Growth and Nutritional Status in Residential Center Versus Home-Living Children and Adolescents with Quadriplegic Cerebral Palsy

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Objective To describe growth and nutrition in nonambulatory youth (<19 years of age) with cerebral palsy (CP) living in residential centers compared with similar youth living at home.

Study design A multicenter, cross-sectional, single observational assessment of 75 subjects living in a residential care facility compared with 205 subjects living at home. Primary outcome measures included anthropometric measures of height, weight, triceps, and subscapular skinfolds, and mid-upper-arm muscle area. *Z* scores were calculated from reference values for healthy children. Age, use of a feeding tube, and Gross Motor Functional Classification System (GMFCS) level were included as important confounders.

Results Use of a feeding tube was associated with higher skinfold *Z* scores, and a significantly higher percentage of the residential subjects had a feeding tube. Height, weight, and arm-muscle area *Z* scores all diverged (negatively) from reference values with age, and the residential subjects were on average older than the home-living subjects. After controlling for age, GMFCS level and use of a feeding tube, residential living was associated with significantly greater weight, height, skinfold thicknesses, and mid-arm muscle area *Z* scores.

Conclusion Poor growth and nutrition in children with CP is a prevalent, important, and complex problem. Although factors intrinsic to the condition of CP likely play a significant role, it is also clear that environmental factors, including the living situation of the child, can have an impact. *(J Pediatr 2007;151:161-6)*

Children with cerebral palsy (CP) frequently grow poorly, compared with their healthy peers.[1] In general, children with CP are smaller, lighter, and thinner with notably less body fat, muscle mass, and bone mass. Moreover, as children with CP age, their growth diverges further and further from that of healthy children. These differences in growth are most evident in those children with severe CP, who may also have many associated impairments (eg, seizures, mental retardation) and secondary conditions (eg, malnutrition, gastroesophageal reflux, osteoporosis).[2] Moreover, these differences in growth are important because there is increasing evidence that improved growth is associated with improved health and quality of life for children with severe CP and their caregivers.[1,3-6]

The reasons for "poor" growth in children with severe CP are likely multifactorial and include nutritional, hormonal, physical, and neurological causes.[7-9] Some of these factors are likely related to disease severity and may not be modifiable. However, other

CCHS	Children's Care Hospital and School
CP	Cerebral palsy
GMFC	Gross Motor Function Classification System
HL	Hattie Larlham Center for Children with Disabilities
HMS	HMS School for Children with Cerebral Palsy
NAGCePP	North American Growth in Cerebral Palsy Project

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factors impacting growth could be secondary health conditions, such as malnutrition, and may be amenable to intervention.[8,9] Most children with severe CP live at home with a parent or guardian in community with their siblings and neighbors, attending local public schools. Because this social arrangement is typical of children without CP, it is widely believed to be the least restrictive socially and educationally and, therefore, most desirable for children with severe CP.

The care of children with severe CP and related associated impairments and secondary conditions is challenging. These children require significant resources, in terms of time, expertise, and money, to maintain health.[2] Some families choose to place their children in a residential care facility, usually because they feel unable to adequately provide for their needs.

The North American Growth in Cerebral Palsy Project (NAGCePP) has studied multiple aspects of growth and nutrition in children with moderate and severe CP. This current study compares the physical growth of children with severe CP living at home with similar children living in residential care. Our research objectives were to describe any differences in growth between the two groups of children and to evaluate potential causes for these differences to guide future studies and possible interventions. Because these children were residing in necessarily different environments, we hoped that we might find clues to modifiable factors that could be exploited to improve growth and health. We expected to find that children in residential care were more severely impaired and consequently grew more poorly.

METHODS

The initial NAGCePP study was a cross-sectional, single observational assessment of more than 250 children and adolescents with moderate to severe CP living at home. Six centers from the United States and Canada participated. Subjects were recruited from predefined geographic regions, and they were identified through multiple means including review of hospital records, special education teachers in the school systems, newspaper notices, pediatric physical therapists, wheelchair equipment vendors, United Cerebral Palsy newsletters, and public service announcements. The goal of the identification and recruitment process was to provide a broadly based, representative cohort. Additional details regarding this initial NAGCePP study have been previously published.[2]

Three residential centers have since joined in the NAGCePP research group: the Hattie Larlham Center for Children with Disabilities (HL) in Mantua, Ohio; the Children's Care Hospital and School (CCHS) in Sioux Falls, South Dakota; and the HMS School for Children with Cerebral Palsy (HMS) in Philadelphia, Pennsylvania. The HL and CCHS facilities provide full-time, year-round residential care for persons with quadriplegic CP. The HMS facility provides full-time residential care during the school year, with the children living at home for 10 to 12 weeks during the summer. All three residential centers have physician, physical therapy, respiratory therapy, and nutrition services on site in addition to "24/7" nursing services. This study was approved by the institutional review board at all participating sites, and informed consent obtained for all subjects.

As detailed elsewhere,[2] the NAGCePP evaluation included a complete medical and surgical history, Tanner staging of pubertal maturation,[10] the Children's Health Status Questionnaire,[11] and a detailed anthropometric assessment. Typically, a reliable direct measure of height cannot be obtained in a child with severe CP because of contractures, scoliosis, and/or an inability to stand erect. Height was, therefore, estimated by a measurement of knee height.[12] Multiple other anthropometric measurements were obtained including upper-arm length, mid-upper-arm circumference, triceps skinfold thickness, and subscapular skinfold thickness.

To help assure uniformity across enrollment sites, the research assistants from all NAGCePP sites received centralized training in anthropometry to predetermined reliability standards at the University of Virginia. In addition, the research assistant from one of the initial NAGCePP enrollment sites was sent to the HL and CCHS sites to assist the local research assistants with their evaluations, which at each site were all completed over a 1- to 2-week time period.

Residential Center Subjects

A total of 125 subjects were enrolled at the three residential centers (HL, 87 subjects; CCHS, 21 subjects; HMS, 17 subjects) from a total of 161 residents who had quadriplegic CP, no identified chromosomal abnormality, and no unrelated medical or physical disorder. Informed consent to participate could not be obtained for the 36 potentially eligible subjects who were not enrolled. Two of the 125 subjects were Gross Motor Function Classification System (GMFCS) level 3.[13] Given this small number of moderately involved subjects, it was elected to limit the analyses to GMFCS level 4 and 5 subjects. There was no age restriction in the residential center study, but the initial NAGCePP study had an upper age limit of 18 years of age for enrollment. Thus to facilitate comparisons between the two groups, this report focuses on the 75 residential center subjects who were <19 years of age with GMFCS level 4 or 5 CP.

Home-living Subjects

To date there have been a total of 273 subjects enrolled at the initial six sites, and all were <19 years of age and living at home. There were 205 subjects included in the analyses after exclusion of 68 GMFCS level 3 subjects. Some of these subjects have been longitudinally evaluated, but only the initial evaluation was utilized in these analyses. Descriptive data on the residential center and home-living groups are summarized in Table I. The prevalence of feeding tubes was higher in the residential center group than the home-living group. The residential center subjects were also more severely involved (GMFCS level), more commonly on seizure medica-

Table I. Comparisons of demographic and clinical characteristics of residential and home-living subjects

	Residential center		Home-living		
Age					
Mean ± SE	13.0 ± 0.5		9.5 ± 0.3		$P < .0001$
2-7 y	8	10%	93	45%	
8-13 y	32	43%	74	36%	
14-18 y	35	47%	38	19%	
Sex					
Male	43	57%	110	54%	$P > .5$
Female	32	43%	95	46%	
Race					
White	57	76%	143	70%	$P = .0004$
African-American	4	5%	49	24%	
Other	14	19%	13	6%	
GMFCS level					
Level 4	8	11%	65	32%	$P = .0004$
Level 5	67	89%	140	68%	
Tube feeding					
Yes	53	71%	75	36%	$P < .0001$
No	22	29%	130	64%	
On anticonvulsants					
Yes	50	67%	105	51%	$P = 0.02$
No	25	33%	100	49%	

P values are based on X^2 tests.

tion, and slightly older. The main racial difference was a significant number of Native American Indians in the South Dakota residential center.

Statistical Analyses

The primary growth and nutritional status outcome measures are height, weight, subscapular and triceps skinfolds, and upper-arm muscle area. Height is estimated from measures of knee height as previously described.[12] Upper-arm muscle area is calculated from measures of the upper-arm circumference and triceps skinfold thickness. All five outcome measures were converted for subsequent analyses to age and sex normalized *Z* scores based on reference data for health children.[14,15]

As a first step, the residential center and home-living subjects were compared for each of the five anthropometric outcome variables with simple univariate analyses. Multiple linear regression analyses of the combined data sets was then utilized to assess the relationship between each of these outcome variables and other potentially significant factors including living situation (residential center versus home-living), age, GMFCS level, and whether the subject was tube fed. In building the statistical regression models variables with *P* values >.15 were excluded. The data from both groups of subjects were combined for the multiple regression analyses because this allowed us to account for key confounders while evaluating the primary variable of interest, which was the subject's living situation.

Table II. Comparisons of growth and nutrition measures in residential and home-living subjects

Z scores	Residential center	Home-living	
Height	−3.17 ± 0.22	−2.68 ± 0.12	$P = .047$
Weight	−2.20 ± 0.30	−2.43 ± 0.17	$P > .4$
Triceps skinfold	0.10 ± 0.13	−0.54 ± 0.09	$P < .0001$
Subscapular skinfold	0.47 ± 0.14	0.16 ± 0.11	$P = .09$
Upper-arm muscle area	−0.65 ± 0.16	−0.69 ± 0.11	$P > .8$

Mean *Z* scores ± standard error; *P* values are based on Student's *t* tests.
Note that these are simple univariate comparisons that *do not* take into consideration other important variables such as age, GMFC level, and tube feeding.

RESULTS

Children in residential care grew differently than children living at home (Table II). Height *Z* scores of the residential center subjects were lower than the home-living group, but weight and upper-arm muscle area *Z* scores did not differ. Conversely, residential center subjects had greater skinfold *Z* scores. It is important to note that these simple univariate comparisons do not take into consideration other potentially relevant confounding factors (eg, severity and feeding tubes) that were clearly different in the two groups.

To better understand the various factors influencing growth, data from residential-living and home-living subjects were combined to examine the associations with other factors including age, severity of involvement (GMFCS level), and use of a feeding tube (Table III). Age, GMFCS level, and tube feeding are important determinates of growth and nutrition measures.[1,7] However, the impact of these factors on growth and nutrition varied between the different measures. For example, tube feedings had the greatest effect on triceps and subscapular skinfold *Z* scores, and advancing age was associated most strongly with declining height, weight, and upper-arm muscle area *Z* scores. Again, it is important to note that Table III presents only simple univariate comparisons, each done without consideration of the other potentially relevant confounding factors.

Living situation, age, GMFCS level, and use of a feeding tube are shown in Tables II and III to all be potentially important factors that may impact on the various growth and nutrition outcome measures. To more reliably evaluate the data it is important to utilize multiple regression analyses that simultaneously evaluate the effects of these potentially relevant factors. Multiple regression analyses provide a predictive equation that is a weighted sum of the various contributing factors, with the more influential factors being more heavily weighted. The "weighting" terms, or variable coefficients, from the multiple regression analysis done on each growth and nutrition outcome measure are summarized in Table IV.

Of particular note is that the living situation of the subjects was the factor most consistently and strongly related to the various outcome measures (Table IV). This was also true when the analyses were re-run on the subset of just those subjects who were *not* tube fed, or just those subjects who

Table III. The effects of differences in age, severity of cerebral palsy, and use of feeding tubes on measures of growth and nutrition

	Growth and nutrition Z scores (all subjects combined)				
	Height	Weight	Triceps skinfold	Subscapular skinfold	Arm muscle area
Age					
2-10 years	−1.9 ± 0.1	−1.7 ± 0.2	−0.5 ± 0.1	0.5 ± 0.1	−0.3 ± 0.1
11-18 years	−3.8 ± 0.1	−3.1 ± 0.2	−0.3 ± 0.1	−0.1 ± 0.1	−1.1 ± 0.1
	$P < .0001$	$P < .0001$	$P > .2$	$P = .001$	$P < .0001$
GMFCS level					
Level 4	−2.6 ± 0.2	−1.9 ± 0.3	−0.4 ± 0.2	0.2 ± 0.1	−0.4 ± 0.2
Level 5	−2.9 ± 0.1	−2.5 ± 0.2	−0.4 ± 0.1	0.3 ± 0.1	−0.8 ± 0.1
	$P > 0.2$	$P = .04$	$P > .9$	$P > .6$	$P = .1$
Tube feeding					
Yes	−2.8 ± 0.2	−2.2 ± 0.2	−0.1 ± 0.1	0.6 ± 0.1	−0.6 ± 0.1
No	−2.8 ± 0.1	−2.5 ± 0.2	−0.6 ± 0.1	0 ± 0.2	−0.7 ± 0.1
	$P > 0.8$	$P > .2$	$P = .0006$	$P = .0009$	$P > .5$

Mean Z scores ± standard error; P values are based on Student's t tests.
Note that these are simple univariate comparisons looking at only age or GMFCS level or tube feeding without consideration of the other variables or living situation.

Table IV. Multiple regression models to predict variance in measures of growth and nutrition

	Regression analyses variable coefficients (± standard error)				
	Height Z	Weight Z	Triceps skinfold Z	Subscapular skinfold Z	Arm muscle area Z
Living situation	0.54 ± 0.19	1.05 ± 0.33	0.44 ± 0.19	0.34 ± 0.22	0.49 ± 0.22
Age	−0.27 ± 0.17	−0.20 ± 0.03	0.03 ± 0.02	−0.06 ± 0.02	−0.11 ± 0.02
GMFCS level	not significant	−0.70 ± 0.32	−0.29 ± 0.17	not significant	−0.36 ± 0.21
Feeding tube	−0.27 ± 0.16	not significant	0.50 ± 0.16	0.48 ± 0.18	not significant
Intercept	0.01 ± 0.20	−0.07 ± 0.40	−0.77 ± 0.22	0.53 ± 0.23	0.62 ± 0.26
R^2	0.50	0.15	0.09	0.07	0.11

The residential and home-living subjects are combined into a single data set for regression analyses. These analyses generate equations that simultaneously take into consideration all of the relevant variables. Categorical variables such as living situation, GMFCS level, and tube feeding are assigned a value of 0 or 1: home-living, GMFCS level 4, no feeding tube = 0; residential center living, GMFCS level 5, yes feeding tube = 1.
The format for the resulting equations is as follows: predicted Z score = intercept + (living situation coefficient × 0 or 1) + (age coefficient × age) + (GMFCS coefficient × 0 or 1) + (feeding tube coefficient × 0 or 1).
For example, predicted triceps skinfold Z score for a child living at home, 10 years of age, GMFCS level 5, with a feeding tube is: predicted triceps skinfold Z score = −0.77 + (0.44 × 0) + (0.03 × 10) + (−0.29 × 1) + (0.50 × 1).
Note that factors with the largest coefficients, either positive or negative, have the largest impact on the outcome variable. For all measures of growth and nutrition the living situation made a significant contribution to the multiple regression model's prediction of variance in outcome.

were GMFCS level 5. Residential center living had a significant positive correlation with growth and nutrition, independent of age, severity, and tube feeding. Additional multiple regression analyses showed that sex, race, and use of anticonvulsants were not significant independent factors.

DISCUSSION

Diminished growth and poor nutrition are prevalent, complex problems in children and adolescents with quadriplegic CP.[3,8] The purpose of this study was to compare children with severe CP living in residential care with a similar group living at home, and to our knowledge this is the first such study to do so. Our results show that the two groups were different with respect to their growth and nutritional status. As a group, the children living in residential care had lower height Z scores, similar weight and muscle mass Z scores, and were "fatter," with greater triceps and subscapular skinfold Z scores compared with those living at home. It is important to note that there appears to be direct clinical relevance to these anthropometric measures. In children with moderate and severe CP "better" growth and nutrition measures have been associated with decreased health-care utilization and increased social participation.[1,3]

Although the residential and home-living groups were matched in that all subjects had "quadriplegic CP," there were still important differences. Therefore, one must go beyond simple comparisons and utilize multiple regression analyses to simultaneously examine the relative impact of functional severity (GMFCS level), tube feeding, age, and living situation on the various measures of growth and nutrition. At first glance these analyses appear to change the findings. For example, Table II shows that height Z scores were on average lower in residential than home-living subjects. But, the residential center subjects were older, more severely involved, and more likely to have a feeding tube; all factors likely to influence a child's height Z score. When the data were appropriately analyzed, with all these factors included, residential living was in fact associated with higher height Z scores. In other words, given equal age, GMFCS level and use of a feeding tube, children in residential care had greater height Z scores than children living at home.

The key finding of this study is that the multiple regression analyses showed residential living to have a significant positive association with all growth and nutrition variables compared with living at home. In fact, for most outcome measures the living situation proved to be a more important factor than either GMFCS level or use of a feeding tube. Although the analyses did control for differences in GMFCS level, age, and use of a feeding tube, there are perhaps other unrecognized differences between the residential and home-living groups. For example, the GMFCS classification is based solely on mobility, and therefore may not capture other aspects of "severity." However, any unrecognized "severity" factor is more likely to negatively, rather than positively, bias the residential group.

The reasons for the consistent positive association of residential care with growth and nutrition are not clear. One potential factor relates to use of feeding tubes. The statistical analyses comparing groups did control for whether a child had a feeding tube, but they could not control for possible differences in how that tube was utilized. Management of tube feedings can be complicated, and perhaps in general this is simply done better or more consistently in a residential care setting. For example, families typically utilize feeding tubes to supplement oral feedings, and they may significantly overestimate actual oral intake.[16] Tube feedings by families may also be influenced by concerns over the child becoming "too large" to handle, which is less likely to be of concern in a residential setting.

Another potential explanation for the improved measures in residential center subjects may relate to the recent observation that better growth and nutrition in this population is associated with better health.[1] Likely the "cause and effect" connection works both ways, meaning better health results in better growth and nutrition, and better growth and nutrition results in better health. For persons with particularly complex health-care needs, the close proximity of physician, nursing, physical therapy, respiratory therapy, and nutrition services in the residential care centers may be of a quantity and quality that are difficult to obtain in a personal home setting. Any and all of these services may positively impact on the reciprocal relationship between a child's health and a child's growth and nutrition. These potential explanations are speculative, but the differences in measures of growth and nutrition associated with living situation were robust and demand further investigations.

The analyses also showed that GMFCS level and tube feeding were independently associated with various growth and nutrition variables after controlling for other relevant factors. This is consistent with previous reports suggesting that both factors intrinsic to CP and extrinsic factors contribute to poor growth and nutrition.[8,17,18] Tube feeding could reflect severity; thus, the negative association between tube feeding and height Z score in this study may reflect the previously reported correlation between severity and poor linear growth, independent of nutritional status.[7] Also perhaps tube feedings were simply initiated "too late," with early poor nutrition causing deficits in growth that are not completely recouped. Advancing age was negatively associated with height, weight, and arm-muscle area Z scores but not skinfold Z scores. This confirms that as children with CP age, their growth diverges further from that of healthy children.

This study does not address the broader, more important question of whether the better growth and nutrition measures were in fact associated with better child health. Given the simplistic design of this study, the broad variety of home and even residential living situations, and the many ways a child may be "better," this study also can not address the complex issue of whether one type of living situation is "better" than another for medically complex children with severe CP. However, this study does raise intriguing questions about the nature of the differences in care experienced by children living in residential care versus those living at home, how these differences in care impact on growth, and whether these differences also lead to differences in health outcomes. Further research with the goal of developing guidelines for nutritional and growth management of children with severe CP is warranted. Further work should focus on care practices that improve health and well-being along with growth, and the necessary resources needed to provide that care. Improved growth is a laudable goal only if it is associated with improvements in function, health, social participation, and overall quality of life.

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