Medical Position Paper

Nutrition Support for Neurologically Impaired Children: A Clinical Report of the North American Society for Pediatric Gastroenterology, Hepatology, and Nutrition

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ABSTRACT

Undernutrition, growth failure, overweight, micronutrient deficiencies, and osteopenia are nutritional comorbidities that affect the neurologically impaired child. Monitoring neurologically impaired children for nutritional comorbidities is an integral part of their care. Early involvement by a multidisciplinary team of physicians, nurses, dieticians, occupational and speech therapists, psychologists, and social workers

is essential to prevent the adverse outcomes associated with feeding difficulties and poor nutritional status. Careful evaluation and monitoring of severely disabled children for nutritional problems are warranted because of the increased risk of nutrition-related morbidity and mortality. *JPGN 43:* 123–135, 2006. Key Words: Feeding intolerance—Developmental delay—Oral motor therapy—Enteral feeding tube. © 2006 Lippincott Williams & Wilkins

INTRODUCTION

Undernutrition, growth failure, overweight, micronutrient deficiencies, and osteopenia are nutritional comorbidities that affect the neurologically impaired child. Previous publications reviewed the epidemiology, pathogenesis, assessment, and treatment of these disorders in neurologically impaired children (1,2). This report from the Nutrition Committee of the North American Society for Pediatric Gastroenterology, Hepatology, and Nutrition examines further the principles and practices associated with the nutritional management of children with neurological disabilities. In this report, neurological impairment refers to a broad spectrum of neurological disorders that are characterized primarily by gross and fine motor dysfunction and may be associated with cognitive or speech delay.

Monitoring neurologically impaired children for nutritional comorbidities is an integral part of their care. Early involvement by a multidisciplinary team of physicians, nurses, dieticians, occupational and speech therapists, psychologists, and social workers is essential to prevent the adverse outcomes associated with feeding difficulties and poor nutritional status. Undernutrition and overweight lead to increased health care use, hospitalization, and physician visits, as well as diminished participation in home and school activities (3). Adequate nutritional support may restore linear growth, normalize weight, improve health and quality of life, reduce the frequency of hospitalization, decrease irritability and spasticity, increase alertness, enhance developmental progress, improve wound healing and peripheral circulation, decrease the frequency of aspiration, and ameliorate gastroesophageal reflux in these children (4–16). Careful evaluation and monitoring of severely disabled children for nutritional problems are warranted because of the increased risk of nutrition-related morbidity and mortality (17).

UNDERNUTRITION, GROWTH FAILURE, AND OVERWEIGHT

Clinical Features of Impaired Growth and Nutritional Status

Height-for-age and weight-for-age growth standards of neurologically impaired children are lower than those of the reference population (18–23). The median weight-for-age for children with spastic quadriplegic cerebral palsy is below the 10th percentile for the National Center for Health Statistics (NCHS) reference population, and their median height-for-age is equal to the 10th percentile for the NCHS reference population. The difference between the observed growth pattern of

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children with spastic quadriplegic cerebral palsy and the NCHS reference population increases with increasing age (19). Neurological disease may adversely affect linear growth even in the absence of undernutrition. As a consequence, growth failure may not be corrected completely by nutritional therapy.

Children with neurological disabilities usually have progressive weight deficits due to fat loss, although muscle and visceral proteins are maintained. Some children demonstrate a lack of weight gain in the presence of linear growth, leading to a decreased body mass index (BMI). Others have progressive muscle atrophy unresponsive to nutritional intervention because of their underlying disorder. Although neurologically impaired children usually are shorter and weigh less than unaffected children, a small proportion (8%–14%) may be overweight based on weight-for-height or triceps skinfold thickness criteria (18,20). The prevalence of overweight may be underestimated because weight-for-height gains are overlooked in the presence of a small body size or an aberrant distribution of body fat that may be present in some neurological disorders (24). Weight-for-height comparisons may be monitored less frequently than weight alone because of the difficulty obtaining accurate height measurements.

Prevalence

The true prevalence of undernutrition, growth failure, and overweight in neurologically impaired children is unknown. Estimates are limited to disorders such as cerebral palsy, myelodysplasia, and Rett syndrome (18,20,25–29). Undernutrition has been documented in 29% to 46% of children with cerebral palsy, linear stunting in 23%, and overweight in 8% to14% based on weight-for-height and triceps skinfold thickness criteria (18,20,27–29). The prevalence of undernutrition increases with increasing age, lower intelligence quotients, and increased severity of neurological impairment (28).

Pathophysiology

Non-nutritional factors including the type and severity of neurological disability, ambulatory status, and cognitive ability contribute to growth failure in neurologically impaired children (30). Children with seizures or spastic quadriplegia and those who are nonambulatory have lower height Z-scores than children who lack these disabilities (29). Children with spastic hemiplegia have smaller measures of breadth and length on the affected side, suggesting that the neurological defect influences growth (30). Inherent genetic factors may be associated with permanent linear stunting. Height-for-age Z-scores may decrease with advancing age independently of weight-for-age Z-scores, suggesting that the effect of scoliosis or contractures worsens over time (29).

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Height and weight Z-score deficits generally correlate well in neurologically impaired children, suggesting that nutritional factors contribute to their growth failure (29). Nutritional status explains 10% to 15% of the variability in linear growth in children with cerebral palsy (21). Nutritional status has a stronger effect on linear growth in younger than in older children, attesting to the irreversible effects of long-term undernutrition on growth. Inappropriate dietary intake relative to nutrient needs, oral motor dysfunction, increased nutrient losses, and altered energy expenditure may account for the poor nutritional status of neurologically impaired children.

Inappropriate Dietary Intake

Inappropriate dietary energy intake relative to nutrient needs is the primary cause of undernutrition, growth failure, and overweight in neurologically impaired children (4,6,31). Children with cerebral palsy consume less dietary energy than unaffected children (32,33). They may be unable to communicate their hunger, food preferences, and satiety, leaving caretakers responsible for regulating their dietary intake. Caretakers often overestimate the child's energy intake and underestimate the time spent feeding the child (33,34). Because the task of feeding these children may be difficult and time consuming, the amount of food provided may be insufficient to meet the child's growth needs. When adequate dietary energy is provided by enteral tube feedings, nutritional therapy leads to weight gain and linear growth (4,6). Careful monitoring may be necessary to avoid overfeeding, and consequently overweight, in these children.

Oral Motor Dysfunction

Feeding problems occur frequently in children with cerebral palsy (20,34). One study estimated that 90% of preschool children with cerebral palsy had oral motor dysfunction during the first year of life; 57% had sucking problems, 38% had swallowing problems, and 80% were fed nonorally at least once as infants (34). Severe feeding difficulties preceded the diagnosis of cerebral palsy in as much as 60% of patients (34). Poor suck, difficulty breast-feeding, problems with the introduction of solid foods, difficulty drinking liquids, difficulty biting or chewing solids, and coughing and choking with meals were common parental complaints (34).

Dependency on a caretaker and the inefficiency of the feeding process, including the amount of food ingested, the amount spilled, and the time required for feeding, influence the child's nutritional status (20,27,34,35). Children with cerebral palsy take 2 to 12 times longer to swallow pureed food and up to 15 times longer to chew and swallow solids compared with unaffected children (35,36). Longer mealtimes may not compensate for their feeding inefficiency (35,36). In one report, 28% of

parents required more than 3 hours daily to feed their child and 3% required more than 6 hours daily (37). Parents may perceive mealtime as a stressful, unpleasant experience (37). Parents' perceptions of mealtime is important because 60% of children with cerebral palsy are totally dependent on a caretaker for their nutrition (34).

Oral motor dysfunction is a major factor in the pathogenesis of undernutrition and usually correlates with the severity of motor impairment (27,38–41). Children may present with inadequate lip closure, drooling, and persistent tongue thrust, resulting in food loss through spillage (35,42). Bolus formation may be difficult to accomplish because of abnormal oral sensation, uncoordinated involuntary movements, or delayed development of ageappropriate oral motor skills. Initiation of the swallowing reflex may be delayed, resulting in food accumulation in the vallecula or pyriform sinuses and possible aspiration. Children with these findings have significantly lower height, weight, and weight-for-height Z-scores; body fat; and arm muscle area than unaffected children (27,40,41). Severity of feeding dysfunction is strongly associated with indicators of poor health and nutritional status (41). Children with more severe impairment who are unable to lift their head or feed themselves have a higher risk of aspiration (43). Early, persistent, and severe feeding difficulties are markers of subsequent poor growth and identify children who may benefit from gastrostomy feedings (44).

Increased Nutrient Losses

Neurologically impaired children who feed themselves may have poor hand-to-mouth coordination, leading to loss of nutrients because of excessive spillage. Gastroesophageal reflux, which affects 75% of neurologically impaired children, and delayed gastric emptying may result in a loss of nutrients because of frequent emesis (45,46).

Abnormal Energy Expenditure

Children with spastic quadriplegic cerebral palsy may grow normally with energy intakes as low as $61 \pm 15\%$ of the Dietary Reference Intake (DRI) for age and sex because their lean body mass, and hence resting energy expenditure (REE), is lower than that of unaffected children (25,33,47). Dietary energy needs of children with cerebral palsy who ambulate or have athetosis are higher than those who do not (48). REE correlates poorly with body cell mass in some neurologically impaired children, suggesting that central nervous system injury may affect energy regulation (47). REE in well-nourished, nonambulatory children with cerebral palsy is significantly lower than that predicted from equations based on age, sex, and weight in healthy children (47,49). The DRI for energy in healthy children $(1.5-1.6 \times REE)$ overestimates the energy needs of children with spastic quadriplegic cerebral palsy in whom a value of $1.1 \times \text{REE}$ may be sufficient (33). The ability to estimate dietary energy needs of neurologically impaired children is difficult because of the heterogeneity in their clinical features. Altered body composition and reduced physical activity make formulas used to calculate energy needs in healthy children invalid for neurologically impaired children.

MICRONUTRIENT DEFICIENCIES

Vitamin, trace element, and essential fatty acid deficiencies have been documented in neurologically impaired children who have reduced dietary intakes (50–53). Iron, selenium, zinc, essential fatty acids, and vitamins C, D, and E were reported to be deficient in 15% to 50% of these children (50–54). Children who are fed enterally may develop nutrient deficiencies because enteral formulas provide adequate amounts of micronutrients only when volumes consumed meet their age-related DRI for energy (55). Because many neurologically impaired children require lower energy intakes, their micronutrient intakes are correspondingly lower. Replacement therapy reverses these abnormalities.

OSTEOPENIA

Osteopenia is prevalent in neurologically impaired children (54,56,57). Nonambulatory children have lower bone mineral content than those who ambulate independently (57). Weight Z-score is the best correlate of bone mineral density Z-score in these children (57). Limited ambulation, increased duration of anticonvulsant therapy, and reduced sun exposure contribute to the pathogenesis of osteopenia (56-61). Dietary calcium, vitamin D, and phosphorus intakes are below the DRI in 50% to 80% of these children (31,60,61). Osteopenia is associated with significant fracture risk in neurologically impaired children (56,57). Supplemental calcium improves bone mineral density in healthy children by 5% over 4 years, but the effect of dietary calcium in neurologically impaired children is unknown (62). The use of bisphosphonates increased bone mineral density in children with cerebral palsy by 89% over 18 months (63). However, the relation between bisphosphonates and fracture risk or frequency in these children is unknown. The use of bisphosphonates generally is limited to research protocols because their indications in childhood diseases are not well defined and their long-term effects on bone remodeling in children are unknown.

NUTRITIONAL ASSESSMENT

Nutritional assessment of the neurologically impaired child includes a thorough medical, nutritional, growth, and social history; accurate growth and anthropometric measurements; a complete physical examination; meal observation; and selected diagnostic studies.

Medical History

The medical history includes information about the etiology, duration, and severity of neurological impairment and its expected course. These factors correlate with the risk of undernutrition and may affect the type of nutritional intervention required. Although the neurological condition itself may remain stable, the manifestations of the disorder may change over time. Periodic reassessment throughout childhood is necessary.

A review of medications is important because drugs prescribed for gastroesophageal reflux, constipation, and seizures may influence the child's eating pattern. Gastric acid inhibitors and laxatives often minimize gastro-intestinal discomfort and reverse feeding refusal. Valproic acid, gabapentin, topiramate, zonisamide, and felbamate may affect appetite and result in weight gain or loss. Many anticonvulsants impact the level of consciousness and have a secondary effect on oral motor skills and airway protection.

The review of systems identifies clinical problems that influence the type of nutritional intervention required by the neurologically impaired child. Respiratory and gastrointestinal problems impact all aspects of nutritional support. Emesis, food refusal, anemia, and intestinal blood loss suggest gastroesophageal reflux and esophagitis. Acid reflux tends to be more frequent in severely handicapped children and those with scoliosis (46). Irritability, infrequent bowel movements, and abdominal distension suggest constipation. Chronic cough, poorly controlled asthma, or recurrent pneumonia raises the possibility of aspiration.

Nutritional History

An assessment of the child's ability to feed independently and the efficiency of the feeding process may reveal an obvious reason for poor weight gain (20,27,34,35). An evaluation of oral motor skills, including the adequacy of lip closure, the presence of drooling, a persistent extrusion reflex, gagging and delayed swallowing, or coughing and choking during meals, reflects poor feeding capabilities. Symptoms may vary according to the texture of the food ingested. Fatigue and lethargy during meals may suggest hypoxemia (64).

A 24-hour recall of habitual food intake or a 3-day record of actual food consumption may be used to assess dietary energy and nutrient intake (40). Limited texture tolerance may indicate poor oral ability to manage food, resulting in self-restricted eating patterns, reduced nutrient intake, and poor weight gain (65,66). Consumption of inappropriate food textures may result in aspiration.

Growth History

Birth weight and length, as well as previous weight, length, and head circumference measurements, when recorded on NCHS growth charts, may be compared with the reference population to determine if growth faltering or abnormal weight gain or loss has occurred. Low birth weight may indicate a greater risk of undernutrition (67). The interpretation of historical data may be flawed because accurate growth measurements, particularly standing heights, may be difficult to obtain in children with neurological impairment. The height of the biological parents may be useful to estimate the child's genetic potential for linear growth.

Social History

The neurologically impaired child requires a considerable amount of care, a factor that impacts the parent's ability to work and the family's social activities. The child's scheduled activities, such as school or physical therapy, and the siblings' school and parents' work schedules require consideration when planning nutritional interventions. Financial issues, medical insurance, and the availability of home care require exploration. All individuals involved in the care and feeding of the child (aides, teachers, babysitters) and all settings in which feeding occurs (school, day care) require inquiry to ensure that nutritional interventions can be integrated into the family or institutional routines.

Growth and Anthropometric Measurements

Growth and anthropometric measurements reflect the child's nutritional status (28). Accurate measurements of height, length—or a proxy measure in children for whom these measurements are not reliable—and weight are obtained using standardized techniques and equipment at every medical encounter. Length is obtained supine in children younger than 2 years or in older children unable to stand. Alternative measures such as upper arm length or lower leg length may be obtained to estimate body length in children who have contractures or scoliosis (68). Reference standards are available for upper arm length and lower leg length in children 2 years and older (68). Standing height, without shoes and braces, is recorded in all other children. Weight is measured on the same scale with the child wearing little or no clothing. Children with severe disabilities may be weighed while being held by a parent or while seated in a wheelchair. BMI can be calculated from height and weight measurements of children 2 years and older. Although the inability to measure standing height theoretically invalidates the calculation of BMI, estimates derived from lower leg length serve as a practical alternative in the clinical setting. Weight-for-length is recorded for children younger than 2 years. Head circumference, usually measured in children younger 3 years, may be of limited use in the presence of microcephaly. Height (length), weight, BMI, and head circumference measurements, when properly measured and recorded on

NCHS growth charts, can be assessed relative to previous measurements and the reference population. Sex- and age-appropriate growth charts can be found at http://www.cdc.gov/growthcharts.

Body fat and arm muscle area can be characterized from mid upper arm circumference and triceps skinfold thickness (18). Reliability is improved when the same observer routinely obtains the measurements. The values for triceps skinfold thickness and arm muscle area may be compared with reference standards (69). Body fat usually is reduced at all sites, the triceps skinfold thickness being affected more than the subscapular skinfold thickness in neurologically impaired children (18,21). Triceps skinfold thickness may better identify those children with undernutrition than weight-for-height. Decreased triceps skinfold thickness identifies 96% of children with depleted fat stores, whereas weight-for-height less than the 10th percentile identifies only 55% (22).

Physical Examination

Physical examination focuses on signs of undernutrition, linear stunting, overweight, and specific nutrient deficiencies. Muscle tone, activity level, and the presence of athetoid movement are relevant because they influence dietary energy needs. Contractures and scoliosis are noteworthy for positioning during meals. Abnormal breath sounds may be suggestive of chronic respiratory problems associated with aspiration. Abdominal distension in conjunction with palpable masses suggests constipation. Examination of the skin may reveal the presence of decubitus ulcers. Pallor, skin rashes, smooth tongue, gingival bleeding, petechiae, bone deformities, or pedal edema may suggest other micronutrient deficiencies.

Meal Observation

Meal observation may be useful because of the variable feeding patterns in neurologically impaired children. Meal observation shows that these children may be offered less, consume less, and spill more food than unaffected children. Mealtime may not be enjoyable and parent-child interactions may be poor during the meal (37). Classification systems based on measures of growth and patterns of food consumption, such as eating efficiency and oral motor feeding skills, may be helpful to assess the effectiveness of oral feeding interventions (70,71).

Diagnostic Studies

Although isolated nutrient deficiencies may be present in children with neurological impairment, extensive laboratory evaluation generally is not necessary (50–53). A complete blood count and serum ferritin may document iron deficiency or anemia. Serum albumin and prealbumin, factors that correlate strongly with the risk of morbidity and mortality, are less reliable

indicators of nutritional status (72). Serum electrolytes and blood urea nitrogen reflect hydration status; however, blood urea nitrogen may be low because of poor protein intake and low muscle mass. Abnormal serum phosphorus, alkaline phosphatase, and 25-hydroxyvitamin D levels may reflect poor bone mineral status. Bone densitometry may be considered in children who have sustained pathological fractures. Bone quantitative ultrasonography may be more easily performed than dual-energy x-ray absorptiometry because of skeletal deformities or motion artifacts; however, normative data for children are not yet available (73).

Additional investigations may be helpful, depending on the child's symptoms and the need for permanent enteral access. A videofluoroscopic assessment of swallowing function, using different food and beverage textures, determines the degree of oral motor dysfunction and risk of aspiration. A swallowing function study may demonstrate silent aspiration in the absence of choking and coughing during meals. Positioning the child during the evaluation is important because some children may not aspirate when placed upright, but do so in a reclined position. Assessment of swallowing function at the end of a meal is informative because feeding fatigue may lead to aspiration. A swallowing function study may provide guidance for appropriate food textures and therapeutic feeding techniques.

The diagnosis of gastroesophageal reflux often is apparent based on symptoms of vomiting, chest or abdominal pain, feeding refusal, or irritability. A 24-hour esophageal pH probe study may be helpful if the diagnosis is not obvious, but it may be normal in some children who have respiratory complications associated with gastroesophageal reflux. A gastric emptying scan may detect gastroparesis and, to some extent, gastroesophageal reflux and aspiration. An upper gastrointestinal series may detect gastroesophageal dysmotility or superior mesenteric artery syndrome, both of which may interfere with feeding. Although episodes of reflux may occur during the study, this finding may not be diagnostic of acid reflux disease. An abnormal location of the stomach in the thorax of children with severe scoliosis may influence the type of intervention used for enteral access.

The child with symptoms suggestive of chronic aspiration may require a chest x-ray and an evaluation by a pulmonologist, especially if surgical intervention for enteral access is considered. Monitoring O_2 saturation during a meal may be important because neurologically impaired children may have hypoxemia while being fed some food textures (64).

NUTRITIONAL SUPPORT

Nutritional support is essential for the care of the neurologically impaired child. After a thorough evaluation, an individualized intervention plan that accounts for the child's nutritional status, feeding ability, and

medical condition may be determined. Nutritional assessments may be performed at least annually in the older child and more frequently in the infant and toddler to document adequate growth and nutrient intakes. The goal is to optimize the child's health, functional status, and quality of life while maintaining adequate growth and nutritional status.

Nutritional support is provided enterally rather than parenterally, assuming competency of the gastrointestinal tract. Evidence of oral motor feeding difficulties, undernutrition (weight-for-height < 80% of expected, BMI < fifth percentile), growth failure (height-for-age < 90% of expected), overweight (BMI > 95th percentile), and individual nutrient deficiencies indicates the need for nutritional intervention (1). Enteral tube feedings are mandatory in children who cannot meet their energy and nutrient needs by oral feeding alone. The approach to enteral feeding requires decisions about nutrient requirements; positioning and oral therapy; behavioral modification; the type, route, and method of formula administration; feeding intolerance; and ethical concerns (74).

Nutritional Requirements

Energy requirements of neurologically impaired children are disease specific and vary with the severity of their disability, their mobility, the presence of feeding difficulties, and the degree of altered metabolism. Dietary energy can be estimated from DRI standards for basal energy expenditure (http://www.nal.usda.gov/ fnic/etext/000105.html), indirect calorimetry (75), or height (76) as summarized in Table 1. The best way to determine the adequacy of the diet is to monitor the rate of weight gain and BMI in response to nutritional therapy. Adequate provision of dietary protein, vitamins, and minerals is mandatory when dietary energy intake is modified to obtain the desired growth rate. In the absence of evidence-based nutrient allowances for neurologically impaired children, the DRI for protein, vitamins, and minerals in healthy children is recommended (http://www.nal.usda.gov/fnic/etext/000105.html). Judicious use of multivitamin and mineral supplements is prudent for neurologically impaired children who rely on table foods and beverages alone for their daily dietary intake.

Positioning and Oral Therapy

The occupational or speech therapist can assist with oral feeding skills, correct positioning of the child, and the use of appropriate chairs and adapted utensils during meals. Therapy to improve oral motor skills may be attempted, especially before 5 years of age. Oral feeding interventions may be effective in enhancing oral motor function, but are not effective in promoting feeding efficiency and weight gain (7). Improvement in oral motor function may be limited (77). Periodic reassess-

ment of oral feeding skills is important to determine the potential for oral feeding. An approach to the treatment of swallowing dysfunction is VitalStim, a device that administers electrical stimulation to the musculature of the neck. The efficacy of this treatment in children has not been documented (78).

Behavioral Modification

Behavioral therapy initiated by a skilled child psychologist may improve the quantity of food consumed, the feeding efficiency, and the range of textures accepted, as well as the quality of feeding interactions between the caretaker and the child (79).

Type of Formula

The choice of enteral formula depends on the child's age, medical condition, energy requirement, and mode of enteral access. Standard, age-appropriate, infant or pediatric casein-based formulas are administered routinely (Table 2). Whey-based formulas may be better tolerated because they enhance gastric emptying (80). Children who manifest symptoms associated with cow milk protein sensitivity (allergy) may require a protein hydrolysate or amino acid formula. Adult formulas may prevent hypoalbuminemia during periods of catch-up growth; but care should be taken to avoid iron, vitamin D, calcium, and phosphorus deficiency (31). If high energy density (1.5 or 2 kcal/mL) formulas are used, monitoring hydration status and protein and micronutrient intake is necessary. A fiber-containing formula may ameliorate constipation, but may aggravate intestinal bloating if volume is increased rapidly.

Route of Administration

Oral feedings can be maintained in children with adequate oral motor skills who have a low risk of aspiration. Adequate positioning and adjusting food consistency with thickening agents may improve feeding efficiency. Increasing the energy density of food maximizes energy intake. If oral intake is insufficient to promote weight gain, linear growth, and adequate hydration; if the amount of time to feed the child is excessive because of chewing and swallowing dysfunction; or if aspiration is a risk, enteral tube feedings may be considered. The type of enteral access selected will depend upon the nutritional and clinical status of the child and the anticipated duration of enteral feedings. Parents will be concerned about the child's loss of oral feeding skills, the risks and benefits of enteral tube feeding, and the manner in which alternative feeding methods fit the family's life style (81).

Nasogastric or nasojejunal tube feedings are minimally invasive methods that may be used for short-term nutritional support in undernourished children or in

TABLE 1. Methods to determine dietary energy needs in neurologically impaired children

Dietary Reference Intake Standards for Basal Energy Expenditure

Energy intake (kcal/d) = Basal Energy Expenditure (BEE) \times 1.1, where:

■ BEE can be found at: http://www.nal.usda.gov/fnic/etext/000105.html Indirect calorimetry (74)

Energy intake (kcal/d) = [basal energy expenditure (BMR) \times muscle tone \times activity] + growth, where:

- BMR (kcal/d) = body surface area (m²) × standard metabolic rate (kcal/m²/h) × 24 h
- Muscle tone = 0.9 if decreased, 1.0 if normal, and 1.1 if increased
- Activity = 1.1 if bedridden, 1.2 if wheel chair dependent or crawling, and 1.3 if ambulatory
- Growth = 5 kcal/g of desired weight gain (normal and catch-up growth)

Height (75)

- 15 kcal/cm in children without motor dysfunction
- 14 kcal/cm in children with motor dysfunction who are ambulatory
- 11 kcal/cm in children who are nonambulatory

those with severe acid reflux or aspiration who are awaiting gastrostomy placement. Nasogastric or nasoje-junal tubes are not used long-term because they may be dislodged easily, may stiffen and cause intestinal perforation, or may result in nasal congestion, sinusitis, otitis media, and skin and mucosal irritation. Bedside placement of nasojejunal tubes can be achieved by allowing the tube to migrate spontaneously or in conjunction with a prokinetic drug (82–89). Newer techniques such as pH-assisted placement are available (90,91). Fluoroscopic or endoscopic tube placement may be required if these approaches are unsuccessful.

Gastrostomy feedings provide an option for children with severe feeding problems who have poor weight gain, although evidence-based practice guidelines with attendant risks and benefits are lacking (8,9). A gastrostomy tube or "button" is recommended for long-term enteral nutrition because it is more comfortable for the child and is less easily dislodged than a nasogastric tube. Gastrostomy feedings may promote weight gain, improve the child's health, and reduce the time spent feeding the child (8,9,92). The best clinical response is

seen in children with the shortest time between the neurological insult and gastrostomy placement with refeeding. Children who have gastrostomies placed within the first year of life are more likely to exceed the fifth percentile for height and weight (10). Gastrostomy feedings initiated within 1 year of the neurological insult are associated with improved weight-forage, weight-for-length, and length-forage. Nutritional intervention initiated 8 years after the neurological insult does not improve length-forage, despite improvement in weight-forage (6).

Percutaneous endoscopic gastrostomy (PEG) placement, a minimally invasive nonsurgical procedure, involves little discomfort; and the feeding device can be used within a few hours of installation (93). Prior abdominal surgery, ascites, hepatomegaly or splenomegaly, and portal hypertension may be contraindications to the PEG procedure. PEG placement in children carries a 2% to 17% risk of major complications such as perforation, peritonitis, or separation of the stomach from the abdominal wall (94–96). PEG placement has a 22% to 67% risk of minor complications, such as stomal

TABLE 2. Infant, pediatric, and adult formulas

Infant	Pediatric	Adult
Cow milk (casein-/whey-based)	Cow milk (casein-based)	Protein blend (casein, whey, soy)
Enfamil Lipil	Kindercal	Boost
Similac Advance	Nutren Jr	Ensure
_	Pediasure	Nutren
_	_	Osmolyte
Soy	_	_
Enfamil Prosobee Lipil	_	_
Good Start Supreme Soy	_	_
Similac Isomil Advance	_	_
Partially hydrolyzed (whey-based)	_	_
Good Start Supreme DHA & ARA	_	_
Hydrolysate (casein-based)	Hydrolysate (whey-based)	Hydrolysate (whey-based)
Nutramigen Lipil	Peptamen Jr	Peptamen
Pregestimil	_	_
Similac Alimentum	_	_
Amino Acids	Amino Acids	Amino Acids
Elecare	Elecare	Vivonex TEN
Neocate	Neocare 1+	_
_	Vivonex Pediatric	_

infection, leakage from the stoma, granulation tissue formation, broken or leaking tubes, and accidental dislodgment of the tube (94,97). Nutrient deficiencies may occur as a consequence of artificial feedings (2,8,9). The higher death rate in children fed by gastrostomy may reflect the severity of their neurological disability compared with those fed orally (9). The risk of inducing acid reflux or esophagitis after PEG placement in neurologically impaired children without previous symptoms is 12% to 60% (94–96,98,99). The likelihood that ongoing medical therapy will be required for preexisting acid reflux after PEG placement is 71% (94). An evaluation for acid reflux before PEG placement may be warranted because 5% of neurologically impaired children who have a normal pH probe study eventually require an antireflux procedure, compared with 29% to 58% of those who have an abnormal pH probe study (94,95). Further evaluation with upper endoscopy and esophageal biopsy does not predict clinical outcome after PEG placement in children (100). Acid reflux may improve in some children after PEG placement and nutritional rehabilitation (11).

Surgical gastrostomy is reserved for children who have contraindications to PEG placement. Surgical gastrostomy is associated with a higher risk of inducing acid reflux severe enough to require fundoplication than is PEG placement (39% vs 10%) (101). Laparoscopic gastrostomy placement with or without a fundoplication is associated with less morbidity, permits earlier enteral nutrition, and has a cost advantage compared with the open surgical technique (102). Overall, laparoscopic or open surgical fundoplication may be required in 8% to 25% of neurologically impaired children (94,95,99,101,103). Laparoscopic fundoplication is associated with a 5% risk of intraoperative complications, a 30% risk of postoperative complications, and a 1% risk of mortality in these children (104). Although a pyloroplasty in conjunction with a fundoplication improves gastric emptying, dumping syndrome may occur and require long-term continuous infusions until bolus feeds are tolerated (105,106). The risk of feeding difficulty, gas bloat or dumping syndrome, and recurrence of acid reflux after a fundoplication varies between 10% and 29% in neurologically impaired children (101,106,107). Retching may be a disturbing symptom after a fundoplication. (108) The presence of the emetic reflex preoperatively may predict postoperative retching (109). A second fundoplication may be required in 4% to 19% of these children (110-117). The Thal operation is associated with a higher failure rate than the Nissen procedure in neurologically impaired children (118). An esophagogastric separation procedure may be indicated for failed fundoplication in neurologically impaired children (119).

Image-guided, retrograde or antegrade, percutaneous placement of gastrostomy or gastrojejunostomy tubes is an alternative, minimally invasive fluoroscopic method for enteral feeding (120,121). The retrograde percuta-

neous technique has a higher rate of successful placement than the PEG method and has a lower rate of major complications than PEG or surgical gastrostomy placement (120). The rate of major complications including peritonitis, abscess, septicemia, and death is 6% to 12%. The rate of minor complications including dislodgment, leakage, obstruction, and migration is 44% to 73% (120,121). Gastrojejunostomy or jejunostomy tube placement may be required in children who do not tolerate gastric feeds, have severe gastroesophageal reflux, are at risk for aspiration, are poor candidates for fundoplication, or are high-risk for failure of a second antireflux procedure (120–123). Comparison of image-guided gastrojejunostomy placement versus surgical gastrostomy placement and fundoplication in neurologically impaired children showed no difference in the rate of infection, aspiration pneumonia, esophagitis, or hospitalization. The surgical group was more likely to experience retching and dysphagia, whereas the radiological group had more technical problems, such as tube breakage, dislodgment, or clogging (123). Intussusception occurs in 16% to 49% of children with gastrojejunostomies and can be managed with medical or surgical reduction and tube replacement (120,124). Some gastrojejunal tubes allow drainage of gastric contents while administering formula into the jejunum, a useful feature in children with retching and the gas bloat syndrome. A surgical or laparoscopic loop or Roux-en-Y jejunostomy is reserved for selected children in whom other options have failed (125).

Method of Administration

Bolus feedings are preferred in children who do not have acid reflux or delayed gastric emptying because they mimic the physiological responses associated with meals, allow a more flexible feeding schedule, and are more convenient in ambulatory children. Continuous infusions of formula may be used throughout the day or night in children who do not tolerate bolus feeds or have formula administered directly into the jejunum. When large volumes are required, bolus feeds can be combined with continuous nocturnal infusions of formula. Continuous nocturnal infusions avoid interruptions during daytime activities, but may disrupt sleep (16,126).

Approach to Feeding Intolerance

Feeding intolerance may be associated with recurrent acid reflux, delayed gastric emptying, diarrhea, or constipation. In the absence of progression of the neurological disorder, intercurrent infection, or intestinal obstruction, the quality and quantity of the feeding regimen require reevaluation. Changing the feeding schedule from bolus to continuous infusion, decreasing the rate of infusion, concentrating the formula to decrease the volume of feeds, or selecting an alternative

formula may ameliorate symptoms. If symptoms persist, medical treatment of acid reflux or delayed gastric emptying may be instituted before exploring laparoscopic or surgical procedures. Medical management of acid reflux and delayed gastric emptying consists of using whey hydrolysate formulas, as well as medications that promote acid suppression (histamine antagonists, proton pump inhibitors) and motility (bethanecol, metoclopramide, erythromycin, cisapride). Although the availability of cisapride is limited, its use in neurological disorders associated with QT wave abnormalities, for example, Rett syndrome, is cautioned. Medical management of constipation consists of single or multiple laxative agents with stool softening and stimulatory effects (polyethylene glycol-electrolyte solution, magnesium hydroxide, senna extract, lactulose, bisacodyl).

Ethical Considerations

Many families find the idea of a feeding gastrostomy difficult to accept (127). Decision making revolves around the constraints of parental autonomy versus the welfare of the neurologically impaired child. Insistence on gastrostomy placement by the medical team may represent a judgment that parents have failed in the care of their child. Recurrent discussions include themes about starvation versus quality of life, prolongation of life, and meaningful family interrelationships. Although medical opinions generally prevail, parental wishes should be considered and respected.

CONCLUSION

A multidisciplinary team of pediatric specialists, including physicians, nurses, dietitians, occupational and speech therapists, psychologists, and social workers, has the responsibility to monitor the nutritional status of neurologically impaired children and provide early, efficient nutritional intervention to ensure normal growth, optimal functional status, and quality of life. The decision to initiate enteral nutrition may be difficult for the family who perceive this approach as a failure on their part to feed their child. Involvement of the child and the family in the decision-making process is important to ensure successful nutritional intervention. Weight gain, ease of feeding the child, and the stress involved with meals usually improve with nutritional intervention. The multidisciplinary team is obligated to provide ongoing support and education to the family throughout the long-term relationship.

RECOMMENDATIONS

 Nutritional support is an integral part of the care of neurologically impaired children and is carried out

- by a multidisciplinary team of pediatric specialists, including physicians, nurses, dietitians, occupational and speech therapists, psychologists, and social workers.
- Nutritional assessments may be performed at least annually in the older child and more frequently in the infant and toddler; height or length, weight, and BMI or weight-for-length may be sufficient to document adequate growth and nutrient intakes.
- 3. Mechanisms must be in place to insure the early identification of children at high risk for undernutrition, growth failure, chronic lung disease due to aspiration, and overweight, particularly younger children, children with severe neurological disability, and children with oral motor dysfunction.
- 4. Alternative anthropometric indices such as mid upper arm circumference, triceps skinfold thickness, and lower leg length can be used to evaluate nutritional status when accurate weight and height measurements are difficult to obtain.
- 5. Monitoring the rate of weight gain and BMI in response to nutritional therapy is an appropriate method to determine the adequacy of dietary intake because nutrient requirements may be lower than the DRI for age and because abnormalities of muscle tone, physical activity, and growth may be present.
- Monitoring for micronutrient deficiencies such as iron and vitamin D may be considered annually; providing prophylactic supplements of micronutrients serves as a reasonable preventive strategy.
- 7. Foods with high nutrient and energy density are an appropriate first step in the nutritional repletion of children who can be fed orally; modification of food and beverage textures and consistencies may be required in children with advanced oral motor dysfunction. Periodic reassessment of oral feeding skills is important to determine the potential for oral feeding.
- 8. Enteral tube feedings can be initiated early in children who are unable to feed orally or who cannot achieve sufficient oral intake to maintain adequate nutritional or hydration status.
- Nasogastric or nasojejunal tube feedings are reserved for short-term nutritional intervention; gastrostomy or gastrojejunostomy tube feedings may be considered when long-term nutritional rehabilitation is required.
- 10. Antireflux procedures such as esophageal fundoplication are reserved for appropriate clinical indications; anticipatory guidance that highlights symptoms such as retching and frequency of fundoplication failure is important.
- 11. Although the health and welfare of the child are paramount, parental concerns and family issues have a role in the decision to provide aggressive nutritional support.

12. Assessments can be performed to provide assurances that a family support system to care for the child exists and that the family has the ability to carry out the nutritional rehabilitation program.

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