European Society for Paediatric Gastroenterology, Hepatology and Nutrition Guidelines for the Evaluation and Treatment of Gastrointestinal and Nutritional Complications in Children With Neurological Impairment

*Claudio Romano, †Myriam van Wynckel, ‡Jessie Hulst, §Ilse Broekaert, ||Jiri Bronsky, ¶Luigi Dall'Oglio, #Nataša F. Mis, **Iva Hojsak, ††Rok Orel, ‡‡Alexandra Papadopoulou, §§Michela Schaeppi, ||||Nikhil Thapar, ¶¶Michael Wilschanski, ##Peter Sullivan, and ***Frédéric Gottrand

ABSTRACT

Objectives: Feeding difficulties are frequent in children with neurological impairments and can be associated with undernutrition, growth failure, micronutrients deficiencies, osteopenia, and nutritional comorbidities. Gastrointestinal problems including gastroesophageal reflux disease, constipation, and dysphagia are also frequent in this population and affect quality of life and nutritional status. There is currently a lack of a systematic approach to the care of these patients. With this report, European Society of Gastroenterology, Hepatology and Nutrition aims to develop uniform guidelines for the management of the gastroenterological and nutritional problems in children with neurological impairment.

Methods: Thirty-one clinical questions addressing the diagnosis, treatment, and prognosis of common gastrointestinal and nutritional problems in neurological impaired children were formulated. Questions aimed to assess the nutritional management including nutritional status, identifying undernutrition, monitoring nutritional status, and defining nutritional requirements; to classify gastrointestinal issues including oropharyngeal dysfunctions, motor and sensory function, gastroesophageal reflux disease, and constipation; to evaluate the indications for nutritional rehabilitation including enteral feeding and percutaneous gastrostomy/jejunostomy; to define indications for surgical interventions (eg, Nissen Fundoplication, esophagogastric disconnection); and finally to consider ethical issues related to digestive and nutritional problems in the severely neurologically impaired children. A systematic literature search was performed from 1980 to October 2015 using MEDLINE. The approach of the Grading of Recommendations Assessment, Development, and Evaluation was applied to evaluate the outcomes. During 2 consensus meetings, all recommendations were discussed and finalized. The group members voted on each recommendation using the nominal voting technique. Expert opinion was applied to support the recommendations where no randomized controlled trials were available.

Key Words: cerebral palsy, gastrointestinal diseases, nutrition

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From the *Unit of Pediatrics, Department of Human Pathology in Adulthood and Childhood ''G. Barresi'', University of Messina, Messina, Italy, the †Department of Paediatric Gastroenterology, Hepatology and Nutrition, Ghent University Hospital, Ghent, Belgium, the ‡Department of Pediatric Gastroenterology, Erasmus Medical Center-Sophia Children's Hospital, Rotterdam, The Netherlands, the §Department of Pediatric Gastroenterology, Faculty of Medicine, University Children's Hospital, University of Cologne, Cologne, Germany, the ||Department of Paediatrics, University Hospital Motol, Prague, Czech Republic, the ¶Department of Digestive Endoscopy and Surgery, Bambino Gesù Children's Hospital, Rome, Italy, the #Department of Gastroenterology, Hepatology and Nutrition, University Children's Hospital Ljubljana, Ljubljana, Slovenia, the **Children's Hospital Zagreb, Zagreb, Croatia, the ††University Children's Hospital Ljubljana, Ljubljana, Slovenia, the ‡‡Division of Gastroenterology, Hepatology and Nutrition, First Department of Pediatrics, University of Athens, Children's Hospital ''Agia Sofia'', Athens, Greece, the §§Pediatric Center, Clinic des Grangettes, Geneva, Switzerland, the ||||Department of Pediatric Gastroenterology, Great Ormond Street Hospital NHS Foundation Trust, London, United Kingdom, the ¶¶Pediatric Gastroenterology, Hadassah-Hebrew University Medical Center, Jerusalem, Israel, the ##Department of Paediatrics, Children's Hospital, University of Oxford, Oxford, United Kingdom, and the ***Department of Pediatric Gastroenterology, Hepatology and Nutrition, CHU Lille, University Lille, Lille, France.

Address correspondence and reprint requests to Claudio Romano, PhD, Unit of Pediatrics, Department of Human Pathology in Adulthood and Childhood ''G. Barresi'', University of Messina, Viale Consolare Valeria, 98124 Messina, Italy (romanoc@unime.it).

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What Is Known

- Children with neurological impairment have feeding and swallowing problems.
- Poor nutritional status is secondary to insufficient caloric intake.
- The spectrum of the clinical conditions associated includes respiratory infections, gastroesophageal reflux, and chronic aspiration.
- The goals of the management are to improve the quality of life for both the child and family.

What Is New

- A number of feeding and oral motor intervention strategies have been developed.
- Multiple approaches may be used in children with growth failure.
- Gastrostomy feeding may reduce aspiration but could exacerbate gastroesophageal reflux disease.
- The impact of antireflux procedures in addition to gastrostomy is relatively unknown.

Gastrointestinal (GI) problems are frequent in children with neurological impairment (NI) and should be considered together with the evaluation of the nutritional status. The NI can affect the GI system, most notably oral motor function and motility. Dysphagia in NI children typically presents as feeding difficulties,

extended feeding times, malnutrition, and/or a history of aspiration pneumonia. Dysmotility, hypotonia, and nonambulation can contribute to constipation or severe gastroesophageal reflux disease (GORD). Regular nutritional assessment is essential and identifies signs and symptoms related to malnutrition. One of the first and often most crucial decisions about nutritional management of NI children is whether or not to use nonoral methods (nasogastric tube feeding or gastrostomy) of delivery to achieve an adequate intake. To date, although the morbidity of GI and nutritional problems are well known and the need for a careful multidisciplinary follow-up is highlighted (1) no recommendations on the GI and nutritional management of infants and children with NI are available. Similarly, there is a lack of a systematic approach to the care of these patients through transition to adulthood.

In this consensus, we will consider NI as a heterogeneous group of disorders that primarily relate to the central nervous system, composed of the brain and spinal cord, affecting an individual's speech, motor skills, vision, memory, muscle actions, and learning abilities. As a proxy, we will also consider cerebral palsy (CP), as the major subgroup of the NI which is defined a group of permanent disorders of the development of movement and posture, causing activity limitation, that are attributed to nonprogressive disturbances that occurred in the developing fetal or infant brain (2).

METHODS

Under the auspices of European Society of Gastroenterology, Hepatology and Nutrition (ESPGHAN), a working group (WG) consisting of selected members from the GI and nutrition committees and experts in the field, including pediatric gastroenterologists and a pediatric surgeon, was formed in January 2015 to formulate current evidence-based clinical practice guidelines for the evaluation and treatment of GI and nutritional problems in children with NI. Clinical questions relevant for the evaluation and treatment of GI and nutritional problems in children with NI were formulated by the members of the WG after several rounds of e-discussion (Table 1). After the questions were formulated, the guidelines committee was subdivided into subgroups based on expertise of the individual members. WG was subdivided into subgroups which focused on different questions.

Questions were addressed using the results of systematic literature searches from 1980 to December 2015, and based also on expert opinions. The MEDLINE and Cochrane Database of Systematic Reviews were searched. Inclusion criteria were as follows:

1. Systematic reviews, prospective or retrospective controlled studies, prospective or retrospective cohort studies.
2. Study population consisting of children ages 0 to 18 years.
3. The keywords used to identify relevant articles were neurological impairment and/or cerebral palsy, plus any of one of the following terms according to the topic covered: nutritional assessment, body composition, anthropometrics, growth charts, dysphagia, nutrition requirements, vitamins, minerals, micronutrients, oral motor dysfunction, dietetics, tube feeding, gastrostomy, jejunostomy, fundoplication, gastroesophageal reflux, constipation, and ethics. Additional strategies for identifying studies included using these keywords to search studies included in the reference lists of review articles. All members of the WG were asked to search the literature with respect to their assigned topics and a common reference list and copy of each article was made available for every participant. The levels and quality of evidence were assessed using the classification system of the Oxford Centre for Evidence-Based Medicine (*http://www.cebm.net*) (diagnostic and prognostic questions) and the GRADE system (therapeutic questions).

TABLE 1. Summary of the clinical questions

Number	Question
1	How to approach nutritional management in NI children?
2	What is the method for assessing nutritional status?
3	How to identify undernutrition?
4	How often to monitor nutritional status?
5	What are the requirements for energy in NI children
6	What are the requirements for protein in NI children?
7	What are the requirements for fluid in NI children?
8	What are the requirements for micronutrients in NI children?
9	Dysphagia/oral motor dysfunction: How to define it?
10	How to evaluate oral motor and sensory function?
11	What is the treatment of oropharyngeal dysfunction?
12	How to monitor oropharyngeal dysfunction?
13	How to diagnose gastroesophageal reflux disease?
14	How to treat gastroesophageal reflux disease?
15	How to monitor gastroesophageal reflux disease?
16	How to diagnose constipation?
17	What is the treatment of constipation?
18	What other problem can contribute to feeding difficulties (ie, dental, drooling, pain, orthopedics, etc)?
19	Which type of diet according to oral/gastric tolerance?
20	Does feeding times compete with rehabilitation?
21	Which sorts of enteral product to use?
22	Which modalities of enteral nutrition to use (bolus/continuous)?
23	Which type of tube (nasogastric, periendoscopic gastrostomy) to use?
24	What are the indications of jejunal feeding?
25	When should tube feeding be started?
26	What investigations be carried out before consideration for surgery?
27	Should a fundoplication systematically performed when a gastrostomy indicated?
28	What are the indications for fundoplication?
29	Is there surgical alternative to fundoplication?
30	What is the effect of nutritional support on quality of life of children and caregivers?
31	Are there ethical issue in relation to nutritional support?

NI = neurological impairment.

Grades of evidence for each statement are based on the grading of the literature. If no therapeutic studies were found, we decided to define the quality of evidence as ''very low.'' Using the GRADE system, the quality of evidence was graded as follows (3–8):

1. High: Further research is unlikely to change our confidence in the estimate of effect.
2. Moderate: Further research is likely to have impact on our confidence in the estimate of effect and may change the estimate.
3. Low: Further research is likely to have an impact on our confidence in the estimate of effect and likely to change the estimate.
4. Very low: Any estimate of effect is uncertain.

Each group of authors (each question was shared by at least 2 coauthors) systematically reviewed all the articles selected in the literature review, summarized the important findings in a tabular format, and graded the articles chosen in the literature review using the GRADE system. Both the summary tables of all the articles and their grading were sent to all the authors before they wrote their relevant sections. No professional librarian was involved in the

process and, although the tables were reviewed during 2 face-to-face meetings, we did not perform a detailed down/upgrading of the level of evidence. We acknowledge that this is a deviation from the GRADE process. The table of the quality assessment of included studies is available in the online-only appendix, *http://links.lww.com/MPG/B24*. During the 2 face-to-face meetings, the qualities of the studies were reviewed and discussed before summary statements underwent voting and grading by the WG (Table 2).

CONSENSUS MEETING AND VOTING

Two consensus meetings were held to achieve consensus on and formulate all recommendations. Each subgroup presented the recommendations during the consensus meetings, where they were discussed and modified according to the comments of the participants. The consensus was formally achieved through nominal group technique, a structured quantitative method. The ESPGHAN WG consisting of members of all the subgroups anonymously voted on each recommendation. A 9-point scale was used (1 strongly disagree to 9 fully agree), and votes are reported for each recommendation. It was decided in advance that consensus was reached if >75% of the WG members voted 6, 7, 8, or 9. The consensus was reached for all of the questions. A decision was made to present one algorithm (Fig. 1). The final draft of the guidelines was sent to all the committee members for approval in September 2016, and then critically reviewed by a multidisciplinary panel of the GI and nutrition committees and members of the council of ESPGHAN.

RECOMMENDATIONS

How to Approach Nutritional Management in Children With Neurological Impairment?

Nutritional assessment and nutritional interventions in children with NI are a challenge for physicians but should be part of the child's comprehensive care and rehabilitation. The aim is not only to advance weight and linear growth but also to secure improved physiological and functional capacity. Given that nutritional problems in this group of children arise from a variety of causes requiring 1 or more of multiple possible interventions (ie, positioning, rehabilitation, diet modification, drugs) a multidisciplinary approach is required, including input from occupational therapists, psychologists, speech therapists, dietitians, physicians, and nurses.

> 1: ESPGHAN WG suggests that nutritional evaluation and management should be performed by a multidisciplinary team ideally including as required a physician, dietitian, nurse, speech therapist, physical therapist, psychologist, and occupational therapist.

Level of evidence (LoE) moderate
Gastroesophageal reflux (GoR) strong
VOTE: 9, 9, 9, 9, 9, 9, 9, 8, 9, 8, 8, 7, 9, 6, 9 (accepted)

What Is the Method for Assessing Nutritional Status?

There are many ways to assess the nutritional status in children with NI, varying from simple to more complex methods. The methods can be divided into anthropometrics, body composition, methods for assessing bone status, and laboratory methods.

Anthropometrics

Anthropometric assessment is frequently used as the method for assessing the growth and nutritional status of children with NI, but is more challenging than in typically developing children as most of measurements are shown to be invalid. Furthermore, specific reference standards, special norms are not available for children with NI.

Weight measurements can be difficult to perform and several methods exist, but there are no studies comparing the different methods. The commonly used methods are wheelchair scales, sitting scales, and hoist scales (9). Although reduced muscle mass may reflect undernutrition and immobility, it may occur secondary to neurological disease and/or myopathy. The large study by Samson-Fang and Stevenson (10) found weight for height (WFH) to be a poor indicator of low fat stores in children with CP (WFH <10th centile failed to identify 45% of children with severely depleted fat stores). On the contrary, finding a low body mass index (BMI) or WFH does not necessarily mean a low fat mass, but can also imply a low muscle mass, but high fat mass (10,11).

Height measurements in children who can stand should take place using a stadiometer. Supine length could be a good alternative when a child can lie straight. A significant proportion of children with neurodevelopmental disability, however, is not able to stand upright and many have joint contractions, spasticity, and/or scoliosis, making height measurements difficult (12). Alternative measurements for the assessment of height are segmental length measurements such as knee-heel length, tibia length, and ulnar length, which can be assessed using sliding calipers. These measures were shown to have a high inter-rater reliability and to be highly repeatable and therefore may be used on their own to monitor growth (13). Growth charts using these alternative measures have been developed, which can be used to assess linear growth (12,14,15). There are several formulae available to estimate height from the segmental lengths (12,16,17), but the limits of agreement with recumbent length were found to be wide, usually in the range of ±10 cm (13,18).

> 2a: ESPGHAN WG recommends that the assessment of nutritional status in children with NI should not be based solely on weight and height measurements.

LoE Moderate
GoR strong
VOTE: 9, 9, 9, 9, 9, 9, 9, 8, 9, 8, 8, 7, 9, 6, 9 (accepted)

> 2b: ESPGHAN WG recommends that measurements of knee height or tibial length in children with NI should be performed routinely to assess linear growth, when height cannot be measured.

LoE strong
GoR strong
VOTES: 8, 9, 7, 8, 8, 9, 8, 8, 8, 9, 8, 8, 9, 7, 7, 9 (accepted)

TABLE 2. Summary of recommendations

Number	Statements
1	ESPGHAN WG suggests that nutritional evaluation and management should be performed by a multidisciplinary team ideally including as required a physician, dietitian, nurse, speech therapist, physical therapist, psychologist, and occupational therapist
2a	ESPGHAN WG recommends that the assessment of nutritional status in children with NI should not be based solely on weight and height measurements
2b	ESPGHAN WG recommends that measurements of knee height or tibial length in NI children should be performed routinely to assess linear growth, when height cannot be measured
2c	ESPGHAN WG recommends that the measurement of fat mass by skinfold thickness should be a routine component of the nutritional assessment in NI children
2d	ESPGHAN WG recommends the use of dual energy x-ray absorptiometry (DXA) scans to measure bone mineral density as part of nutritional assessment in children with NI
2e	ESPGHAN WG recommends the assessment of micronutrient status (eg, vitamin D, iron status, calcium, phosphorus) as part of nutritional assessment of children with NI
3a	ESPGHAN WG suggests that the identification of children with NI as undernourished should be based on the interpretation of anthropometric data
3b	ESPGHAN WG does not recommend the use of CP-specific growth charts to identify undernutrition
3c	ESPGHAN WG suggests the use of 1 or more of the following red flag warning signs for the identification of undernutrition in NI children: Physical signs of undernutrition such as decubitus skin problems and poor peripheral circulation Weight for age z score <-2 Triceps skinfold thickness $<$10th centile for age and sex Mid-upper arm fat or muscle area $<$10th percentile Faltering weight and/or failure to thrive
3d	ESPGHAN WG recommends the use of follow-up anthropometry (weight, linear growth, and fat mass) in the monitoring of nutritional status of children with NI
4	ESPGHAN WG suggests that children with NI have anthropometry at least every 6 months and micronutrients checked annually
5a	ESPGHAN WG recommends the use of the dietary reference standards for typically developing children to estimate the caloric needs for children with NI
5b	ESPGHAN WG recommends regular monitoring of body weight and fat mass as an indicator of energy requirements
6a	ESPGHAN WG recommends the use of the dietary reference intake for protein in typically developing children to estimate the appropriate protein intake for children with NI
6b	ESPGHAN WG recommends the use of supplementary protein intake in specific clinical situations such as decubitus ulcers or in children with a low calorie requirement
7	ESPGHAN WG recommends that careful attention should be paid to hydration status, as children with NI are at risk of dehydration for a variety of reasons (eg, inability to communicate thirst, drooling, unsafe swallow)
8	ESPGHAN WG recommends use of the dietary reference intake for micronutrients in typically developing children to estimate the appropriate micronutrients intake for children with NI
9	ESPGHAN WG suggests considering oropharyngeal dysfunction in all patients with NI even in the absence of obvious clinical signs and symptoms
10a	ESPGHAN WG suggests including both feeding history starting from early infancy and direct visual assessment of feeding carried out by appropriately trained professionals. Such professionals would generally consist of speech and language therapists but could include medical doctors, nurses, dieticians, or GI physiologists trained or highly experienced in evaluating oropharyngeal function
10b	ESPGHAN WG recommends the use of videofluoroscopy in which there is suspicion of an abnormal pharyngeal phase of swallowing and/or concerns about aspiration. Where available this could be combined with high-resolution esophageal manometry to increase diagnostic yield
11	ESPGHAN WG suggests considering speech and language interventions in the treatment of children with NI with oropharyngeal dysfunction, and/or where there is need for modification of the consistency of feeds
12	ESPGHAN WG recommends regular monitoring of growth and nutritional status in children with NI with oral pharyngeal dysfunction
13	ESPGHAN WG recommends use of objective measures for the diagnosis of gastroesophageal reflux disease (GORD) in children with NI (esophageal pH- or pH/multichannel intraluminal impedance monitoring, and/or upper GI endoscopy). Given their high prevalence of GORD, a trial of proton pump inhibitors with careful clinical follow-up is acceptable management in this clinically fragile group of children
14a	ESPGHAN WG suggests modification of enteral nutrition (thickening of liquid enteral formulas, whey-based formulas) in addition to other therapeutic options of gastroesophageal reflux disease in children with NI
14b	ESPGHAN WG group recommends use of proton pump inhibitors as the first-line treatment in children with NI with gastroesophageal reflux disease
14c	ESPGHAN WG recommends not to routinely use prokinetic agents in NI children with gastroesophageal reflux disease because of their weak efficacy and side effects. Their use may be considered, however, in uncontrolled gastroesophageal reflux disease
15	ESPGHAN WG recommends the periodical re-evaluation of long-term therapy of gastroesophageal reflux disease in children with NI
16	ESPGHAN WG recommends diagnosis of constipation in children with NI by a careful history, abdominal, perineal, and if necessary rectal digital examination
17a	ESPGHAN WG recommends in children with NI with constipation to use standard treatments as in typically developing children, unless there is a risk of aspiration of polyethylene glycol or liquid paraffin
17b	ESPGHAN WG suggests increasing fluid and fiber intake as an additional strategy to treat constipation in children with NI
18	ESPGHAN WG recommends that careful attention is paid to dental problems, general posture, and orthopedic issues in patients with NI, because these may contribute to feeding difficulties

TABLE 2. (*Continued*)

Number	Statements
19	ESPGHAN WG recommends using oral feeding in NI children if it is nutritionally sufficient, safe, stress-free, and feeding time is not prolonged
20	ESPGHAN WG recommends considering use of enteral feeding if total oral feeding time exceeds 3 hours per day
21a	ESPGHAN WG recommends using standard (1.0 kcal/mL) polymeric age-appropriate formula including fiber for children with NI older than 1 year
21b	ESPGHAN WG recommends using a high-energy density formula (1.5 kcal/mL) containing fiber in cases of poor volume tolerance in children with NI, provided hydration is carefully monitored
21c	ESPGHAN WG recommends using human milk, a standard infant formula, or nutrient dense infant enteral formula as clinically indicated in infants with NI
21d	ESPGHAN WG recommends using a low-fat, low-calorie, high-fiber, and micronutrient replete formula for the maintenance of enteral tube feeding after nutritional rehabilitation in immobile children with NI
21e	ESPGHAN WG recommends using a trial of whey-based formula in cases of gastroesophageal reflux, gagging, and retching in children with NI
21f	ESPGHAN WG recommends caution if pureed food is used for enteral tube feeding in children with NI, because of concerns regarding nutritional adequacy and safety
22	ESPGHAN WG recommends using a combination of nocturnal continuous feeds with daytime bolus feeds in children with high-caloric needs or poor tolerance to volume
23	ESPGHAN WG recommended using a gastrostomy as the preferred way to provide intragastric access for long-term tube feeding in children with NI
24	ESPGHAN WG suggests using jejunal feeding in cases of aspiration due to gastroesophageal reflux disease, refractory vomiting, retching, and bloating in children with NI
25	ESPGHAN WG recommends using enteral tube feeding in cases of unsafe or inefficient oral feeding, preferably before the development of undernutrition.
26	ESPGHAN WG recommends that upper GI endoscopy with biopsies is performed before fundoplication in NI children. Other investigations (eg, contrast studies, gastric emptying studies, and pH± impedancemetry) may also be indicated
27	ESPGHAN WG recommends that a routine antireflux procedure should not be performed at the time of PEG placement in children with NI as it could add significant morbidity
28	ESPGHAN WG recommends that fundoplication be considered in cases of failure of optimized medical therapy for gastroesophageal reflux disease in children with NI
29	ESPGHAN WG recommends restricting the indication for total esophagogastric disconnection and Roux-en-Y esophagojejunostomy, as an alternative of classical antireflux surgery, to selected cases in children with NI
30	ESPGHAN WG recommends that parents and/or caregivers are always involved in decision making especially around gastrostomy feeding
31	ESPGHAN WG recommends involvement of a professional ethicist to assist decision making in cases in which invasive investigations or procedures (eg, gastrostomy, fundoplication, parenteral nutrition) pose ethical dilemmas

CP = cerebral palsy; ESPGHAN = European Society of Gastroenterology, Hepatology and Nutrition; GI = gastrointestinal; NI = neurological impairment; PEG = periendoscopic gastrostomy; WG = working group.

Skinfolds and limb circumferences: measurement of limb circumferences such as mid upper arm circumference, upper leg circumference, and calf circumference can easily be performed with a nonstretchable tape, but results lack specific information because they comprise bone, muscle, and fat mass. Body fat can be estimated by the use of skinfold measurement usually at the biceps ad triceps region of the mid-upper arm by using a caliper.

Assessment of mid-upper arm fat and muscle areas from triceps skinfold and mid-upper arm circumference measurements can be calculated using several equations (19). In comparison with BMI, skinfold measurements are a more direct measurement of body fat, but their interpretation can also be challenging because children with NI tend to store fat more centrally (abdomen) than peripherally (skinfolds) (11).

2c: ESPGHAN WG recommends that the measurement of fat mass by skinfold thickness should be a routine component of the nutritional assessment in children with NI.

LoE moderate
GoR weak
VOTES: 9, 8, 8, 9, 8, 9, 9, 9, 7, 7, 7, 9, 6, 9, 9 (accepted)

Body Composition Assessment

Children with NI often need measures of body composition to assess nutritional status more accurately. Body composition refers to quantifiable components of the body including fat, water, protein, and bone (20). Whole-body dual-energy x-ray absorptiometry (DXA) has become the ''criterion standard'' for the measurement of body composition (21). If DXA can be obtained and interpreted with confidence then, it is the best way to ensure that a child's fat stores are neither depleted nor excessive (22). Skinfold thickness is easy to obtain and body fat can be calculated by using specific equations. The most widely used Slaughter et al (23) equations are used in typically developed children; however, these equations do not take into account the different body composition of children with NI and tend to underestimate their body fat percentage (21). Furthermore, several studies (24–27) evaluated the accuracy of the Slaughter equation in the estimation of the body composition in children with NI. Three studies (21,25,26) found that the use of Slaughter equation underestimated the percentage body fat compared to reference methods; another study (27) found good correlation; however, it included only a small number of participants. In order to improve the Slaughter equation, Gurka et al (26) derived new equations with a correction factor based on sex, race, size, pubertal status, and gross motor function level. These equations were assessed by 3 studies (28–30). Two studies (28,29) found that percentage body fat derived from skinfolds using Gurka's NI-specific equation was not significantly different from that measured

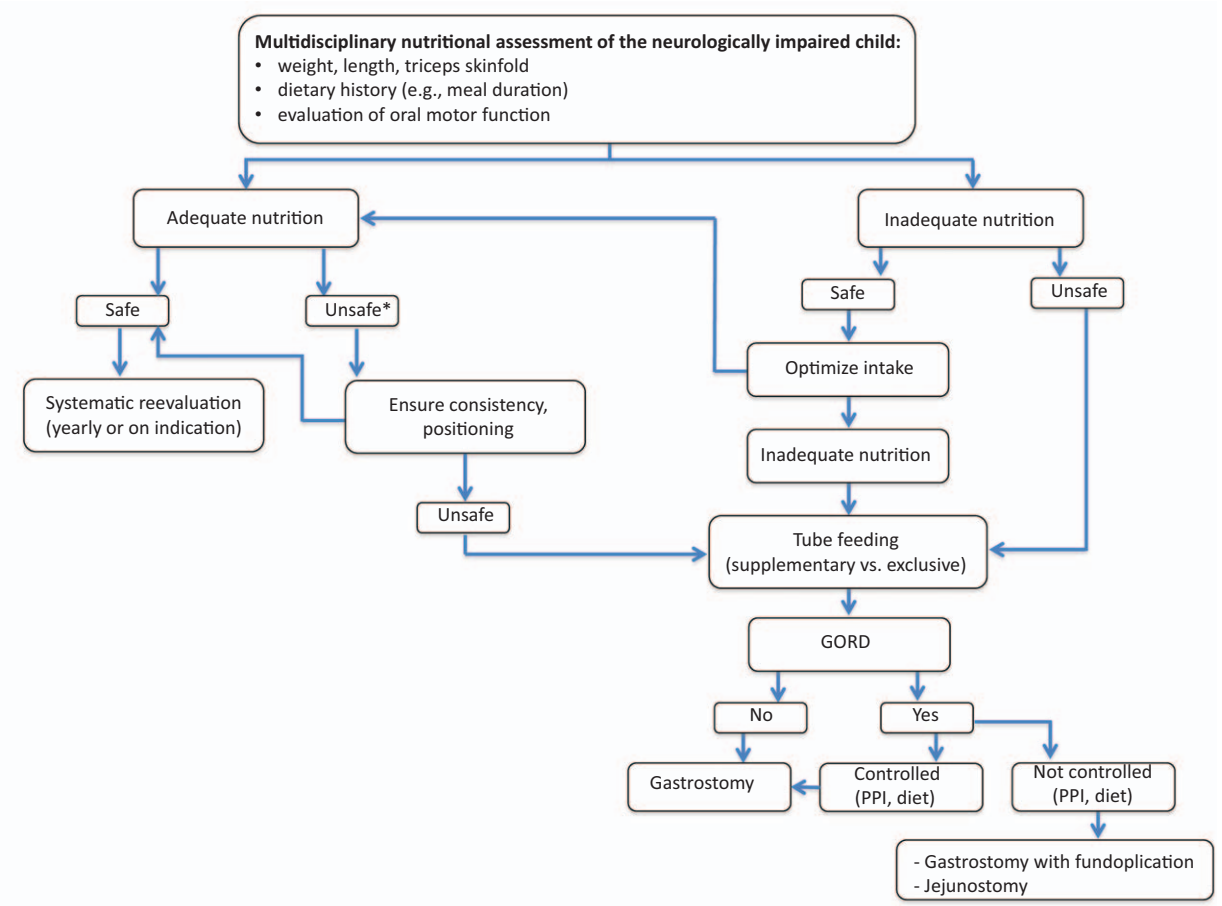

FIGURE 1. Unsafe swallow is defined as occurring in a child who has both a history of aspiration pneumonia (antibiotics or hospital admission for chest infection) and objective evidence of aspiration or penetration on contrast video fluoroscopy. GORD = gastroesophageal reflux; PPI = proton pump inhibitor.

by DXA. Although skinfold thickness is easy to obtain, it may not be as accurate in children with CP; reduced peripheral skinfolds may not necessarily mean low fat stores because children with CP store fat more centrally. Therefore, other methods are developed and evaluated, mostly bioimpedancemetry (BIA). Four studies evaluated the role of BIA in the body composition assessment in children with CP (27,29–31) and found that BIA estimated body composition well when compared to standard methods (DXA, D_2O).

Bone Status Assessment

Low bone mineralization is a serious problem in severe NI children, with mean z scores ranging from −3.4 in the distal femur to −0.8 in the lumbar spine, a prevalence of bone mineral density (BMD) z scores <-2 in more than 70%, with an annual incidence of fractures of 4%. Significant determinants of low BMD are limited ambulation, feeding difficulties, previous fracture, anticonvulsant use, and lower fat mass (32).

Bone health should be assessed in children with NI because of an increased risk of poor bone health resulting in fractures. BMD assessment by DXA is usually limited to lumbar spine and hip. Because of hip flexion contractures, in children with severe NI, it is, however, mostly only lumbar DEXA measurements that are performed (20). There are data, however, which show that BMD of lumbar spine is not a predictive parameter for the fracture risk in children with NI (33). Therefore, some studies evaluated the BMD of the distal femur and found strong correlation between BMD z scores of this site and fracture history (34). The International Society for Clinical Densitometry recommends assessment of BMD at the lateral distal femur site in children with chronic immobilization, which is the most common fracture site in children with NI (32). Other techniques have been used in children with NI, including quantitative computed tomography and quantitative ultrasound (35); however, due to limited availability and lack of standardization they are not routinely used (36).

2d: ESPGHAN WG recommends the use of DXA scans to measure BMD as part of nutritional assessment in NI children.

LoE moderate
GoR weak
VOTES: 9, 8, 8, 7, 7, 8, 8, 8, 7, 7, 8, 6, 6, 8, 8 (accepted)

TABLE 3. Blood laboratory variables included in the assessment of neurologically impaired children

Urea and electrolytes
Creatinine
Glucose
Full blood count
Hemoglobin, mean corpuscular volume, ferritin, iron
Calcium, magnesium, phosphate
Albumin or total protein
Liver enzymes
Vitamins A, B12, D, E, folic acid
PTH
Zinc

PTH = parathyroid hormone.
From Ref (41).

Laboratory Parameters

Laboratory assessment can be performed, but there is no single marker representing good or poor nutritional status in children with NI (Table 3). Albumin and prealbumin are not of much use as markers of undernutrition, because in general there is rarely a protein deficit, but more a caloric deficit is present (37). Lower values of serum albumin, prealbumin, and retinol binding protein can be found (38), but routine measurements of prealbumin and albumin appear to be of little value and may lead to a false sense of security regarding the nutritional status of a child with NI. Children with NI often have lower mineral intakes than healthy children, which predispose them to having a poor micronutrient status. Few studies have evaluated the micronutrient status of children with NI (38–42) and the implications of various deficiencies on health outcome. These studies show that deficiencies for iron, zinc, copper, vitamin D, carnitine, folic acid, and vitamin B12 are common with percentages ranging between 10% and 55%. Factors associated with low levels were found to be vitamin C intake (iron), use of antiepileptics (carnitine, vitamin B12, folic acid, calcium, and phosphorus), and reduced exposure to sunlight (vitamin D). Tube feeding and the use of nutrition supplements were associated with higher concentrations of micronutrients in blood and serum (41).

2e: ESPGHAN WG recommends the assessment of micronutrient status (eg, vitamin D, iron status, calcium, phosphorus) as part of nutritional assessment of children with NI.

LoE moderate
GoR strong
VOTES: 5, 8, 8, 9, 8, 9, 9, 8, 8, 7, 7, 7, 9, 8, 8 (accepted)

HOW TO IDENTIFY UNDERNUTRITION?

In general, there is no single, universally agreed definition of undernutrition in children, but criteria based on height-for-age, weight-for-height, and BMI-for-age are commonly used (43,44). Children can experience many illness-related factors contributing to undernutrition such as nutrient losses, increased energy expenditure, inflammation, decreased nutrient intake, or altered nutrient utilization (44). Moreover, for children with NI, no strict criteria to define undernutrition are in use due to the complexity and clinical variability among patients (22). For clinical practice, in the absence of strict criteria for identification of undernutrition in children with NI, it is important to look at the presence of warning signs of undernutrition, such as physical signs of undernutrition such as decubitus, skin problems, and poor peripheral circulation; weight for age (z score <-2); triceps skinfold thickness <10th centile for age and sex; mid-upper arm fat or muscle area <10th centile; and faltering weight and/or failure to thrive.

Growth Charts

Standard growth charts may not be helpful for children with NI, whose growth patterns are often markedly different from the general pediatric population. The first CP-specific growth charts were produced by Krick et al (45) who evaluated weight and stature of children with severe quadriplegia. Other studies produced centile curves for several other growth parameters, including weight, knee height, upper-arm length, mid–upper arm muscle area, triceps skinfold, and subscapular skinfold (9,46). Day et al (46) constructed a series of height, weight, and BMI charts, which were stratified by motor and feeding skills; they found that centiles of height and weight of patients with CP were close to those of the general population for the highest functioning groups with CP, but substantially different for those moderately or severely disabled children (46). The same group further developed growth charts stratified according to gross motor function classification system level and tube feeding status, and described not only weight gain and growth, but also the W/A percentile at which point there is an increased risk of morbidity and mortality (47). These CP-specific growth charts, however, describe growth which is not necessarily ideal as they include many children with other health conditions affecting growth, mostly malnutrition. Thus they cannot be considered as a measure of how this group of children should ideally grow (48). Furthermore, clinicians often need a growth chart that indicates ideal growth based on a standardized reference population, such as the World Health Organization growth standards (49). Although there is no relevant data, authorities often recommend the use of World Health Organization growth charts in children with NI in whom a reliable height or a calculated height can be obtained up to 2 (or 5) years of age and in older children a relevant national growth chart should be used (22).

Statement 3a: ESPGHAN WG suggests that the identification of children with NI as undernourished should be based on the interpretation of anthropometric data.

LoE high
GoR strong
VOTES: 8, 9, 7, 7, 9, 7, 9, 9, 9, 9, 7, 9, 9, 9, 9 (accepted)

3b: ESPGHAN WG does not recommend the use of CP-specific growth charts to identify undernutrition.

LoE low
GoR weak
VOTES: 9, 7, 8, 7, 6, 8, 9, 9, 9, 8, 9, 8, 8, 9, 9 (accepted)

3c: ESPGHAN WG suggests the use of 1 or more of the following red flag warning signs for the identification of undernutrition in children with NI:

1. Physical signs of undernutrition such as decubitus skin problems and poor peripheral circulation
2. Weight for age z score <-2.
3. Triceps skinfold thickness $<$10th centile for age and sex.
4. Mid-upper arm fat or muscle area $<$10th percentile.
5. Faltering weight and/or failure to thrive.

LoE moderate
GoR strong
VOTES: 9, 9, 9, 9, 8, 9, 9, 8, 8, 9, 9, 8, 8, 9, 8 (accepted)

3d: ESPGHAN WG recommends the use of follow-up anthropometry (weight, linear growth, and fat mass) in the monitoring of nutritional status of children with NI.

LoE moderate
GoR strong
VOTES: 9, 9, 8, 9, 9, 9, 8, 9, 9, 9, 9, 8, 9, 8 (accepted)

HOW OFTEN SHOULD NUTRITIONAL STATUS BE MONITORED?

For infants, it is recommended to assess growth every 1 to 3 months and in older children the frequency of assessment may vary depending on their nutritional and health status (50). There are no data on the optimal follow-up schedule for body composition assessment and this should be individually depending on risk factors and initial assessment. It is, however, important to use same methods to have comparable values. For the assessment of growth velocity, the use of calculated heights based on segmental measures may be unreliable (10). There is no consensus on the appropriate laboratory indices to be measured or on how frequent this should occur.

4: ESPGHAN WG suggests that children with NI have anthropometry at least every 6 months and micronutrients checked annually.

LoE low
GoR strong
VOTES: 6, 8, 9, 9, 8, 7, 7, 8, 8, 9, 8, 7, 6, 9, 8 (accepted)

NUTRITIONAL REQUIREMENTS (ENERGY, PROTEINS, FLUIDS, MICRONUTRIENTS)

What Are the Requirements for Energy Intake in Children With Neurological Impairment?

The assessment of energy needs of the child with NI is difficult because there are no appropriate specific recommendations for this category of patients (1,51). Dietary reference intake (DRI) overestimate energy needs, because of the severe growth delay and the decreased physical activity. Patients with NI have lower body fat, muscle mass, and protein (46,52). Energy intake is linked to mobility and activity level. There is an impact of NI in children on body growth and nutritional status, which becomes more marked in those with a greater degree of motor impairment. The major deficit is in energy intake (53).

Patients with NI require more energy for walking (54,55), whereas patients dependent on a wheelchair require 60% to 70% energy, compared to healthy children (22,56). Compared with a reference population of age- and sex-matched typically developed children, 40 children with marked NI showed lower energy expenditure and high body fat content, particularly if they were enterally fed (57). Mean total energy intake was 60% of average energy allowance (58). The contribution of spasticity was approximately 10% of total energy expenditure. Children with spastic quadriplegia were found to have a lower energy expenditure than unaffected children (59). Yet no correlation was found between energy intake, the estimated average requirement, and anthropometric z scores. Increase in feeding difficulties correlates with successive decrease in nutritional status, in measurements of weight, body fat stores, and arm muscle mass (60). Published equations underestimate energy needs in nonambulant children by $\sim$22%. The greatest predictor of energy needs is fat-free mass, followed by ambulatory status (61). Total energy expenditure to resting energy expenditure ratio is estimated to be 1.5 to 1.6 for normal activity, whereas it can be as low as 1.1 in quadriplegic CP (62).

Overestimation of energy needs can lead to being overweight, which is observed in 10% to 15% of children (1). There is a risk of overfeeding with enteral feeds due to a potential shift from negative to positive energy balance that enhances fat accumulation (57). Energy requirements must be individualized to take into account mobility, muscle tone, activity level, altered metabolism, and growth. Indirect calorimetry may be useful for the assessment of these needs (1).

DRIs (63) are used to estimate calorie needs. Total energy expenditure is based on measurements of the doubly labeled water technique and is based on the needs of healthy children (64,65). The equations overestimate calorie requirements of the child with NI even when used without the physical activity coefficient (64) or physical activity level (65) (PAL). The Schofield equation (Table 4) is reasonable in estimating calorie needs (66). Other special equations can be used (Table 5). These formulas are only a starting point and the effect of dietary intervention must be reassessed (67).

5a: ESPGHAN WG recommends the use of the dietary reference standards for typically developing children to estimate the caloric needs for children with NI.

LoE moderate
GoR weak
VOTES: 8, 8, 8, 9, 9, 7, 8, 8, 7, 7, 8, 7, 6, 8, 9 (accepted)

TABLE 4. The Schofield equation

	Age	Equation
Males	10–18	$([0.074 \times wt] + 2.754) \times 1000$
	18–30	$([0.063 \times wt] + 2.896) \times 1000$
	30–60	$([0.048 \times wt] + 3.653) \times 1000$
	Older than 60	$([0.049 \times wt] + 2.459) \times 1000$
Females	10–18	$([0.056 \times wt] + 2.898) \times 1000$
	18–30	$([0.062 \times wt] + 2.036) \times 1000$
	30–60	$([0.034 \times wt] + 3.538) \times 1000$
	Older than 60	$([0.038 \times wt] + 2.755) \times 1000$

From Schofield WN. Predicting basal metabolic rate, new standards and review of previous work. Hum Nutr Clin Nutr 1985;39 suppl 1:5–41.

5b: ESPGHAN WG recommends regular monitoring of body weight and fat mass as an indicator of energy requirements.

LoE moderate
GoR strong
VOTES: 7, 7, 9, 9, 8, 9, 8, 9, 8, 9, 9, 7, 7, 8, 8 (accepted)

WHAT ARE THE REQUIREMENTS FOR PROTEIN IN CHILDREN WITH NEUROLOGICAL IMPAIRMENT?

Protein requirements for children with NI are similar to the protein requirements of unaffected children (66,68). The DRIs are adequate for this group of children. Increased protein is needed if decubitus ulcers are present. Problems with protein intake may arise when calorie needs are low; it may be difficult to provide adequate protein in tube-fed children who require a very low calorie intake to prevent overfeeding. A higher protein formula or a protein supplement should be used with these children (66).

In preschool-aged children with NI the tube-fed, nonambulant children have lower protein intakes compared with orally fed children (69). Schoendorfer et al (70) examined differences in protein intake and a variety of protein metabolism indices in children with NI compared with controls. Despite all children consuming more than recommended levels, children with CP had reduced levels of protein metabolic indices (albumin, creatinine, and urate) versus controls. Data showed potentially greater protein metabolism issues in enterally fed children, compared with the other groups. Schoendorfer et al (70) reported decreased levels of albumin and urea in NI enterally fed group compared with NI orally fed and control group (70). The children with NI had reduced levels of plasma urate, and many with high-level cognitive impairment, when compared with typically developed children.

In severely undernourished patients the protein intake may be augmented to 2 to 2.4 $g \cdot kg^{-1} \cdot day^{-1}$ (56). In 1 study, term and preterm infants fed with 120% of the recommend daily allowance showed an increased head circumference and corticospinal tract diameter (71). Commercially available sip feeds (oral nutritional supplement) are an easy way to add proteins, with or without fibers and micronutrients (56). Dietary supplementation with glucose polymer and/or long-chain triglycerides or use of hypercaloric or high-density feed is required in poor nutrition or growth failure (59).

6a: ESPGHAN WG recommends the use of the DRI for protein in typically developing children to estimate the appropriate protein intake for children with NI.

LoE moderate
GoR strong
VOTES: 7, 8, 8, 8, 9, 9, 9, 8, 9, 8, 8, 8, 8, 8, 8 (accepted)

6b: ESPGHAN WG recommends the use of supplementary protein intake in specific clinical situations such as decubitus ulcers or in children with a low calorie requirement.

LoE moderate
GoR strong
VOTES: 9, 8, 7, 9, 8, 9, 9, 9, 9, 8, 9, 8, 8, 9, 9 (accepted)

WHAT ARE THE REQUIREMENTS FOR FLUID IN CHILDREN WITH NEUROLOGICAL IMPAIRMENT?

Children with NI may have an impaired hydration status. Body composition is altered in children with NI; a decrease in body

TABLE 5. Equations for estimating energy requirements in children with neurological impairment

Method	Equation
Dietary reference intake standard for BEE	Energy intake (kcal/day) = BEE × 1.1, where BEE is: Male: 66.5 + (13.75 × weight in kg) + (5.003 × height in cm) – (6.775 × age) Female: 65.1 + (9.56 × weight in kg) + (1.850 × height in cm) – (4.676 × age)
Indirect calorimetry	Energy intake (kcal/day) = BMR × muscle tone × activity] + growth, where: Muscle tone = 0.9 if decreased, 1.0 if normal, and 1.1 if increased Activity = 1.1 if bedridden, 1.2 if wheelchair dependent or crawling, and 1.3 if ambulatory Growth = 5 kcal/g of desired weight gain (normal and catch-up growth)
Height	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 not ambulatory

BEE = basal energy expenditure; BMR = basal metabolic rate.
From Andrew et al (67).

cell mass accompanies an expansion of the extracellular fluid (59). One study showed that children with NI (n = 35, aged 9–13 years) had a reduction in salivary flow rate (50%), together with an increase in salivary (50%), plasma (3%), and urine osmolality (20%) versus a control group (n = 27 nondisabled children, ages 10–12 years). Salivary flow rate was negatively correlated with the salivary, plasma, and urine osmolality, whereas salivary osmolality correlated positively with plasma and urine osmolality (72). Children with NI can present low salivary flow rate, pH, and buffer capacity (72). NI individuals appear to exhibit impaired hydration due to compromised oral motor function (73).

7: ESPGHAN WG recommends that careful attention should be paid to hydration status, as children with NI are at risk of dehydration for a variety of reasons (eg, inability to communicate thirst, drooling, unsafe swallow).

LoE moderate
GoR strong
VOTES: 9, 9, 9, 9, 8, 9, 9, 8, 9, 9, 9, 8, 8, 9, 9 (accepted)

WHAT ARE THE REQUIREMENTS FOR MICRONUTRIENTS IN CHILDREN WITH NEUROLOGICAL IMPAIRMENT?

The monitoring of micronutrient status in children with NI may have a substantial and measurable impact on their nutritional adequacy, hospital costs, and future outcomes (74). Micronutrient deficiencies (calcium; iron; zinc; vitamins C, D, and E; selenium) are common, especially in children who are exclusively tube fed. Many children with NI require less energy to avoid being overweight and, as a consequence of a reduced energy intake, their micronutrient intake can be less than their daily requirements. Essential fatty acid (FA) deficiency may also be related to suboptimal energy intake (1).

There was no difference in energy, protein, iron, zinc, copper, or folate intake before and 6 months after gastrostomy placement (75). No change in Zn, Fe, and Cu and in liposoluble vitamins were noticed in patient with NI fed with or without fiber-supplemented formula (76). Compared to a reference group, patients with NI had low concentration of docosaenoic acid, linoleic acid, and total n-6 FA, whereas arachidonic acid, eicosapentaenoic acid, n-3 FA concentrations were similar. After a 6-month supplementation of docosaenoic acid, eicosapentaenoic acid and n-3 FA levels were higher than the reference group, whereas linoleic acid and total n-6 FA remained lower (1).

Iron

Children with disabilities are at greater risk of iron deficiency as their diets are often limited, especially if the diet is based largely on cow′s milk. Only 46% of children with disabilities achieved 100% of their recommended nutritional intake (53). The increased incidence of iron-deficiency anemia in children with NI with diets low in iron supports the conclusion that this is secondary to low iron intake and decreased iron absorption. Prepared liquid diets may include foods that are a poor source of iron (milk, cheese, cream, yoghurt, rice) or that inhibit iron absorption (vegetables, pulses, grains, cereals) (77). The recommended daily intake of iron is 10 mg/day in children (7–10 years), 12 mg/day adolescent boys (15–19 years), and 15 mg/day in adolescent girls (15–19 years) (65). In the treatment of iron deficiency in children with NI it is reasonable to provide iron supplementation as the first diagnostic and therapeutic measure in such patients. Endoscopic procedures should be postponed for a later stage, unless there are clinical or laboratory findings (such as fecal occult blood) suggestive of GI blood loss (77).

8: ESPGHAN WG recommends use of the DRI for micronutrients in typically developing children to estimate the appropriate micronutrients intake for children with NI.

LoE moderate
GoR strong
VOTES: 9, 9, 8, 8, 9, 9, 8, 8, 9, 9, 7, 7, 6, 8, 9 (accepted)

GASTROINTESTINAL ISSUES (DYSPHAGIA/ ORAL MOTOR DYSFUNCTION, CONSTIPATION, DYSMOTILITY AS GASTROESOPHAGEAL REFLUX DISEASE)

Dysphagia/Oral Motor Dysfunction: How to Define It?

Oropharyngeal dysfunction (OPD) is defined by the presence of disturbances in one of more of the 3 phases of swallowing (oral, pharyngeal, and esophageal) and is common amongst children with NI, with reported prevalences in excess of 90% (78,79). In a study of 166 children with NI the prevalence of dysphagia was 99% with 8% classed as mild, 76% moderate to severe, and 15% profound dysphagia. In agreement with other studies dysphagia appears to be positively correlated with the severity of motor impairment (79–82). The presence of OPD is often suggested by the clinical picture, the evaluation of which should include the feeding history from early infancy (eg, problems in sucking and swallowing (78)). In a large study of children with NI, 27% of mothers of children referred for advice on their present swallowing difficulties stated that they did not recall any suckle feeding problems. The present study suggested there was no association between the severity of present swallowing difficulties and whether infants had suckle fed well or experienced severe difficulties (83). In addition to swallowing dysfunction children with NI may display sialorrhea, coughing, multiple swallows, gurgly voice, wet breathing, gagging, and choking and alterations in appetite, feeding difficulties, and prolonged feeding times (81,84,85). Many of these symptoms are associated with dysfunction in the pharyngeal phase of swallowing, more significant OPD, and poorer long-term prognosis.

The mainstay of evaluation of OPD has been the direct observation of meal times with or without the use of standardized and validated scoring systems. Although a number of scoring systems have been suggested to have good clinical utility including Eating and Drinking Ability Classification System, the Schedule for Oral Motor Assessment, Dysphagia Disorders Survey, and the Functional Feeding Assessment, this remains to be validated in large high-quality studies (80,82,86–91).

Lip functions play an important role in oral stages of feeding. Problems with incomplete lip closure during swallowing, low lip and suction pressure, and prolonged delay between the suction and propelling stages have been described (92,93). Furthermore, malocclusion of teeth may also contribute with preparation of food for swallowing (94).

9. ESPGHAN WG suggests considering OPD in all patients with NI even in the absence of obvious clinical signs and symptoms.

LoE moderate
GoR strong
VOTES: 8, 9, 9, 9, 9, 8, 9, 8, 9, 9, 7, 7, 9, 9, 9 (accepted)

How to Evaluate Oral Motor and Sensory Function?

Videofluoroscopy (VFS) remains one of the key investigations for the assessment of OPD with a number of studies supporting its utility to identify discoordinate pharyngeal motility and silent aspiration in the diagnostic work-up of children with neurodisability and to guide effective feeding strategies (95–98). VFS may also be used to assess other parameters that relate to dysphagia and impaired feeding, including reduced lip closure, inadequate bolus formation, residue in the oral cavity, delayed triggering of pharyngeal swallow, reduced larynx elevation, coating on the pharyngeal wall, delayed pharyngeal transit time, and multiple swallows (99). Although ultrasound and electrophysiology have been suggested as practical alternatives, or additional tests, to more established methods of assessment their utility still remains to be confirmed (100–104). Although data on the use in children with OPD and NI are limited, VFS has also been combined with high-resolution esophageal manometry to be more discriminating in identifying specific defects and potentially improve clinical utility (105). When there is a high suspicion of an abnormal pharyngeal phase of swallowing but the VFS is normal or where it is difficult to differentiate between upper esophageal sphincter function and pharyngeal dysmotility, combined modalities (eg, videomanometry) could be considered if appropriate equipment and expertise are available.

GI endoscopy is not routinely used in children with NI to investigate the cause for dysphagia. Fiberoptic endoscopy has been used to detect aspiration and penetration of the upper respiratory tract (106). The presence and nature of esophageal dysmotility in NI is not well studied, although studies utilizing esophageal 24-hour pH monitoring and impedance and manometry have suggested it may be common in NI (107,108). Most recently, impedance measurements have been used to detect alterations in flow characteristics of pharyngeal swallow that have the potential to predict to deglutitive aspiration risk (109).

10a: ESPGHAN WG suggests including both feeding history starting from early infancy and direct visual assessment of feeding carried out by appropriately trained professionals. Such professionals would generally consist of speech and language therapists but could include medical doctors, nurses, dieticians, or GI physiologists trained or highly experienced in evaluating oropharyngeal function.

LoE moderate
GoR strong
VOTES: 9, 8, 8, 8, 9, 9, 9, 8, 9, 9, 9, 9, 9, 9, 9 (accepted)

10b: ESPGHAN WG recommends the use of VFS in which there is suspicion of an abnormal pharyngeal phase of swallowing and/or concerns about aspiration. Where available this could be combined with high-resolution esophageal manometry to increase diagnostic yield.

LoE low
GoR: weak
VOTES: 8, 9, 8, 9, 9, 8, 7, 7, 8, 9, 8, 9, 8, 9, 7 (accepted)

What Is the Treatment of Oropharyngeal Dysfunction?

Management of dysphagic children involves an appropriately skilled multidisciplinary team to support treatment strategies. A Cochrane review undertaken to examine the effectiveness of interventions for OPD in children with NI was only able to identify 3 randomized or quasirandomized controlled trials. Overall, the review concluded that there was insufficient high-quality evidence to provide conclusive results about the effectiveness of any particular type of oral motor therapy and larger-scale randomized trials were needed (110).

Management should aim to optimize oral ingestion, where this has been shown to be safe, and address the behavioral expression of the many different pathologies causing OPD namely: resistance to accepting food orally; lack of energy and endurance to do the ''work'' of eating; and oral motor disabilities resulting in an inability to produce the necessary motor skills for ingestion (111).

Modifications of Feeds and Feeding Time

It is likely that a significant proportion of children with NI will be managed by modification of time allocated to feeding, posture, and feed consistency and content to provide safe feeding and limit complications such as aspiration. A cross-sectional, population-based cohort study comprising 99 children with NI (65 boys, 35 girls) aged 18 to 36 months showed that 39% of the children were on modified feed textures. Those with poorer gross motor function tended to receive a greater proportion of energy from fluids in their diets and fewer chewable foods compared to less affected children. Fluids, however, represented a texture most associated with OPD and being identified as unsafe (112).

Speech and Language Therapy

Speech and language therapy often forms the mainstay of treatment offered to children with neurodisability. Oral sensorimotor therapies aim to improve the individual and combined functioning of the lips, cheeks, tongue, and pharyngeal structures. Hirata and Santos (113) performed a systematic review of the medical and speech therapy literature on the rehabilitation of OPD in children with NI spanning 1977 to 2010 and found a paucity of studies addressing the therapeutic rehabilitation of oropharyngeal dysphagia in children with CP. Compared to control treatments, sensorimotor interventions have been variably shown to result in some improvement in eating and feeding time but not in drinking skills.

Children appeared to maintain their weight but did not show catch-up growth (114–117).

11: ESPGHAN WG suggests considering speech and language interventions in the treatment of NI children with OPD, and/or where there is need for modification of the consistency of feeds.

LoE moderate
GoR strong
VOTES: 8, 8, 8, 8, 7, 8, 9, 7, 7, 9, 8, 9, 9, 8, 9 (accepted)

How to Monitor Oropharyngeal Dysfunction?

In terms of long-term prognosis, the severity of OPD appears to remain relatively stable and gross motor function appears to be its best predictor (118–121). Feeding data were collected from 23 children with NI using parent questionnaires at 6-month intervals during 30 months. Children with NI with severe oral motor involvement had marked and pervasive feeding difficulties, but this appeared to remain relatively stable over time (119). Although disorders persist into adolescence, improvement has mainly been observed when only the oral phase of swallowing is affected. Involvement of the pharyngeal phase suggests that further investigation is warranted (121). The studies highlight the need for proactive screening of all young children with NI, including those with mild impairments, to improve growth and nutritional outcomes and respiratory health (80). Oral pharyngeal dysfunction is one of the main factors for the reduction of oral food intakes and so a risk factor for undernutrition.

12: ESPGHAN WG recommends regular monitoring of growth and nutritional status in children with NI with oral pharyngeal dysfunction.

LoE low
GoR: weak
VOTES: 8, 9, 8, 9, 9, 8, 7, 6, 7, 9, 8, 8, 7, 8, 8 (accepted)

GASTROESOPHAGEAL REFLUX DISEASE

How to Diagnose Gastroesophageal Reflux Disease?

GORD is a problem commonly seen in children with NI with reported incidence as high as 70% (122–125). Because of the high frequency of GORD and fragility of this group of patients for whom investigations are more difficult to organize and perform than for typically developed children, a trial of proton pump inhibitors (PPIs) with careful clinical follow-up is acceptable (126). Esophagogastroduodenoscopy is the method of choice to diagnose esophageal involvement (127). Biopsies are important to identify or rule out other causes of esophagitis, and to diagnose and monitor Barrett esophagus. Esophageal pH-metry is a valid quantitative measure of esophageal acid exposure. When combined with esophageal multichannel intraluminal impedance pH-metry can detect acidic, weakly acidic, and nonacidic reflux episodes. Scintigraphy may have a role in the diagnosis of pulmonary aspiration. In patients with persistent gastric stasis and vomiting, upper GI barium swallow or abdominal ultrasound should be performed to exclude intestinal obstruction. Patients with severe NI are at risk for development of superior mesenteric artery syndrome because of frequent scoliosis and malnutrition resulting in lack of retroperitoneal fat around the third part of the duodenum, which is thought to avoid compression by increasing the aortomesenteric angle (128).

13: ESPGHAN WG recommends use of objective measures for the diagnosis of GORD in children with NI (esophageal pH- or pH/multichannel intraluminal impedance monitoring, and/or upper GI endoscopy). Given their high prevalence of GORD, a trial of PPIs with careful clinical follow-up is acceptable management in this clinically fragile group of children.

LoE low
GoR weak
VOTES: 9, 8, 7, 9, 9, 8, 5, 8, 6, 5, 6, 9, 8, 7, 8 (accepted)

How to Treat Gastroesophageal Reflux Disease?

Treatment of GORD in children and adolescents consists of lifestyle changes, pharmacologic therapies, and surgical treatment (127).

Lifestyle Changes

Only a few small studies have evaluated the effects of nutritional intervention on GORD in children with NI. Miyazawa et al (129) studied the effect of food-thickener pectin on GORD symptoms in 18 children with NI. High-pectin diet significantly decreased the reflux index, number of reflux episodes per day, duration of longest reflux, and the number of reflux episodes. Vomiting episodes decreased with high-pectin formula and cough score decreased with both concentrations of pectin. In a study by Khoshoo et al (130), exclusively gastrostomy-fed NI children with gastroesophageal reflux were randomly assigned to receive either casein- or whey-based formula (130). A significant reduction in number of reflux episodes and duration of reflux was observed while consuming the whey-based formula. In addition, malnutrition itself seems to influence GORD in children with NI, as Campanozzi et al (131) noted a marked improvement of GORD in 4 out of 9 children with NI after a 6-month feeding with hypercaloric diet and increase of body weight and BMI.

Treatment with acid-suppression drugs is the main therapy in children with NI with GORD. It is well accepted that PPIs are superior to histamine-2 receptor antagonists for both healing of erosive esophagitis and relief of GORD symptoms (127). Despite the fact that PPIs are effective in reducing acid reflux and treatment of reflux esophagitis, they do not influence the volume of the reflux, the number of reflux episodes, and the proximal extension of the reflux (132). Therefore, some symptoms, such as vomiting, usually persist despite PPI therapy (133), although 1 small prospective study documented a reduction in vomiting in children with NI treated with PPI (134). Like in any other condition, special attention to side effects, especially when prolonged treatment is considered, is warranted (including pulmonary and digestive infections, and malabsorption of micronutrients).

Kawai et al (135) studied the effect of the gamma-aminobutyric acid type B receptor agonist baclofen (0.7 $mg \cdot kg^{-1} \cdot day^{-1}$) on GORD in 8 children with NI. The frequency of emesis significantly decreased, and the total number of acid refluxes and number of acid refluxes longer than 5 minutes. The percentage of total time of esophageal pH <4 and esophageal acid clearance time were, however, not significantly different when compared with pH-monitoring results before treatment. No adverse effects were observed, except for a slight reduction in muscle tone in 1 subject. The efficacy and safety of other prokinetic drugs, such as metoclopramide, domperidone, bethanechol, and erythromycin for GORD treatment in children with NI have not been studied.

14a: ESPGHAN WG suggests modification of enteral nutrition (thickening of liquid enteral formulas, whey-based formulas) in addition to other therapeutic options of GORD in children with NI.

LoE very low
GoR weak
VOTES: 9, 8, 6, 7, 8, 8, 7, 7, 7, 6, 2, 8, 8, 7, 8 (accepted)

14b: ESPGHAN WG group recommends use of PPIs as the first-line treatment in children with NI with GORD.

LoE strong
GoR strong
VOTES: 9, 9, 9, 9, 9, 9, 9, 9, 7, 9, 8, 9, 9, 9, 7 (accepted)

14c: ESPGHAN WG recommends not to routinely use prokinetic agents in children with NI with GORD because of their weak efficacy and side effects. Their use may be considered, however, in uncontrolled GORD.

LoE moderate
GoR weak
VOTES: 7, 8, 9, 7, 9, 8, 9, 7, 7, 5, 6, 9, 9, 8, 8 (accepted)

How to Monitor Gastroesophageal Reflux Disease?

As severely neurologically disabled children cannot adequately report symptoms such as pain and heartburn, and visible regurgitation and dysphagia are not necessarily caused by GORD, only objective diagnostic tests are reliable for monitoring whether GORD is successfully controlled by therapy or not. When long-term therapy for GORD is needed and stopping treatments such as PPI is considered potentially detrimental, multichannel intraluminal impedance (±combined with pH-metry), if available, may assist in monitoring GORD.

15: ESPGHAN WG recommends the periodical re-evaluation of long-term therapy of GORD in children with NI

LoE weak
GoR strong
VOTES: 7, 9, 9, 8, 8, 7, 9, 9, 7, 5, 7, 9, 9, 8, 8 (accepted)

CONSTIPATION

How to Diagnose Constipation

In patients with NI, constipation may be diagnosed through a careful history, symptoms-based, abdominal-rectal digital examination, and colonic transit times. Constipation is significantly more common among children using medication known to slow intestinal motility, and in children who are tube fed (136). A digital rectal examination should be performed at least once when assessing constipation in children, because it is possible to evaluate perianal sensation, anal tone, size of the rectum, presence of an anal wink, and determine the amount and consistency of stool and its location within the rectum (137). In children without neurodevelopmental disorders, use of transabdominal ultrasound can be considered as noninvasive technique to assess the rectal filling state (138), but there are no studies concerning children with NI. If the diagnosis is uncertain an abdominal radiograph may be helpful. Colonic transit time assessment can be used as quantitative measure of constipation in NI. A transit time delay at the proximal segment of colon is the dominant finding that suggests alterations of the motility of the smooth muscle associated with the reduction of activity of the striated muscles of the anal sphincter and/or of the pelvic floor. Brain abnormalities may play a role in colonic transit time delay because there is evidence that delayed colonic transit is more frequent in children with severe brain lesions (139).

16: ESPGHAN WG recommends diagnosis of constipation in children with NI by a careful history, abdominal, perineal, and if necessary rectal digital examination.

LoE moderate
GoR strong
VOTES: 9, 9, 8, 8, 9, 9, 9, 8, 9, 9, 7, 7, 9, 9, 9 (accepted)

What Is the Treatment of Constipation?

The treatment of constipation in children with NI should conform to the standard for non-disabled children. The initial approach involves a fecal disimpaction before maintenance therapy, using enemas for 3 consecutive days and osmotic agents such as polyethylene glycol (1.5 $g \cdot kg^{-1} \cdot day^{-1}$) until the child performs a liquid and clear evacuation (140). More than 50% of children with NI have chronic use of laxatives but they are less responsive to treatment than typically developed children (141). Fiber and fluid intakes are inadequate in 53% of children with NI (142). Modest relief of constipation with reduction of laxatives usage have been demonstrated by increasing fiber intakes to 17 to 21 g/day but high fiber intake may cause intolerance (flatulence, distension, and bloating). Maintenance therapy requires use of osmotic laxatives such as lactulose (1–2 $mL \cdot kg^{-1} \cdot day^{-1}$) or polyethylene glycol (0.8 $g \cdot kg^{-1} \cdot day^{-1}$) (136). There have been reports of severe

pneumonia due to aspiration of laxatives and therefore use of macrogol or liquid paraffin must be provided with caution in children with NI with high risk of aspiration (137). In refractory cases, hydrocolonic enema and anterograde continence enema (ACE) has been reported as an effective treatment option (143). The ACE procedure involves a surgically constructed conduit into the colon that allows the administration of anterograde irrigations. It is most often done as a laparoscopic cecostomy or placement of cecostomy by interventional radiology. Previous studies have shown that the ACE procedure is safe and effective in children with defecation abnormalities but limited information about long-term outcomes is available in children with NI (144).

17a: ESPGHAN WG recommends in children with NI with constipation to use standard treatments as in typically developing children, unless there is a risk of aspiration of polyethylene glycol or liquid paraffin.

LoE moderate
GoR strong
VOTES: 9, 9, 9, 8, 8, 9, 9, 8, 9, 8, 7, 7, 9, 9, 9 (accepted)

17b: ESPGHAN WG suggests increasing fluid and fiber intake as an additional strategy to treat constipation in children with NI.

LoE low
GoR weak
VOTES: 9, 8, 8, 7, 9, 7, 7, 8, 8, 8, 7, 7, 8, 9, 7 (accepted)

What Other Problems Can Contribute to Feeding Difficulties (ie, Dental, Drooling, Pain, Orthopedics, etc)?

Dental

Children with NI have a high incidence oral/dental problems contributing to feeding difficulties. These include the stability of the jaws, lip tone and movement, and problems with biting including tonic biting and overbiting. Jaw instability limits graded opening and closure, impairing manipulation of food in the mouth and leading to poor bolus formation and swallowing difficulty. Jaw thrusting and retraction may cause difficulties taking food from a spoon, drinking, retaining and manipulating food within the mouth, bolus formation, and safe and effective swallowing (67). Children with NI exhibit almost a 3-fold greater chance of having an occlusion abnormality (145). Bruxism, the habitual grinding of teeth, is a common occurrence in people with NI. In extreme cases, bruxism leads to tooth abrasion and flat biting surfaces. Ortega et al (146) found that along with bruxism there were habits such as pacifier sucking, finger sucking, habit of biting objects, and tongue interpositioning. Drooling of saliva, sialorrhea, appears to be the consequence of a dysfunction in the coordination of the swallowing mechanism, resulting in excess pooling of saliva in the anterior portion of the oral cavity and the unintentional loss of saliva from the mouth. Prevalence rates of sialorrhea in children with NI are reported range from 10% to 58% (147). The lips and tongue also play an important role in effective feeding. The lips may be hypotonic, hypertonic, or have a mixed tone with constant movement at rest. Poor lip control can cause leakage of food and fluids, resulting in decreased intake and contributing to poor nutrition and dehydration. Poor tongue movements including thrusting may compromise the formation of the food bolus.

Orthopedic Problems

Many children with NI have trunk hypotonia. In an upright sitting position, therefore, the thoracic column becomes kyphotic and the cervical spine lordotic. Because of the problem of drooling the head of the child is often tilted backwards. The children therefore become lordotic in the cervical spine, which has a negative influence on the function of the pharynx during swallowing. Neck extension may hamper closure of the laryngeal vestibule. Many NI children undergo surgery for scoliosis. Apart from the routine problems after surgery, they may develop gastric dysmotility (148). The cause of this complication is not clear, but could be related to the continuous traction applied to the spine, which may result in overstimulation of the sympathetic fibers. Sympathetic overstimulation may cause postprandial antral hypomotility and delayed gastric emptying leading to persistent nausea and recurrent emesis. Secondary malnutrition can further contribute to the GI motility disorder.

18: ESPGHAN WG recommends that careful attention is paid to dental problems, general posture, and orthopedic issues in patients with NI, because these may contribute to feeding difficulties.

LoE: moderate
GoE: strong
VOTES: 9, 9, 9, 9, 8, 8, 9, 8, 9, 9, 8, 9, 9, 8, 8 (accepted)

DIETETIC MANAGEMENT AND MONITORING (OTHER THAN ENTERAL NUTRITION)

Which Type of Diet According to Oral/Gastric Tolerance?

Oral feeding should be preferred in all children including children with NI. Feeding must be safe and so if severe OPD (dysphagia, unsafe swallow) is associated with repeated pulmonary aspirations, pneumonias, dehydration, and/or life-threatening events then an early switch to (partial or full) enteral feeding is advocated (Fig. 1). The duration of a trial of oral feeding depends on the child's age and the severity of malnutrition. A follow-up period of 1 to 3 months is usually sufficient but infants and severely malnourished patients need to be seen more frequently. Older children should be seen at least annually (1,56). The optimal energy content of oral feeds may differ according to type of the impairment, mobility of the patient, medication, and other factors. In order to increase total energy content of meals without excessively increasing volume, additional fat or oils (eg, high fat spreads), dry milk powders, cream, or ice cream may be supplemented (56). Recommendations on fiber intake are the same as for typically developing children (age plus 5 g/day in children older than 2 years).

Composition of the diet should be discussed with specialized feeding therapist/dietitians (56,149). In cooperation with a feeding therapist/dietitian, it is reasonable to modify textures of food and thickness of fluids to ensure safe and efficient food intake.

19: ESPGHAN WG recommends using oral feeding in children with NI if it is nutritionally sufficient, safe, stress-free, and feeding time is not prolonged.

LoE moderate
GoR strong
VOTES: 9, 8, 9, 9, 9, 9, 8, 8, 9, 9, 9, 8, 9, 9, 9 (accepted)

Does Feeding Times Compete With Rehabilitation?

In some children, attempts at oral feeding at any cost may lead to an excessive amount of time spent on feeding the child during the day, which in turn may lead to a lack of time left for other activities as rehabilitation, and severe impairment of the caregivers' quality of life (QoL). This occurs especially in children with chewing and swallowing dysfunction and affects up to 90% of children with NI (1,53,78,150–156). Some patients are able to feed themselves, but lack hand-mouth coordination and may eat slowly and spill part of food. Many children with NI are not able to communicate hunger and satiety (157,158). Usually, total feeding time during the day of between 3 and 6 hours or >30 minutes per feed is considered as excessive (50,157,159,160). ESPGHAN defines a feeding time >4 to 6 h/day as one of the conditions for considering enteral nutrition support (161). It should, however, be taken into account that caregivers often overestimate the time spent feeding the child and also overestimate the child's caloric intake (62,78,157).

20: ESPGHAN WG recommends considering use of enteral feeding if total oral feeding time exceeds 3 hours per day.

LoE low
GoR weak
VOTES: 9, 8, 9, 8, 9, 9, 9, 8, 7, 9, 9, 5, 7, 8, 8 (accepted)

ENTERAL NUTRITION (ENTERAL TUBE FEEDINGS, PERCUTANEOUS ENDOSCOPIC GASTROTOMY/JEJUNOSTOMY)

Which Sorts of Enteral Product to Use?

The choice of enteral formula depends not only on the child's age, but also on its energy requirements and mode of enteral access. Most enteral feeds are designed to meet all essential nutrient requirements (161). The initial feed of choice is usually a standard energy density (1.0 kcal/mL) polymeric feed. For children with an increased energy requirement or poor tolerance of large volumes of feed, a high-energy density formula (eg, 1.5 kcal/mL) (1,162), or dietary supplementation with glucose polymers and/or long-chain triglycerides to increase calorie intake may be useful. The addition of modular nutrients, however, should be made with the help of a dietitian to ensure that the final composition of the diet is adequate and to avoid preparation errors. For severely undernourished children, additional protein ($2.0\ g \cdot kg^{-1} \cdot day^{-1}$) and energy (additional 20% increase in energy intake) may be required to promote ''catch up'' growth (163,50). Before 12 months of age, an infant formula should be used (164). Most children will tolerate a polymeric formula, but some children may require a semielemental or elemental formula. Casein hydrolysates and amino acid–based formulas may be used in selected patients (164). In some countries an enteral feed specifically designed for tube-fed children with severe NI after nutritional rehabilitation is available: it is low-fat, low-calorie, high-fiber, and micronutrient replete (58,165). Whey-based formulas may be beneficial in children with poor feed tolerance because of delayed gastric emptying (164,166,167). Whey-based enteral formula has also been shown to significantly reduce acid gastroesophageal reflux episodes in children (but not infants) with severe NI and a 50% whey formula significantly reduces gagging and retching in children with severe NI (168). Pureed food given via gastrostomy has been suggested to reduce gagging and retching in children after fundoplication surgery due to higher viscosity and different hormonal responses favorably affecting GI motility (167). Concerns regarding the nutritional adequacy and safety of home-prepared tube feeds have been reported and even with the involvement of a dietitian, poor weight gain has been reported (167). Microbial contamination of enteral tube feeds can occur even with the use of commercial formulas (169,170). Risk factors, however, include the environment and the manner in which the feed is prepared, poor attention to hygiene during handling, repeated topping up of the feed container, and increasing feed-hanging times (161). Commercially available ''ready to hand'' closed enteral feeding systems are designed to limit handling procedures with the introduction of the giving set spike into the pack.

21a: ESPGHAN WG recommends using standard (1.0 kcal/mL) polymeric age-appropriate formula including fiber for children with NI older than 1 year.

LoE moderate
GoR strong
VOTES: 9, 9, 9, 9, 9, 9, 9, 8, 8, 8, 8, 8, 8, 7, 7 (accepted)

21b: ESPGHAN WG recommends using a high-energy density formula (1.5 kcal/mL) containing fiber in cases of poor volume tolerance in children with NI, provided hydration is carefully monitored.

LoE moderate
GoR strong
VOTES: 9, 9, 9, 8, 8, 8, 8, 8, 8, 8, 8, 8, 8, 7, 7 (accepted)

21c: ESPGHAN WG recommends using human milk, a standard infant formula, or nutrient dense infant enteral formula as clinically indicated in infants with NI.

LoE low
GoR strong
VOTES: 9, 9, 9, 9, 9, 9, 9, 9, 9, 8, 8, 8, 7, 6, 6 (accepted)

21d: ESPGHAN WG recommends using a low-fat, low-calorie, high-fiber, and micronutrient-replete formula for the maintenance of enteral tube feeding after nutritional rehabilitation in immobile children with NI.

LoE moderate
GoR strong
VOTES: 9, 8, 8, 8, 8, 8, 8, 8, 8, 8, 8, 8, 7, 7, 6, 6 (accepted)

**21e: ESPGHAN WG recommends using a trial of whey-based formula in cases of gastroesophageal reflux, gagging, and retching in children with NI.

LoE moderate
GoR weak
VOTES: 9, 8, 8, 8, 8, 7, 7, 7, 7, 7, 6, 6, 6, 6, 5 (accepted)

21f: ESPGHAN WG recommends caution if pureed food is used for enteral tube feeding in children with NI, because of concerns regarding nutritional adequacy and safety.

LoE low
GoR strong
VOTES: 9, 9, 8, 8, 8, 8, 8, 8, 8, 7, 7, 7, 6, 6, 5, 4 (accepted)

Which Modalities of EN to Use (Bolus/Continuous)?

Enteral tube feeding can be administered as a bolus, intermittently, or continuously. The choice of feeding regimen will be based on the child's enteral access, their activities, caloric needs, and tolerance to feeds (1). Continuous feeding is the preferred method in feeding intolerance. In continuous feeding the feed is delivered by dripping by gravity or assisted by an enteral feeding pump over a specified number of hours into a tube. In bolus feeding the nutritional product is administered during 15 to 30 minutes several times a day. Bolus feeding allows more freedom and may be more suitable to the lifestyles of many families. The timing of bolus feeds is important to provide adequate opportunity for the development of hunger before oral meals. A child with high-caloric needs or with poor tolerance to volume may benefit from a combination of overnight continuous feeds with boluses during the day (1,56,164).

22: ESPGHAN WG recommends using a combination of nocturnal continuous feeds with daytime bolus feeds in children with high-caloric needs or poor tolerance to volume.

LoE low
GoR *weak*
VOTES: 9, 9, 9, 9, 9, 9, 9, 8, 8, 8, 8, 7, 7, 6, 5 (accepted)

Which Type of Tube (Nasogastric, PEG) to Use?

Intragastric access can be provided by either a nasogastric tube or a gastrostomy, created surgically (preferably laparoscopic), radiology assisted or more usually a percutaneous endoscopic gastrostomy or periendoscopic gastrostomy [PEG]) (171). Prospective randomized studies in children, comparing nasogastric with gastrostomy feeding in children are not available. In adults with swallowing difficulties, a Cochrane review showed that PEG was associated with a lower probability of intervention failure. PEG was found to cause less discomfort, to be more convenient, and to interfere less with social activities. There was no significant difference in mortality rates between groups, or in adverse events, including pneumonia related to aspiration. These results suggest that a gastrostomy may be more effective and safe compared with nasogastric tube (172). A prospective cohort study with a follow-up of 12 months of a cohort of 57 children with NI receiving a gastrostomy, showed a substantial increase in weight gain, improved health as reported by the parents and a significant reduction in feeding time with no increase in respiratory infections (57,165). Common complications reported in this and other studies, are minor site infections and granulation tissue, occurring in 40% to 60% of patients. Peritonitis, tube migration, tube blockage, major site infections, buried bumper, and colon perforation are far less common.

23: ESPGHAN WG recommends using a gastrostomy as the preferred way to provide intragastric access for long-term tube feeding in children with NI.

LoE moderate
GoR strong
VOTES: 9, 9, 9, 9, 9, 9, 9, 9, 9, 9, 9, 8, 8, 9, 9 (accepted)

What Are the Indications of Jejunal Feeding?

In cases in which intragastric feeding is contraindicated because of severe gastric motility disorder, or severe GORD is not amenable to antireflux surgery, jejunal tube feeding can offer enteral access. A jejunal tube needs to be positioned distal to the Treitz ligament to prevent retrograde filling of a dysfunctioning stomach. Jejunal access can be provided by a nasojejunal tube, jejunal tube introduced through a gastrostomy, or surgical transcutaneous jejunostomy.

In patients who already have a gastrostomy, a jejunal tube can be introduced through the gastrostomy. These jejunal tubes, however, frequently migrate back to the stomach. The mean functional duration of these tubes was found to be 55 days in adults and 39 days in children. Retrograde dislodgment of the jejunal extension tube, tube obstruction, and mechanical failure have been described as the most common device-related complications (173).

Jejunal feeding is appropriate in patients with recurrent vomiting and/or tube feeding-related aspiration, severe gastroesophageal reflux, and gastroparesis (174). The combination of gastric decompression via PEG and simultaneous jejunal nutrition was shown to provide clinical benefit in patients with NI.

24: ESPGHAN WG suggests using jejunal feeding in cases of aspiration due to GORD, refractory vomiting, retching, and bloating in children with NI.

LoE moderate
GoR weak
VOTES: 9, 9, 8, 8, 8, 8, 9, 9, 8, 7, 7, 7, 5, 9, 9 (accepted)

When Should Tube Feeding Be Started?

Tube feeding is indicated in cases of inadequate oral intake manifesting as insufficient weight gain or weight stagnation, evidence of low body fat stores, low weight in respect to height/length, prolonged or stressful oral feeding, recurrent pulmonary infections as sign of aspiration, or food refusal which do not respond to noninvasive nutritional support (1,56).

25: ESPGHAN WG recommends using enteral tube feeding in cases of unsafe or inefficient oral feeding, preferably before the development of undernutrition.

LoE moderate
GoR strong
VOTES: 9, 9, 9, 9, 9, 9, 9, 9, 8, 8, 7, 7, 5, 9, 9 (accepted)

SURGICAL INTERVENTIONS (NISSEN FUNDOPLICATION)

What Investigations Should Be Carried out Before Consideration for Surgery?

Children with NI account for the great majority of patients with GORD requiring antireflux surgery in the pediatric surgical field, but there have been very few studies that have evaluated the GORD of NI patients before surgery in relation to the outcome (175). Careful evaluation of GORD is required before fundoplication because symptoms of GORD are often lacking (communication deficits) or nonspecific (increased spasticity, seizures, pulmonary or laryngologic manifestations) or associated with other complications (inhalation, swallowing difficulties) in this high-risk population. Investigations are required before surgery to confirm GORD, to search for complications (esophageal stenosis, Barrett), and to rule out differential diagnosis (ie, eosinophilic esophagitis). The 24-hour pH monitoring has been widely used to evaluate and quantify GORD, but is not able to be detected nonacid reflux. pH/impedancemetry has been established as a pH-independent measurement tool that allows for the analysis of the movement, direction, and height attained by the bolus, making it possible to distinguish antegrade and retrograde bolus movement. The technique still has limitations: high cost, limited added value regarding therapeutic implications, and lack of evidence-based parameters for the assessment of GORD and symptom association in children. Assessing GORD could be difficult in cases of continuous enteral nutrition and/or PPI treatment. Upper GI endoscopy with biopsies is required before surgery to search for esophagitis and Barrett. Patients with NI are considered as a high-risk group for peptic esophagitis, Barrett esophagus, and esophageal adenocarcinoma. The utility of the upper GI study to rule out anatomic abnormalities in the preoperative evaluation is questionable (176). There are no data on predictive value of high-resolution esophageal manometry on postfundoplication complications in patients with NI. Abnormal gastric emptying, is frequent in children with NI and may be assessed by using octanoic acid breath test or scintigraphy, but its usefulness for deciding surgery or predict outcome after fundoplication has never been assessed. There is today no investigation that could predict failure, complication (ie, dysphagia) of fundoplication, or recurrence of GORD.

26: ESPGHAN WG recommends that upper GI endoscopy with biopsies is performed before fundoplication in children with NI. Other investigations (eg, contrast studies, gastric emptying studies, and pH± impedancemetry) may also be indicated.

LoE low
GoR strong
VOTES: 9, 8, 9, 9, 9, 9, 8, 9, 7, 5, 4, 9, 9, 9, 8 (accepted)

SHOULD A FUNDOPLICATION ROUTINELY BE PERFORMED WHEN A PEG INDICATED?

Among the children requiring PEG those with NI are more likely to require a subsequent antireflux procedure (177). One potential benefit of associating gastrostomy to fundoplication is to prevent inhalation and the respiratory complications of enteral feeding. Infants with NI who, however, underwent fundoplication at the time of gastrostomy placement did not have a reduced rate of reflux-related hospitalizations (including asthma, inhalation, GORD, pneumopathies) when compared with those who underwent gastrostomy placement alone (178). Antireflux surgery also has pitfalls and complications. There are no randomized controlled trials of fundoplication versus postoperative medication for children with NI and severe GORD undergoing gastrostomy (179) (Fig. 1).

Most of the publications on the relationship between PEG and GORD using pH/impedancemetry before and after PEG conclude that GORD is not aggravated by PEG (180–183), although some studies showed that PEG increased GORD (184–186). Another approach is to assess the outcome of GORD after PEG in children with NI. In the experience of one of us only 16% of patients with a neurological disease, needed antireflux surgery at follow-up (unpublished data). In another study only 9% of patients requiring PEG underwent fundoplication 20 months after PEG (187). Even if we cannot rule out the responsibility of PEG worsening GORD, we hypothesize that the increased volume of food intakes after PEG placement could reveal or aggravate a preexisting GORD. Routine fundoplication at the time of gastrostomy would unnecessarily expose a large proportion of children with NI to antireflux surgery complications including gas bloat syndrome, dysphagia, and dumping syndrome.

27: ESPGHAN WG recommends that a routine antireflux procedure should not be performed at the time of PEG placement in children with NI because it could add significant morbidity.

LoE high
GoR strong
VOTES: 9, 9, 9, 9, 9, 9, 9, 8, 9, 9, 7, 9, 9, 9, 8 (accepted)

WHAT ARE THE INDICATIONS FOR FUNDOPLICATION?

In a retrospective cohort study on caregiver perceptions and complication rates in 122 patients with NI who underwent fundoplication, the majority of caregivers indicated that surgery improved weight gain, chest infections, vomiting, and feeding tolerance. Although gagging and retching were common after surgery, a high percentage of caregivers reported improved nutrition, reflux-related symptoms, and high levels of satisfaction (188). Children with NI represent a special group of patients with increased risk for operative morbidity and postoperative failure and persistence/recurrence of GORD (127). As for normally developed children, antireflux surgery may be of benefit in children with confirmed GORD who have failed optimal medical therapy, who are dependent on medical therapy over a long period of time, who are significantly nonadherent with medical therapy, or who have life-threatening complications of GORD. Children with respiratory complications including asthma or recurrent aspiration related to GORD are generally considered most likely to benefit from antireflux surgery when medical therapy fails. Given the morbidity and high failure rates of antireflux surgery in children with NI, patients whose symptoms are well controlled on medical therapy may not derive additional benefit from antireflux surgery. In a systematic review, it was found that the need for reoperation in children with NI was 15.4% in comparison with 7.0% in those without NI (189). Ferluga et al (190) concluded that there is poor or no evidence of effectiveness of fundoplication in treatment of nutritional problems. In patients with NI, the potential benefit of fundoplication should be weighed against the risk of potential complications before surgery is decided upon (191) (Fig. 1).

28: ESPGHAN WG recommends that fundoplication be considered in cases of failure of optimized medical therapy for GORD in children with NI.

LoE strong
GoR strong
VOTES: 9, 9, 8, 9, 8, 8, 9, 6, 9, 8, 9, 8, 8, 8, 9 (accepted)

Are There Surgical Alternatives to Fundoplication?

Total esophagogastric disconnection (EGD) and Roux-en Y esophagojejunostomy has been developed as a ''once-and-for-all'' effective therapy for GORD in patients with NI. This strategy is, however, more invasive, requiring longer periods of rehabilitation (192). The advantage of laparoscopic Nissen fundoplication, in terms of both reduction of hospital stay and postoperative peritoneal adhesions, reduces the indications for total EGD. This should be considered as primary surgical management of GORD only in special and complex clinical situations; in severe NI children needing repeated anti-GORD surgery, EGD could represent the only opportunity of definitive resolution. Microgastria, in selected cases that cannot be treated with one of the gastric augmentation techniques, could also represent an indication for EGD (193).

29: ESPGHAN WG recommends restricting the indication for total esophagogastric disconnection and Roux-en-Y esophagojejunostomy, as an alternative of classical antireflux surgery, to selected cases in children with NI.

LoE weak
GoR weak
VOTES: 9, 9, 8, 9, 8, 8, 9, 6, 9, 8, 9, 8, 8, 8, 9 (accepted)

ETHICAL ISSUES RELATED TO DIGESTIVE AND NUTRITIONAL PROBLEMS IN THE SEVERELY HANDICAPPED

What Is the Effect of Nutritional Support on Quality of Life of Children and Caregivers?

The severity of the disease and the presence and severity of malnutrition both have an impact on QoL impairment. Gastrostomy feeding is effective in reversing malnutrition in children with NI and has positive effects on the QoL of the patients and the caregivers. QoL is often the most important outcome treatment for chronic conditions such as NI (194). Children with NI have reduced health-related quality of life and the degree to which it is reduced is related to the severity of their NI (195,196). Almost 50% of children with NI are able to self-report their perceptions of their health-related QoL. Healthcare professionals and parents should, therefore, rely on a proxy report only when the children are not capable of self-report, or to ascertain potential differences in perceptions between children and their parents (197). Nevertheless, for severely disabled children parent-proxy reported QoL are the only available data. Caring for a child with NI affects a parent's physical well-being, social well-being, freedom, independence, family well-being, and financial stability (198). Carers of children with NI have poor QoL, worse mental health, and higher burnout levels than controls (199). Parents often feel unsupported by the services they access (200). Children with the most severe motor disability who have feeding tubes are an especially frail group, that is, having the poorest health, the worst well-being, and using the most health-related resources (201). Previous qualitative studies have found issues of social isolation, difficulty in obtaining care, and high caregiving demands among parents of children with NI who are fed through a gastrostomy tube (149,202,203). Using a validated instrument for measurement of QoL, however, Sullivan et al (204) found a significant improvement in the QoL of carers 6 and 12 months after insertion of a gastrostomy feeding tube in children with CP. A clear need for additional support for parents of children with a PEG has been identified that goes beyond simply meeting clinical need (149). Ongoing medical and psychosocial support is needed after initiation of nonoral feedings and is best provided through the collaborative efforts of the family and a team of professionals (205).

30: ESPGHAN WG recommends that parents and/or caregivers are always involved in decision making especially around gastrostomy feeding.

LoE high
GoR strong
VOTES: 8, 9, 9, 9, 9, 9, 9, 8, 9, 9, 9, 9, 9, 9, 9 (accepted)

Are There Ethical Issues in Relation to Nutritional Support?

PEG feeding for reversing malnutrition in children with NI is a therapeutic intervention and as such is governed by standard ethical rules. The decision on initiation of the treatment is based on the likely net balance between advantages and disadvantages to

promote the best interest of the individual patient. Similarly, to other treatments, informed and educated consent of the parents is an important ethical principle. PEG feeding is associated with several complications and is costly. Gastrostomy feeding has been shown to reverse malnutrition (165) and to reduce the number of feed-related choking episodes, vomiting, and chest infections (57). The decision-making process for parents is, however, often difficult due to negative caregiver perceptions (75) and the gastrostomy tube placement is often delayed (206). Fears about loss of normal eating, dependency on gastrostomy feeds, and complications of the procedure can make parents accept this option only as a last resort (200). Nonetheless, the majority of caregivers recognize improvement in the children after placement and the majority admit that they would have accepted an earlier placement of the gastrostomy tube if they had anticipated the overall outcome (207,208). Obtaining parents' consent before initiating PEG feeding is important ethical principle, similarly to any other medical intervention. The parents need to be given detailed information on the benefits, risks, and alternatives of the treatment and also, enough time to retain the information to make a conscious decision. Health care workers need to develop effective, family-centered, patient-appropriate adherence strategies for gastrostomy fed children with NI. Furthermore, education and training on gastrostomy feeding both in hospital and in the community help the carers of patients to cope during the transition from oral to gastrostomy feeding, while continuing social support is essential to improve QoL of carers.

31: ESPGHAN WG recommends involvement of a professional ethicist to assist decision making in cases in which invasive investigations or procedures (eg, gastrostomy, fundoplication, parenteral nutrition) pose ethical dilemmas.

LoE moderate
GoR strong
VOTES: 9, 9, 9, 9, 9, 9, 9, 9, 8, 8, 9, 9, 8, 9, 9 (accepted)

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