Life expectancy among people with cerebral palsy in Western Australia

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This report describes trends, predictors, and causes of mortality in persons with cerebral palsy (CP) using individuals identified by the Western Australian Cerebral Palsy Register and born between 1958 and 1994. Two thousand and fourteen people were identified (1154 males, 860 females), of whom 225 had died by 1 June 1997. Using date-of-death data, crude and standardized mortality rates were estimated and predictors of mortality sought using survival analysis stratified by decade of birth, description of impairments, and demographic and perinatal variables. For those born after 1967, the cause of death profile was examined over time. Mortality exceeded 1% per annum in the first 5 years and declined to age 15 years after which it remained steady at about 0.35% for the next 20 years. The strongest single predictor was intellectual disability, but all forms of disability contributed to decreased life expectancy. Half of those with IQ/DQ score <20 survived to adulthood, increasing to 76% with IQ/DQ score 20–34, and exceeding 92% for higher scores. Severe motor impairment primarily increased the risk of early mortality. Despite there being 72 persons aged from 25 to 41 years with severe motor impairment in our data set, none had died after the age of 25 years. Infants born after more than 32 weeks' gestation were at significantly higher risk of mortality than very preterm infants, accounted for by their higher rates of intellectual disability. No improvements in survival of persons with CP were seen over the study period despite advances in medical care, improved community awareness, and the increasing proportion of very preterm births among people with CP. This may be the result of improved neonatal care enabling the survival of infants with increasingly severe disabilities.

The question of life expectancy is of paramount importance to people with cerebral palsy (CP) and their families. Accurate information concerning possible lifespan is essential for planning services; and the predicted longevity of a person with CP is a major factor in the amount of money awarded in litigation.

Data from CP registers go back only as far as the 1950s, and so can only report on deaths of persons aged from 40 to 50 years. However, before the mid-twentieth century, very few people with severe CP survived to adulthood. Since then the widespread use of antibiotics, improvements in intensive care techniques, increasing awareness of the rights of people with disabilities, and the increase in community care as opposed to institutional care, are all anticipated to affect mortality. Therefore, the lifespan of those with CP born before the mid-twentieth century may not be predictive of infants born later.

There are a few population-based studies of life expectancy in people with CP ascertained from multiple sources, two of which involve long-standing registers similar to the Western Australian Cerebral Palsy Register (Hutton et al. 1994, Crichton et al. 1995). The studies by Evans et al. (1990) and by Williams and Alberman (1998) were based on multiple sources of ascertainment but could include only more recent cohorts, allowing investigation of mortality at 8 years or up to 10 years respectively. Several publications have considered mortality of persons with CP selected from the State of California Register for people requiring services (Strauss et al. 1997, 1998, 1999; Strauss and Shavelle 1998), which may preferentially include the more severe end of the spectrum of CP. Much older persons are included than is currently possible from longitudinal follow-up studies, but observations on this group may be less useful for long-term prognosis of newly described children with CP because the age at entry to the study, at which age the type and severity of impairments are described, is variable and survival to commencement of the study was a prerequisite for inclusion. For example, the oldest survivors would have been born before the antibiotic era and having survived, would be unlikely to have had severe motor disability in childhood, regardless of their current severity (Strauss and Shavelle 1998).

Two studies, one also based on the Californian data set (Eyman et al. 1993) and one from Chicago (Plioplys et al. 1998) have considered survival with extremely severe disability. They are of considerable interest for the prognosis of children with similar disabilities, but include only the most severe forms of multiple disabilities and cannot be considered to represent the majority of persons with CP.

The purpose of the present study was to describe the rates and causes of death until 31 May 1997 in all people with CP born in Western Australia from 1956 to 1994. The study was approved by the Advisory Committee of the Western Australian Cerebral Palsy Register, the Research and Ethics Committee of Princess Margaret and King Edward Memorial Hospitals, the Confidentiality of Health Information Committee of the Health Department of Western Australia, the National Death Index, and the National Health and Medical Research Council who fund CP studies in Western Australia.

Method

POPULATION WITH CP

Persons included in this study were ascertained from the Western Australian Cerebral Palsy Register. This is an ongoing collection of basic diagnostic, perinatal, and demographic information on all individuals described as having CP who

were born or resident in Western Australia from 1956 onwards (Stanley and Watson 1985). The present study included 2014 people (1154 males, 860 females) on the register born in Western Australia between 1956 and 1994, including those with CP due to postneonatal causes occurring before the age of 5 years. The cut-off point of 1994 was used because a year-of-birth cohort is considered complete for the register only after information is updated at the age of 5 years.

DEATHS

Deaths occurring up to the age of 5 years are recorded on the register from routine medical record review. Deaths after that age were ascertained by linking the Cerebral Palsy Register to the Registrar General's Western Australian Deaths File in October 1999 or, for deaths among migrants to other states in Australia, to the National Death Index at the Australian Institute of Health and Welfare, Canberra in July 1997 at which time data were complete only to 31 May 1997. This study, therefore, excludes deaths that occurred after 31 May 1997.

These methods do not identify any deaths occurring overseas. Service providers that we approached identified 168 (46.7%) of the 360 individuals born before 1967 not known to have died, including 92% of those with the most severe impairments who are at highest risk of mortality. None were known to have died before 31 May 1997; 143 (86%) were known to be alive, contact had been lost with 22 (13.2%), and only 2 (1.2%) were known to be living abroad neither of whom were severely motor or cognitively impaired, suggesting that migration overseas occurred extremely rarely, if at all, in the severely affected group.

For those born between 1956 and 1966, the Cerebral Palsy Register records only date of death and whether or not a post mortem was performed. For those born from 1967 onwards, cause of death data were obtained from death certificates, hospital records, post-mortem reports, and/or, where death occurred in other Australian states, from the National Death Index linkage. For the purpose of the present study the immediate cause of death was classified according to Table I and further classified by whether or not CP was considered to be an underlying cause.

Table I: Causes of death

Causes of death	*n*	*Total (%)*
Infant death with no cause other than CP		7 (4.6)
Presumed intrapartum cause	6	
Presumed antepartum cause	1	
Respiratory		89 (58.9)
Inhalation of liquid or vomitus	6	
Aspiration pneumonia	25	
Pneumonia, other, or not otherwise specified	56	
Asthma	2	
Other infections		8 (5.3)
Gastroenteritis	0	
Septicaemia	4	
Viral infection	1	
Meningitis	0	
Myocarditis	2	
Glomerulonephritis	1	
Status epilepticus		13 (8.6)
Birth defects		7 (4.6)
Brain	5	
Cardiac	2	
Major organ failure		2 (1.3)
Cardiac	0	
Renal	1	
Multiple	1	
Cancers		1 (0.7)
Accidental or traumatic death		4 (2.6)
Non-accidental death	1	
Accidental death secondary to motor impairments	0	
Accidental death independent of motor impairments	3	
Unknown/inadequate explanation		17 (11.3)
Miscellaneous other		3 (2)
Pulmonary embolism	1	
Haematemesis	2	
Total		151 (100)

DESCRIPTION OF CP

For this study the predominant types of CP were classified as spastic hemiplegia, diplegia, or quadriplegia; ataxia; athetosis; dystonia; or hypotonia. Severity of CP was categorized as minimal, mild, moderate, or severe (Table II). Deaths were over represented among those registered as having unknown severity of motor impairment, at least in part because deaths occurred before finalization of the clinical description at 5 years. Where possible, severity of motor impairment for each of these early deaths was determined by record review.

INTELLECTUAL STATUS

The Cerebral Palsy Register categorizes intellectual status as normal (IQ/DQ >85); borderline intellectual disability (ID) (IQ/DQ 70 to 85); mild ID (IQ/DQ 50 to 69); moderate ID (IQ/DQ 35 to 49); severe ID (IQ/DQ 20 to 34); and profound ID (IQ/DQ <20). These data are obtained from a variety of psychometric measurement tools or from any clinical observations recorded in the medical notes. However, this accurate categorization was not available for 140 persons (7%). The data indicated that many CP type and severity combinations were powerful predictors of IQ range. Those without an IQ classification and those who were known to have intellectual disability but of uncertain degree were assigned a simplified IQ classification (in which the first two categories were combined as were the last two: resulting in four categories: 1, normal/borderline; 2, mild; 3, moderate; and 4, severe/profound on the basis of type and severity of CP. In eight instances where reassignment by this method was not

Table II: Guidelines for classifying severity of CP

Severity	*Function*
Minimal	Motor signs present but no functional impairment
Mild	Symptoms result in some functional impairment
Moderate	Between mild and severe, e.g. ambulant with walking frame
Severe	Little purposeful voluntary action, though function may be acquired, IQ permitting

considered reliable, data from the Cerebral Palsy Register were reviewed and an IQ classification assigned on the basis of strong presumptive clinical evidence. Only 10 individuals (0.5%) could not be classified with this simplified categorization, which, in the interests of including as many instances as possible, was used for multivariate analyses and the categorization of overall disability score.

DISABILITY SCORE

In order to assess the combined impact on survival of several coexisting disabilities, an overall disability score was derived by summing the score assigned to each of the following disabilities: category of movement disorder (hemiplegia=1, diplegia=2, other=3); severity of movement disorder (minimal=0, mild=1, moderate=2, severe=3); severity of cognitive deficit (IQ 50 to 69=1, IQ 35 to 49=2, IQ<35=3); other impairments (blind=1, bilateral deafness=1; current epilepsy=1).

Thus the maximum possible disability score is 12 and the minimum (minimal hemiplegia without other impairment) is 1. The most frequently occurring score was 4 (in 17.2% of individuals).

This scoring system entails assumptions, for example, that the disability conferred by being blind is equal to the disability conferred by increasing one category in IQ deficit or severity of movement disorder. However, it has the advantage of simplicity and reflects therapists' perceptions of overall disability (Blair and Wallman 2000).

Table III: Characteristics of total sample of 2014 persons with CP and of 225 who died

Characteristic	*Total*		*Deaths*	
	n	%	*n*	%
Decade of birth				
1956–65	388	19.2	64	28.4
1966–75	476	23.6	68	30.2
1976–85	543	26.9	49	21.8
1986–94	607	30.1	44	19.5
Sex				
Male	1154	57.3	130	57.8
Female	860	42.7	95	42.2
Plurality of birth				
Multiple	156	7.8	19	8.4
Gestational age at delivery				
>36 weeks	1393	69.2	172	76.4
33–36 weeks	224	11.1	26	11.6
28–32 weeks	247	12.2	7	3.1
<28 weeks	70	3.4	3	1.3
Unknown	80	4	17	7.6
Maternal race				
Indigenous	210	10.4	47	20.9
Non-indigenous	1804	89.6	178	79.1
Type of motor impairment				
Spastic hemiplegia	703	34.9	26	11.6
Spastic diplegia	562	27.9	22	9.8
Spastic quadriplegia	339	16.8	120	53.3
Predominantly non-spastic	301	14.9	54	24
Unknown	9	0.4	3	1.3
Severity of motor impairment				
Minimal	170	8.4	2	0.9
Mild	732	36.3	35	15.6
Moderate	584	29	48	21.3
Severe	470	23.3	135	60
Unknown	58	2.9	5	2.2
Intellectual impairment				
None	1046	51.9	14	6.2
Mild	292	14.5	21	9.3
Moderate	189	9.4	16	7.1
Severe/profound	477	23.7	170	75.6
Unknown	10	0.5	4	1.8
Other impairments				
Ongoing epilepsy	785	39	149	66.2
Blindness	182	9	53	23.6
Bilateral deafness	92	4.6	16	7.1

RACE

Race was classified as indigenous (of Aboriginal or Torres Strait Islander descent) or non-indigenous, according to the race of the mother recorded in the Midwives' Notification of Births, a statutory data collection of all births in the state.

GESTATIONAL AGE

The Cerebral Palsy Register obtains gestational age at delivery from the discharge summary from the hospital of birth or the Midwives' Notification of Births, with priority given to the former in the event of discrepancy. Gestational age was categorized as extremely preterm (20 to 27 weeks), very preterm (28 to 32 weeks), moderately preterm (33 to 36 weeks), term (≥ 37 weeks), or unknown.

STATISTICAL ANALYSIS

Using the 'lifetest' and 'gplot' procedures of SAS software (SAS, version 8) survival curves were constructed for different levels of single variables and inspected visually. The relative risks of mortality and 95% confidence intervals (CI) associated with different levels of a given variable were estimated, as were the simultaneous effects on mortality of coexisting variables, as indicated in the Results section, with the 'risklimits' option of the 'phreg' (proportional hazards regression) procedure of SAS software. Crude mortality rates were estimated by dividing the number of deaths by the number of person-years* in each disability category, and in each 5-year age stratum except the first. Infants with brain damage responsible for severe forms of CP are at high risk of very early mortality and may die before their disability is diagnosed as CP. Preferential ascertainment of survivors would reduce the estimated mortality rate. Thus mortality rates for infants under 1 year of age were estimated separately to those for children from the first to fifth birthday.

Results

The study considered 2014 people with CP born in Western Australia between 1956 and 1994. Of these, 225 were known to have died by 1 June 1997, 71 (31.6%) of whom had received a post-mortem examination. Distributions of decade of birth, sex, plurality of birth, and type and severity of impairment are shown for the whole sample and for deaths in Table III. The crude mortality rate for the whole sample was 6.23 deaths per

*Person-years are estimated by summing the number of years during which a person was at risk of dying over all the people in the category or stratum. The number of years at risk in this study is the number of years from birth either to death or to 31 May 1997, whichever occurred first.

1000 person-years (however this includes infants under 1 year). Table IV shows crude mortality by age and the standardized mortality ratio. Standardized mortality ratios are very high up to the age of 15 years (with the exception of <1 year) and between 4 and 5 times the population rate from 15 to 40 years. Table IV also shows the extent of the data available: there were only 22 person-years of experience for people with CP aged 40 or more, and even in the 4th decade of life, mortality rates are based on very small numbers of deaths.

Figure 1 shows that an estimated 6% of all people with CP died before the age of 5 years and a further 11% between the ages of 5 and 40 years. At older ages, however, survival was estimated from very few individuals.

CAUSE OF DEATH

Cause of death was available for the 151 deaths of people born in 1967 or later. The causes of death are shown in Table I with respiratory causes, accounting for 59%. Respiratory deaths were further categorized as inhalation (n=6, 4% of all deaths), aspiration pneumonia (n=25, 16.6%), other pneumonias (n=56, 37.1%), and asthma (n=2, 1.3%).

CP was considered to be the underlying cause of death in 119 cases (78.8%), not to be an underlying cause in nine individuals (6%), and the relation between CP and cause of death was uncertain in 23 individuals (15.2%).

Death from aspiration pneumonia was associated with profound intellectual deficit, particularly for death after the age of 5 years. The proportion of deaths attributed to aspiration pneumonia increased from 11.9% to 18.8% to 20.5% over the three periods commencing 1967, 1976, and 1986.

Accidental or traumatic causes were responsible for three of the 13 deaths after the age of 18 years but only one of 138 deaths before age 18 years, and the seven deaths attributed to birth defects occurred under the age of 10 years. Otherwise cause of death was not associated with age of death.

UNIVARIATE ANALYSES

Figure 2 shows survival of people with CP stratified by intellectual ability. Of those with profound intellectual disability, it is estimated that 22% die by the age of 5 years and 50% by age

Table IV: Crude and standardized mortality rates per 1000 person-years by age

Age (y)	*Crude mortality (nr deaths/person-years)*	*Standardized mortality ratio*[a]
<1	9.48 (19/2004)	1.7
1–<5	11.56 (87/7526)	38.86
5–<10	6.11 (47/7691)	45.27
10–<15	4.12 (25/6061)	25.78
15–<20	2.96 (14/4725)	5.29
20–<25	3.94 (14/3555)	4.92
25–<30	2.80 (7/2502)	3.33
30–<35	4.15 (6/1447)	4.32
35–<40	5.44 (3/552)	4.77
40+	0 (0/22.1)	0
All ≥ 1 year	5.96 (203/34082)	

[a] Standardized to mean population mortality rates of mid-year age group for males and females in 1995–97 as supplied by Australian Government Actuary on a diskette accompanying 'Australian Life Tables 1995–97' (Australian Prudential Regulatory Authority 1999).

Table V: Crude mortality rates per 1000 person-years by overall disability score for children of 1 to 5 years and of 5 or more years

Overall disability score	*Crude mortality (nr deaths/person-years)*	
	1 to <5 y	*≥ 5 y*
1	0 (0/266)	0 (0/438)
2	0 (0/980)	0.73 (2/2740)
3	1.7 (2/1176)	1.23 (5/4053)
4	0.75 (1/1335)	1.11 (6/5400)
5	3.99 (3/752)	1.28 (4/3129)
6	6.23 (4/642)	3.1 (8/2578)
7	2.19 (1/456)	4.49 (8/1781)
8	22.2 (8/361)	8.5 (12/1411)
9	51.9 (28/540)	14.8 (26/1756)
10	46.7 (23/492)	18.4 (24/1304)
11	59.2 (14/237)	46(15/326)
12	79.8 (3/37.6)	8.2 (1/122)
Missing	0 (0/255)	3.3 (5/1516)
Total	11.56 (87/7526)	4.37 (116/26556)

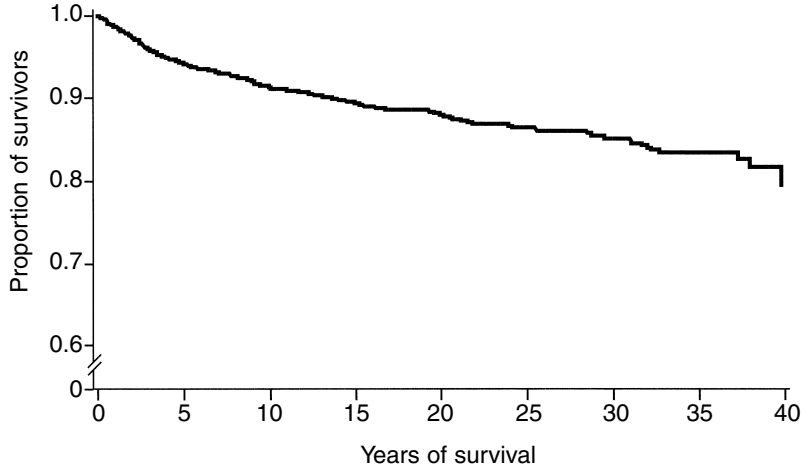


Figure 1: *Survival in people with CP in Western Australia.*

18, compared with 10% and 24% of those with severe intellectual disability and 1.1% and 2.8% of those with a higher intellectual ability. The apparent decline in mortality with age in those with severe impairment may be a chance observation since sample sizes are very small at these ages.

Figure 3 shows that survival correlated inversely with severity of motor impairment.

These measures of impairment are combined in the overall disability score which correlates well with mortality rates (as shown in Table V), stratified by age. This exponential correlation is shown graphically, with 95% CI in Figure 4. Mortality risk increased by 60% for each unit increment in disability score (mortality risk ratio=1.60; 95% CI 1.5 to 1.7).

Figure 5 shows that children with CP born before 33 weeks' gestation tended to survive longer than children born at term or moderately preterm.

Figure 6 shows that survival of indigenous people with CP is significantly shorter than that of non-indigenous people.

There was no association between mortality risk and sex.

MULTIVARIATE ANALYSES

Comparing the effects of severity of motor impairment (as a four-category linear variable) and intellectual ability (as a six-category linear variable) indicated that intellectual ability was a much stronger predictor of mortality, with risk doubling in passing from one category to the next (mortality risk ratio=2.14; 95% CI 1.88 to 2.44). In contrast, the risk of mortality increased by only 39% for each increase in category of severity of motor impairment (mortality risk ratio=1.39; 95% CI 1.14 to 1.71). However, the log linear overall disability model fit the data better than the combination of cognitive and motor disabilities. Adjusting for overall disability score, there was no increased mortality risk for indigenous persons (mortality risk ratio=0.74; 95% CI 0.54 to 1.02). Thus their observed higher mortality must be attributed to greater severity of impairment. Their deaths were more likely to be the result of respiratory causes (69% versus 57%), but this difference was not statistically significant.

Again, adjusting for overall disability score, there was no difference in mortality risk in each of the four decades of birth cohorts (relative to 1986 to 1994 risk ratios were 1956 to 1965 =0.98, 95% CI 0.6 to 1.5; 1966 to 1975=1.18, 95% CI 0.8 to 1.8; and 1976 to 1985=1, 95% CI 0.7 to 1.5; nor of postneonatally acquired instances relative to congenital instances (1.33, 95% CI 0.9 to 1.9; before adjustment and 0.94, 95% CI 0.7 to 1.4; following adjustment for disability score).

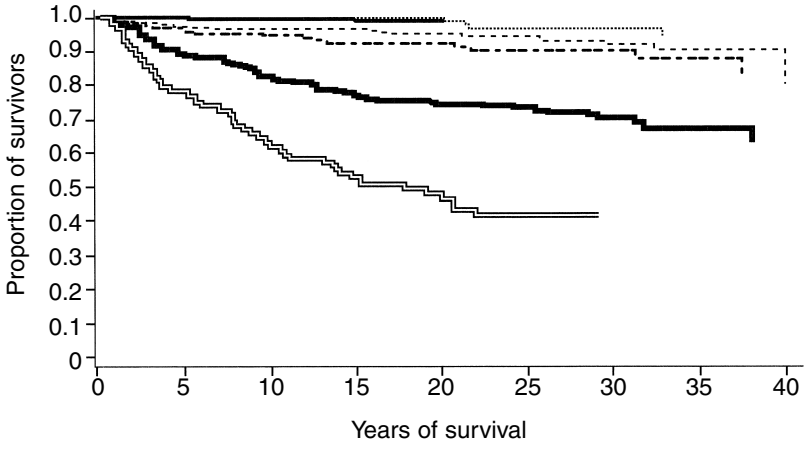


Figure 2: *Survival by intellectual ability.*

IQ>85
IQ 70–85
IQ 50–69
IQ 35–49
IQ 20–34
IQ <20

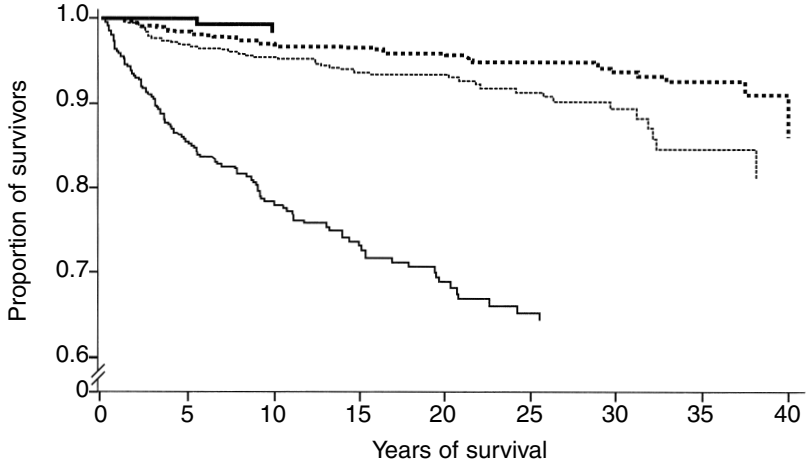


Figure 3: *Survival by severity of CP.*

Levels of severity:

Minimal
Mild
Moderate
Severe

Figure 4: *Survival by overall disability score.*

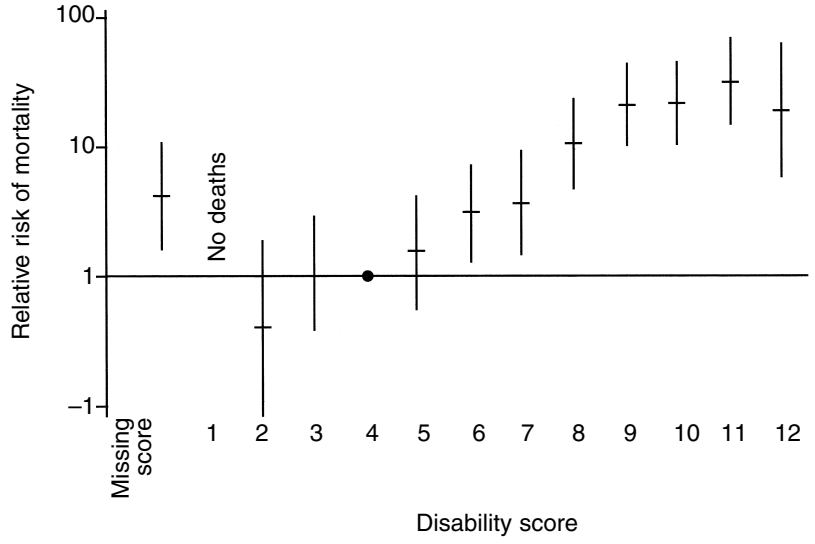


Figure 5: *Survival by gestational age (wks) at delivery.*

- *20–27*
- *28–32*
- *33–36*
- *37–50*

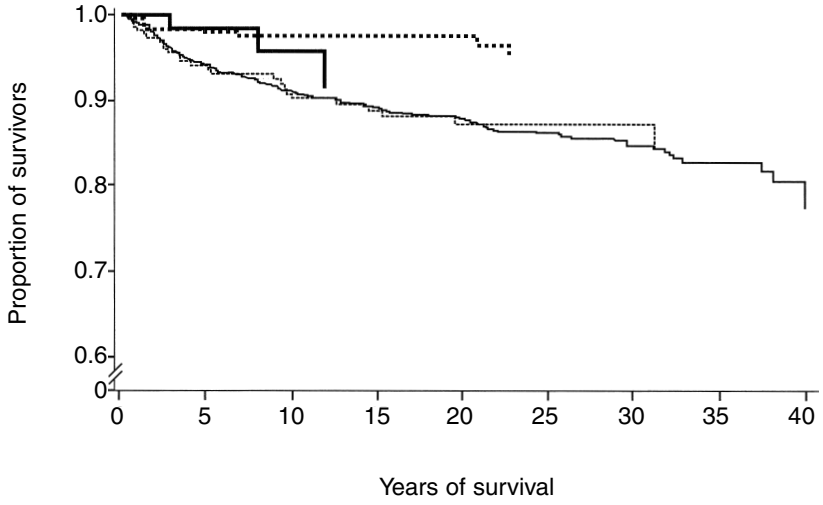
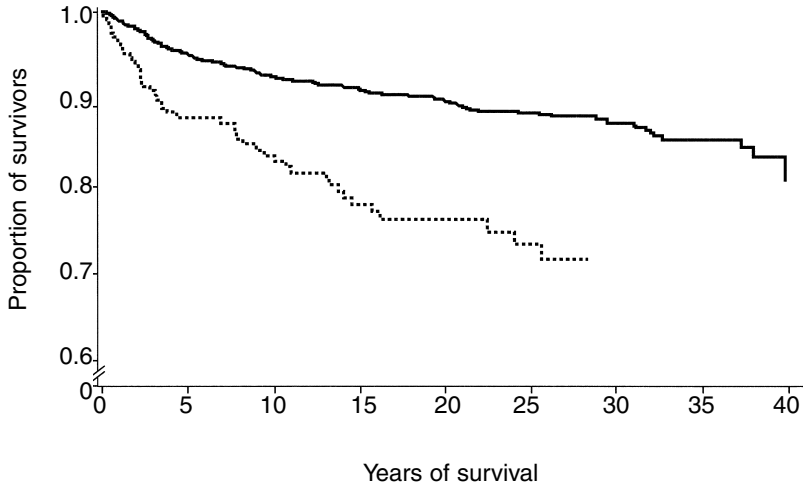


Figure 6: *Survival by mother's race.*

- *Non-indigenous*
- *Indigenous*



Discussion

Our study agrees with other published observations that mortality risk increases with increasing intellectual impairment, motor impairment, and number of severe impairments. Quantitative comparisons are hampered by different categorizations, but our rates may approximate those reported for more recent cohorts by Hutton and colleagues (1994) more closer than the lower mortality rates reported by Crichton and coworkers (1995).

Our observation of the overwhelming contribution of respiratory causes of death and the low rate of cancers contrasts with the Californian observations of Strauss and coworkers (1999) but much less so with the British observations of Maudesley, and colleagues (1999). The origins of these discrepancies undoubtedly lies in the differing age structures of the study samples, increased severity of impairments of later-born cohorts referred to in our introductory section, and possibly in differing community attitudes to those with severe impairments.

Our study suggests that with the exception of those with profound intellectual deficit, most persons with CP can expect to survive to adulthood. Therefore long-term health and social plans need to take this into account. Our data are insufficient to predict accurately the current likelihood of mortality in persons with CP between 18 and 44 years, particularly those with severe impairments. However, there are as yet no data on which to base estimates of life expectancy beyond the fourth decade of life because survival with very severe congenital CP has only been possible since the routine use of antibiotics.

Not surprisingly, CP was recorded as the underlying cause of death in most individuals, and longevity correlated strongly with the degree of intellectual deficit although mortality declined with age through childhood. In 59% of individuals, the immediate cause of death was respiratory problems, and this proportion has not changed over time. Aspiration pneumonia is strongly associated with profound intellectual deficit, and the proportion attributed to this cause is increasing. Status epilepticus was the second most common cause of death and may be associated with severity of both motor and intellectual impairments.

Our severe category for motor impairment covers a wide range, encompassing both the wheelchair-bound person with normal cognitive function who is likely to achieve a reasonable degree of independence and the totally dependent person. Adjustment for severity of impairment using this category cannot adjust for changes in distribution of severity of impairment within the severe category. Since intellectual ability and severity of motor impairment tend to be correlated, the intellectual ability variable, which is available with greater precision, may be acting as a surrogate for severity of motor impairment or of overall disability. Nonetheless the 20% of people with severe motor impairment who have normal or near normal intellect are at low risk of death. The best predictor of life expectancy was the overall disability score that considered all types of impairment.

In contrast with their outcomes in other health arenas, indigenous people have better disability-adjusted life expectancy; however, because their disability tends to be more severe (mean overall disability score 6.3 [95% CI 5.9 to 6.7] compared with 5.2 [95% CI 5.0 to 5.3] in non-indigenous persons), their actual life expectancy is reduced.

The tendency to longer life expectancy of people with CP born very preterm may be explained by their tendency to exhibit milder forms of CP.

We did not find any evidence for increased duration of survival since the 1950s despite advances in medical care. This could be due to artefacts in our data. Collection for the Western Australian Cerebral Palsy Register started in 1977 with registration being confirmed at age 5 years. Thus births before 1975 were ascertained retrospectively, and it is possible that early deaths in these cohorts were under-ascertained. Any such under-ascertainment would decrease both estimated mortality rates and the severity of impairments seen in earlier cohorts.

On the other hand, the same observations are compatible with increasingly sophisticated perinatal care allowing infants with severe impairment to survive long enough to be identified as having CP. Any tendency to increasing severity of impairment would tend to mask any increases in survival over time accruing from improved conditions of care. Both these possible explanations would suggest that there has been increasing survival of infants with brain damage compatible with CP. In the first explanation, the infants were identified as having CP before they died but were not ascertained by the Cerebral Palsy Register, and in the second they died before being identified as having CP. However, we could not identify any systematic increase over time either in mean overall disability score or in the proportion with a score exceeding 8 (range 1 to 12): though both were increased in the 1986 to 1994 period. It may be that our measure of overall disability is insufficiently sensitive to detect a degree of change in the distribution of severity of disability, that is nonetheless sufficient to affect mortality. Alternatively of these four birth cohorts it is only the changes in care experienced by the last cohort that have affected mortality, or possibly the changes in the care that these people receive has not affected their life expectancy in the first four decades of life.

Conclusions

With the exception of those with profound intellectual deficit, most persons with CP survive to adulthood. Survival in persons with CP is strongly associated with degree of intellectual deficit. Mortality declines with age during childhood. There is inadequate data to assess survival in persons with CP beyond the age of 18 years, particularly in those with severe motor or intellectual deficits and no data from which to assess survival beyond 40 years. There is no evidence for any increase in duration of survival since the 1950s.

CP was an underlying cause of death in most instances. The immediate cause of death was respiratory problems in 59% of individuals, and this proportion has not changed over time. Aspiration pneumonia is strongly associated with profound intellectual deficit and the proportion attributed to this cause is increasing which is compatible with an increasing severity of impairment among children described as having CP.

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Note: we agreed to share this paper with Shavelle and colleagues before publication. *See letter page 574.*

Acknowledgements
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Mac Keith Meetings

Customary Consanguineous Marriage (**Closed Meeting**)
Royal Society of Medicine, London, UK. September 4, 2001.
Richard Morton and Bernadette Modell

Catatonia in Childhood (**Closed Meeting**)
Royal Society of Medicine, London, UK. September 26–27, 2001.
Michael Prendergast

Drugs in Pregnancy and their Consequences: Little Foundation Annual Open Meeting
Royal Society of Medicine, London, UK. October 24, 2001.
The Little Foundation with Martin Bax

Asperger Syndrome – Management in Children and Young People (**Open Meeting**)
Royal Society of Medicine, London, UK. January 18, 2002.
Christopher Gillberg and Roger Freeman

Customary Consanguineous Marriage (**Open Meeting**)
Royal Society of Medicine, London, UK. February 4, 2002.
Richard Morton and Bernadette Modell

Menstruation and Fertility in Disability (**Open Meeting**)
Royal Society of Medicine, London, UK. March 22, 2002.
Michael Prendergast and Claire Burns

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