Survival at 19 years of age in a total population of children and young people with cerebral palsy

LENA WESTBOM[1] | LINDA BERGSTRAND[1] | PHILIPPE WAGNER[2] | EVA NORDMARK[3]

1 Department of Clinical Sciences Lund, Division of Paediatrics, Lund University. **2** National Competence Centre for Musculoskeletal Disorders, Lund University Hospital. **3** Department of Health Sciences, Medical Faculty, Lund University, Sweden.

Correspondence to Dr Lena Westbom at Department of Clinical Sciences Lund, Division of Paediatrics, Lund University, SE-221 00 Lund, Sweden. E-mail: lena.westbom@med.lu.se

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AIM The aims were to investigate survival of children with cerebral palsy (CP) and to search for modifiable factors that influence survival in CP.

METHOD The total population of children with CP in southern Sweden born between 1990 and 2005, and followed from 1994 to 2010 comprised 718 children. The study included 708 of these children (297 females, 411 males) participating in a secondary prevention programme. CP subtype, Gross Motor Function Classification System (GMFCS) levels, and comorbidities were described. Kaplan–Meier survival curves were plotted. The following factors were investigated using Cox regression analysis: GMFCS level (co-varies with overall health), size of health care catchment area, gastrostomy feeding, and sex.

RESULTS The estimated survival at 19 years of age was 60% in children with the most severe gross motor limitations (GMFCS level V). Death occurred throughout childhood. All children at GMFCS level I or II, and 96% of the whole CP population, survived. The mortality risk in childhood CP was three times higher in catchment areas that covered small populations than in areas with a large population. Gastrostomy feeding was associated with a ninefold increased risk of dying, regardless of GMFCS level and catchment area.

INTERPRETATION Fragile children with CP, as indicated by GMFCS level V and gastrostomy feeding, had the lowest chance of surviving childhood. Health care catchment area seemed to influence survival rate.

Improved quality of life, especially by reducing painful hip dislocation and severe contractures, is the main priority of the Swedish secondary prevention follow-up programme (Swedish National Health Care Quality Programme for prevention of hip dislocation and severe contractures in Cerebral Palsy [CPUP]) for individuals with cerebral palsy (CP). The programme was instituted in the southern-most counties of Sweden (Skåne and Blekinge) in 1994. Other aims of the programme are to describe the 'natural' course of functioning and development in CP, to evaluate treatment methods, and to increase cooperation between health care professionals. CPUP has been effective.[1–3] In 2005, it was approved as a national health care quality registry by the Swedish National Board of Health and Welfare. Since 2007, children throughout Sweden have participated in the programme. CPUP is well known internationally and has been implemented in Norway, Denmark, and Iceland.

Inventories of children living in Skåne and Blekinge have been performed regularly in order to identify and offer participation in the CPUP programme to all children with CP. The prevalence of CP was found to be 2.4 to 2.6 per 1000. The prevalence and the distribution of CP subtypes and Gross Motor Function Classification System (GMFCS) levels, have been described in previous papers.[4–6] An unpublished study carried out in Skåne and Blekinge in 2002 found that children with CP living in health care catchment areas with a small population were more often undernourished, regardless of whether or not they had a gastrostomy, than those living in areas with large populations.

In the present study we wanted to investigate the survival of children and young people with CP in the total population of Skåne and Blekinge born between 1990 and 2005.

Another aim was to identify factors that affect survival in children with CP, especially factors that can be influenced by different interventions, such as nutritional support.

The specific research questions were: (1) What proportion of children with CP born between 1990 and 2005, living in Skåne and Blekinge at any time, survived until 31st January 2010? (2) At what age did the children die, and what were the causes of death? (3) What was the distribution of demographic factors (sex, country of birth, place of residence), disorders (CP subtypes, epilepsy, hydrocephalus), level of functioning (gross motor, cognitive), and complications of CP (hip dislocation, scoliosis) in the surviving children and in those who died?

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(4) What was the hazard ratio for mortality by size of the health care catchment area population, GMFCS level, having a gastrostomy, and sex?

METHOD

CP was defined according to Mutch et al.[7] Children who died before their second birthday were not included according to the CP definition used. Other exclusion and inclusion criteria were in accordance with the Surveillance of Cerebral Palsy in Europe (SCPE).[8] Children with motor impairment and specific neurological signs (ataxia, dyskinesia and/or spasticity) caused by different genetic syndromes without progressive brain dysfunction were included. Children with pure hypotonia after 3 years of age were excluded according to the definition of CP used.

All children with CP born from 1990 to 2005 were included if they lived or had lived in the counties of Skåne and Blekinge at any time from birth up until 31st January 2010. A total of 718 children with a confirmed CP diagnosis fulfilled these inclusion criteria. Five of these children had moved abroad, and their health status in January 2010 was unknown.

The parents of 10 children declined to participate in the CPUP follow-up programme. Year of birth, sex, home district, and CP subtype in these 10 children did not differ from the participating group of children and they were all alive at 31st January 2010.

The 708 CPUP participants with CP (297 females, 411 males) were all living with their biological or foster families. Half of them (54%) lived in small-population health care catchment areas; 14% were born abroad. Fourteen per cent were classified in level V of the GMFCS. This, and the distribution of CP subtypes and comorbidities are presented in Table I. Nine per cent of the children had shunted hydrocephalus, and 13% had a gastrostomy. The hip prevention programme was not available to children born between 1990 and 1992. Hip dislocation and scoliosis affected 1.7% and 4.4% of the study population respectively. In January 2010 the total population of the study area was 1.4 million, of whom 253 088 were born between 1990 and 2005.[9]

The geographical area was divided into 12 health care catchment areas, all with paediatric outpatient clinics. A child and youth habilitation unit in each catchment area offered specialized multidisciplinary services to about 2% of the child population with a range of developmental disabilities. Five of the catchment areas had a hospital with paediatric in-patient wards. Two of them were tertiary hospitals located in the two most heavily populated catchment areas, Malmö and Lund.

At the end of the study on 31 January 2010, the number of inhabitants who were born between 1990 and 2005 was 61 620, 47 112, and 39 569 in three 'large' catchment areas. In nine 'small' catchment areas, the median number of inhabitants born between 1990 and 2005 was 16 388 (range 12 869–24 707).[9]

The following multiple sources of information about the child population were used during the study: the Swedish population register, the CPUP database including reports from the child's occupational therapists and physiotherapists, hip and scoliosis radiographs according to the CPUP prevention programme, and neuropaediatric reports from 1998, 2002, 2006, and 2010. The health and functioning of the children were ascertained as close as possible to 31st January 2010. Most death certificates were unavailable, but in many medical records the cause and manner of death were described, as were autopsy findings.

The CP subtype was classified at 4 to 7 years of age, according to the Swedish classification based on the dominant neurological sign.[10] Spastic tetraplegia is defined as massive total motor disability involving all four limbs, with the upper limbs disabled to at least the same degree as the lower ones. All spasticity dominated cases in which the lower limbs were more

What this paper adds

- Survival rates for a total child population with CP, classified according to GMFCS level and subtype, and followed from 1994 to 2010, are documented.
- Mortality risks for children with CP differ between health care catchment areas.
- This article indicates that changes in service provision could affect survival.

Table I: Characteristics of the study population with cerebral palsy (CP): 708 children born 1990–2005 followed until 31st January 2010

	Total children, *n* (%)	Missing information, *n* (%)	Deceased children, *n* (%)
Sex		–	
Female	297 (42)		13 (43)
Male	411 (58)		17 (57)
Born abroad		–	
Yes	102 (14)		1 (3)
No	606 (86)		29 (97)
Catchment area population		–	
Small	382 (54)		23 (77)
Large	326 (46)		7 (23)
GMFCS level		1 (0.1)	
I–IV	605 (86)		5 (17)
V	102 (14)		25 (83)
CP subtype		–	
Spastic hemiplegia	211 (30)		0 (0)
Spastic diplegia	257 (36)		4 (13)
Spastic tetraplegia	27 (4)		12 (40)
Dyskinetic	120 (17)		13 (43)
Ataxic	81 (11)		0 (0)
Mixed	12 (2)		1 (3)
Epilepsy		–	
Yes	258 (36)		26 (87)
No	450 (64)		4 (13)
Cognition		35 (5)	
IQ ≥50	494 (70)		5 (17)
IQ <50	179 (25)		25 (83)
Hip dislocation		–	
Yes	12 (2)		5 (17)
No	696 (98)		25 (83)
Scoliosis		–	
Yes	31 (4)		12 (40)
No	677 (96)		18 (60)
Shunted hydrocephalus		–	
Yes	64 (9)		5 (17)
No	644 (91)		25 (83)
Gastrostomy		–	
Yes	91 (13)		23 (73)
No	617 (87)		7 (27)

GMFCS, Gross Motor Function Classification System.

affected than the upper limbs were assigned to the spastic diplegic CP type; this included children with substantial involvement of the upper limbs as well as asymmetrical involvement of the left and right side of the body. These two syndromes are included in the SCPE term 'bilateral spastic CP'.[8] Unilateral spastic CP is the SCPE term for spastic hemiplegia in the Swedish classification. The ataxic and dyskinetic types of CP were not further subdivided.

Gross motor function was determined according to the GMFCS, which comprises five levels.[11] The most severe functional limitation is level V, with difficulties controlling head and trunk posture in most positions, and severely limited or no voluntary control of movement.

Epilepsy was defined as having had at least two unprovoked seizures after the neonatal period. Cognitive level was subdivided into severe learning disabilities,* corresponding to an IQ level below 50 or a higher cognitive level. Hip dislocation was defined as a Reimers' index of 100% in at least one hip.[12] Scoliosis was defined as Cobb angle >40° or operated scoliosis.[13]

Statistical analysis

The mortality rate was dependent on the severity of CP and was closely correlated with GMFCS level.[14] Therefore, and owing to a multiplicity of issues, the data presented in Table I were described without setting up any previous hypothesis to test the connection between mortality and the different comorbidity variables separately.

Cox regression analysis was used to explore the hazard ratios for mortality in children with CP who were living in a small-population health care catchment area; children who were living in a small-population health care catchment area and with motor function classified as GMFCS level V; and children who were living in a small-population health care catchment area with motor function classified as GMFCS level V and with a gastrostomy. Having a gastrostomy was included in the statistical model as a time-varying covariate. Finally, the mortality hazard ratio for males compared with females with CP was explored in the regression analysis. Inclusion was done sequentially in order to assess possible confounding. The 95% confidence intervals (CIs) were calculated for all hazard ratio estimates.

The small number of deceased children with gross motor function better than GMFCS level V governed the dichotomization of the GMFCS levels and reduced the number of factors that could be tested in the regression analysis. The size of the catchment area was chosen as the first factor, as a previous study in the region had indicated more malnourishment in 'small' catchment areas. GMFCS level was chosen to mirror the 'case mix'. Gastrostomy was included in the regression analysis, presuming a special importance for survival. Sex was included to discover any unjust sex differences in health care provision.

Additionally, Kaplan–Meier survival curves were plotted for groups of children in GMFCS level V and GMFCS levels I to IV.

*North American usage: mental retardation.

The study was approved by the Medical Research Ethics Committee at Lund University.

RESULTS

In this total child population 96% of all children with CP born between 1990 and 2005 survived (683 of 713), whereas 30 (4%) had died by 31st January 2010. The majority of the deceased children had epilepsy and severe motor and cognitive disability (Table I). Of the 30 children who died, 27 had a gastrostomy.

The most recent gross motor function levels of the children before death were GMFCS III in two, GMFCS IV in three, and GMFCS V in 25 children. All children in GMFCS levels I to II were alive in January 2010, as were all children with spastic hemiplegic (GMFCS levels I–IV) and ataxic CP (GMFCS levels I–V). Children with spastic tetraplegia (GMFCS level V) and dyskinetic CP (GMFCS levels I–V) had the highest mortality rates. Four children with spastic diplegia died, of whom two with hydrocephalus and severe learning disability died because of shunt problems (GMFCS levels III and IV). The other two had good cognitive function (GMFCS levels III and V) and both had an unknown cause of death (Table II).

The cause of death remained unknown in 12 cases, even after autopsy. Pneumonia was the most common cause of death in those with a known cause (eight children). One of the deaths due to aspiration pneumonia occurred after a small operation in a child with a known preoperative respiratory insufficiency. The other causes are described in Table II, as is location of death (15 children died at home and 11 in hospital, of whom six died in tertiary hospitals).

Most of the children were found dead in their beds. Some of these were known to have suffered episodes of hypopnoea, central or obstructive, and/or epilepsy. Two children had peritonitis, in one case caused by a shunt infection, the other arising from a ventricular perforation caused by the child's gastrostomy.

The Kaplan–Meier survival curves in Figure 1 describe the chance of survival with age based on the study population classified according to GMFCS levels. The probability of survival to 19 years of age in children with GMFCS level V was 60% compared with a very high survival in children with better gross motor function.

The proportion of deceased children living in small-population health care catchment areas was high (Table I), and the Cox regression analysis showed a higher hazard ratio (HR) of death for them (HR 2.89; 95% CI 1.24–6.75). Adding the most severe disability level, as indicated by GMFCS level V, to the analysis did not change the result, nor did adding gastrostomy or sex (Table III). On the other hand, the Cox regression analysis showed an increased hazard ratio of death in children with gastrostomy independent of type of catchment area and GMFCS level (HR 8.79; 95% CI 3.38–22.86). No statistically significant difference was found between death hazard ratios in males compared with females with CP (HR 0.84; 95% CI 0.41–1.73; Table III).

The rather small study size did not allow sufficient statistical precision to evaluate potential interaction effects, such as dif-

Table II: Children of the study cohort who did not survive (*n*=30)

Child	Catchment area population	GA	CP subtype	GMFCS level	Age at death, y	Cause/place of death	Cognitive level	Epilepsy	Hydrocephalus	Gastrostomy	Age at hip displacement, y	Age at scoliosis, y
1	Small	32–36wk	Spastic tetraplegia	V	2–4	Unknown/home	SLD	Yes	Yes	0–5mo	–	–
2	Small	Term	Dyskinetic	V	2–4	Unknown	SLD	Yes	No	12–17mo	–	–
3	Small	28–31wk	Dyskinetic	V	2–4	Unknown/tertiary hospital	SLD	Yes	No	18–23mo	–	–
4	Small	Term	Spastic tetraplegia	V	2–4	Unknown/home	SLD	No	No	2–4y	–	–
5	Large	Term	Spastic tetraplegia	V	2–4	Infection, respiratory insufficiency/hospital	SLD	Yes	No	–	–	–
6	Large	Term	Dyskinetic	V	2–4	Unknown/home	SLD	No	No	12–17mo	–	–
7	Small	Term	Dyskinetic	V	2–4	Unknown	SLD	Yes	No	12–17mo	–	–
8	Small	32–36wk	Dyskinetic	IV	2–4	Pneumonia/hospital	Mild LD	Yes	No	0–5mo	–	–
9	Small	Term	Spastic tetraplegia	V	5–9	Myocarditis/home	SLD	Yes	No	–	5–9	
10	Small	Term	Dyskinetic	V	5–9	Peritonitis/gastrostomy complication /home	SLD	No	No	2–4y	–	–
11	Small	Term	Dyskinetic	V	5–9	Unknown/home	SLD	Yes	No	6–11mo	–	5–9
12	Small	Term, postnatal CP	Spastic tetraplegia	V	5–9	Pneumonia/home	SLD	Yes	No	–	2–4	5–9
13	Large	Term	Dyskinetic	V	5–9	Pneumonia/tertiary hospital	SLD	Yes	No	18–23mo	–	5–9
14	Large	Term	Dyskinetic	V	5–9	Pneumonia/tertiary hospital	SLD	Yes	No	2–4y	–	5–9
15	Small	Term	Spastic tetraplegia	V	5–9	Sepsis? Gastro-oesophageal bleeding/hospital	SLD	Yes	No	18–23mo	–	2–4
16	Small	Term	Dyskinetic	V	5–9	Chickenpox/home	SLD	Yes	No	0–5mo	–	2–4
17	Small	32–36wk	Dyskinetic	IV	10–14	Unknown/home	Mild LD	Yes	No	12–17mo	–	–
18	Large	32–36wk	Spastic diplegia	IV	10–14	Shunt dysfunction/tertiary hospital	SLD	Yes	Yes	–	2–4	10–14
19	Small	28–31wk	Spastic diplegia	III	10–14	Shunt infection-peritonitis/home	SLD	Yes	Yes	–	–	–
20	Small	Term	Spastic tetraplegia	V	10–14	Pneumonia/home	SLD	Yes	No	5–9y	2–4	–
21	Small	Term	Spastic tetraplegia	V	10–14	Unknown	SLD	Yes	No	2–4y	–	5–9
22	Large	Term	Dyskinetic	V	10–14	Cardiac arrest/outdoors	Mild LD	Yes	No	6–11mo	–	–
23	Small	Term	Spastic tetraplegia	V	10–14	Unknown/home	SLD	Yes	No	6–11mo	–	–
24	Small	28–31wk	Spastic diplegia	III	10–14	Unknown, unconscious/ambulance	Typical	No	No	–	–	–
25	Small	Term, postnatal CP	Mixed	V	10–14	Pneumonia/hospital	SLD	Yes	Yes	5–9y	–	5–9
26	Small	32–36wk	Spastic diplegia	V	10–14	Unknown/home	Mild LD	Yes	Yes	2–4y	–	–
27	Small	Term	Dyskinetic	V	10–14	Pneumonia/hospital	Mild LD	Yes	No	2–4y	–	–
28	Small	Term	Spastic tetraplegia	V	15–17	Respiratory insufficiency/tertiary hospital	SLD	Yes	No	–	5–9	10–14
29	Large	Term	Spastic tetraplegia	V	15–17	Infection, respiratory insufficiency/ home	SLD	Yes	No	2–4y	–	5–9
30	Small	<26wk	Spastic tetraplegia	V	15–17	Postoperative pneumonia/tertiary hospital ICU	SLD	Yes	No	5–9y	–	2–4

GA, gestational age; CP, cerebral palsy; GMFCS, Gross Motor Function Classification System; LD, learning disability; SLD, severe learning disability; ICU, intensive care unit.

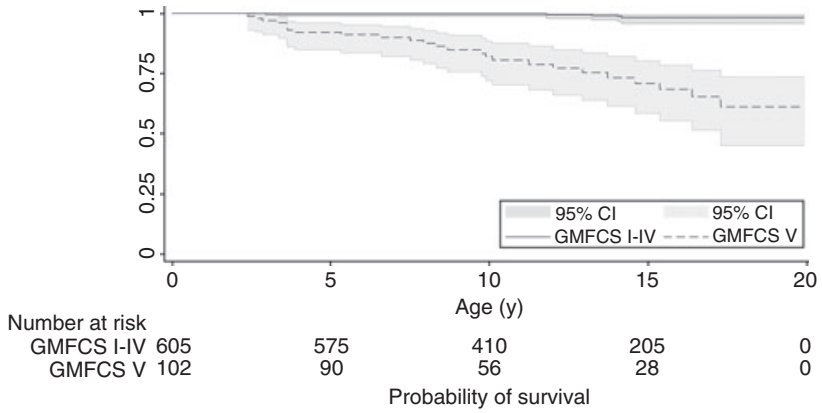

Figure 1: Estimated proportion of surviving children with cerebral palsy (CP) at different ages in terms of gross motor function level (using the Gross Motor Function Classification System [GMFCS]). The Kaplan–Meier survival curves start at 2 years of age according to the CP definition. CI, confidence interval.

ferences in the effect on mortality associated with having a gastrostomy between those with different GMFCS levels.

A statistical test of the proportional hazards assumption using the Schoenfeld residuals did not reveal any significant deviation from the assumptions of the Cox model (p=0.8969).

DISCUSSION

This study covers a total population of children and young people with CP in a specified geographical area who were followed prospectively over 15 years, which is a strength of this study. The CPUP programme involved 98.6% of all children with CP. We found no reason to suspect any bias due to systematic drop-out. At the end of the study, survival status was known for 99.3% of the whole study population with CP. The low death rate, on the other hand, limited the analysis of factors of importance for survival.

The high survival rate in children with CP, especially for children with milder functional limitations in gross motor and cognitive levels, was concordant with earlier studies.[15–18] In the study by Hutton et al.,[16] 50% of children with CP and severe disability born between 1966 and 1984 survived until the age of 20 years. Baird et al.[18] reported a 42.7% survival rate to 18 years of age among children with bilateral CP born between 1989 and 1992 who had both severe hand manipulation and communication impairment. The 20-year survival in our population born between 1990 and 2005 was not much better (60% for children in GMFCS level V). More fragile neonates and infants survive nowadays, which may be one explanation for the default decrease in childhood CP mortality. It is difficult, however, to compare these three studies, as the classifications of function differ.

In future studies of survival in CP, the GMFCS classification should be used to stratify study populations by gross motor ability. The GMFCS levels are shown to vary with the degree of comorbidity, especially cognitive level, vision, and epilepsy. The more severe the gross motor dysfunction, as described by GMFCS level, the higher the prevalence and severity of comorbidity.[14] Secondary complications of CP, such as hip dislocation, windswept deformity, and other severe contractures, increase in prevalence with increasing motor dysfunction.[1–3] Therefore, in our analysis, the GMFCS level is used as a surrogate covariate to describe the degree of comorbidity, hopefully counteracting the potential bias in the studied risk estimate due to omission of important covariates.

Children living in the study area but who were born abroad had a higher CP prevalence and more severe disability than those born in Sweden.[5,6] Despite this, a higher proportion of children born abroad seemed to survive than those born in Sweden (Table I). One interpretation could be that most immigrants to Sweden come from less privileged circumstances and survived their first period of life through being more robust than some children born in Sweden, who may have survived only thanks to advanced neonatal care.

Table III: The estimated hazard ratios (HR) between the predicted hazard for mortality in children with cerebral palsy, holding other factors in the table constant

	HR	SE	p value	95% CI
Catchment area population[a]				
Small	2.89	1.25	0.014	1.24–6.75
Catchment area population[a] and GMFCS level[b]				
Small	3.17	1.37	0.008	1.36–7.40
GMFCS V	35.00	17.16	<0.001	13.38–91.50
Catchment area population[a], GMFCS level,[b] and gastrostomy[c]				
Small	3.15	1.36	0.008	1.35–7.36
GMFCS V	11.36	6.43	<0.001	3.74–34.47
Gastrostomy	8.79	4.29	<0.001	3.38–22.86
Catchment area population[a], GMFCS level[b], gastrostomy,[c] and sex[d]				
Small	3.18	1.38	0.008	1.36–7.45
GMFCS V	11.40	6.45	<0.001	3.76–35.57
Gastrostomy	8.83	4.31	<0.001	3.39–22.96
Male	0.84	0.31	0.629	0.41–1.73

[a]Reference group consists of those living in catchment areas with large populations. [b]Reference group consists of those with gross motor function in Gross Motor Function Classification System (GMFCS) levels I–IV. [c]Reference group consists of those without gastrostomy. [d]Reference group consists of females. SE, standard error; CI, confidence interval.

We found that mortality risk for children with CP living in small-population catchment areas was three times higher than that of children in large-population catchment areas. It is not known what causes this higher risk. The distance to the nearest hospital was less than 30 minutes in all areas, and the type of hospital did not seem to be important. Half of the children dying in hospital of pneumonia or other respiratory insufficiency were in a tertiary hospital. One sudden death in bed before a planned operation, as well as the only fatal postoperative complication and a brain herniation due to shunt dysfunction also occurred among in-patients in a tertiary hospital. Malnourishment may also contribute. All units had full access to gastrostomy operations during the whole study period, but child habilitation units in 'small' catchment areas were without their own dietitians in 1994 to 2003, in contrast to the teams in the large catchment areas.

Regional differences in patterns of survival of children with CP are described in affluent versus deprived regions in the UK.[19] Socio-economic disadvantage in small-population catchment areas may contribute to the difference in survival. However, in the largest catchment area, Malmö, the survival rate was high despite having the highest proportion of children living in poor families in all of Sweden (30%).[9]

In another study, different life expectancy for children with CP in regions within the UK was described but left unexplained.[17] Unequal quality of health care could be a cause, be it pre-, peri- or postnatal care. Regional differences in management of post-term pregnancies are described in a recent Swedish study,[20] with significant effects on neonatal morbidity and mortality. This may also influence the regional prevalence and severity of CP. Prenatal health surveillance and delivery planning differ within our study region. A routine ultrasound investigation was performed at gestational week 32 in the catchment areas of the two tertiary hospitals during the whole study period, but only when needed in the other areas. In our study, the case mix effect was reduced by including GMFCS level, having a gastrostomy or not, and sex. Effects from other differences in case mix between districts may remain.

Gastrostomy feeding provides safe and sufficient nutrition in dysphagia and is considered to increase life expectancy in individuals with CP, at least compared with nasogastric tube feeding.[21] In this study it seemed the opposite. Children with gastrostomy had a ninefold increased hazard ratio for dying. The recent UK study of bilateral CP showed a fivefold increased risk.[18] The explanation is probably that the need for gastrostomy is an indicator of which children are the most fragile. Children in GMFCS level V with a gastrostomy or feeding tube have been shown to have poorer health status than children with GMFCS level V without a gastrostomy. They need a very high level and intensity of care.[22–24] However, it may be dangerous to have a gastrostomy, at least in some situations. For example, formula volume load may increase gastro-oesophageal reflux and contribute to a further increase in respiratory problems, which is most prevalent in children with dysphagia and gastrostomy.[22] In our population, two children with CP died from gastrostomy complications, one from ventricular wall perforation in the early days and one from more recent bleeding after a shift of placement of the gastrostomy tube. In the 2010 UK study, gastrostomy complications were the cause of death in 3 of 61 children who died.[18] As in earlier studies, survival rates did not differ between males and females.[15,25]

CONCLUSIONS

Ninety-six per cent of the total population of children with CP aged 2 to 19 years survived from 1990 to 2010. All those with milder functional limitations (GMFCS levels I–II) survived, as did all those with spastic hemiplegic or ataxic CP at all GMFCS levels. Deaths occurred throughout the childhood and adolescent years. Survival to 20 years of age was 60% in those with the most severe gross motor function impairment (GMFCS level V). Gastrostomy feeding probably indicates the most fragile children, but may also be a risk per se.

Children with CP living in small health care catchment areas had a threefold risk of dying, irrespective of severity of GMFCS level or having a gastrostomy or not. There was a ninefold increased hazard ratio of death if the child had a gastrostomy, irrespective of type of catchment area and gross motor function.

The difference between health care catchment areas in mortality rates in children with CP may be only the tip of the iceberg, indicating different quality of health care. The study does not tell exactly what to focus efforts on. It could be pregnancy surveillance and obstetric care, rather than something in paediatric health care. For the time being, the most fragile children should be thoroughly followed by, or in close cooperation with, the most experienced multidisciplinary professional teams.

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