Life expectancy of adults with cerebral palsy

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To determine the predictors of mortality and find the life expectancies of adults with cerebral palsy (CP), data on 24 768 individuals aged 15 years and over who received services in California between January 1980 and December 1995 were analyzed. Multivariate statistical methods to identify mortality predictors, and actuarial methods to determine corresponding life expectancies were used. The key predictors were lack of basic functional skills: mobility and feeding. Adults lacking these skills had much reduced life expectancies, as short as 11 years for the worst functioning groups. By contrast, survival of high-functioning adults was close to that of the general population. The influence on survival of cognitive skills, type of CP, and other factors appears to be expressed largely through their effect on basic functioning. Life expectancies of adults of a given age can differ by 40 years or more, according to their functional level.

Data on life expectancy and mortality in people with cerebral palsy (CP) can be valuable for physicians who counsel patients and their families, for planning school and employment, and for medicolegal purposes. There is a substantial coverage of the topic in the literature on spinal-cord injury (Geisler et al. 1977, 1983; Whiteneck et al. 1992; Samsa et al. 1993; DeVivo and Ivie 1995; Hartkopp et al. 1997) and on Down syndrome (e.g. Baird and Sadovnick 1987, Strauss and Eyman 1996). Mortality studies in CP, however, are comparatively few and have for the most part followed cohorts of infants (Evans et al. 1990, Hutton et al. 1994, Crichton et al. 1995, Strauss et al. 1998a).

The present investigation focuses on life expectancy of adults with CP. Numerous studies of populations with various disabilities have shown life expectancy to be strongly affected by mobility and other functional skills (Evans et al. 1990; Eyman et al. 1990, 1993; Hutton et al. 1994; Strauss et al. 1998b). It is therefore necessary to stratify on the basis of functional level. The findings of the pediatric CP studies noted above do not apply directly to adults because of change in functioning over time. For example, adolescents who lack mobility have a poorer prognosis than the adolescent survivors of a cohort of immobile infants, because many of the latter acquire mobility by adolescence. For this reason the prognosis for survival of adults requires separate consideration.

Analyses sensitive enough to take account of many levels of functioning and other factors require very large samples. The present study used the California Developmental Disabilities database, which contains longitudinal information from 1980 on the 43 859 people with CP who received services such as medical treatment, occupational or physical therapy, and board and care from the state. This included 24 768 people aged 15 years or over. The database is believed to include nearly all people in the state with severe CP, as such people have extensive need of medical and other services; in nearly all cases they or their families would avail themselves of the services provided by the state and thus be in the register. Presumably, however, many people with mild disability would not be included. We will return to this issue later.

The primary questions we wished to address were: (1) How likely is change in function after early childhood, and does the possibility of change affect the prognosis for survival? (2) What are the chief factors influencing life expectancy in adults with CP? (3) What are the life expectancies for various ages and profiles of functioning? How do these compare with the general population?

Method

Our base population was composed of the 182 623 people with developmental disability who received services from the State of California between January 1980 and December 1995. All such people are evaluated approximately annually, using the Client Development Evaluation Report (California Department of Developmental Services 1986). This instrument contains some 200 psychological, medical, functional, behavioral, and cognitive items. It is administered by the social worker, information being provided by the caregiver most familiar with the client. For clients living at home, for example, this would be a family member. The reliability of the functional items has been assessed previously and judged to be satisfactory (Harris et al. 1982, Arias et al. 1983,

Widaman 1984, Widaman et al. 1985). Interrater reliabilities (Agresti 1990) of the motoric and feeding variables used in this study exceeded 0.85.

CP was assessed by an evaluation team contracted by the California Department of Developmental Services as part of an initial work-up for receiving services. The composition of the team varies from region to region, members being pediatricians, developmental neurologists, or occupational or physical therapists.

We used three CDER items to identify subjects with CP. These were severity, type, and location of CP; see below for definitions. We defined a CDER evaluation as being one of CP if all three items indicated the presence of CP. All three inter-item reliabilities exceeded 0.99.

Mortality information was obtained from the California Department of Health Services.

We worked with data on all people aged 15 or over with an evaluation of CP. This resulted in a sample of 24 768 people. Coded etiologic information according to the International Classification of Diseases (ICD-9 1995) was given in the CDER for some people, although its reliability is not known. Numbers of cases were: infections (ICD-9 codes 000 to 139), $N=191$; circulatory disorders (390 to 459), $N=132$; congenital anomalies (740 to 759), $N=543$; ill-defined (799), $N=4325$; injuries/poisonings (800 to 999), $N=793$; other etiologic codes, $N=4408$; no code specified, $N=14376$.

Because CP is generally considered a congenital or perinatal condition we excluded 973 people listed as having suffered a major accident, such as near-drowning or motor-vehicle related, as determined from the 'special conditions' section of the CDER. This left a sample of 23 795 people. Of these, 2600 died in California during the 1980 to 1995 study period. Subjects were considered 'at risk' for the purpose of the study from the date of the first CDER evaluation indicating CP until the earliest of: date of death; the end of the study period (December 31 1995); or 3 years after the date of their last CDER evaluation. This last condition was included to minimize the potential bias due to subjects who left California. Deaths of such people would not appear in our records, but because of the third condition these subjects would also not be counted as being at risk for more than a fairly short period. (We note that such migration is generally believed to be uncommon, because California is the only state in the USA that provides services to people with developmental disability as an entitlement.)

Table I shows some of the major variables considered in the study. Each 'hazard ratio' (Collett 1994, p 54) compares the mortality rate for a given subgroup with that of a comparison, or reference group. For example, the Table indicates that males had a mortality risk 11% higher than females. These 'simple' hazard ratios make no adjustment for other variables (see Statistical Analysis), and are provided for descriptive purposes only.

Lack of mobility was strongly associated with risk, people unable to lift their heads being at 5.9 times the risk of those who could roll or sit. Similarly, complete inability to walk was a major risk factor. The 678 subjects who were tube-fed had 8.2 times the risk of those with some self-feeding skills. By contrast, type, severity, and location of CP appeared to have a much smaller effect on survival. The Table also shows some of the 18 CDER cognitive items, such as receptive non-verbal communication. Subjects lacking these skills were at higher risk.

As noted previously, the sample is weighted towards the more severely involved subjects. The Table shows, for example, a higher proportion of people with quadriplegia and a lower proportion with hemiplegia than many studies. This underscores the need to take account of functional level when making comparisons.

STATISTICAL ANALYSIS

We constructed prognostic charts to track the change in subjects' level of functioning over time. These charts give the probability of a subject in a given initial condition being in any given condition after a specified number of years. Figure 1, for example, tracks subjects aged 5 who were at that time able to roll over but could not sit unaided. Initially, therefore, 100% of the subjects were in that condition. Figure 1 also shows the fraction who died, regressed, stayed in the same condition, or improved over the next 15 years. The method is an extension of the usual Kaplan–Meier estimator of survival probability (Collett 1994). Technical details are given elsewhere (Strauss and Shavelle, forthcoming).

The Cox proportional hazards survival model (Collett 1994) was used for initial screening of risk factors and for combining categories. Briefly, this model estimates the effect of each factor on mortality risk, other factors held constant, on the assumption that relative risks stay constant over time. The adjustment for effects of other factors permits identification of factors having the most influence on survival. The large sample size enabled us to use a stringent 0.01 significance level for retaining risk factors. Each CDER functional item, which originally had between four and nine levels, was collapsed when adjacent levels were not associated with significantly different mortality risks. Survival time was measured from the date of first evaluation indicating CP. Tests for significant risk factors, their possible interactions, and the proportional hazards assumption were based on likelihood ratio tests (McCullagh and Nelder 1989) for nested factors and the Akaike Information Criterion (Collett 1994) otherwise. We tested whether there was a secular trend (a systematic change in mortality risks over time, other factors being equal) by including linear and other terms based on the year of entry into the study, and also by the creation of variables indicating whether the subject entered the study during the early, middle, or late portion of the 16-year period.

The best predictive factors were used to classify the subjects into cohorts. Subsequent survival prognosis for each cohort was computed from a Cox model, using standard methods (Collett 1994). Where the hazards for different cohorts over time were not proportional, separate models were fitted. For example, the hazards for groups that were fed by gastrostomy tube were initially greater and then declined over time, compared with the other groups. (This may reflect the serious but sometimes temporary medical conditions that indicate the use of gastrostomy feeding.) Median survival times were reported when these were less than the 16-year study period. All computations were carried out in SAS (Stastical Analysis Software 1990), with S-PLUS (Statistical Sciences 1990) used for graphics. Estimation of a survival curve for a child with a specific profile of risk factors was based on standard procedures for the Cox model (Collett 1994).

Life expectancies were computed for people of a given age, gender, and cohort by estimating the relative risk (the ratio of the mortality risk based on the survival analysis and

Table I: Characteristics and associated hazard ratios of people with CP aged ≥15 years (total: 23 795 subjects, 2600 deaths)

	Subjects N (%)	*Nr of deaths*	*Hazard ratio*[c]
Age at first CP evaluation (y)			
0–14[d]	25560	2738	
15–24	14827 (62)	1329	[1.00]
25–34	14904 (21)	516	0.9[a]
35–44	2204 (9)	275	1.2[b]
45–54	1097 (5)	200	1.9[b]
55–64	536 (2)	173	3.8[b]
≥ 65	227 (1)	107	7.9[b]
Sex			
Male	12750 (54)	1461	1.11[b]
Female	11045 (46)	1139	[1.00]
Rolling-and-sitting[e]			
Cannot lift head	1396 (6)	546	5.9[b]
Lifts head, no rolling	1608 (7)	429	3.4[b]
At least partial rolling	20791 (87)	1625	[1.00]
Hand use[f]			
No functional use	2329 (10)	730	3.9[b]
Some functional use	21466 (90)	1870	[1.00]
Ambulation			
Does not walk	8334 (35)	1630	4.0[b]
Walks with support	3076 (13)	279	1.9[b]
Walks unsteadily alone at least 10 ft	3155 (13)	226	1.4[b]
Walks well alone at least 20 ft	9230 (39)	465	[1.00]
Feeding			
Tube fed	678 (3)	250	8.2[b]
Fed by others, no feeding tube	4027 (17)	991	3.5[b]
At least some self-feeding skill	19090 (80)	1359	[1.00]
Severity of CP			
Mild	5876 (25)	367	[1.00]
Moderate	7502 (32)	558	1.2[b]
Severe	8093 (34)	1347	2.9[b]
Unspecified	2324 (10)	328	2.1[b]
Location of CP			
Monoplegia	560 (2)	47	1.3
Hemiplegia	4163 (17)	269	[1.00]
Diplegia	2365 (10)	157	1.1
Triplegia	419 (2)	50	1.7[b]
Paraplegia	1727 (7)	182	1.5[b]
Quadriplegia	11595 (49)	1654	2.1[b]
Unspecified	2966 (12)	241	1.3[b]
Type of dysfunction			
Spasticity	12257 (52)	1444	1.4[b]
Ataxia	2938 (12)	277	[1.00]
Dyskinesis	1846 (8)	193	1.1
Hypotonia	1747 (7)	200	1.4[b]
Other	5007 (21)	486	1.1[a]
Severity of mental retardation[g]			
Mild	4725 (20)	263	[1.00]
Moderate	3667 (15)	262	1.1
Severe	3534 (15)	360	1.6[b]
Profound	6939 (29)	1388	2.9[b]
Unspecified/None	4930 (21)	327	1.2
Year of first CP evaluation			
1980–85	13948 (59)	1959	[1.00]
1986–90	5379 (23)	504	1.2[b]
1991–95	4468 (19)	137	1.2
Word usage			
No use of words	8266 (35)	1506	2.8[b]
Simple one-syllable words	4650 (20)	398	1.3[b]
Complex words, associates with objects, but limited vocubulary	5446 (23)	363	1.1
Broad vocabulary, appropriate use	5433 (23)	333	[1.00]

that of the general population) and modeling it over the subsequent lifetime. We have found (Strauss and Shavelle 1997) that the logarithm of the relative risk declines approximately linearly until parity is reached at age 90 years. This approach, with a declining relative risk, was shown to be preferable to that of extrapolating based on a constant excess risk (Singer 1992). The distinction between life expectancy and median survival time is discussed elsewhere (Eyman et al. 1996). We then modified the standard life tables for the USA (Schoen 1988) using these modified age-, gender-, and cohort-specific mortality rates in place of those for the general population. The modified rates were computed from a Cox model for each age group.

The entire procedure was carried out separately for the non-overlapping groups of subjects at ages 15, 30, and 45. The groups were not combined into a single analysis because the patterns of mortality over the subsequent 15 years are different for each age group, contradicting the proportional

Table I: (continued)

	Subjects N (%)	*Nr of deaths*	*Hazard ratio*[c]
Expressive non-verbal communication			
None	4551 (19)	866	3.1[b]
Expresses by squirming, returning smiles, etc.	4782 (20)	750	2.6[b]
Communicates by pointing, shaking head, etc.	4954 (21)	401	1.3[b]
Gestures with hands, uses facial expressions for communication	9508 (40)	583	[1.00]
Epilepsy[h]			
None	4762 (55)	209	[1.00]
Partial	446 (5)	19	1.0
General	1714 (20)	152	2.0[b]
Undetermined	1801 (21)	144	1.8[b]
Receptive non-verbal communication			
Does not demonstrate understanding of gestures/ facial expressions	5873 (25)	1140	3.3[b]
Understands simple gestures ('yes', 'no', pointing)	6731 (28)	735	1.7[b]
Understands complex gestures	3666 (15)	255	1.2[a]
Demonstrates understanding of a series of gestures	7525 (32)	470	[1.00]

[a] Significantly greater than 1.00 at $P < 0.05$

[b] Significantly greater than 1.00 at $P < 0.01$

[c] Ratio of mortality risk for each category relative to the referent category, which has hazard ratio of 1.00 by convention. Hazards set to 1.00 by convention indicated by square brackets. Hazard ratios based on a Cox survival analysis, with no other factors taken into account

[d] Children aged < 15 y not included in the main part of this study; information for reference only. Some of the 25 560 children reached age 15 y during the study period, and thus contributed information from that time. Such people are included in the 23 795 adults in the sample

[e] Condensed from the 9-point CDER scale

[f] Condensed from the 4-point CDER scale

[g] Categories for severity of retardation are as in Grossman (1983).

[h] Epilepsy information only recorded after 1987, so data available on 8723 people instead of the full sample of 23795.

hazards assumption (Collett 1994). Thus the life expectancies at these ages should not be regarded as part of a single (abridged) life table. Instead, we computed a separate life table for each age, gender, and cohort, each table contributing a single remaining life expectancy for the specific age, gender, and cohort. We computed 95% confidence intervals for each life expectancy using the corresponding model-based 95% confidence interval for the hazard (mortality rate). To indicate the precision of the estimates, we have reported the half-ranges of these intervals here.

Results

CHANGES IN FUNCTION AFTER EARLY CHILDHOOD

Figure 1 shows a prognostic chart for survival and change in level of function. It tracks people who at the age of 5 years were able to roll over but could not sit unaided. The Figure shows, for example, that 10 years later 28% of the cohort will have acquired some sitting ability, 43% will be at the same level, 12% will have regressed, and the remaining 17% will have died. Thus there may be a difference in mortality risk between (a) 15-year-old subjects able to roll but not sit unaided, and (b) those in the cohort of 5 year olds who survived 10 years initially in that condition. We found from separate survival analyses (not shown here) that in fact the 5-year mortality probability is 6.2% for (a), compared with 9.1% for (b), the latter being nearly 50% larger than the former. This demonstrates that prognosis for adults in a given condition may not be reliably deduced from a follow-up of a group of children originally in that condition. Instead, a group of people of the appropriate age and condition should be identified and followed.

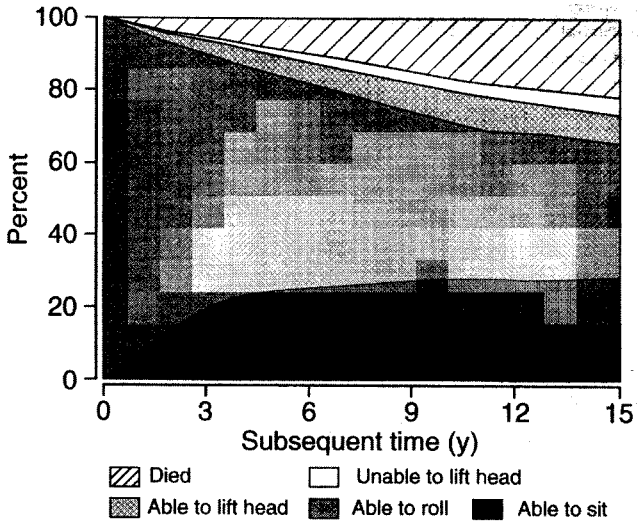

Figure 1: *Prognostic chart for people aged 5 years who initially could roll over but not sit unaided. Thus at time 0, 100% of subjects are in that condition. Ten years later, for example, 28% will have acquired some sitting ability* (darkest shaded region), *43% will be in the same condition, 12% will have regressed, and 17% will have died* (cross-hatched region).

CHIEF FACTORS INFLUENCING LIFE EXPECTANCY

Table II shows proportional hazards models for the non-overlapping groups of subjects at ages 15, 30, and 45 years. The Table shows only those risk factors that contributed significantly to the prediction of mortality for at least one of the groups. These were primarily functional skills in mobility, feeding, and toileting.

Table II also shows the increase in mortality risk for each factor, relative to a suitable referent group, other factors held constant. Thus the first row indicates that 15-year-old subjects unable to lift their heads were at 2.29 times greater risk than those in the referent group (those able to roll). This means a 2.29 times greater probability of dying in any short interval of time. At age 15, those able to lift their head but not roll were at 1.77 times the risk of the referent group. The relation between rolling/sitting and mortality was statistically significant in all three age groups. For this risk factor and most others, however, the strength of association was smaller in the older age groups. This probably reflects the increasing importance with age of the 'usual' risk factors, such as cardiovascular disease and cancer.

At the age of 15 years, the need for tube feeding was associated with a roughly five-fold risk, compared with the referent group (those with some self-feeding skills, if only with fingers). Being fed by others, but without requiring gastrostomy feeding, was associated with a two-fold increase. These results are consistent with studies of other groups with developmental disabilities (Eyman et al. 1993, Strauss and Kastner 1996, Strauss et al. 1996).

There was an effect of gender, males typically being at about 20% higher risk than females. This difference, though significant, is in fact much smaller than the corresponding difference in the general population (Keyfitz 1985).

A number of factors that may have been expected to be important predictors are absent from Table II. This means that they did not contribute significantly to mortality prediction when the other factors (primarily functional level) were taken into account. Although many of the non-contributing factors are associated with mortality (Table I), their effect appears to be largely expressed through their influence on functional skills.

Factors that did not contribute substantially to the prediction of mortality included etiology of CP, as given by ICD-9 codes; location of motor dysfunction (quadriplegia, diplegia, paraplegia, hemiplegia, etc.); epilepsy – type and frequency of seizure disorder; severity of mental retardation (except for a contrast of profound mental retardation with all other levels, which at age 15 was associated with a significant 32% increase in mortality); cognitive and communication skills; and secular trend. There was no evidence of a change in risk-adjusted mortality rates during the study period.

On the basis of the data shown in Table II, inspection of individual survival curves, and analyses of corresponding results for other age groups, we stratified the subjects into nine cohorts for analysis of subsequent survival and life expectancy. These were combinations of three levels of mobility (cannot lift head/lifts head/at least partial rolling) with three levels of feeding (tube fed/fed by others but without tube/some self-feeding skills). The cohort of subjects unable to lift their heads but able to feed themselves, was (understandably) very small and was excluded from consideration; this left eight groups for the study.

Figure 2 shows survival curves for the eight cohorts at age 15. The figure shows the relatively poor prognosis for the lower-functioning groups; for example, the median survival time for subjects initially fed by gastrostomy tube and unable to lift their heads was only 7.8 additional years. The corresponding figure for those fed by others and unable to lift their heads was 11.3 years. By contrast, 94% of those able to roll or sit and feed themselves survived the next 15 years.

LIFE EXPECTANCIES FOR VARIOUS AGES AND PROFILES OF FUNCTIONING

Tables III and IV give the remaining life expectancies for the eight groups at ages 15, 30, and 45 years, together with the corresponding results for the general population. Again, the low-functioning groups have greatly reduced life expectancies. On the other hand, life expectancies for people able to self-feed and to roll or sit, were at most 12 years lower than those of the general population. To indicate the precision of these estimates, we also show one-half of the width of the 95% confidence intervals (Table IV). The widest intervals, corresponding to the estimates with the lowest precision, are generally those of people who are tube fed and/or in the oldest age-group; this reflects the smaller sample sizes available. For the other groups, the half-ranges were at most 7 years.

Finally, we extracted an additional, highest-functioning, subgroup with full sitting, ambulatory, and feeding skills according to the CDER. There were a total of 4506 such people aged 15, 30, or 45. On average, their life expectancy was reduced by only 5 years compared with the general population.

Discussion

We identified significant predictors of mortality among adults with CP, based on records of the 24 768 such people

Table II: Proportional hazards models for mortality predictors

Variable	*Hazard ratio[a] (95% CI)*		
	Age 15y, N=10399	*Age 30y, N=8908*	*Age 45y, N=3477*
Cannot lift head[b]	2.29 (1.85, 2.85)	2.21 (1.69, 2.89)	1.56 (0.97, 2.52)
Lifts head	1.77 (1.45, 2.17)	1.56 (1.22, 2.00)	1.60 (1.05, 2.44)
Some hand use[c]	1.36 (1.13, 1.63)	1.17 (0.92, 1.50)	1.13 (0.73, 1.75)
Tube fed[d]	4.72 (3.40, 6.56)	3.83 (2.42, 6.06)	1.82 (0.66, 5.03)
Fed by others	2.10 (1.71, 2.60)	1.17 (0.92, 1.49)	1.32 (0.89, 1.94)
Male	1.23 (1.08, 1.39)	1.18 (1.01, 1.38)	1.25 (0.98, 1.60)
No toilet skills[e]	2.91 (2.11, 4.00)	3.54 (2.58, 4.86)	2.04 (1.29, 3.20)
Habit trained	1.72 (1.27, 2.32)	2.48 (1.93, 3.18)	1.49 (1.08, 2.05)
Hypotonia[f]	1.44 (1.17, 1.77)	1.28 (0.95, 1.73)	1.46 (0.91, 2.34)
Profound mental retardation[g]	1.32 (1.12, 1.56)	0.86 (0.70, 1.06)	0.87 (0.63, 1.19)

[a] Mortality risk, compared with referent group, other factors held constant; e.g. in any short time interval, other things being equal, males age 15 were 1.23 times more likely to die than females.
[b] Referent group is people with at least partial rolling ability.
[c] Referent group is people with no functional use of hand.
[d] People with gastrostomy tubes; referent group is people with some self-feeding skills.
[e] Referent group is people who can indicate need to toilet self, or better.
[f] Referent group is people with other types of CP.
[g] Referent group is people with other levels of mental retardation.

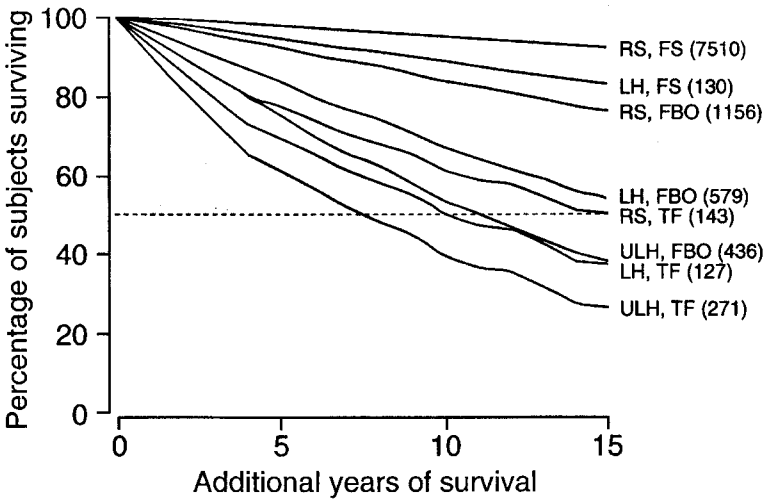

Figure 2: *Survival curves after age 15 years for eight groups defined by level of functional skill. The curves show the proportion of the group surviving a given number of years. Median survival times were: tube fed and unable to lift head, 7.8 additional years; tube fed, lifts head but does not roll, 10.1 years; fed by others, does not lift head, 11.3 years; tube fed, rolls or sits, 14.7 years. Other groups: median survival time exceeded the 16-year study period.*
ULH, unable to lift head when lying on stomach; LH, able to lift head, but not able to roll; RS, able to roll or sit; TF, tube fed; FBO, fed by others, but not tube fed; FS, feeds self, if only with fingers.

who received services in California between 1980 and 1995. The most important risk factors were deficits in functional skills such as mobility and feeding. At age 15, for example, people requiring feeding by gastrostomy tube were subject to 4.7 times the mortality risk of those able to feed themselves, other factors equal. Mortality risks for 15 year olds lacking the ability to lift their heads when lying on their stomach were more than double those of 15 year olds able to sit independently. These results are consistent with studies of infants with CP (Evans et al. 1990, Hutton et al. 1994, Crichton et al. 1995). A previous study of adult mortality (Eyman et al. 1988) had shown the absence of toileting skill to be a mortality predictor. Although the causal link between poor mobility and respiratory problems is well known, no doubt the functional limitations are also serve to some extent as markers for other medical conditions that are themselves risk factors.

A number of risk factors previously reported in the literature proved not to contribute significantly when functional level was taken into account. These included lack of cognitive skills and the type, location, and etiology of CP. Etiology of CP is notoriously difficult to determine and this might account for its apparent lack of predictive power. Further, we recognize that type and severity of CP is largely determined from observations on functional limitations. Our finding was that data on simple functional items contains most of the information on risk. For example, while people with quadriplegia were at about twice the mortality risk of people with hemiplegia when no adjustment was made for functional data (Table I), there was no significant difference between the two after such adjustment was made.

Life expectancies, as opposed to median survival times, for people with CP appear not to have been reported previously. Life expectancies for the highest functioning group, with full motor and feeding abilities, were on average only 5 years less than those for the general population. This optimistic prognosis is consistent with those reported previously by Evans et al. (1990). The much poorer prognosis for people with minimal functioning has not previously been reported, however, perhaps because of limitations in sample size and variables available in previous studies.

The issue of generalizability deserves comment. As noted previously, our sample is believed to include nearly all residents of California with severe CP, as such people have extensive need of services, but presumably many people with mild disability would not be included. Thus it is likely that the sample sizes in the highest-functioning cohorts underestimate the true population sizes. If this were to bias the results

Table III: Life expectancy (additional years) by age and cohort

Sex/	*Cannot lift head*			*Lifts head*			*Rolls/sits*			*General*
age	*TF*	*FBO*	*SF*	*TF*	*FBO*	*SF*	*TF*	*FBO*	*SF*	*population*
Female										
15 y	15.4	21.3	–	21.1	27.7	43.4	25.0	39.2	52.7	65.0
30 y	13.4	23.8	–	16.2	28.1	33.0	21.5	34.1	40.1	50.4
45 y	–	20.4	–	16.1	20.6	23.6	23.3	24.1	29.4	36.2
Male										
15 y	11.7	16.9	–	16.7	22.8	38.8	20.3	34.3	48.7	58.3
30 y	12.0	22.0	–	14.7	26.2	31.0	19.8	32.1	38.0	44.5
45 y	–	17.5	–	13.6	17.7	20.6	20.3	21.0	26.3	31.1

TF, tube fed; FBO, fed by others, without feeding tube; SF, self-feeds; –, group too small for reliable computation of life expectancy or confidence interval.

Table IV: Half-width of the model-based 95% confidence intervals for life expectancy

Sex/	*Cannot lift head*			*Lifts head*			*Rolls/sits*		
age	*TF*	*FBO*	*SF*	*TF*	*FBO*	*SF*	*TF*	*FBO*	*SF*
Female									
15 y	2.4	2.6	–	4.6	2.6	6.5	5.4	2.5	1.3
30 y	3.2	2.7	–	4.7	2.9	4.4	7.2	2.4	1.2
45 y	–	4.2	–	11.2	4.3	5.6	7.6[a]	3.2	1.6
Male									
15 y	2.0	2.2	–	4.1	2.5	6.9	5.2	2.4	1.3
30 y	3.0	2.6	–	4.6	2.8	4.3	7.0	2.3	1.1
45 y	–	3.9	–	10.4	4.1	5.4	7.1[a]	3.0	1.4

[a] Difference between the estimated life expectancy and the lower endpoint of the confidence interval; upper endpoint could not be computed.
TF, tube fed; FBO, fed by others, without feeding tube; SF, self-feeds; –, group too small for reliable computation of life expectancy or confidence interval.

it would do so by reducing life expectancies, as the excluded people would tend to be in better health than those receiving services. Such a bias must be relatively small, however, because, as we have seen, the higher-functioning cohorts have life expectancies only slightly less than those for the general population. Because the lower-functioning groups studied here capture the great majority of Californian residents with severe disabilities, it seems unlikely that these groups reflect any serious bias.

A limitation of the life expectancy and survival analyses reported here (see Fig. 2, Tables III and IV) and in other studies is that they are based on only a crude classification of functional level. More appropriate estimates of life expectancy and survival probabilities for a subject with a given profile of age, gender, functional skills, etc. may be obtained using the methods described here. Specifically, a Cox hazards analysis may be used to determine the risk, and hence the excess risk relative to the general population, associated with the given profile of skills, and so on. This excess may then be applied to a standard life table, as described previously.

Finally, it would be of interest to determine the causes of death that account for the higher mortality in people with CP. Cause-specific mortality in CP seems not to have been studied previously on a population basis. We hope to report on such a study shortly.

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