Nutritional Management of Children With Neurological Impairment in China: Current Status and Future Directions

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Objectives: The aim of this study is to assess the awareness of Chinese physicians on gastrointestinal and nutritional management of children with neurological impairment (NI) and to assess the practical application of the European Society of Pediatric Gastroenterology, Hepatology, and Nutrition guidelines on the management of nutritional and gastrointestinal problems in children with NI in Asian countries, particularly in several major medical centers in China.

Methods: A web-based questionnaire was distributed between November 2020 and January 2021 among Chinese healthcare professionals involved in the clinical management of children with NI. Fifteen questions covering the most relevant aspects of nutritional management and gastrointestinal issues of children with NI were surveyed. A descriptive analysis of responses was performed.

Results: A total of 577 healthcare professionals from over 28 provinces in China answered the questionnaire. Anthropometrics were the most used parameters (n = 539) to assess nutritional status. Most respondents (n = 455) indicated weight faltering and/or failure to thrive as definition of undernutrition. Direct observation of meals was considered the recommended method for diagnosing oropharyngeal dysfunction by 542 professionals. Fundoplication was indicated at the time of gastrostomy placement in patients with uncontrolled gastroesophageal reflux disease by 437 respondents.

Conclusions: The clinical practice of Chinese healthcare professionals does not completely match the European Society of Pediatric Gastroenterology, Hepatology, and Nutrition guidelines, probably due to the medical system and the economic, social, and cultural differences. Further studies are needed to improve clinical practice and knowledge. Multidisciplinary approach is crucial to optimize the overall medical care and quality of life for children with NI.

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What Is Known

- Children with neurological impairment (NI) often have gastrointestinal problems that affect their nutritional status and quality of life.
- The interest in nutritional and gastrointestinal management of NI children in China has recently raised.

What Is New

- Gaps between Chinese healthcare professionals' daily clinical practice and current recommendations on the nutritional management of children with NI seem to exist.
- Further studies are needed to improve clinical practice and knowledge, also addressing aspects that need consensus.

Key Words: children, dysphagia, enteral nutrition, gastroesophageal reflux disease, neurological impairment, survey

INTRODUCTION

Children with neurological impairment (NI), such as cerebral palsy, often have dysphagia and gastrointestinal problems that affect their nutritional status and quality of life (1–4). Nutritional interventions are challenging but necessary for the overall disease management and quality of life.

In 2017, the European Society of Pediatric Gastroenterology, Hepatology, and Nutrition (ESPGHAN) published its first guidelines on the diagnosis and management of nutritional and gastrointestinal problems in children with NI (5). Recently, the same working group carried out a web-based survey aimed to assess the current clinical practice with respect to the ESPGHAN recommendations and the knowledge and awareness of healthcare professionals dealing with NI patients on gastrointestinal and nutritional management. The questionnaire results were published with most responses coming from physicians living in European countries (6).

A research collaboration program between China and Italy has recently been built to raise awareness of nutritional management among Chinese healthcare professionals involved in the clinical management of children with NI, promote the standardization of nutritional care protocols, and explore the most appropriate nutritional interventions in China. A survey to collect the Chinese healthcare professionals' perception and daily clinical practice has been conducted.

MATERIALS AND METHODS

The questionnaire initially prepared by ESPGHAN and used in the recent publication (6) was provided by one of the authors and then translated into Chinese by the researchers from the China-Italy NI Clinical Research Program on Nutrition Management.

The authors report no conflicts of interest.

The translated questionnaire was posted online via https://www. wjx.cn/ (a free online questionnaire platform in China) and distributed among Chinese healthcare professionals involved in the clinical management of children with NI between November 2020 and January 2021. Based on their understanding of the guidelines and their own clinical experience, healthcare professionals across China voluntarily completed the questionnaire. The questionnaire was made up of 15 questions covering the most relevant aspects on nutritional management and gastrointestinal issues of children with NI, such as diagnosis of oropharyngeal dysfunction, definition of malnutrition, management of gastroesophageal reflux disease (GERD), and indication for enteral nutrition as well as for anti-reflux surgery. General information on respondents was collected, including awareness of the 2017 ESPGHAN position paper. A descriptive analysis of responses was performed.

RESULTS

A total of 577 healthcare professionals from over 28 provinces in China (accounting for 82% of the provinces in China) answered the questionnaire. The largest number of participants (n = 119) were from Fujian Province, which is in the coastal area of southeast China, followed by Henan Province (n = 105), one of the most populous provinces in the middle of China, Guangdong (n = 57), and Yunnan (n = 43), as showed in Figure 1.

Most physicians (n = 378; 66%) followed-up less than 10 NI children per month; 16% of physicians followed-up 11–20 NI children per month, while 19% only over 20 NI children per month. Two-hundred seventy-eight (49%) physicians were from rehabilitation department, 130 (23%) were general pediatricians, followed by healthcare providers from nutrition department (n = 113; 20%), gastroenterologists (n = 29; 5%), and neurologists (n = 17; 3%).

Assessment of Nutritional Status

Anthropometrics (ie, height and weight) were the most used parameters to assess the nutritional status (n = 539, 93%). Most clinicians also used skinfold thickness and/or limb circumference

(biceps and triceps) (n = 488, 78%), laboratory tests and bone mineral densitometry (n = 406, 70%), and alternative segmental length measurements (knee-heel, tibia, and ulnar length) (n = 356, 62%) when height is not available. About bone mineral densitometry, most hospitals/clinics reported to use ultrasound, while only tertiary hospitals reported to use dual X-ray absorptiometry.

Various definitions of undernutrition were reported. Most respondents (n = 455, 79%) indicated weight faltering and/or failure to thrive as definition of undernutrition in children with NI. Four-hundred forty-six (77%) respondents defined undernutrition based on anthropometric indices, such as height-for-age, weight-for-height, and body mass index (BMI)-for-age ratio plotted on growth charts for a typically developing population, whereas 229 (52%) reported to rely on the same anthropometrics plotted on specific growth charts for children with NI (ie, cerebral palsy growth charts). Four-hundred five (70%) considered undernutrition in case of finding mid-upper arm fat (triceps skinfold) or muscle area <10th percentile for age and sex, not necessarily in association with other indices.

About micronutrient status, the majority of respondents (n = 513, 89%) agreed vitamin D should be monitored, together with calcium and phosphorus (n = 482, 84%), iron (n = 455, 79%), and folic acid and vitamin B12 (n = 441, 76%). Forty-seven (8%) respondents reported that no recommendation on micronutrient status monitoring exists.

Two-hundred forty-eight respondents (43%) reported that nutritional status should be assessed at least every 6 months and micronutrients annually, according to 232 (40%) nutritional status every 3 months and micronutrients status every 6 months; according to 77 (13%) both at least every 3 months; and according to 14 (2%) both at least annually. Six respondents thought the frequency of monitoring should be variable, depending on children's age, growth, and the degree of NI.

Energy Needs

Two-hundred thirty-six (41%) respondents reported daily energy requirements estimation in children with NI should be based



FIGURE 1. Demographic information of the respondents.

on dietary reference standards for typically developing children, 146 (25%) respondents reported to calculate 20% higher than reference standards, whereas 130 (23%) respondents reported that they use special calculating formula for NI children or to rely on disease symptoms, NI degree, rehabilitation training, Gross Motor Function Classification System, and BMI.

Oropharyngeal Dysfunction

The recommended method for diagnosing oropharyngeal dysfunction in children with NI was reported to be the direct observation of meals by 542 professionals (94%), together with videofluoroscopy (n = 285; 49%) and upper gastrointestinal endoscopy (n = 246; 43%) (Fig. 2). The minority of respondents indicated ultrasound (n = 132; 23%).

Nearly all the professionals considered the recommended management of oropharyngeal dysfunction being the modification of time allocated to feeding and feed consistency (n = 565; 95%), as well as the modification of posture during feeding (n = 541; 94%). Speech and language therapy was indicated as the best therapeutic option by 438 (75%) participants. The use of antiemetic drugs was considered by a minority (n = 40; 7%) of participants.

Gastroesophageal Reflux Disease

When asked how to best treat GERD, most respondents (n = 462; 80%) indicated prokinetic agents, followed by food thickeners (n = 417; 72%), proton pump inhibitors (PPIs) (n = 384; 67%), and histamine-2 receptor antagonists (n = 316; 55%) (Fig. 3).

The majority (n = 517; 90%) of the respondents reported failure of medical therapy to control GERD as an indication to perform fundoplication in children with NI. Other indications were feeding intolerance (n = 297; 51%), long-term PPI treatment (n = 240; 42%), and severe malnutrition (n = 245; 42%).

Enteral Nutrition

Enteral nutrition was considered to be indicated by all respondents when at least 1 of the following conditions were met: (1) feeding time exceeding 4 hours/day, (2) evident chewing and/or swallowing dysfunction, (3) oral feeding associated with low-energy intake, (4) low fluid intake, and (5) stressful oral feeding.

The opinions of all surveyed physicians on the best type of long-term enteral access greatly varied, with 32% (n = 184) of the physicians choosing gastrostomy, and 31% (n = 181) nasogastric tube. A minority of respondents indicated jejunostomy (n = 90; 16%), nasal-jejunal tube (n = 67; 12%), and gastric-jejunal tube (n = 55; 10%) (Fig. 4).

Three-hundred fifty-nine (62%) participants reported that enteral nutrition should be started with a polymeric age-appropriate formula (1 kcal/mL) containing fiber. High-energy density formula (1.5 kcal/mL) containing fiber, low-energy/low-fat/ high-fiber formula, and home-blended diet were considered the first choice by 115 (20%), 70 (12%), and 33 (6%) of respondents, respectively.

Jejunal (post-pyloric) feeding was considered as an option by 82% (n = 472) of all the surveyed physicians for patients who suffer from refractory vomiting, retching, and abdominal distension. Other indications for jejunal feeding were reported to be repetitive catheter displacement after gastrostomy placement (n = 362; 63%), aspiration due to gastroesophageal reflux (n = 334; 58%) and constipation (n = 63; 11%).

According to 437 (76%) respondents, fundoplication was indicated at the time of gastrostomy placement in case of uncontrolled GERD. Smaller number of respondents reported that they suggest simultaneous fundoplication in case of severe malnutrition (n = 46, 8%), routinely (n = 40; 7%) or in case of recurrent pneumonia (n = 39; 7%). Fifteen respondents (3%) reported that they would never find it indicated at the time of gastrostomy placement.

DISCUSSION

The interest in nutritional and gastrointestinal management of NI children in China has recently raised. In 2020, the Subspecialty Group of Rehabilitation under the Society of Pediatrics Chinese Medical Association and the Subspecialty Group of Pediatrics of the Society of Parenteral and Enteral Nutrition Chinese Medical Association published the China Expert Consensus on Nutrition Management for Children with Cerebral Palsy (7). This consensus considered the actual situation in China. International guidelines developed nutritional support strategies for children

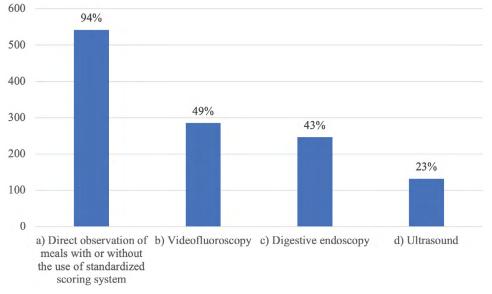


FIGURE 2. How dysphagia/oral motor dysfunction should be diagnosed in neurologically impaired children according to survey respondents.

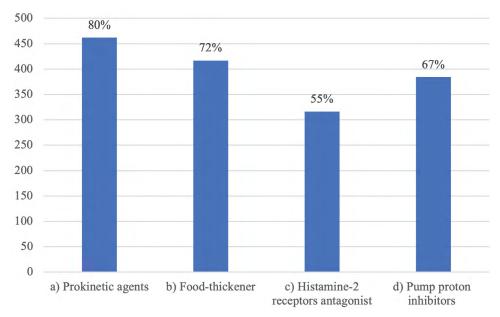


FIGURE 3. Best treatment reported for gastroesophageal reflux disease.

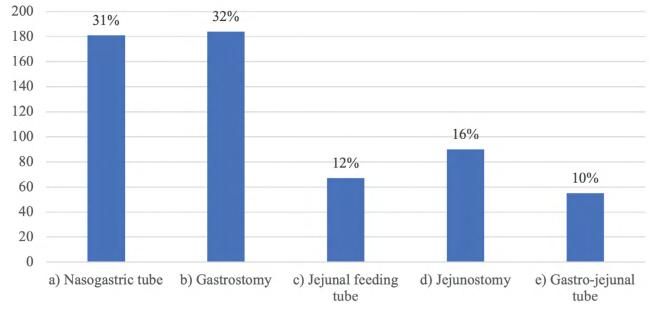


FIGURE 4. Feeding route for long-term enteral feeding.

with cerebral palsy that are suitable for China national conditions and local clinical practice, about the selection of growth charts, the assessment of dysphagia, the identification of malnutrition, the indications, goals and methods of nutritional intervention, the nutritional intakes, as well as the management of GERD, chronic constipation, etc. An adequate management of nutritional issues would be very helpful to improve clinical outcome and quality of life (8-10).

The survey results showed the current awareness level and knowledge of Chinese physicians on the nutrition management of children with NI (Table 1). The answers reflected the Chinese physicians' perceptions and clinical practice. Regarding the techniques used to assess the nutritional status of children with NI, the responses of the professionals were broadly in line with the guidelines. Anthropometrics, skinfold thickness and/ or limb circumference (biceps and triceps), laboratory tests, and bone mineral density are all used, and when height cannot be measured, alternative segmental length measurements are used. In establishing whether a child is malnourished, suggestions are to refer to the normal population growth curve for height-for-age, weight-for-height and BMI-for-age, with slow to put on weight and/or development stagnation, or middle upper arm fat (triceps skinfold) or muscle area <10th percentile as standards. A recent publication suggested the Pediatric Subjective Global Nutrition Assessment would be helpful

ESPGHAN	recommendation	Consistency rate. %*	
survey			
TABLE 1.	Consistency between the ESPGHAN recommendations (adapted from Romano et al [5]) and the	between the ESPGHAN recommendations (adapted from Romano et al [5]) and the results from the	

ESPGHAN recommendation	Consistency rate, %*
The measurements of knee height or tibial length should be performed routinely to assess linear growth when height cannot be measured	62
The measurement of fat mass by skinfold thickness should be a routine component of the nutritional assessment	78
The assessment of micronutrient status (such as vitamin D, iron status, calcium, phosphorus) should be a part of nutritional assessment	92
The use of cerebral palsy-specific growth charts is not recommended to identify undernutrition	48
Anthropometrics should be checked at least every 6 months and micronutrients annually	43
The dietary reference standards for typically developing children should be used to estimate the caloric needs	41
Oropharyngeal dysfunction should be diagnosed through both feeding history starting from early infancy and direct visual assessment of feeding carried out by appropriately trained professionals	94
Speech and language interventions could be considered for oropharyngeal dysfunction treatment and/or where there is need for modi- fication of the consistency of feeds	75
The use of proton pump inhibitors is recommended as the first-line treatment for GERD	67
Modification of enteral nutrition (thickening of liquid enteral formulas, whey-based formulas) could be considered in addition to other therapeutic options of GERD	72
Prokinetic agents should not be routinely used for GERD because of their weak efficacy and side effects	20
Enteral nutrition should be considered if total oral feeding time exceeds 4 h per day, in cases of unsafe or inefficient oral feeding, pref- erably before the development of undernutrition	100
Gastrostomy should be considered as the preferred way to provide intragastric access for long-term tube feeding	32
A standard (1.0 kcal/mL) polymeric age-appropriate formula including fiber should be used for NI children older than 1 y	62
Jejunal feeding should be considered in cases of aspiration due to GERD, refractory vomiting, retching, and bloating	82
Fundoplication can be considered in cases of failure of optimized medical therapy for GERD	90
A routine fundoplication should not be performed at the time of gastrostomy placement as it could add significant morbidity	24

to identify malnutrition in children with cerebral palsy and to provide a multidimensional approach to evaluate the overall nutritional status of these children (11).

When Chinese professionals reported how to estimate the daily energy requirements of children with NI, the feedback varied. The ESPGHAN guidelines stated that the assessment of the daily energy needs in children with NI is based on multiple factors, including body weight and body composition (1). When asked about the monitoring of micronutrients, most participants believed that iron, vitamin D, calcium, phosphorus, folic acid, and vitamin B12 were all indicators that should be monitored, in line with the ESPGHAN recommendations. According to the consensus reached in the ESPGHAN guidelines, dietary reference standards for typical developmental children can be used to estimate the caloric needs of NI children, and a regular monitoring of body weight and body composition as indicators of estimated energy needs should be performed. Chinese healthcare professionals have different clinical experience and awareness in estimating the daily energy needs of children, with most respondents align with ESPGHAN guidelines.

Oropharyngeal dysfunction is prevalent in children with NI, especially cerebral palsy (12-14). Oropharyngeal dysfunction is characterized by the presence of disturbances in 1 or more of the 3 swallowing phases (oral, pharyngeal, and esophageal) (15). It needs to be evaluated in all patients with NI even in the absence of obvious clinical signs and symptoms (5). This survey revealed that most respondents agreed with the ESPGHAN recommendations on the best approach to evaluate oropharyngeal dysfunction. The cornerstone of diagnosis consists in a detailed feeding history, direct visual assessment of feeding by observation of mealtimes with or without the use of standardized scoring systems. Videofluoroscopy is also used to identify pharyngeal dysmotility and silent aspiration, while

upper digestive endoscopy and ultrasound seem to be useless for the investigation of oropharyngeal dysfunction. Regarding treatment, most participants (about 70%) correctly indicated the need for modification of time allocated to feeding, feed consistency and posture during feeding, together with speech and language therapy.

In terms of treating GERD, respondents' opinions were not in line with current international guidelines. Most respondents chose prokinetic agents. According to ESPGHAN guidelines, PPIs represent the first-line treatment for GERD in children with NI, combined with lifestyle changes, such as the thickening of liquid formula and selection of whey-based, instead of casein-based, enteral formulas. Prokinetic agents, such as baclofen, are not recommended for routine use because of weak efficacy and side effects but may be considered in selected cases with uncontrolled GERD (5). The recommendation from the North American Society for Pediatric Gastroenterology, Hepatology, and Nutrition and the European Society for Pediatric Gastroenterology, Hepatology, and Nutrition (16) stated baclofen can be considered only when other pharmacological treatments have failed prior to surgery. Notably, a recent survey (17) on GERD management in Asian countries, reported that PPI was the most prescribed drug to treat GERD in all countries, including China. However, the survey was administered to adult physicians.

Although previous studies (18,19) reported the benefit of fundoplication in managing GERD, the experience in China is scarce. Most healthcare professionals considered GERD refractory to medical treatment as the main indication for anti-reflux surgery, followed by feeding intolerance, whereas the need for long-term PPI treatment itself did not represent an indication for fundoplication. However, for patients with oral feeding under pressure and feeding time more than 4 hours, the proportion of selecting enteral tube feeding was lower than that for chewing and/or swallowing disorders and for low-energy intake by mouth. Gastrostomy and jejunostomy are rarely performed in children with NI in China, related to the low acceptance by parents. Tube feeding and home enteral nutrition positively affect the quality of life of NI children (20). Fortunately, Chinese physicians have gradually realized the advantages of tube feeding, and the use of this technology is rapidly increasing. Consistently with ESPGHAN recommendations, most physicians would choose a polymeric, age-appropriate enteral formula containing fibers and would suggest jejunal feeding in patients with refractory vomiting, retching and abdominal distension.

One-hundred ten physicians answered the open questions about proposal for future research. The proposed research areas included (1) the assessment tool and treatment for dysphagia/oral motor dysfunction, (2) the nutrition intervention, (3) the practical nutrition assessment tool, (4) the appropriate enteral feeding schedule, (5) the gastrointestinal motility disorders, (6) the measurement of energy requirement, (7) the management of tube feeding, (8) the impact of gut microbiota on nutrition status, (9) the management of speech sound disorder, and (10) others.

Taking the large heterogeneity of NI diseases (cerebral palsy, spinal muscular atrophy, etc.) into consideration, standardized assessment tools and management programs should be developed according to the disease underlying NI. Determining the energy requirement and consumption is very important for individual nutritional intervention. However, because of the Chinese complex and various diet, accurate food record and dietary recall are almost impossible, while a generic formula calculating energy requirement could be helpful. Finally, although swallowing dysfunction is common in children with NI, the proportion of children fed via nasogastric tube or gastrostomy is relatively low in China, probably due to the unacceptance of parents. Based on the national situation of China, the awareness and knowledge of dysphagia should be strengthened. Tips for managing nutritional issues and gastrointestinal symptoms in children with NI were published by European researchers (21). Future research in China would be helpful to provide practical guidelines to address nutritional issues of NI children.

In China, physicians who manage NI children include general pediatricians, rehabilitation physicians, gastroenterologists, pediatric neurologists, and nutrition physicians/dietitians. Although nutrition physicians/dietitians are the healthcare providers with most expertise in nutrition, they are currently not widely and actively involved in the nutritional management of children with NI. Most nutrition departments in hospitals are consult basis, and outpatient clinics are usually performed by rehabilitation physicians, while the nutritional assessment is not usually combined with a routine visit. Early identification and intervention of nutritional issues are important (6,22). A multidisciplinary approach is crucial to optimize the overall medical care and quality of life of NI children.

The purpose of this study was to emphasize the awareness of Chinese physicians on the nutritional management of children with NI and to focus on knowledge gaps and future directions. The clinical practice and awareness of Chinese healthcare professionals do not completely match the European guidelines, probably due to differences in the medical system, together with economic, social, and cultural aspects. Further studies are needed to improve clinical practice and knowledge, also addressing aspects that need consensus. The China-Italy NI Clinical Research Program on Nutrition Management will further explore appropriate management principles and conduct collaboration studies aimed to address open issues.

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