THE LIFE-EXPECTANCY OF PERSONS WITH CEREBRAL PALSY

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Cerebral palsy has been defined as a persistent though not unchanging disorder of movement and posture, appearing early in life and due to a non-progressive lesion of the developing brain (Little Club 1959). It is often associated with other conditions such as mental retardation, epilepsy, and loss of hearing and vision. Little is known about the life-expectancy of people with cerebral palsy, but it is generally assumed to be lower than that of the general population.

Health professionals need reasonably accurate information about life-expectancy so that they may provide better counselling for the families of those with cerebral palsy, as well as better planning for their care, education and employment needs. If long-term survival is to be expected for the majority of people with cerebral palsy, including the most severely disabled, this has significant implications for the resources needed to provide for them. This aspect of the natural history of cerebral palsy was raised by Ingram *et al.* (1964), in their discussion of the provision of care in the east of Scotland.

A few studies have analysed survival rates of people with cerebral palsy. Kudrajavcev *et al.* (1985) studied 64 children with cerebral palsy up to the age of 10 years and found that 10 per cent died within the first 10 years. All those who died had been severely mentally disabled. 54 per cent of this subgroup survived to the age of 10 years, while 32 per cent died within the first five years. 19 per cent of the cohort of 69 children with cerebral palsy studied by von Wendt *et al.* (1985) had died by the age of 14 years. Evans *et al.* (1990) studied a regional registry of cases of cerebral palsy and stated that the majority of even the most severely affected now reached adulthood, with 90 per cent of these children surviving to the age of 10 years. At 10 years the survival rate for children with quadriplegia—the most severe form of cerebral palsy—was 80 per cent. No child with normal intelligence died, compared with 21 per cent in the group with severe retardation.

These relatively short-term studies have suggested that the most important factors influencing survival are the presence of severe mental disability and reduced mobility.

Recent large studies have used data from a service usage agency in California (Eyman *et al.* 1990, 1993). It is hard to analyse their figures accurately because they defined their study group according to developmental disability, but 78.5 per cent of them were considered to have cerebral palsy. Most of the older subjects were mostly victims of accidents. Life-expectancy figures derived from these

data indicate that severe retardation, inability to feed oneself and lack of mobility were the chief factors associated with lower life-expectancy. In the later study (Eyman *et al.* 1993), in which at least 43.9 per cent of the study group had cerebral palsy, the lack of mobility and the lack of hand/arm use were further identified as risk factors. Those who fell into these risk categories had much shorter survival times.

Method

In British Columbia, which has a population of approximately 3½ million, a population-based Health Surveillance Registry serving the entire population has been collecting data since 1952. Data on disabled individuals are collected from many sources, including special schools and institutions, public health units, hospital discharge records of children under the age of seven years, and the agency of the provincial government which distributes allowances to disabled people from the age of 18 years (Baird 1987). The Registry uses the ICD-9 diagnostic codes (World Health Organization 1978).

Our study cohort consisted of all cases of cerebral palsy reported to the Registry born between 1952 and 1989. The classification of cerebral palsy is not possible from a neuropathological viewpoint, so a clinical classification has been used (Aicardi 1992), modified to correspond to that of Crothers and Paine (1959). Four categories were identified: (1) spastic quadriplegia and diplegia (QD), (2) hemiplegia and monoplegia (HM), (3) athetosis (A), and (4) other forms (MISC). Unfortunately, as Mutch *et al.* (1992) admitted when they attempted to classify the different types of cerebral palsy, all methods of data collection rely on 'fine clinical judgements' and therefore patients with similar disabilities may be categorized in different ways. Their team included Professor Bengt Hagberg, and quoted his earlier statement about the 'weakness of the dividing line between the tetraplegias and the diplegias'. While we agree that there are similarities between the clinical and pathological manifestations of these types of cerebral palsy, the World Health Organization (1978) has said that it is valid to distinguish between the two; therefore we analysed our data in accordance with this, in order to show clearly the effect of mobility on prognosis. Despite several attempts by Mutch *et al.* (1992) to improve the classification of cerebral palsy from an epidemiological point of view, we think that the older classification of Crothers and Paine (1959) remains clinically valid.

The classification of epilepsy has been condensed and simplified to compensate for the difficulty of accurate classification used in comprehensive studies of epilepsy (*e.g.* Aicardi 1992). We have used four categories of epilepsy: (1) generalized seizures, (2) partial epilepsy, with or without secondary generalization, (3) infantile spasms and (4) unclassified forms. Mental retardation has also proved difficult to categorize accurately according to the definitions used in the ICD-9 (World Health Organization 1978). We therefore divided our cases into three categories of mental retardation: (1) non-existent or mild, (2) moderate, and (3) severe or profound. The Registry lists these disabilities, among others, and the records are continuously updated as information becomes available.

The Division of Vital Statistics of the Ministry of Health in British Columbia has produced a series of programs to extract the annual records from the Health Surveillance Registry. Although there is now computer cross-checking of cases against death records, due to the age of the computer registry, before 1989 this was done manually four times a year. Where information about deaths was missing, extensive manual searches were performed, resulting in complete information on the date and cause of death for 98 per cent of the cases. Finally, further programs were written to link birth data and information about deaths. This information was then downloaded to a personal computer database file.

Data analysis

In order to assess possible birth-cohort effects on life-expectancy, the sample was subdivided into four cohorts according to whether the subjects had been born in the 1950s, the 1960s, the 1970s or the 1980s, and a log rank test was used to

TABLE I
Demographics

	Median	*25th centile*	*75th centile*
Age at registration (yrs)	2.4	1.2	5.1
Duration of disability (yrs)			
Survivors	23	14	30
Non-survivors	8	3	15
Overall	21	12	30

assess differences in survival rates.

Kaplan–Meier survival function plots (Kalbfleisch and Prentice 1980) were used to display these data for the various classifications of the major prognostic factors, *i.e.* the type or degree of cerebral palsy, epilepsy and mental retardation. The individual classification categories of a prognostic factor were first compared globally using a log rank test to see if there were overall differences in survival rates. When a significant overall difference for a factor was detected, the individual classification categories were compared in a pairwise manner to find approximately homogeneous classifications. Because this method of multiple testing leads to an increased number of type I errors (false-positive differences), a Bonferroni correction factor was applied to the pairwise log rank tests (Miller 1985), with the multiplier being the number of comparisons made for the factor. These revised factors, which generally have fewer levels, were used in the more detailed analysis.

In order to examine the possible synergistic or antagonistic effects (statistical interactions) of the revised factors on survival time, Cox's proportional hazards model was used (Kalbfleisch and Prentice 1980). This method assumes that the survival function over time is the consequence of a baseline survival function which is modified by the effect of the prognostic factors. When the death rate (*i.e.* the hazard function) is used instead of the survival function, the equivalent formulation of the model states that the effect of prognostic factors on the hazard at any time is to modify the baseline hazard in a multiplicative manner (proportionally). In particular, the effect of a prognostic factor can be assessed by considering the ratio of the hazard in the presence of the prognostic factor to that without it (the hazard ratio). Like the previous methods, Cox's model allows for the fact that some subjects may still be alive at the end of the period and so cannot contribute risk information beyond this point. (This is known as 'right-censoring'.) The proportionality assumption of this model was checked by reviewing the log(-log) plots of the Kaplan–Meier survival plots for the factor levels and by estimating the possible interaction of time on a log scale with the factor. Because of the large number of risk sets in these data, a 30 per cent random sample was used to determine these time-dependent interactions.

Standard life-survival probabilities with standard errors, using 10-year intervals, were used to quantify the chance of surviving from one decade of life to another and the cumulative probability of surviving to the end of a decade (see Table IV). Because all the cases were born within a 38-year period and the data were heavily right-censored (*i.e.* the fate of each individual surviving beyond the date of the study was not known), there is no information on the risks for the longer-surviving cases. Since nothing can be inferred about the risks in later life, it is not possible to estimate an average life-expectancy. The statistical packages SPSS for Windows (Norusis 1992) and EGRET (1991) were used to analyse the data.

Results

When the above criteria were applied, a total of 3189 cases were identified. Two were excluded because of insufficient information about date of birth, leaving

TABLE II
Factors influencing survival in subjects with cerebral palsy

Factor	*Total*	*Deaths*		*Survivors*	
		N	*(%)*	*N*	*(%)*
Sex					
Female	1454	142	(10)	1312	(90)
Male	1733	181	(10)	1522	(90)
Type of cerebral palsy					
Quadriplegia or diplegia	1169	146	(17)	1023	(83)
Diplegia	412	19	(5)	393	(95)
Quadriplegia	757	127	(17)	630	(83)
Hemiplegia or monoplegia	835	33	(4)	802	(96)
Other or unspecified	1003	124	(12)	879	(87)
Epilepsy					
Non-existent	2440	200	(12)	2240	(88)
Generalized	162	30	(18.5)	132	(81.5)
Partial	41	2	(5)	39	(95)
Infantile spasms	19	3	(16)	16	(84)
Unspecified	525	88	(17)	437	(83)
Mental retardation					
None or mild	2552	165	(6.5)	2387	(93.5)
Moderate	118	3	(2.5)	115	(97.5)
Severe or profound	517	155	(30)	362	(70)

3187 cases to form the cohort.

By the end of the study period (31st December 1989), 142 of the 1454 females (9.8 per cent) and 181 of the 1735 males (9.6 per cent) had died. As shown in Table I, the median age at first registration was 2.4 years and the median Registry-recorded time was 21 years. Since the Registry had not recorded anyone for longer than 38 years and there was 90 per cent right-censoring (*i.e.* only 10 per cent of the population had died during the period), caution must be exercised when extrapolating results beyond 38 years.

Initially the major prognostic factors (*i.e.* sex and type or degree of cerebral palsy, epilepsy and mental retardation) were considered separately. Table II shows the number of cases and the number of deaths in each category. There was no sign of a birth-cohort effect as measured by the decade of birth (p=0.6).

The relationships within these four parameters yielded the following results.

Sex

There was no apparent difference in survival times between the sexes (p=0.5).

Cerebral palsy

Kaplan–Meier plots of the survival for the four groups are displayed in Figure 1. Those in group 2 (HM) fared significantly better than those in the other groups (p<0.004), while there was no evidence of differences between the other groups (p>0.9). For the purposes of further analysis, group 2 (HM) was compared with the others, which gave a hazard ratio for the others to group 2 of 3.3 (95% CI 2.3, 4.7).

The difference between the diplegic and the quadriplegic cases, which from an etiological viewpoint we considered as one group, is shown in Table II and in Figure 2.

Epilepsy

Figure 3 shows the Kaplan–Meier plots of survival for the four types classified. Because there were only two and three deaths, respectively, among those with partial epilepsy or infantile spasms, these cases were excluded from comparison. There was no difference between the other two groups (p>0.9). However, there was significant evidence of a difference between those without epilepsy and those

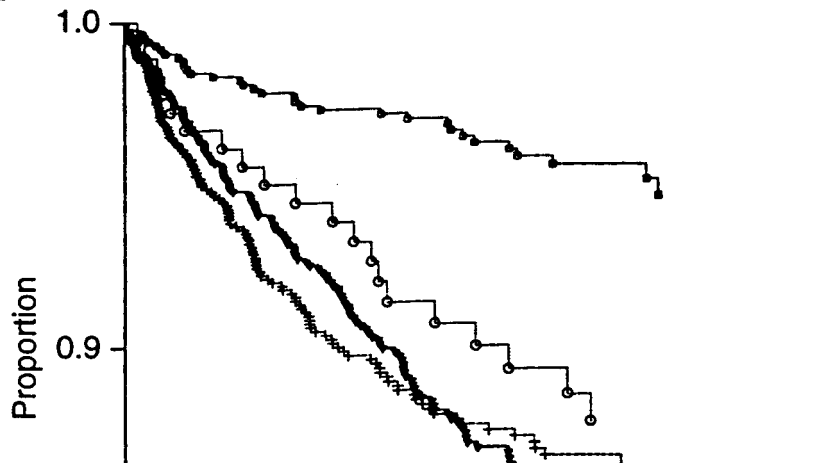

Fig. 1. Relation of type of cerebral palsy to proportion of persons surviving for up to 38 years.

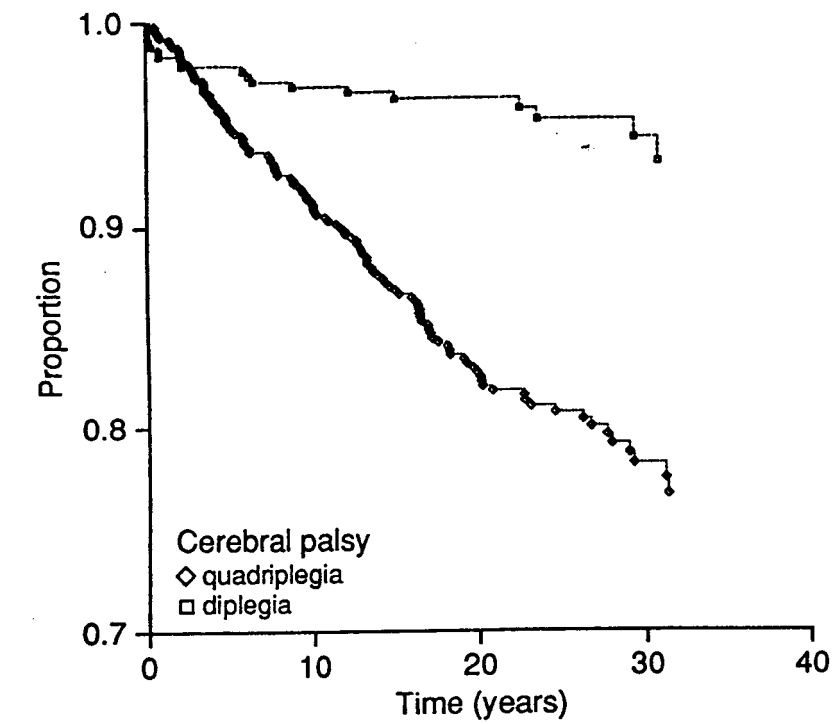

Fig. 2 Relation of spastic quadriplegia and spastic diplegia to proportion of persons surviving for up to 38 years.

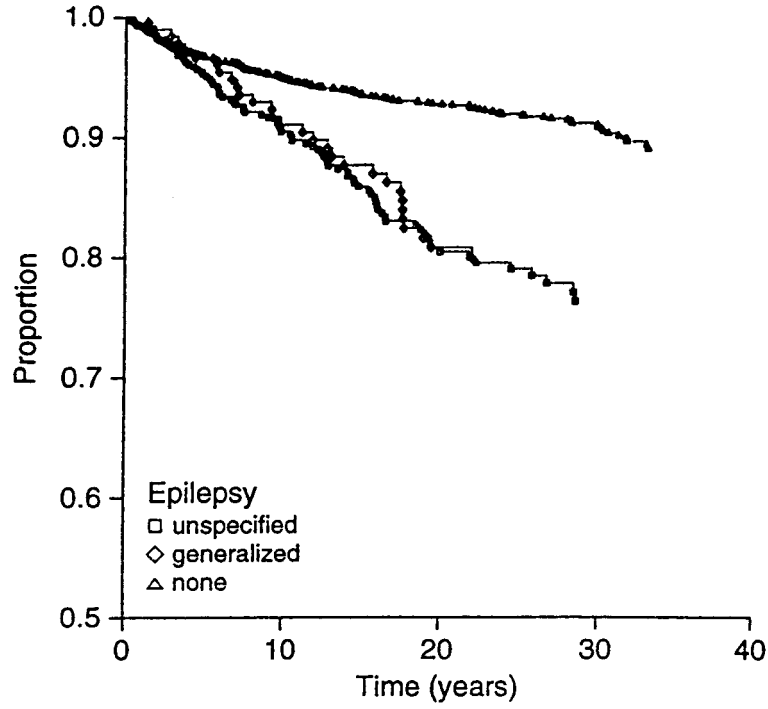

Fig. 3. Relation of type of epilepsy to proportion of persons surviving for times up to 38 years. For sake of clarity, data referring to partial epilepsy (N=41) and infantile spasms (N=19) have been omitted.

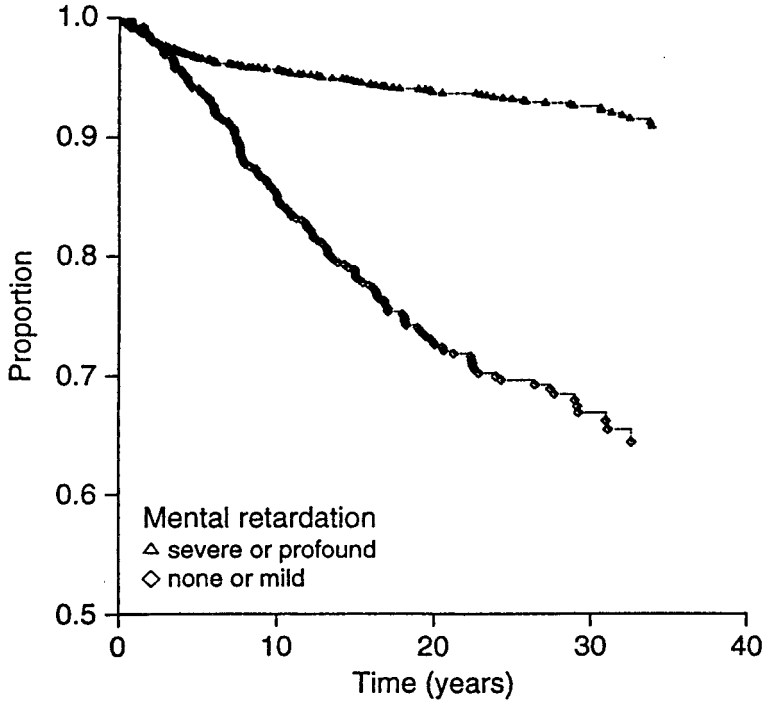

Fig. 4. Relation of severity of mental retardation to proportion of persons surviving for times up to 38 years. There were only three deaths in 'moderate' category and they have been omitted from this graph.

TABLE III
Inter-relationship of prognostic factors in subjects with cerebral palsy

Factor[1]	*Total*	*Deaths*		*Survivors*	
		N	*(%)*	*N*	*(%)*
Cerebral palsy/epilepsy					
HM, no EP	614	21	(3.4)	593	(96.6)
HM and EP	221	12	(5.4)	209	(94.6)
No HM or EP	1826	179	(9.8)	1647	(90.2)
EP but no HM	526	111	(21.1)	415	(78.9)
Cerebral palsy/mental retardation					
HM, no MR	784	26	(3.3)	758	(96.7)
HM and MR	51	7	(13.7)	44	(86.3)
No HM or MR	1886	142	(7.5)	1744	(92.5)
MR but no HM	466	148	(31.8)	318	(68.2)
Mental retardation/epilepsy					
MR, no EP	268	74	(27.6)	194	(72.4)
MR and EP	249	81	(32.5)	168	(67.5)
No MR or EP	2172	126	(5.8)	2046	(94.2)
EP but no MR	498	42	(8.4)	456	(91.6)

[1]HM = hemiplegic or monoplegic cerebral palsy; EP = epilepsy; MR = mental retardation. [2]Profound or severe *vs* none to moderate.

in group 1 ($p<0.0003$) or group 4 ($p<0.0003$), so for the purposes of further analysis it seems reasonable to treat epilepsy as a homogeneous prognostic factor. The hazard ratio for epilepsy was 2.2 (95% CI 1.8, 2.8).

MENTAL RETARDATION

Survival plots for the three group classifications are shown in Figure 4. The 'moderate' category, in which there were only three deaths, was omitted for clarity. No mildly retarded cases were registered. There was evidence ($p<0.0001$) of a difference in survival between those with non-existent or mild mental retardation and those with severe to profound retardation. In order to maintain large strata sizes in multifactor analysis, only severe to profound mental retardation was considered and the others were combined with those with no retardation. The hazard ratio for severe to profound mental retardation to the rest was 4.7 (95% CI 3.8, 5.8).

The above hazard ratios showed that the strongest association with reduced survival was that of severe to profound mental retardation, followed by cerebral palsy other than HM, followed by epilepsy.

With such a large data set it was possible to investigate whether there were synergistic or antagonistic combinations (interactions) of prognostic factors that could have affected survival. The number of cases and the number of deaths in each stratum of the pairwise cross-classification of factors is displayed in Table III.

There was no evidence to suggest that combinations of the prognostic factors had any synergistic or antagonistic effects ($p>0.2$)* over and above their individual contributions to survival. In particular, each can be considered an independent predictor of survival ($p<0.0005$ for all factors).

The probability of surviving each decade of life is displayed in the fourth column of Table IV for the overall population as well as for those in the revised classification of prognostic factors. The

*A review of log(–log) plots of the Kaplan–Meier survival functions with factor stratification gave no reason to suspect that the proportional hazards assumption of Cox's model were violated for any of the prognostic factors. Some evidence of a time interaction with mental retardation ($p<0.02$) was revealed, but this was not considered important in view of the similar patterns in the log(–log) plots for all factors and the relatively large sample size.

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TABLE IV
Probability of survival from one decade to the next

	Age-range (yrs)	*N at start of decade*	*N deaths during decade*	*Proportion surviving this decade*	*SE*	*Cumulative proportion surviving to date*	*S.E.*
Cerebral palsy							
Hemiplegia or monoplegia	0–9	835	18	97.7	0.005	97.7	0.005
	10–19	695	9	98.5	0.005	96.2	0.007
	20–29	495	4	98.9	0.006	95.2	0.009
	30–39	225	2	98.2	0.012	93.5	0.015
Other	0–9	2352	168	92.4	0.006	92.4	0.006
	10–19	1891	88	94.5	0.006	87.3	0.008
	20–29	1227	26	97.1	0.006	84.8	0.009
	30–39	530	8	97.0	0.010	82.2	0.012
Epilepsy							
None	0–9	2440	126	94.5	0.005	94.5	0.005
	10–19	2022	44	97.5	0.004	92.1	0.006
	20–29	1393	20	98.0	0.004	90.3	0.007
	30–39	623	10	96.8	0.010	87.4	0.011
Any	0–9	747	60	91.3	0.011	91.3	0.011
	10–19	564	53	88.8	0.015	81.0	0.016
	20–29	329	10	95.8	0.013	77.6	0.019
	30–39	132	0	100.0	—	77.6	0.019
Mental retardation							
Non-existent to moderate	0–9	2670	111	95.5	0.004	95.5	0.004
	10–19	2158	38	97.9	0.003	93.5	0.005
	20–29	1420	12	98.8	0.003	92.4	0.006
	30–39	637	7	97.8	0.008	90.4	0.010
Severe to profound	0–9	517	75	85.3	0.016	85.3	0.016
	10–19	428	59	85.0	0.018	72.6	0.020
	20–29	302	18	91.8	0.019	66.6	0.023
	30–39	118	3	95.0	0.028	63.3	0.029
Overall							
	0–9	3187	186	93.8	0.004	93.8	0.004
	10–19	2586	97	95.6	0.004	89.6	0.006
	20–29	1722	30	97.6	0.004	87.4	0.007
	30–39	755	10	97.4	0.008	85.2	0.010

fifth column lists the cumulative survival of the current and preceding decades of life.

Discussion

The Registry was instituted early in the computer age, and since it had been in existence for only 38 years before the data were summarized, longer-term survival rates will not be available for some years yet. However, the data presented here give some idea of medium-term survival rates. Our reasons for not extrapolating the data beyond 30 years are given above. The methods of assessing survival rates, for reasons also explained above, make it impractical to make comparisons with the data of Eyman *et al.* (1993). However, accepting that severity of cerebral palsy is related to mobility and hand–arm use, the survival rates in this study are compatible with their data.

The population of British Columbia, while largely of European origin, is not homogeneous, since it contains substantial numbers of persons of Asian origin and (perhaps more relevant here) a substantial native American population which is largely rural. The data did not allow these populations to be compared, and although many different sources were used, the data represent minimum ascertainment figures (as is the case with most registries). It was not possible to estimate the number of cases which had been missed, but it seems unlikely to be very

large, given that individuals with cerebral palsy use a number of different services provided by the Ministries of Health and Social Services, and would thereby be registered.

Clearly some cases have been lost to follow-up. However, there is reason to believe that this number is small, given the follow-up procedures and the unlikelihood of a disabled person emigrating to another country.

Approaches to the management of cerebral palsy have changed considerably over the years of this study. In the 1950s and 1960s, much more emphasis was placed on institutional care of such patients, whereas nowadays the emphasis is on home care, group homes or institutional care on a short-term basis, perhaps as a respite mechanism. It was not possible from these data to indicate whether or not this had any effect on longevity.

The data demonstrate clearly the adverse effect of mental retardation and epilepsy on survival. The lack of mobility may also have had an adverse effect. Newer factors which might influence length of survival include technical advances such as gastrostomy feeding, advanced antibiotic treatment and technical improvement in the management of respiratory infections. It will not be possible to evaluate the effect of these changes on long-term survival for a number of years, but it appears that the overall survival rate at 30 years is at least 87 per cent.

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RÉSUMÉ
Espérance de vie chez les IMC/IMOC
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ZUSAMMENFASSUNG
Lebenserwartung von Personen mit Cerebralparese
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RESUMEN
Expectativas de vida de personas con parálisis cerebral
Se calculó el porcentaje de supervivencias de personas con paràlisis cerebral utilizando la información suministrada por un registro de una población base, cuyos datos se habia recogido a partir de 1952. El porcentaje de supervivencia a los 30 años de edad era aproximadamente del 87 por ciento. Los factores que afectan negativamente la supervivencia son ciertos tipos de paràlisis cerebral (la que tiene peor pronóstico es la cudriplejia espástica), la epilepsis y un retraso mental profundo o grave. El largo tiempo durante el cual se recogieron los datos, impide hacer la estimación más allá de los 30 años.

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