.6
25-29	9,008	111	5.63	1,970	12.3	0.6	11.7
30-34	7,707	93	6.45	1,440	12.1	0.8	11.3
35-39	5,832	80	6.89	1,160	13.7	1.2	12.5
40-49	6,316	77	12.61	610	12.2	2.0	10.2
50-59	2,471	49	13.00	375	19.8	5.3	14.5
60-69	1,250	37	15.64	235	29.6	12.5	17.1
70 up	417	31	16.13	230	89	39	50

\*Basis of expected deaths: 1992 U.S. Life Tables for the total female population.

\*\*Infants under 1 year of age excluded.

**Table 4**

Comparative Mortality of Male Patients with Non-quadriplegic Cerebral Palsy,  
California Registry of the Developmentally Disabled, 1980-1996

Attained Age (years)	Exposure Patient-Yrs. E	No. of Deaths		Mortality Ratio 100d/d'	Mean Annual Mortality Rate per 1000		
		Observed d	Expected* d'		Observed q	Expected q'	Excess (q-q')
1-4**	12,558	107	5.93	1,800%	8.5	0.5	8.0
5-9	14,285	93	3.41	2,700	6.5	0.2	6.3
10-14	10,742	73	8.27	885	6.8	0.8	6.0
15-19	9,634	70	11.76	595	7.3	1.2	6.1
20-24	11,232	62	17.90	345	5.5	1.6	3.9
25-29	10,133	69	18.03	385	6.8	1.8	5.0
30-34	8,472	66	19.01	345	7.8	2.2	5.6
35-39	6,490	44	18.50	240	6.8	2.9	3.9
40-49	7,366	70	30.13	230	9.5	4.1	5.4
50-59	3,046	58	27.29	215	19.0	9.0	10.0
60-69	1,282	56	27.78	200	44	22	22
70 up	354	28	18.19	154	79	51	28

\*Basis of expected deaths: 1992 U.S. Life Tables for the total male population.

\*\*Infants under 1 year excluded.

**Table 5**

Comparative Mortality of Female Patients with Non-quadriplegic Cerebral Palsy,  
California Registry of the Developmentally Disabled, 1980-1996

Attained Age (years)	Exposure Patient-Yrs. E	No. of Deaths		Mortality Ratio 100d/d'	Mean Annual Mortality Rate per 1000		
		Observed d	Expected* d'		Observed q	Expected q'	Excess (q-q')
1-4**	10,084	93	3.89	2,400%	9.2	0.4	8.8
5-9	10,801	83	1.81	4,600	7.7	0.2	7.5
10-14	8,313	58	1.50	3,900	7.0	0.2	6.8
15-19	8,014	41	3.52	1,160	5.1	0.4	4.7
20-24	9,136	63	4.58	1,380	6.9	0.5	6.4
25-29	8,166	35	5.10	685	4.3	0.6	3.7
30-34	7,322	38	6.13	620	5.2	0.8	4.4
35-39	5,928	35	7.01	500	5.9	1.2	4.7
40-49	6,493	54	12.98	260	5.2	2.0	3.2
50-59	2,731	34	14.17	240	12.4	5.2	7.2
60-69	1,312	58	16.40	355	44	12	32
70 up	611	34	23.90	142	56	39	17

\*Basis of expected deaths: 1992 U.S. Life Tables for the total female population.

\*\*Infants under 1 year excluded.

Table 6

Summary Table of Comparative Mortality of Patients with Cerebral Palsy  
by Age, Sex and Presence or Absence of Quadriplegia,  
California Registry of the Developmentally Disabled, 1980-1996

Attained Age (years)	Exposure Patient-Yrs. E	No. of Deaths		Mortality Ratio 100d/d'	Mean Annual Mortality Rate per 1000		
		Observed d	Expected* d'		Observed q	Expected q'	Excess (q-q')
<b>Male Quadriplegic Patients</b>							
1-14**	42,973	903	20.23	4,500%	21.0	0.5	20.5
15-34	43,738	666	73.28	910	15.2	1.7	13.5
35-54	15,504	242	60.14	400	15.6	3.9	11.7
55 up	2,400	101	49.11	205	42.1	20.5	21.6
All ages	104,615	1,912	202.76	945	18.3	1.9	16.4
<b>Female Quadriplegic Patients</b>							
1-14**	34,896	740	8.43	8,800%	21.2	0.2	21.0
15-34	36,854	535	21.56	2,500	14.5	0.6	13.9
35-54	13,544	184	25.31	725	13.6	1.9	11.7
55 up	2,742	90	38.96	230	32.8	14.2	18.6
All ages	88,036	1,549	94.26	1,640	17.6	1.1	16.5
<b>Male Non-quadriplegic Patients</b>							
1-14**	37,585	273	17.62	1,550%	7.3	0.5	6.8
15-34	39,471	267	66.69	400	6.8	1.7	5.1
35-54	15,625	143	61.48	235	9.2	3.9	9.3
55 up	2,883	113	60.40	187	39.2	21.0	18.2
All ages	95,564	796	206.18	385	8.3	2.2	6.1
<b>Female Non-quadriplegic Patients</b>							
1-14**	29,198	234	7.20	3,300%	8.0	0.2	7.8
15-34	32,638	177	19.33	915	5.4	0.6	4.8
35-54	14,041	101	26.72	380	7.2	1.9	5.3
55 up	3,014	116	46.04	250	38.5	15.3	23.2
All ages	78,891	628	99.29	635	8.0	1.3	6.7

\*Basis of expected deaths: 1992 U.S. Life Tables for the total male or female population.

\*\*Infants under age 1 year excluded.