

# Survival in cerebral palsy in the last 20 years: signs of improvement?

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This study investigated the possibility of improved survival in cerebral palsy (CP) over a 20-year period. Participants were 47 259 persons with CP receiving services from the State of California between 1983 and 2002. The person-year approach was used. This asks whether the probability of dying in a given calendar year changes over the study period after age and severity of disability are taken into account. An appreciable improvement over time was found in children with severe disabilities and in adults who required gastrostomy feeding. In these groups, mortality rates fell by 3.4% per year. Therefore, life expectancies reported in earlier studies should be increased by approximately 5 years if adjustments to 2002 mortality rates are made. For other persons with CP there was, at most, a small improvement over the 20-year period. The results suggest there have been improvements in the treatment and care of the most medically fragile children. Gastrostomy feeding has become much more widespread over the past two decades, and the improved survival of persons with gastrostomies may reflect better understanding of their requirements.

There is little doubt that survival in cerebral palsy (CP) has improved over the past half-century.<sup>1</sup> However, no clear improvement in survival over the past two to three decades has been documented in the literature on CP. Although Strauss et al.,<sup>2</sup> in their Californian study of children with CP, observed some improvement over time, it was not statistically significant. No evidence for such a trend was found in the Australian study of Blair et al.,<sup>3</sup> the UK studies of Hutton et al.,<sup>4,5</sup> and the Californian study of adults by Strauss and Shavelle.<sup>6</sup>

Such an improvement would be an example of a secular trend. Secular trends have been reported in spinal cord injury over a 20-year period,<sup>7,8</sup> and for infants in a vegetative state over a 15-year period.<sup>9</sup>

Secular trends in survival are of interest for at least two reasons. First, when referring to longevity studies in the literature the reader will want to know whether the published estimates need to be revised upwards and, if so, by how much. Second, such trends may be a marker for progress in medical treatment and therapy. For example, a 1992 article on fundoplication in children with profound neurological disability (Smith et al.<sup>10</sup>) was subtitled 'High risks and unmet goals'. However, anecdotal evidence suggests that since the 1980s there has been a better understanding of the importance of appropriate nutritional status in children and adults with disabilities. Further, there has been a greater appreciation of the risks of aspiration, improvements in surgical procedures for gastrostomy and fundoplication, and progress in gastrostomy-feeding techniques. As a result, it seems unlikely that Smith's subtitle would apply today. Nevertheless, so far, no such improvement appears to have been documented in a published study on mortality or morbidity in CP.

To identify a possible secular trend in survival in CP, it is necessary to control for factors such as age and the severity of disability. In particular, it has been shown in previous work that the degree of preserved motor function (e.g. the abilities to roll over, crawl, walk, and self-feed) is a key factor in this regard.<sup>2,5</sup> These factors were taken into account in the present study.

We analyzed data from the large California database over the 20-year period 1983–2002 and asked: (1) has there been improvement in the survival of persons with CP over this period? (2) If so, does this trend apply to all persons with CP, regardless of age or severity of condition, or only to certain subgroups? (3) How much have mortality rates decreased, and what effect has this had on life expectancy?

## Method

### PARTICIPANTS

Our participants were persons who: (1) had CP; (2) received services (e.g. medical services, therapies, board and care, respite services) from the California Department of Developmental Services between January 1983 and December 2002; and (3) were at least 4 years of age at some time during this period. According to the Department, 'Cerebral palsy includes two types of motor dysfunction: (1) a nonprogressive lesion or disorder in the brain occurring during intrauterine life or the perinatal period and characterized by paralysis, spasticity, or abnormal control of movement or posture, such as poor coordination or lack of balance, which manifests before 2 or 3 years of age, and (2) other significant motor dysfunction appearing before age 18.'<sup>11</sup> We then excluded persons with an

International Classification of Disease (9th revision)<sup>12</sup> code for any of several degenerative conditions or conditions acquired after infancy, as these might not be considered CP. A list of these is available from the first author.

In all, 28 513 children aged 4 to 14 years and 30 185 adults aged 15 years and older met these criteria.

We reviewed data collected by the California Department of Developmental Services on Client Development Evaluation Reports (CDER)<sup>13</sup> for January 1983 to December 2002. The CDER include 261 items. Each CDER during the study period included demographic information for etiology, information on other medical conditions, and level of motor, self-care, and cognitive functioning. Each participant's CDER is updated approximately once a year, thus yielding repeated measures on risk factors for most persons in the study. The reliability of the CDER items used here has been previously assessed as satisfactory.<sup>14-16</sup>

Information about mortality was obtained from the California Department of Health Services. In accordance with Californian law, all deaths in the state are reported to that department.

#### STATISTICAL METHODS

We used the pooled repeated observations method for analysis.<sup>17-19</sup> In this method, the unit of observation is not a person, but a person-year. With each person-year we associated a binary outcome variable, indicating whether the person lived or died in that year, and a set of explanatory variables, as listed below. Logistic regression analysis<sup>19</sup> was used to relate the outcome variable (lived/died) to the explanatory variables. This approach has been widely used in similar work. As explained elsewhere,<sup>18</sup> the method is preferable to the more familiar cohort analysis (e.g. proportional hazards modeling) because the latter does not focus on specific ages or calendar years. For example, if mortality rates were unusually high or low for a particular decade or particular age range, this would be difficult to identify in a conventional cohort analysis. The analysis is actually equivalent to a Cox proportional hazards model with time-varying covariates.<sup>18</sup> Variables considered in the analyses were as follows:

*Severity of CP.* The participants were stratified into two groups: the first consisted of those who were (1) unable to crawl, creep, scoot, stand without support, or walk, and (2) fed completely by others. All others were in the second group. For convenience, the groups were labeled 'severe' and 'not-severe' disabilities, though it is recognized that many participants in the latter group would in other contexts be considered to have severe CP.

*Age.* After some preliminary analyses, we chose to work with three age groups (4-7y, 8-14y, and 15-30y), with a simple linear term in age for age 30 and above. The analysis indicated that these terms were sufficient; for example, quadratic or higher terms for age (over the age of 30) did not add significantly to the prediction of mortality.

*Sex.* Perhaps not surprisingly, this variable did not contribute significantly to the prediction of mortality. It was, therefore, dropped from subsequent analyses.

*Mode of feeding.* Three groups were considered: tube fed, fed orally by others, and self-feeds. As long-term tube feeding was usually by gastrostomy, we use the two terms interchangeably (there were only a few children with a jejunostomy, long-term nasogastric feeding, or other form of tube feeding).

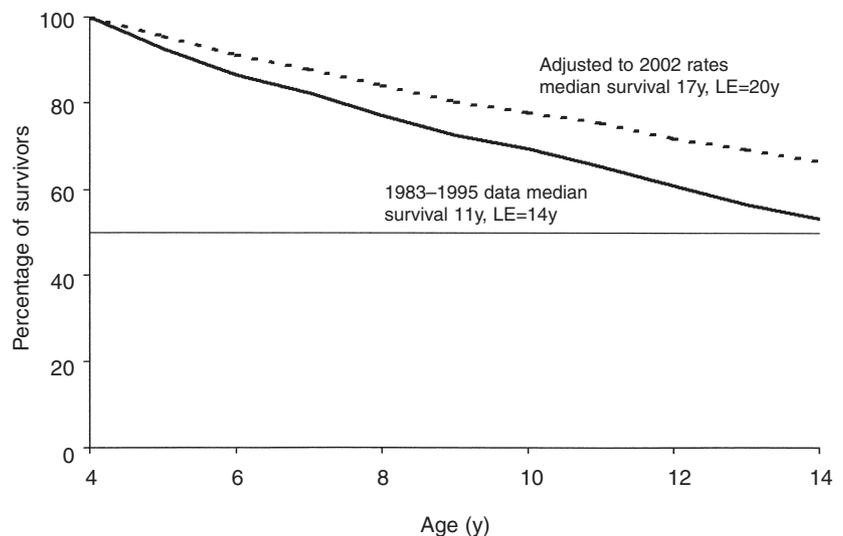
*Mobility.* For the severe group, three levels of mobility were considered: (1) does not lift head when lying prone; (2) lifts head (and possibly chest) when lying prone, but does not consistently roll or sit; and (3) rolls or sits independently. For the not-severe group, where functional skills were generally somewhat greater, the three levels were: (1) does not walk; (2) walks only with support, or unsteadily alone at least 3 meters; and (3) walks well alone at least 6 meters and balances well.

*Calendar year.* The relation of this variable to mortality risk, other factors being equal, was the central issue in the present study.

Model selection was performed using Wald and deviance statistics for nested models,<sup>20</sup> and the Akaike information criterion otherwise.<sup>21</sup>

The children (age under 15y) contributed 136 757 person-years of follow-up, and the adults contributed 271 138 person-years, for a total of 407 895 person-years. During this

**Figure 1:** Survival of children aged 4 years with cerebral palsy, who did not lift head in prone, and who were fed by others (either orally or by gastrostomy). Curves show proportion of persons surviving to each age. Solid curve is based on 1983 to 1995 data; dotted curve is adjusted to 2002 mortality rates. Respective 10-year survival probabilities, for example, are 53% and 67%. Use of standard methods yields respective medians of 11 and 17 years, and life expectancies of 14 and 20 years respectively. LE, life expectancy.



period 4408 participants died, for an overall mortality rate of 11 deaths per 1000 person-years.

Life tables<sup>22</sup> were used to determine life expectancy (i.e. average number of additional years of life in a large group of similar persons) and median survival times (the time at which 50% of the group would still be alive) for various groups. Mortality rates for ages beyond the ranges of the cohort analyses were computed using the assumption of proportional life expectancy.<sup>23</sup>

To take account of the secular trend, we adjusted the estimated mortality rates to be those for the end of the study period (i.e. 2002). This procedure is to reduce each mortality rate by an appropriate amount to reflect the improvement that has occurred over the study period. Naturally, the size of the reduction depends greatly on the number of years until 2002. For example, mortality rates derived from 2001 data will only be reduced very slightly, whereas rates based on 1985 data are reduced much more.

We illustrate the procedure with the example of a 10-year follow-up of a cohort of 4-year-old children who were fed by others and who did not lift their heads in prone or roll or sit independently. The original analysis is based on data for the period 1983 to 1995, and the task is to adjust the results to reflect mortality rates obtaining in 2002, the end of the study period. The results of the procedure are shown in Figure 1, and are discussed later in this article. The steps are as follows:

(1) At the end of a 10-year follow-up, which was based entirely on data from the 1983 to 1995 period, 53% of the children were alive. Standard methods<sup>21</sup> show that this corresponds to an annual mortality rate of  $\{\ln(0.53)/10\} = -0.063$ , i.e. 63 deaths per 1000 persons per year. The median survival time is 11 additional years (to age 15y) and the life expectancy is an additional 14 years 4 months.

(2) The calendar year of each person-year of the underlying data was known. For the person-years contributing to the computation of the first 5 years of follow-up, the average calendar year proved to be 1988.

(3) For this first 5-year rate, an adjustment for 14 years (from the middle of 1988 to the middle of 2002) of secular trend is, therefore, required.

(4) As shown in the Results, the estimated decline in mortality is 3.4% per year. Over a 14-year period, therefore, the mortality rate declines to  $(1-0.034)^{14} = 61.6\%$  of its previous value. That is, the first 5-year rate becomes  $0.063 \times 0.616 = 0.039$ .

(5) Similarly, for the second 5-year rate an adjustment for 11 years (rather than 14) proves necessary, and the appropriate multiplier is  $(1-0.034)^{11} = 68.4\%$ . Thus, the second 5-year mortality rate becomes  $0.063 \times 0.684 = 0.043$ .

(6) Thus, to take account of the secular trend we simply replace the two unadjusted 5-year death rates, 0.063 and 0.063, by 0.039 and 0.043. The new rates lead to a median survival time and a life expectancy of an additional 16 years 8 months and 20 years 2 months respectively.

(7) It may be noted that the result of the adjustment is to increase both the median survival time and the life expectancy by approximately 6 years, by comparison with the figures in (1) above.

## Results

Table I gives summary information on the 28 513 children aged 4 to 14 years. The severe group contributed 18% of the person-years, but 69% of the deaths. The prevalence of gastrostomy feeding was 26% in the severe group, compared with only 3% in the not-severe group.

As indicated in footnotes to Table I, there was a marked increase in the use of gastrostomy feeding during the 20-year study period. In the severe group, for example, the prevalence of tube feeding rose steadily from 16% in 1983 to 38% in 2002.

As may be seen, mortality rates were much higher among those who required gastrostomy feeding than among those who did not. As expected, mortality rates were strongly

**Table I: Crude death rates in children by age, feeding status, and mobility<sup>a</sup>**

Item	Severe CP <sup>b</sup>		Not-severe CP <sup>b</sup>	
	Number or percentage	Crude death rate <sup>c</sup>	Number or percentage	Crude death rate <sup>c</sup>
Nr of children	6277	–	22 236	–
Nr of deaths	917	–	407	–
Nr of person-years	24 996	37	11 1761	4
Age, %				
4–7y	45	36	42	4
8–14y	55	37	58	4
Gastrostomy feeding status <sup>d</sup> , %				
Tube fed	26	65	3	21
Not tube fed	74	27	97	3
Mobility, <sup>e</sup> %				
Low	25	65	28	8
Intermediate	52	32	33	3
High	23	17	39	1

<sup>a</sup>Person-year data from 28 513 children aged 4–14 years; <sup>b</sup>Severe CP: unable to crawl, walk, or self-feed (see text for detailed explanation);

<sup>c</sup>deaths per 1000 person-years; <sup>d</sup>proportion in severe group requiring tube feeding: 16% in 1983, 38% in 2002; proportion in not-severe

group requiring tube feeding: 0.6% in 1983, 6% in 2002; <sup>e</sup>mobility in the severe group: low, does not lift head in prone; intermediate, lifts head in prone or rolls; high, full rolling and sitting; mobility in the not-severe group: low, does not walk; intermediate, walks with support or unsteadily alone; high, walks well alone.

dependent on the degree of mobility: in the severe group, those with the poorest mobility (unable to lift their heads in prone) had approximately four times the mortality of those with the best motor function (could roll or sit independently). In the not-severe group, the disparity was even greater, with a relative risk of 8.

Table II provides similar information for the 30 185 adults aged 15 years and older. Again, the severe group is relatively small but contributes disproportionately to the mortality. Mortality rates rise with age, as expected, especially in the not-severe group. Gastrostomy feeding was relatively common (20%) in the severe group, but rare (1%) in the not-severe group. Again, as shown in the footnote to Table II, the prevalence of gastrostomy feeding increased sharply during the study period. As before, the need for gastrostomy feeding was associated with much higher mortality.

Table III shows the final logistic regression model for the severe CP group. The last entry under 'Age' shows that each year over the age of 30 was associated with an increase of 0.4% in mortality, after functional status and need for gastrostomy feeding were taken into account (as noted below, this applies only to persons in the low-mobility group). This was small and did not attain statistical significance at the 5% level. Further, the age groups under age 30 did not have significantly different mortality rates. Need for gastrostomy feeding was associated with 2.3 times higher mortality than the reference group (those who could be fed orally by others). This, of course, does not indicate that gastrostomy feeding is harmful, but that those who require such feeding have disabilities that are more severe. Mobility also had a strong effect on mortality: rates for persons unable to lift their heads in prone (poor mobility) were more than double the rates for persons able to roll or sit (high mobility). There was only one significant interaction term, which reflected the fact that for persons with intermediate or higher mobility, mortality rates increased with age past the age of 30; as noted above, the trend was smaller and non-significant for those with low mobility.

The most interesting finding revealed by Table III is the secular trend. For children under the age of 15 years, and for older persons who were gastrostomy-fed, there was a steady decline in mortality over the 20-year period. The odds ratio of 0.966 indicates that each year the mortality risk in these groups was 96.6% of its value in the preceding year. This is equivalent to a decline of approximately 3.4% per year over the study period. This is a substantial decline over a 20-year period. For example, it equates to a 50% reduction in the mortality rate. Note that no decline was observed for persons older than 15 who were not gastrostomy-fed.

Table IV shows the result of the logistic regression modeling for the not-severe group. Again, the Table IV shows the higher mortality associated with both poor mobility and the need for tube feeding. The most salient feature of Table IV, however, is the last row. This shows only a small secular trend: mortality rates appear to decline by 0.9% ( $=1-0.991$ ) for each calendar year. This effect is much smaller than the 3.4% decline observed in Table III, and is in fact only marginally statistically significant at the 5% level. As an example of the effect of assuming this 0.9% annual decline in mortality: if we adjusted a life expectancy of 30 years based on data from, say, 1990 to 2002, the life expectancy would increase by only 1 to 2 years. This is comparable to the increase in life expectancy in the general population.

To illustrate the improved survival over the 20-year period in the severe group, we show two survival curves for cohorts of children aged 4 years who were initially fed by others and who were unable to lift their heads when lying prone (Fig. 1). The lower curve is based on data from 1983 to 1995; it roughly approximates the results obtaining at the time of our 1998 study of survival of children with CP.<sup>2</sup> Ten-year survival for this group was 53%. Standard methods indicate that the median survival time was 11 years and the life expectancy 14 years. The upper curve is similar except that (1) it incorporates data through 2002 rather than 1995, and (2) it reflects mortality rates adjusted to 2002, i.e. it follows a hypothetical cohort of

**Table II: Crude death rates in adults by age, feeding status, and mobility<sup>a</sup>**

Item	Severe CP <sup>b</sup>		Not-severe CP <sup>b</sup>	
	Number or percentage	Crude death rate <sup>c</sup>	Number or percentage	Crude death rate <sup>c</sup>
Nr of adults	4822	–	25 363	–
Nr of deaths	1368	–	1716	–
Nr of person-years	34 657	40	236 482	10
Age, %				
15–30y	54	40	49	4
30–45y	32	32	35	6
45–60y	11	42	13	11
60y+	3	99	3	44
Gastrostomy feeding status, <sup>d</sup> %				
Tube fed	20	70	1	37
Not tube fed	80	32	99	7
Mobility, <sup>e</sup> %				
Low	29	57	25	13
Intermediate	47	34	30	8
High	24	28	45	4

<sup>a</sup>Person-year data from 30 185 adults aged 15 years and older; <sup>b</sup>Severe CP: unable to crawl, walk, or self-feed (see text for detailed explanation);

<sup>c</sup>death rate per 1000 person-years; <sup>d</sup>proportion tube fed in severe group: 10% in 1983, 31% in 2002; proportion tube fed in not-severe group: 0.3% in 1983, 1.9% in 2002; <sup>e</sup>mobility in the severe group: low, does not lift head in prone; intermediate, lifts head in prone or rolls; high, full rolling and sitting; mobility in the not-severe group: low, does not walk; intermediate, walks with support or unsteadily alone; high, walks well alone.

children whose mortality rates at all ages are those of 2002 rather than of earlier years. As may be seen, the 10 year survival rate of 67% is appreciably higher, as are the corresponding median survival time (17y) and life expectancy (20y). Both

the median survival time and the life expectancy are increased by 6 years.

As noted previously, a secular trend for persons with severe CP over the age of 15 years was only observed for those fed by gastrostomy. Therefore, we compared the survival of gastrostomy-fed persons as reported in our 1998 study<sup>6</sup> with results that are updated and adjusted to the year 2002. For the former we used mortality rates from Figure 2 of the 1998 study, which were based on data before 1996. For persons aged 15 years we found that the adjustment to 2002 rates increased the median survival times by approximately 3 years, and the life expectancy by 5 years.

**Table III: Logistic regression model predicting risk of mortality by age and other factors for severe cerebral palsy group<sup>a</sup>**

Effect	Odds ratio	95% CI
Age, y		
4–7	0.89	(0.76–1.03)
8–14	0.95	(0.84–1.07)
15–30	1.00	–
Each year over 30	1.004	(0.995–1.012)
Feeding tube <sup>b</sup>	2.34	(2.00–2.74)
Mobility <sup>c</sup>		
Low	2.59	(2.23–3.01)
Intermediate	1.58	(1.38–1.82)
High	1.00	–
Interaction (age >30 only) (Age–30) × mobility <sup>d</sup>	1.019	(1.013–1.025)
Each calendar year:		
Tube fed <15y, or >15y	0.966	(0.957–0.975)
Not tube fed, >15y	1.006	(0.995–1.018)

<sup>a</sup>n=59 653 person–years, 2285 deaths; <sup>b</sup>reference group is no feeding tube; <sup>c</sup>mobility: low, cannot lift head when lying on stomach; intermediate, lifts head when lying on stomach or has partial rolling; high, full rolling or sitting; <sup>d</sup>interaction term was defined using mobility scores of 0, 1, and 2 for the low-, intermediate-, and high-mobility groups defined above. CI, confidence interval.

**Table IV: Logistic regression model predicting mortality by age and other factors for not-severe cerebral palsy group<sup>a</sup>**

Effect	Odds ratio	95% CI
Age, y		
4–8	1.001	(0.82–1.23)
8–15	0.96	(0.79–1.17)
15–30	1.00	–
Each year over 30	1.053	(1.048–1.058)
Feeding tube <sup>b</sup>	4.46	(3.74–5.33)
Mobility <sup>c</sup>		
Low	2.86	(2.42–3.38)
Intermediate	1.05	(0.93–1.20)
High	1.00	–
Interaction terms		
Mobility × age 4–8 <sup>d</sup>	0.60	(0.47–0.77)
Mobility × age 8–15 <sup>e</sup>	0.75	(0.62–0.91)
Mobility × each year past 30 <sup>f</sup>	1.005	(1.001–1.010)
Each calendar year	0.991	(0.984–0.999)

<sup>a</sup>n=348 243 person–years, 2123 deaths; <sup>b</sup>reference group is no feeding tube; <sup>c</sup>mobility: low, unable to walk; intermediate, walks with support or unsteadily alone; high, walks well alone; <sup>d</sup>interaction term was defined as: 0 if age greater than 8 or unable to walk; 1 if age 4–8 and walks with support or unsteadily alone; and 2 if age 4–8 and walks well alone; <sup>e</sup>this interaction term was defined as: 0 if not age 8–15 or unable to walk; 1 if age 8–15 and walks with support or unsteadily alone; and 2 if age 8–15 and walks well alone; <sup>f</sup>this interaction term was defined as: 0 if unable to walk; (age–30) if walks with support or unsteadily alone; and (age–30)×2 if walks well alone. CI, confidence interval.

## Discussion

This study is of significance in indicating that children who have CP and severe disabilities have had demonstrable increases in their life expectancy over the course of the past 20 years. Our data do not provide the reasons for this but it is likely that these are multiple and overlapping. Although those who are wholly immobile and dependent remain very vulnerable, we speculate that the early recognition and vigorous treatment of infections, including, where indicated, the use of ventilatory support, has been a major factor in reducing the number of children who have died. We also suggest that a variety of socioeconomic factors, such as the provision of appropriate housing, that are in general likely to promote health, are of significance. Along with this it may be that the provision of suitable schooling, therapies, aids and appliances, and social and occupational opportunities, by improving the quality of life for people with disabilities and those caring for them will have had a non-specific beneficial effect. All of these factors are worthy of further examination, but that is beyond the remit of this paper.

Independently of the above factors, we also suggest that attention to and management of the nutritional requirements of children and adults with disabilities is of particular importance. We have demonstrated elsewhere<sup>24</sup> that the individuals with the most severe disabilities are smaller and lighter than those who are less severely affected. Although a lack of mobility per se may restrict growth it is probable that a major factor in limiting growth and weight gain in this population is less than optimal nutrition. Historically, gastrostomy for children and adults with disabilities has been something of a last resort, and resistance to feeding by this route is still seen in many families and some practitioners. Nevertheless, the pendulum has swung to a considerable extent. In consequence, children who are failing to thrive or to gain weight, and those who are considered or are demonstrated to be at risk of aspiration, are offered gastrostomy much sooner in their lives. The use of percutaneous gastrostomy procedures and the demonstration that gastrostomy does not usually promote gastroesophageal reflux have been additional factors in increasing the prevalence of tube feeding. Similarly, other surgical procedures, such as fundoplication to limit reflux, are now more readily performed, and they appear to have reduced morbidity and mortality. It is also recognized that, for some individuals, gastrostomy and oral feeding can be complementary rather than mutually exclusive.

It is unsurprising, therefore, that we found improved survival of children with the most severe disabilities, and of adults who are fed by gastrostomy. Mortality rates in these groups fell by some 50% over the 20-year period. If mortality

rates from the period 1983 to 1995 are adjusted to 2002, the end of the study period, life expectancies rise by approximately 5 years. Among persons who did not have the most extreme disabilities, however, there was at most a weak trend.

Such trends have not been reported in previous work on CP. There are at least three reasons for this. First, a large database with a reasonably long follow-up is required if a secular trend is to be detected. Second, as discussed above, the usual cohort methods of analysis (such as the Cox proportional hazards model) are much less suitable for investigating secular trends than the person-year approach used here. Third, the trends are observed only for the persons with the most severe disabilities. If the data are not stratified according to severity then only an 'average' trend over all persons with CP will be observed, and this will be small and weak.

The improved survival reported here, although encouraging, is limited to persons with the most severe disabilities. In this group, almost all causes of death have greatly elevated death rates compared with the general population.<sup>25</sup> It is still not reasonable to argue that life expectancy in severe CP could approach normal. As an example: children aged 10 years who are tube fed and do not lift their heads in prone are subject to roughly 500 times the mortality rates of the general population. The secular trends reported here would only have a small effect on this disparity.

It is natural to ask whether the trend toward improved survival may be expected to continue in the future. While some modest further improvement in future years would not be surprising, the principle of diminishing returns may be expected to operate. Although much progress seems to have been made in nutrition, for example, it is not clear that substantial further gains in this area are feasible. We recognize, however, that any prognostication about future trends in life expectancy is highly speculative.

We have noted the very substantial increase in the use of gastrostomy feeding over the past 20 years. Whereas gastrostomies were previously performed only on individuals with the most extreme disabilities, tube feeding has been increasingly used for those with less extreme disabilities. Thus, the average degree of disability in those who are tube fed has diminished over time. Paradoxically, the same may be true of those not tube fed, as the members of that group with the severe disabilities are now more likely to be 'transferred' to the tube fed group. This suggests the somewhat surprising conclusion that the average severity of disability has diminished over time in both groups. And in view of this, one might ask whether some of the improved survival over time in both groups may be explained by this trend.

The evidence suggests that this explanation is not a major part of the story. For example, we considered the survival over time of cohorts of 4-year-old children who were essentially immobile – they could not lift their heads in prone, or roll or sit independently – and were fed orally by others (Fig. 1). No distinction between oral versus tube feeding was considered in this analysis. Nevertheless, the improvement in survival over the years was comparable to that observed both in the tube-fed and not-tube-fed groups separately.

Is the increased longevity of those with the most severe disabilities accompanied by improved life quality? The issue is a complex one, as such persons are reported to have the lowest quality of life and to suffer the most from pain.<sup>26–29</sup> On the other hand, research indicates that gastrostomy feeding,

which has become much more common in this group, has had a positive impact both on the children and their families.<sup>30,31</sup>

A limitation of the study is that it is restricted to data from California. While we see no reason to expect a markedly different pattern of improvement in other parts of the Western world, at present this is not known. Comparable studies from other countries would be helpful here.

A second limitation concerns the causes of the secular trend. As noted, we suspect that improvements in the understanding and provision of nutrition have contributed significantly to the observed secular trend. Supporting this idea is the fact that the improved survival is largely restricted to those with the most severe disabilities, and these persons are much more likely to be malnourished. Further, these persons are much more dependent on medical treatment and services than higher-functioning persons. It follows that the improvement is more likely to reflect improvements in medicine in a broad sense than changes affecting all the population, such as more positive attitudes towards persons with disabilities. However, at this point we cannot be sure. Further research, perhaps based on trends in cause-specific death rates, would be helpful.

*Accepted for publication 1st August 2006.*

#### *Acknowledgments*

Provision of data from the California Departments of Developmental Services and Health Services is gratefully acknowledged.

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# Mac Keith Meetings

## Forthcoming Meetings



**SCOPE Anniversary Meeting – Cerebral Palsy after Age 40**

**13 February 2007**

**Fetal Brain Damage and Placenta**

**7 March 2007**

The impact of impaired placental function on neurodisability and interventions to reduce it.

**Managing Mystery Illnesses –  
Specialty Treatment of Hard to Explain Symptoms**

**30 April 2007**

**Health Issues for Child Refugees and Asylum Seekers**

**31 May 2007**

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