Gastrostomy tube feeding of children with cerebral palsy: variation across six European countries

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ABBREVIATION
GTF Gastrostomy tube feeding

AIM To compare the prevalence of gastrostomy tube feeding (GTF) of children with cerebral palsy (CP) in six European countries.

METHOD Data on 1295 children (754 males, 541 females; mean age 5y 11mo, range 11y 2mo, min 6mo, max 11y 8mo) with CP born from 1999 to 2001 were collected from geographically defined areas in six European countries; four of the areas covered the whole country. Distribution of CP was unilateral 37%, bilateral 51%, dyskinetic 8%, and ataxic 4%. Sixty children were classified in Gross Motor Function Classification System (GMFCS) levels I and II, 6 in level III and 34 in levels IV and Vas Outcome measures were GTF, age at placement, feeding difficulties and the children's height and weight for age standard deviation scores (z-scores).

RESULTS The use of GTF among all children with CP was highest in western Sweden (22%, 95% confidence interval [CI] 16–29), and lowest in Portugal (6%, 95% CI 3–10), northern England (6%, 95% CI 3–9) and in Iceland (3%, 95% CI 0–13; $p<0.001$). The difference between areas was greater among children in GMFCS levels IV and V (non-ambulant); in this group, lower height z-scores were more prevalent in the areas with lower prevalence of GTF. The children's age at placement of gastrostomy also varied between areas ($p<0.002$).

INTERPRETATION The observed differences in the use of GTF may reflect differences in access to treatment or clinical practice, or both. Our results suggest that the use of GTF may improve growth in height and weight among children with more severely affected gross motor function – the group most likely to have associated feeding difficulties.

Feeding difficulties and poor growth are common among children with cerebral palsy (CP), in particular among children with bilateral dyskinetic or bilateral spastic CP with four limb involvement. [1–3] Multiple factors contribute to feeding difficulties, such as disordered oral motor, pharyngeal and/or oesophageal function and gastro-oesophageal reflux, leading to problems with chewing and swallowing. Children with such problems have high morbidity, often associated with aspiration of food, and they are at increased risk of being undernourished. Poor nutrition may in turn lead to impaired growth. Finally, disordered feeding and restricted growth are prognostic factors for poor survival of children and adults with CP. [4–6]

Since feeding difficulties often start early, and since growth restriction increases with increasing age,[7] it is important to ensure optimal nutrition as early as possible. In children with disordered oral motor, pharyngeal and/or oesophageal function, adequate nutrition may be achieved through gastrostomy tube feeding (GTF). However, the use of gastrostomy and the age at placement vary between studies. [3,8–13] We have previously reported that children who had their gastrostomy placed at an early age were less growth retarded than those who were older. [3] Although placement of gastrostomy is a simple procedure, the prevalence may differ. This could be as a result of differences in access to this treatment and also variations in

clinicians' views regarding which children need gastrostomy. The timing of insertion depends on the child's experience, enjoyment of oral feeding, and oromotor function development for speech, the risk of infection, the potential worsening of gastro-oesophageal reflux, etc. Parents' views about the psychosocial benefits and pleasures of oral feeding weighed against the requirement for 'equipment' for feeding may also vary in different settings and countries.

The aim of the present study was, therefore, to explore the prevalence of feeding difficulties and differences in the approach to supporting nutrition in children with CP in geographically defined areas in six European countries by assessing the prevalence of GTF. Owing to lack of clear indications for insertion of gastrostomy and possible differences in access to care, we hypothesised that the prevalence of GTF would vary considerably across Europe even after controlling for level of motor functioning as described by the Gross Motor Function Classification System (GMFCS). We also hypothesised that the children's age when the gastrostomy tube was inserted would vary significantly and, finally, that growth restriction would be more marked in areas where GTF was less prevalent and where tube feeding was introduced later, compared with areas with high prevalence and where the tube was inserted at an earlier age.

What this paper adds

- The use of gastrostomy and age at placement among children with CP differ considerably within Europe.
- Gastrostomy may improve growth in weight/height among children in GMFCS levels IV and V.
- Validated scales for the assessment of feeding abilities among children with CP are needed.

METHOD

Study design

This study is part of the Surveillance of Cerebral Palsy in Europe Network (SCPE-NET; http://www.scpenetwork.eu), a three-year programme based on the Surveillance of Cerebral Palsy in Europe,[14] an existing collaboration of 21 registers in 13 European countries to promote best practice in describing children with CP and to document variations in access to health care and in health outcomes.

Data were collected through CP registries in six European areas – two regional registries in western Sweden and northern England, as well as four national registries in Denmark, Norway, Portugal and Iceland. In Norway, Sweden and Portugal the necessary data had already been collected and recorded by the registries, while in Iceland, Denmark and northern England such data were retrospectively collected from medical records.

Study population

Children born from 1999 to 2001 were included in the study, although for Portugal only children born in 2001 were included. Children with all CP subtypes and all GMFCS levels were eligible. A total of 1295 children were included. In all, 144 children (corresponding to 100% of the total number of children with CP in the local registry) were living in western Sweden, 218 (100%) in northern England, 414 (98%) in Denmark, 263 (61%) in Norway, 218 (97%) in Portugal and 38 (100%) in Iceland.

Variables

The primary outcome was the presence of a GTF. Nasogastric tube feeding was not included. Secondary outcomes were age at placement of gastrostomy, growth and feeding difficulties.

Anthropometric measurements were obtained by a number of clinicians according to local practice and reported to, or collected by, their respective registry. No standardised segmental measurements of height/length were recorded. Only one measurement of weight and height for each child was recorded. Weight was recorded to the nearest 0.1 kg and height to the nearest 0.1 cm. Standard deviation scores (z-scores) for weight and height were calculated using region-specific growth references. For children in the Nordic registers we used Norwegian growth curves as reference,[15] for children in northern England we used UK curves,[16] and for the Portuguese children we used curves developed by the Centers for Disease Control and Prevention[17] consistent with clinical practice and in accordance with the guidelines from the Portuguese National Health Department. In addition to the use of regional growth references, we also analysed our data using World Health Organization (WHO) growth references.[18,19]

Exposure variables were CP subtypes and gross motor function level. CP subtypes were recorded as spastic, dyskinetic and ataxic, and the spastic subtype was further divided into unilateral or bilateral subtypes, according to the criteria of SCPE.[14] Gross motor function was recorded according to the GMFCS.[20] Children were categorised as GMFCS level I–II, level III, and level IV–V. Other variables recorded were sex and age.

All registries provided data on CP subtype, GMFCS level, and the use of gastrostomy. In northern England, GMFCS level was not routinely recorded in earlier birth cohorts and was thus missing in 85 (39%) cases. In Portugal, data on age at placement of gastrostomy were not available. Data on weight and height were available in 998 (77%) and 899 (69%) of the children respectively. Feeding difficulties were recorded as a dichotomised variable (yes/no). In Portugal and Norway two different, self-developed feeding scales were used. In the four remaining regions these data were collected from free text information in the children's medical records. Information on feeding abilities was missing in 24% of the cases.

To study potential inequalities in access to care, we related the prevalence of GTF in each area to the Gini coefficient of income in the corresponding country.[21] The Gini coefficient is a measure of inequality of income distribution calculated by international agencies such as the United Nations and Eurostat (EU-SILC 2010 data). The Gini coefficient varies from 0 (complete equality) to 1.0 (complete inequality). The majority of countries in the world have coefficients higher than 0.40.

National ethical guidelines were followed in each country by the local teams collecting the data. Informed consent and ethical approval to collect data and submit them to the SCPE common database was required in Norway, Portugal and northern England. In western Sweden and in Iceland ethical approval was given by regional ethical review boards, while in

Denmark the CP register was approved by the Danish Data Protection Agency.

Statistical analysis

The Statistical Package for Social Sciences, version 18 (SPSS Inc., Chicago IL, USA) was used for data analyses. The χ test was used to analyse differences in proportions between areas. Differences in proportions were also visualised by presenting 95% confidence intervals (CI) calculated according to Newcombe and Altman (2000).[22] Group differences of continuous variables with non-normal distribution were analysed using the Mann–Whitney *U* test and the Kruskal–Wallis one-way analysis of variance. One-way analysis of variance with Scheffé's *post hoc* test was also used to analyse whether there were differences between areas in mean z-scores for weight and height. In addition, a general linear model was used to adjust for differences in age and CP subtypes between the areas. Spearman's rank correlation coefficient was used to study the correlation between the Gini coefficient and growth deviation. The significance level was set to 0.05.

RESULTS

A total of 1295 children (754 males, 541 females; mean age 5y 11mo, age range 11y 2mo, min 6mo, max 11y 8mo) were included in this study. There were significant differences between areas in the proportions of various CP subtypes and GMFCS levels (Table I). Among 1295 children eligible for the study, 42 (3.2%, CI 2 to 5) had died at a mean age of 4 years 9 months (SD 2y). There was no difference between the populations regarding mortality (p=0.468) or age at death (p=0.108). The Gini coefficient was low in all countries ranging from 0.23 in Sweden to 0.39 in Portugal (Table I).

Gastrostomy tube feeding

Among all 1295 children, 133 (11%, 95% CI 9–12) had a gastrostomy tube (Table II). The prevalence was highest in western Sweden (31/144, 22%, CI 16–29), and lowest in Portugal (11/194, 6%, CI 3–10), northern England (12/218, 6%, CI 3–9) and in Iceland (1/38, 3%, CI 0–13). When we limited the analyses to children in GMFCS level IV and V, the differences were even more marked, ranging from 67% (29/43, CI 53–80) in western Sweden to 12% (10/84, CI 7–21) in Portugal. In Norway, the prevalence in this group was 44% (28/63, CI 33–57), in northern England 42% (11/26, CI 26–61) and in Denmark the prevalence was 26% (45/170, CI 20–34) (Table III).

Table II: The distribution of gastrostomy tube feeding according to cerebral palsy subtypes and GMFCS level in geographically defined areas in six European countries

	Gastrostomy		No gastrostomy		p^d
	n	% (CI)	*n*	% (CI)	
Total	133	11 (9–12)	1126	91 (88–91)	
Centre[a]					
Western Sweden	31	22 (16–29)	113	78 (71–84)	<0.001
Northern England	12	6 (3–9)	206	94 (91–97)	
Denmark	46	11 (8–14)	368	89 (86–92)	
Norway	32	13 (9–17)	19	87 (83–91)	
Portugal	11	6 (3–10)	183	94 (90–97)	
Iceland	1	3 (0–13)	37	97 (87–100)	
CP subtype[b]					
Unilateral	3	1 (0–2)	454	99 (98–100)	<0.001
Bilateral	96	15 (13–18)	538	85 (82–87)	
Dyskinetic	32	33 (24–43)	65	67 (57–76)	
Ataxic	1	2 (0–11)	47	98 (89–100)	
GMFCS level[c]					
I–II	4	1 (0–1)	693	99 (99–100)	<0.001
III	3	4 (1–12)	69	96 (88–99)	
IV–V	124	32 (27–36)	268	68 (64–73)	

Missing data: [a]36 cases. [b]59 cases. [c]134 cases. [d]Pearson χ^2. GMFCS, Gross Motor Function Classification System.

Age at placement of gastrostomy tube

Median age at placement of gastrostomy in the total population was 22 months (range 1–120). The median age ranged

Table I: The distribution of cerebral palsy subtypes, GMFCS levels, sex and Gini coefficient in geographically defined areas in six European countries

	Western Sweden		Northern England		Denmark		Norway		Portugal		Iceland		Total		p^c
	n	% (CI)	*n*	% (CI)	*n*	% (CI)	*n*	% (CI)	*n*	% (CI)	*n*	% (CI)	*n*	% (CI)	
Total	144	(100)	218	(100)	414	(100)	263	(100)	218	(100)	38	(100)	1295	(100)	
CP subtype[a]															
Unilateral	60	42 (32–50)	86	41 (35–48)	155	38 (33–43)	107	42 (36–48)	46	21 (16–27)	10	26 (15–42)	464	37 (34–39)	<0.001
Bilateral	55	38 (31–46)	118	56 (50–63)	206	50 (46–55)	116	45 (39–51)	142	66 (60–72)	23	61 (45–74)	660	51 (49–55)	
Dyskinetic	22	15 (10–22)	3	1 (0–4)	33	8 (6–11)	16	6 (4–10)	20	9 (6–14)	3	8 (3–21)	97	8 (6–9)	
Ataxic	7	5 (2–10)	2	1 (0–3)	15	4 (2–6)	17	7 (4–10)	7	3 (2–7)	2	5 (1–17)	50	4 (3–5)	
GMFCS[b]															
Level I–II	97	67 (59–74)	89	67 (59–74)	230	56 (51–61)	167	65 (59–71)	98	47 (41–54)	29	76 (61–87)	710	60 (57–63)	<0.001
Level III	4	3 (1–7)	18	13 (9–20)	11	3 (1–5)	22	9 (6–13)	17	8 (5–13)	3	8 (3–21)	75	6 (5–8)	
Level IV–V	43	30 (23–38)	26	20 (13–27)	170	41 (37–46)	66	26 (21–32)	92	45 (38–51)	6	16 (7–30)	403	34 (31–37)	
Sex															
Male	71	49 (41–57)	134	61 (55–68)	241	58 (53–63)	164	62 (56–68)	126	58 (51–64)	18	47 (32–63)	754	58 (55–61)	0.096
Female	73	51 (43–59)	84	39 (32–45)	173	42 (37–47)	99	38 (32–44)	92	42 (36–49)	20	53 (37–68)	541	42 (39–45)	
Gini coeffcient	0.23		0.34		0.29		0.25		0.39		0.287				

Missing data: [a]14 cases. [b]107 cases. [c]Statistical test: Pearson χ^2. GMFCS, Gross Motor Function Classification System.

Table III: The distribution of gastrostomy tube feeding among children in GMFCS levels IV and V in geographically defined areas in six European countries

	Gastrostomy		No gastrostomy		
	n	% (CI)	*n*	% (CI)	p^b
Total	124	32 (27–36)	268	68 (54–73)	
Centre[a]					
Western Sweden	29	67 (53–80)	14	33 (20–47)	<0.001
Northern England	11	42 (26–61)	15	58 (39–74)	
Denmark	45	26 (20–34)	125	74 (66–80)	
Norway	28	44 (33–57)	35	56 (43–67)	
Portugal	10	12 (7–21)	74	88 (79–93)	
Iceland	1	17 (3–56)	5	83 (44–97)	

Missing data: [a]11 cases. [b]Pearson χ^2. GMFCS, Gross Motor Function Classification System.

from 16 months in western Sweden (range 5–108mo) to 70 months in northern England (range 12–120mo). In Norway, median age was 19 months (range 1–66mo) and in Denmark the median age at placement was 26 months (range 4–84mo). The children in northern England were older when they had their gastrostomy inserted than children in western Sweden, Norway and Denmark (p=0.002 vs Scandinavian children as a group). Iceland (n=1) and Portugal (age not available) were not included in these analyses.

Growth

Weight measurements were reported at a mean age of 5 years 9 months (SD 2y 3mo) and height measurements at 5 years 9 months (SD 2.2). For weight, the mean age at recording was 4 years 3 months (SD 1y 6mo) in Denmark, 4 years 6 months (SD 1y) in western Sweden, 5 years 5 months (SD 1y 2mo) in Iceland, 6 years (SD 1y 3mo) in Portugal, 7 years 3 months (SD 1y 6mo) in Norway and 9 years (SD 2y 1mo) years in northern England. There were similar differences between the areas in mean age at recording of height. In the total population mean z-scores for weight was −0.86 (SD 1.71) and −0.87 for height (SD: 1.50; Table IV). Children with spastic unilateral and ataxic CP subtypes were considerably less growth retarded than children with spastic bilateral and dyskinetic subtypes. There was no correlation between duration of GTF and z-score for weight and height (data not shown).

When we restricted our analyses to children in GMFCS level IV and V, excluding children from Iceland (n=6) due to low numbers, we found significant differences in z-scores for weight and height between the areas. The Portuguese children were most and the Swedish children least growth retarded (Table IV). Portuguese children had lower weight z-scores compared with Norwegian, Swedish and Danish children (p<0.001), while their height z-scores were lower only compared with Swedish and Danish children (p=0.002). These difference in weight and height z-scores between centres persisted when we adjusted for age at measurement in multivariable analyses. For children in GMFCS levels I and II, no significant differences in weight (p=0.114) or height (p=0.472) z-scores were observed between the different populations. Among children in GMFCS level IV–V there was a weak, inverse correlation between the Gini coefficient and the weight (r=−0.22; p<0.001) and height z-scores (r=−0.12; p=0.042). The differences in z-scores between the countries were more marked when we used WHO growth references.

Table IV: z-scores for weight and height for children age ≥2 years according to cerebral palsy subtypes and GMFCS levels in geographically defined areas in six European countries

	Western Sweden			Northern England			Denmark			Norway			Portugal			Iceland			Total		
Weight	*n*	Mean	SD	*n*	Mean	SD	*n*	Mean	SD	*n*	Mean	SD	*n*	Mean	SD	*n*	Mean	SD	*n*	Mean	SD
Total[a]	144	−0.69	1.48	128	−0.47	1.79	351	−0.95	1.57	204	−0.76	1.68	105	−1.40	2.26	31	−0.96	1.41	963	−0.86	1.71
CP subtype																					
Unilateral	60	−0.31	1.53	50	0.22	1.27	129	−0.36	1.28	75	−0.46	1.68	24	−0.45	1.19	8	−0.78	1.12	346	−0.31	1.47
Bilateral	55	−0.95	1.55	70	−0.91	2.03	176	−1.30	1.35	100	−0.86	1.55	64	−1.85	2.52	19	−0.97	1.65	484	−1.17	1.84
Dyskinetic	22	−1.05	1.03	2	−1.78	0.14	30	−1.60	1.68	10	−2.72	1.18	11	−2.01	1.34	2	−1.65	0.63	77	−1.65	1.43
Ataxic	7	−0.77	0.93	2	0.21	0.72	13	−0.75	1.02	13	0.02	1.46	5	0.86	1.52	2	−1.13	0.83	42	−0.29	1.29
GMFCS level																					
I–II[b]	97	−0.51	1.49	85	0	1.34	191	−0.45	1.36	124	−0.37	1.37	48	−0.46	1.67	27	−0.84	1.46	572	−0.40	1.42
III	4	−0.59	1.17	18	−0.61	1.84	10	−0.96	1.26	18	−1.71	1.87	9	−0.20	2.19	2	−2.10	0.54	61	−0.98	1.80
IV–V[c]	43	−1.12	1.4	23	−2.29	2.07	148	−1.59	1.62	56	−1.42	1.94	48	−2.56	2.26	2	−1.43	0.66	320	−1.69	1.83
Height																					
Total[d]	141	−0.72	1.41	110	−0.71	1.48	316	−0.82	1.54	185	−0.88	1.47	82	−1.45	1.57	29	−1.00	1.39	863	−0.87	1.50
CP-subtype																					
Unilateral	58	−0.34	1.31	46	−0.21	1.21	119	−0.40	1.37	68	−0.62	1.54	21	−0.81	1.26	8	−0.85	1.42	320	−0.45	1.37
Bilateral	54	−1.00	1.37	56	−1.05	1.62	154	−1.15	1.66	90	−1.02	1.38	46	−1.83	1.55	17	−0.86	1.41	417	−1.15	1.55
Dyskinetic	22	−1.03	1.67	2	−2.02	0.14	27	−0.75	1.53	9	−1.82	1.48	9	−1.81	1.61	2	−2.22	1.87	71	−1.18	1.59
Ataxic	7	−0.80	1.09	2	−0.07	2.10	13	−0.80	0.82	13	−0.39	1.49	5	−0.03	1.66	2	−1.53	0.25	42	−0.58	1.24
GMFCS level																					
I–II[e]	95	−0.47	1.27	80	−0.42	1.24	178	−0.50	1.44	116	−0.49	1.25	41	−0.87	1.39	27	−0.88	1.34	537	−0.53	1.33
III	4	−1.63	0.60	15	−1.26	1.06	9	−1.17	0.92	17	−1.88	1.77	7	−0.26	0.94	1	−1.71	0	53	−1.35	1.34
IV–V[f]	42	−1.22	1.60	14	−1.86	2.30	127	−1.22	1.64	48	−1.54	1.50	34	−2.38	1.39	1	−3.54	0	266	−1.47	1.65

Scheffé's *post hoc* test: [a]p<0.001. [b]p=0.114. [c]p=0.001. [d]p=0.005. [e]p=0.472. [f]p=0.004. GMFCS, Gross Motor Function Classification System.

However, using the WHO growth references also resulted in statistically significant differences for height z-scores between countries among children in GMFCS levels I and II (Table V).

Feeding difficulties

Only 262 of 980 (27%, CI 24 to 30) children had documentation of feeding difficulties (data not shown). The highest prevalence was western Sweden (52/122, 43%, CI 34 to 51) and lowest in Northern England (18/131, 14%, CI 9 to 21).

DISCUSSION

We found considerable variations in the use of GTF in children with CP across different areas in six European countries. The differences were even more marked when we restricted the analyses to children in GMFCS levels IV and V, which is the group most likely to have associated feeding difficulties. For the latter group, z-scores for weight and height differed between countries, showing less growth restriction in the areas with high prevalence of GTF and more growth restriction in areas with low prevalence of GTF. The age at introduction of GTF also differed considerably, being lowest in the area with the highest prevalence of GTF. The low *p* values suggest that the results are unlikely to be due to chance.

The strength of the study is the population-based multicentre design and the large number of children, providing relatively narrow confidence intervals in the total study population.

A limitation of the study is the lack of standardisation of anthropometric measurements. This is likely to affect height measurements more than weight, in particular among the most severely affected children, and in this subgroup the results related to height measurements should be considered with caution. In a recent, unpublished survey among European clinicians we found that only a minority of clinicians used standardised methods (i.e. segmental measures with callipers) to measure height/length in children with CP unable to stand, and the use of such standardised methods was not restricted to a specific country or region. It is therefore unlikely that a systematic bias due to different methods or to lack of standardised measurement explain the differences in growth between centres. A further limitation is that we only have one measurement of weight and height, making it impossible to study changes in growth over time.

We preferred to use local growth charts in the calculation of z-scores. Since there were no differences in weight and height z-scores among children in GMFCS levels I and II, who are more independently mobile and who are less likely to have nutritional problems, we consider it unlikely that the use of different growth charts has confounded our results. Moreover, we also analysed our data using WHO growth standards, resulting in more marked differences in growth between centres. However, WHO growth standards are supposed to indicate optimal growth and our results using these standards may therefore partly be confounded by differences in growth in the background population. This interpretation may be further supported by the finding of significant differences in growth among children in GMFCS levels I and II between regions.

The differences in prevalence of GTF and in weight and height/length z-scores between the populations persisted after multivariable analyses, making confounding by differences in

Table V: z-scores for weight and height for children age ≥2.0 years according to cerebral palsy subtypes and GMFCS levels in geographically defined areas in six European countries based on WHO growth references

	Western Sweden			Northern England			Denmark			Norway			Portugal			Iceland			Total		
Weight	*n*	Mean	SD	*n*	Mean	SD	*n*	Mean	SD	*n*	Mean	SD	*n*	Mean	SD	*n*	Mean	SD	*n*	Mean	SD
Total[a]	144	−0.26	1.30	85	−0.18	1.79	351	−0.48	1.38	199	−0.23	1.55	105	−1.13	1.94	31	−0.52	1.31	915	−0.44	1.54
CP-subtype																					
Unilateral	60	0.08	1.40	34	0.53	1.35	129	0.05	1.13	74	−0.06	1.56	24	−0.39	1.15	8	−0.39	0.99	329	0.06	1.32
Bilateral	55	−0.50	1.32	47	−0.66	1.97	176	−0.78	1.46	96	−0.33	1.43	64	−1.49	2.13	19	−0.52	1.55	457	−0.73	1.64
Dyskinetic	22	−0.58	0.89	1	−1.55	0	30	−1.05	1.41	10	−2.01	1.06	11	−1.79	1.18	2	−0.97	0.56	76	−1.16	1.25
Ataxic	7	−0.32	0.89	1	−0.18	0	13	−0.33	0.91	13	0.47	1.37	5	1.03	1.59	2	−0.62	0.66	41	0.08	1.21
GMFCS level																					
I–II[b]	97	−0.10	1.34	56	0.19	1.44	191	−0.03	1.20	120	−0.12	1.32	48	−0.34	1.57	27	−0.42	1.36	539	−0.04	1.32
III	4	−0.18	1.01	11	−0.40	1.62	10	−0.50	1.07	18	−1.06	1.63	9	−0.04	1.94	2	−1.51	0.60	54	−0.60	1.54
IV–V[c]	43	−0.63	1.20	16	−1.56	2.29	148	−1.03	1.42	55	−0.80	1.75	48	−2.12	1.84	2	−0.85	0.72	312	−1.13	1.63
Height																					
Total[d]	141	−0.56	1.30	111	−0.70	1.45	318	−0.61	1.43	185	−0.38	1.39	82	−1.61	1.53	29	−0.67	1.31	866	−0.66	1.44
CP-subtype																					
Unilateral	58	−0.19	1.22	47	−0.24	1.23	119	−0.22	1.29	68	−0.12	1.46	21	−1.00	1.26	8	−0.55	1.34	321	−0.26	1.32
Bilateral	54	−0.83	1.25	56	−1.03	1.58	156	−0.91	1.53	90	−0.51	1.30	46	−2.01	1.50	17	−0.54	1.34	419	−0.93	1.50
Dyskinetic	22	−0.86	1.51	2	−1.90	0.15	27	−0.64	1.39	9	−1.21	1.44	9	−1.96	1.53	2	−1.82	1.78	71	−1.02	1.47
Ataxic	7	−0.59	1.08	2	−0.05	2.00	13	−0.55	0.76	13	−0.04	1.38	5	−0.07	1.47	2	−1.09	0.17	42	−0.32	1.15
GMFCS level																					
I–II[e]	95	−0.32	1.19	81	−0.41	1.24	178	−0.31	1.35	116	−0.01	1.17	41	−1.04	1.35	27	−0.56	1.26	538	−0.33	1.28
III	4	−1.41	0.62	15	−1.30	1.03	9	−0.81	0.79	17	−1.33	1.68	7	−0.44	0.91	1	−1.21	0	53	−1.12	1.22
IV–V[f]	42	−1.03	1.44	14	−1.84	2.16	127	−1.00	1.50	48	−1.00	1.42	34	−2.55	1.33	1	−3.07	0	268	−1.25	1.58

Scheffé's *post hoc* test: [a]$p< 0.001$. [b]$p=0.207$. [c]$p<0.001$. [d]$p<0.001$. [e]$p<0.001$. [f]$p<0.001$. GMFCS, Gross Motor function Classification System.

CP subtypes, gross motor function and the age at assessment of the children unlikely. Moreover, in analyses restricted to GMFCS levels IV–V the differences in GTF were even greater. Moreover, in the latter group, an association between high prevalence of GTF and less growth restriction could be observed, an association that was not apparent in the total population.

Both the prevalence of GTF and age at placement are consistent with a number of single centre studies.[3,8,9,23] In western Sweden the prevalence was 22% (31/144, CI 16 to 29), clearly higher than in a population-based study conducted in southern Sweden where the prevalence was 13%.[6] However, in the latter study the proportion of children in GMFCS level V was lower.

The differences in the use of GTF across areas observed in this study may be due to differences in access to gastrostomy, clinical decision-making, lack of clear guidelines, and parents' views about the psychosocial benefits and pleasures of oral feeding or a combination of these. We did not include use of nasogastric tube feeding in this study, since nasogastric tube feeding is not recommended for longer periods, i.e. exceeding six weeks.[24] However, we cannot exclude the fact that such feeding had been given to some patients for a longer time.

We originally wanted to study the prevalence of feeding difficulties. However, this was not possible because of a lack of a consistent description of feeding difficulties. Only in two areas were feeding scales used, and both scales were developed locally and only one had been validated.[25] Thus, an important implication of our study is that there is a need for an international classification scale of feeding difficulties, not only for epidemiological purposes, but also to provide a better basis for making a clinical decision on whether or not a gastrostomy tube should be inserted. One such scale has been developed in Portugal,[25] another scale is currently being developed in the UK.[26]

It is interesting that there was a correlation between the Gini coefficient and height and weight z-scores among children in GMFCS levels IV and V, and that the prevalence of GTF was lowest in the country with the highest Gini coefficient and *vice versa*, despite the fact that all countries had low Gini coefficients. These associations could suggest that the observed differences in gastrostomy between the populations may partly reflect differences in access to care.

An important finding was that among the children in GMFCS levels IV and V, i.e. those at the highest risk of associated feeding and swallowing difficulties, there was a clear association between low prevalence of gastrostomy and more severe growth restriction. These findings suggest that a gastrostomy tube may improve nutritional status and consequently growth even in those children whose motor function is in GMFCS levels IV and V. This is particularly important considering the association between growth restriction and early death.[27] However, concerns have been raised about potential overfeeding.[28] GTF has been reported to have positive effects regarding the quality of life of the individual child and its family.[1,11]

In conclusion we found that the use of GTF varied considerably between areas in six European countries. We postulate that this was due to a lack of clear guidelines and differences in the decision making processes. Among children who had gross motor impairments corresponding with GMFCS levels IV–V, those living in areas where GTF was less common were more growth restricted than children in countries where GTF was more prevalent.

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SUPPORTING INFORMATION

The following additional material may be found online.

Appendix SI: Members of the SCPE network.

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REFERENCES

1. Sullivan PB, Juszczak E, Bachlet AM, et al. Impact of gastrostomy tube feeding on the quality of life of carers of children with cerebral palsy. *Dev Med Child Neurol* 2004; **46:** 796–800.
2. Fung EB, Samson-Fang L, Stallings VA, et al. Feeding dysfunction is associated with poor growth and health status in children with cerebral palsy. *J Am Diet Assoc* 2002; **102:** 361–73.
3. Dahlseng MO, Finbraten AK, Juliusson PB, Skranes J, Andersen G, Vik T. Feeding problems, growth and nutritional status in children with cerebral palsy. *Acta Paediatr* 2012; **101:** 92–8.
4. Strauss DJ, Shavelle RM, Anderson TW. Life expectancy of children with cerebral palsy. *Pediatr Neurol* 1998; **18:** 143–9.
5. Strauss D, Shavelle R. Life expectancy of adults with cerebral palsy. *Dev Med Child Neurol* 1998; **40:** 369–75.
6. Westbom L, Bergstrand L, Wagner P, Nordmark E. Survival at 19 years of age in a total population of children and young people with cerebral palsy. *Dev Med Child Neurol* 2011; **53:** 808–14.
7. Andrew MJ, Sullivan PB. Growth in cerebral palsy. *Nutr Clin Pract* 2010; **25:** 357–61.
8. Vik T, Skrove MS, Dollner H, Helland G. [Feeding problems and growth disorders among children with cerebral palsy in south and north Trondelag.] *Tidsskr Norske Laege* 2001; **121:** 1570–4.
9. Sullivan PB, Lambert B, Rose M, Ford-Adams M, Johnson A, Griffiths P. Prevalence and severity of feeding and nutritional problems in children with neurological impairment: Oxford Feeding Study. *Dev Med Child Neurol* 2000; **42:** 674–80.
10. Henderson RC, Grossberg RI, Matuszewski J, et al. Growth and nutritional status in residential center versus home-living children and adolescents with quadriplegic cerebral palsy. *J Pediatr* 2007; **151:** 161–6.
11. Mahant S, Friedman JN, Connolly B, Goia C, Macarthur C. Tube feeding and quality of life in children with severe neurological impairment. *Arch Dis Child* 2009; **94:** 668–73.
12. Sullivan PB, Juszczak E, Bachlet AM, et al. Gastrostomy tube feeding in children with cerebral palsy: a prospective, longitudinal study. *Dev Med Child Neurol* 2005; **47:** 77–85.
13. Lewis EC, Connolly B, Temple M, et al. Growth outcomes and complications after radiologic gastrostomy in 120 children. *Pediatr Radiol* 2008; **38:** 963–70.

14. Cans C. Surveillance of cerebral palsy in Europe: a collaboration of cerebral palsy surveys and registers. Surveillance of Cerebral Palsy in Europe (SCPE). *Dev Med Child Neurol* 2000; **42:** 816–24.

15. Juliusson PB, Roelants M, Eide GE, et al. [Growth references for Norwegian children.] *Tidsskr Norske Laege* 2009; **129:** 281–6.

16. Cole TJ, Freeman JV, Preece MA. British 1990 growth reference centiles for weight, height, body mass index and head circumference fitted by maximum penalized likelihood. *Stat Med* 1998; **17:** 407–29.

17. Kuczmarski RJ, Ogden CL, Grummer-Strawn LM, et al. CDC growth charts: United States. *Adv Data* 2000; **314:** 1–27.

18. World Health Organization. WHO Child Growth Standards [Internet]. Geneva: World Health Organization. Available at http://www.who.int/childgrowth/en/ (accessed 29 March 2012).

19. World Health Organization. Growth Reference Data for 5–19 years [Internet]. Geneva: World Health Organization. Available at http://www.who.int/growthref/en/(accessed 29 March 2012).

20. Palisano R, Rosenbaum P, Walter S, Russell D, Wood E, Galuppi B. Development and reliability of a system to classify gross motor function in children with cerebral palsy. *Dev Med Child Neurol* 1997; **39:** 214–23.

21. Central Intelligence Agency. Distribution of Family Income – Gini Index, The World Factbook [Internet]. Washington, DC: Central Intelligence Agency. Available at https://www.cia.gov/library/publications/the-world-factbook/rankorder/2172rank.html (accessed 26 May 2012).

22. Newcombe RG, Altman DG. Proportions and their differences. In: Altman DGMachin D, Bryant TN, Gardner MJ, editors. Statistics with Confidence, 2nd edn. Bristol: BMJ books, 2000, : 45–56.

23. Stevenson RD, Conaway M, Chumlea WC, et al. Growth and health in children with moderate-to-severe cerebral palsy. *Pediatrics* 2006; **118:** 1010–8.

24. Sullivan PB. Feeding and Nutrition in Children with Neurodevelopmental Disability. London: Mac Keith Press, 2009.

25. Andrada M. Validation of assessment scales for communication and oro-motor function in children with cerebral palsy. *Dev Med Child Neurol* 2008; **50:** 29–36.

26. Sellers D. The Eating and Drinking Ability Classification System for Individuals with Cerebral Palsy – EDACS. [Internet] http://www.sussexcommunity.nhs.uk/index.cfm?request=c2008582 (accessed 10 April 2012).

27. Brooks J, Day S, Shavelle R, Strauss D. Low weight, morbidity, and mortality in children with cerebral palsy: new clinical growth charts. *Pediatrics* 2011; **128:** e299–307.

28. Sullivan PB, Alder N, Bachlet AM, et al. Gastrostomy feeding in cerebral palsy: too much of a good thing? *Dev Med Child Neurol* 2006; **48:** 877–82.