Nutrition And Children with Developmental Disabilities: Assessment, Impact and Evidence-Based Management

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Objectives

1. Define cerebral palsy (CP), and describe the prevalence

2. Discuss the importance of nutritional care for children with developmental disabilities, and the impact of nutrition on this population

3. Identify tools that can be used to assess the nutritional status of children with developmental disabilities

4. Describe issues that may interfere with adequate nutrition in this population

5. Review the evidence around improving feeding tolerance in this population
Cerebral Palsy

- Neurological disorder caused by a non-progressive brain injury or malformation that occurs while the child’s brain is under development.
  - CP primarily affects body movement and muscle coordination.
- Estimated prevalence: 17 million people worldwide
- Most common cause of childhood-onset disability in most countries

Classification of CP

Classified according to motor abnormalities:

- **Spastic (~80%)**
  - Diplegia
  - Hemiplegia
  - Quadriplegia

- **Dyskinetic (10-15%)** have variable movement that is involuntary
  - Dystonia: twisting and repetitive movements
  - Athetosis: slow, ‘stormy’ movements
  - Chorea: irregular, unpredictable movements

- **Ataxic (<5%)** means ‘without order’ or ‘incoordination’ and be unsteady, shaky movements or tremor; difficulties maintaining balance

Motor Patterns of CP

**Quadruplegia**
- All four limbs are involved.

**Diplegia**
- All four limbs are involved. Both legs are more severely affected than the arms.

**Hemiplegia**
- One side of the body is affected. The arm is usually more involved than the leg.

**Triplegia**
- Three limbs are involved, usually both arms and a leg.

**Monoplegia**
- Only one limb is affected, usually an arm.
The Gross Motor Function Classification System for CP (GMFCS)

System developed to consider changes in motor function with age and development in these children.

- GMFCS objectively classifies a child’s current gross motor function
- Function is divided into 5 levels (Level I most independent motor function to level 5 being least)

Importance of Nutrition In Developmentally Delayed Children

• Malnutrition affects a large proportion of neurologically impaired children
  • Overnutrition
    • 8%-14% based on weight-for-height or triceps skinfold thickness criteria\(^1,2\)
  • Undernutrition
    • 29% to 46% of children with CP, linear stunting in 23\(^3,5\)

• Malnutrition should not be considered part of the disease
  • Historically, poor nutritional status believed to be unavoidable in children with severe neurodisability
  • We now understand that result = poor outcomes such as malnutrition, dehydration and poor growth

Importance of Nutrition In Developmentally Delayed Children

Malnutrition Is Associated With:

- Increased risk of infections
- Increased hospital length of stay (LOS)
- Increased healthcare costs
- Increased complication rates & readmission rates
- Increased mortality risk
- Poor long-term growth
- Reduced mental and psychomotor development
- Increased behavioral problems

Importance of Nutrition In Developmentally Delayed Children

Importing nutritional status

- Improves quality of life and overall health
- Improves gross motor abilities
- Decreases irritability and spasticity
- Improves peripheral circulation
- Helps heal pressure ulcers
- May improve GE reflux
- Helps heal pressure ulcers

Non-Nutritional Factors Affecting Growth

**Related to neurological disease**

- Severity of malnutrition correlates with severity of neurological disease
- Neurological disease affects growth even in the absence of malnutrition
- Correction of malnutrition does not correct statural growth completely
- Patients with spastic hemiplegia have significantly smaller measures of breadth/length on affected side

Nutritional Factors Affecting Growth

Inadequate intake

• Caloric intake has been shown to be lower than age-matched controls

• Those able to feed themselves may lack coordination and speed

• Those dependent on a caregiver may not be able to communicate hunger and satiety

What is Known?

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

Feeding difficulties in children with CP

The Oxford Feeding Study evaluated 271 children with CP and found common feeding problems included:

- Need for help with feeding (89%),
- Choking with food (56%)
- Feeding time > 3hrs per day (28%)
- Constipation (26%)
- Frequent vomiting (22%)
- Feeding described as stressful and un-enjoyable (20%)
- Never had feeding/nutritional assessment (64%)

Figure 1: Causal relationships between factors contributing to feeding difficulties and growth and general health in children with cerebral palsy.
Nutritional Factors Affecting Growth

Altered metabolism

- REE is lower than in age and weight-matched controls

- Total Energy Expenditure is affected by
  - Type of neurological involvement (athetoid)
  - Muscle tone (spasticity, hypotonia)
  - Activity level (bedridden, wheelchair bound, ambulatory)

Illness-Related Factors Affecting Growth

- Oral motor dysfunction
  - Inadequate suction
  - Dysfunctional swallowing
  - Persistent extrusion reflex
  - Inadequate lip closure
  - Reduced ability to chew

- Nutrient losses
- Altered energy expenditure
- Inflammation
- Decreased nutrient intake/altered nutrient utilization

Nutritional Factors Affecting Growth

Oral motor dysfunction

• Affects up to 90% of patients with CP
  • Up to 80% of patients with CP have been fed non-orally at least once as infants

• Is a major contributor to malnutrition
  • Affected children have lower weight-for-height
  • Prolonged mealtime does not compensate for feeding inefficiency

Evaluate the Nutritional Needs of NI Patients

Growth standards
Nutritional assessment
Multidisciplinary Assessment

Assessing Nutrition Status in Children with NI

• 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
  • Laboratory methods

CP Growth Charts

First growth charts for children with CP

- Based on 1,630 observations in 360 patients
- Weight, height and weight-for-height
CP Growth Charts


- 2011 growth charts for patients with CP
  - 102,163 measurements from 25,545 patients (1988-2002)
  - Stratified by GMFCS; level 5 additionally divided into those requiring a feeding tube (TF) and those not (NT).
    - **Level I:** Walks without limitations
    - **Level II:** Walks with limitations
    - **Level III:** Walks using a hand-held mobility device
    - **Level IV:** Self-mobility with limitations, may use powered mobility
    - **Level V:** Transported in a manual wheelchair
  
- Weight, Height and BMI

http://www.lifeexpectancy.org/articles/NewGrowthCharts.shtml
GMFCS I, Boys 2-20 Years


Evidence based link between low weight and mortality risk in children with CP
Weight-For-Age and Mortality

• For GMFCS levels III-V, children with weight for age below the 20th percentile had significantly higher mortality rates compared with children with weight for age in the 20th to 80th percentile range.

CP-specific growth charts describe growth which is not necessarily ideal as they include many children with other health conditions affecting growth, mostly malnutrition.

- Thus cannot be considered as a measure of how this group of children should ideally grow

Furthermore, clinicians often need a growth chart that indicates ideal growth based on a standardized reference population, such as the WHO growth standards.

Although there is no relevant data, experts often recommend the use of WHO growth charts in children with NI in whom a reliable height or 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.

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

1. Physical signs of undernutrition such as decubitus skin problems, 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
Z-Scores

• Z-score comparisons preferred for assessment of growth parameters
  • Negative z-score can indicate malnutrition

• Shows how a single data point compares to the norm
  • More sensitive to small changes than percentiles
  • Vs. percentiles, which are a point of reference to the total population

Z-scores

WHO

• Interpreting growth indicators:
  www.who.int/childgrowth/training/module_c_interpreting_indicators.pdf

Peditools.org
Weight and Height

2A ESPGHAN WG recommends that the assessment of nutritional status in NI children 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 in order to assess linear growth, when height cannot be measured.

- Significant proportion of children with NI not able to stand upright, or have joint contractions, spasticity and/or scoliosis, making height measurements difficult.
- Alternative measurements such as knee-heel length (KHL), tibia length and ulnar length can be assessed using sliding calipers.
  - These measures shown to have a high interrater reliability and be highly repeatable; therefore may be used on their own to monitor growth.
- Several formulas available to estimate height from the segmental lengths but limits of agreement with recumbent length found to be wide, usually in the range of ± 10 cm.

Estimation of Stature from Segmental Measures

| Age 0-12 | (4.35 x UAL) + 21.8  
|          | (3.26 x TL) + 30.8  
|          | (2.68 x KH) + 24.2  

North American Growth in Cerebral Palsy Project: www.healthsystem.virginia.edu

| Age 6-18 | White male: (2.22 x KH) + 40.54  
|          | AA male: (2.18 x KH) + 39.60  
|          | White female: (2.15 x KH) + 43.21  
|          | AA female: (2.02 x KH) + 46.59  

Upper-arm Length

Obtained with an anthropometer to measure distance between acromion and head of the radius
Lower-leg (Tibial) Length

Measure distance between superomedial border of tibia and inferior border of medial malleolus with child sitting, one leg crossed horizontally across the other
Skinfold thickness measurements show changes in total body fat

- Triceps skin fold thickness is the easiest to measure:
  - Using the thumb and index finger, grasp and pull the skinfold with subcutaneous fat so that it is separate from the muscle
  - Place the calipers around the skinfold
  - Record the measurement in millimeters (mm)
  - Compare with z-scores in a WHO standardized chart: [http://www.who.int/childgrowth/standards/tsf_for_age/e/](http://www.who.int/childgrowth/standards/tsf_for_age/e/)

ESPGHAN WG recommends that the measurement of fat mass by skinfold thickness should be a routine component of the nutritional assessment in NI children.
Mid Upper Arm Circumference

• Correlates with BMI but more sensitive to changes in muscle or fat mass

• Age 6-59 months
• Useful in children with edema or ascites

Energy Requirements

• Several studies indicate that the energy requirements of this patient population are reduced:

• **Bandini et al**: RMR, FFM and TEE in a group of 9 adolescents with CP were significantly lower than in healthy adolescents.

• **Stallings et al**: measured EE in 61 non-ambulatory children with spastic quadriplegia and 37 controls:
  • REE was found to be significantly lower in the group of SQCP subjects vs controls.

  • Total daily energy expenditure was significantly lower in the SQCP group than in the controls.
Energy Requirements

- **Bandini et al:** measured RMR in 12 patients (10-30 yrs) with severe CNS impairment who were fed exclusively by g-tube:
  - RMR predicted from Harris-Benedict or WHO overestimated measured RMR by 24-36%.

- **Azcue et al:** found that energy intake in the CP population they studied was 1.1 x RMR.

- Evidence available shows that EE and associated energy requirements are significantly reduced compared to age-matched controls.
The assessment of energy needs of the child with NI is difficult because there are no appropriate specific recommendations for this category of patients.

Patients with NI have lower body fat, muscle mass, and protein.

Energy intake is linked to mobility and activity level.

Schofield equation is reasonable in estimating calorie needs.

Other special equations can be used, but these are a starting point and the effect of dietary intervention must be reassessed.


Protein Needs

LEAN BODY MASS:

• Ambulant children and adults with CP have reduced muscle volumes in their lower limbs
  • as low as 50% of their weight-matched typically-developing peers

• The most significant muscle impairment may be lack of muscle growth

Total Body Protein

• Children with developmental disabilities tend to experience declines in LBM related to inactivity and ambulatory status.
  • Compounded by malnutrition and poor growth.

• Previously published studies demonstrate a reduction in body protein in children with spastic quadriplegic CP.
  • Significantly reduced for age and height.

Protein Needs

• Adequate protein still required to support growth & development despite lower energy needs
  • Adequate protein may be especially important, as further loss of LBM may result from a protein-deficient diet

• In absence of evidence-based guidelines re: protein needs for NI children, DRI is recommended
  • Providing adequate protein may be more difficult in tube-fed children who require lower calorie intake to prevent overfeeding

<table>
<thead>
<tr>
<th>Age, y</th>
<th>Maintenance Requirement</th>
<th>Growth Requirement</th>
<th>Average Requirement</th>
<th>DRI</th>
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Girls

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<td>16–18</td>
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<td>0.01</td>
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Boys

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<th>Average Requirement</th>
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<td>0.70</td>
<td>0.88</td>
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</tbody>
</table>

DRI, dietary reference intake.

Estimating Protein Needs

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

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

Enteral nutrition

• Indications:
  • If oral intake is unsafe (risk of aspiration)
  • Insufficient oral intake
  • Excessive duration of meals

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

Assessment Algorithm

Problems that may Interfere with Adequate Nutrition

Gastroesophageal Reflux/Delayed Gastric Emptying
Gut motility
Feeding intolerance
Osteoporosis
Constipation
Gastric Emptying

• GE reflux, a frequent complication in patients with CP, may result in undernutrition and aspiration pneumonia\(^1\)

• Delayed gastric emptying is an important factor in GER in children >3 years, especially those with CP\(^1,2\)

• The rate of gastric emptying associated with formula affected by the type of protein:
  • GE occurs more slowly in patients fed a casein-predominant formula than in those fed whey-based formulas\(^3-5\)

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Factors Affecting Gastric Emptying

• Protein type:
  • Typical protein sources: Casein, whey, soy
  • Whey protein
    • Remains liquid in acidic environment of the stomach
    • May be helpful with motility disorders

Effects of a Whey-Based Formula on Gastric Emptying Time

Nutrition Management of GOR: ESPGHAN Guidelines

14a ESPGHAN WG suggests modification of enteral nutrition (thickening of liquid enteral formulas, whey-based formulas) in addition to other therapeutic options of GOR disease in NI children
Formula Switch Leads to Enteral Feeding Tolerance Improvements in Children with Developmental Delays

Retrospective trial designed to:

• Evaluate changes in feeding tolerance in children with developmental delays who were switched from an intact protein-based feeding to a 100% whey, peptide-based formula

• Assess feeding intolerance parameter(s) identified before formula switch (gagging/retching, vomiting, abdominal distention/gas, stool consistency issues)

• Assess medications utilized to facilitate feeding tolerance and bowel management before and after formula switch

Study Design: Inclusion and Exclusion Criteria

Inclusion Criteria

• Diagnosis of developmental delay
• 13 months to < 18 years of age on admission to facility
• Prescribed to receive ≥90% energy needs via tube feeding before formula switch
• On intact protein formula for 2+ weeks before formula switch
• Switched to a 100% whey, peptide-based formula from an intact protein due to feeding intolerance
• Formulas received must be indicated for use in children or adults (not infant formulas)

Exclusion Criteria:

• Abdominal surgery or change in tube position within past 30 days prior to switch
• Any infection within two weeks prior to switch
• Documented cow’s milk protein allergy at time of switch
• Medical record lacking documentation on reason for, or response to, formula switch
RESULTS

• 92% of subjects (12/13) with improved feeding tolerance resulting from switch to 100% whey, peptide-based formula

• 75% of subject (9/12) had tolerance improvements within 7 days of formula switch

• 71% of subject (5/7) were able to tolerate increased feeding volumes after formula switch

• Of the 8 different medications administered for feeding intolerance-related issues
  • 6 medications were used in fewer subjects after switch
  • None of these medications were increased after switch
- 86% had improvement in vomiting (6/7)
- 75% had improvement in gagging & retching (3/4)
- 63% had improvement in high residual volumes (5/8)
- 43% had a decrease in constipation (3/7)
- 100% had a decrease in diarrhea (3/3)
- 100% had improved weight gain (5/5)
CONCLUSION

Switching to a 100% whey peptide-based formula improved symptoms of feeding intolerance in developmentally delayed children suffering from these symptoms.
The Effect of A Low Calorie, Nutrient Dense Formula on the Use of Modular Nutrition Supplements in Children with Developmental Disabilities

- Subgroups of pediatric patients with neurological impairment expend less energy and are susceptible to excessive weight gain
  - Many are dependent on tube feedings and may need an energy intake of less than 800 kcals/day

- As standard enteral formulas for children traditionally meet protein and energy needs in >1000 kcals, these formulas are often manipulated to meet protein and other nutrient requirements without exceeding energy needs

- This may involve the use of a base enteral formula plus additives such as protein modulares, vitamins, minerals and water.
Study Objective

• Assess the impact of a low calorie, high protein, micronutrient-enhanced enteral product on types & quantities of modular nutrition supplements required to meet nutritional needs of children 1-13 years with developmental disabilities.
Results

- Prior to initiation of study formula all subjects were receiving at least 1 modular supplement or water, and 94% were receiving 2 or more.
  - Modulars included protein supplements, MVI, vitamin D, calcium and free water

- Following initiation of study formula no additional modular supplements were used to meet the patients nutrient needs.
## Formula Recommendations for Children with NI: ESPGHAN WG Recommendations

<table>
<thead>
<tr>
<th>Recommendation Number</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>21a</td>
<td>Recommend using standard (1.0 kcal/mL) polymeric age appropriate formula including fiber for NI children older than one year</td>
</tr>
<tr>
<td>21b</td>
<td>Recommend using a high-energy density formula (1.5 kcal/ml) containing fiber in cases of poor volume tolerance in NI children, provided hydration is carefully monitored</td>
</tr>
<tr>
<td>21c</td>
<td>Recommend using human milk, a standard infant formula or nutrient dense infant enteral formula as clinically indicated in NI infants</td>
</tr>
<tr>
<td>21d</td>
<td>Recommend using a low-fat, low-calorie, high fiber, and micronutrient replete formula for the maintenance of enteral tube feeding after nutritional rehabilitation in immobile NI children</td>
</tr>
<tr>
<td>21e</td>
<td>Recommend using a trial of whey-based formula in cases of gastrooesophageal reflux, gagging and retching in NI children</td>
</tr>
<tr>
<td>21f</td>
<td>Recommend caution if pureed food is used for enteral tube feeding in NI children, because of concerns regarding nutritional adequacy and safety</td>
</tr>
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</table>

Increased Risk of Fracture

- Osteoporosis more common in patients with CP
- A number of studies report reduced BMD and increased fracture rates in children with neuromuscular disorders.
- Significant reductions in BMD found in nearly all non-ambulatory children with moderate to severe CP >10 years
  - fractures reported in more than one fourth of children this age

Increased Risk of Fracture

Risk factors:
• Lack of weight bearing activity
• Lack of exposure to sun
• Insufficient calcium & vitamin D intake
• Anticonvulsants

Treatment:
• Supplements: calcium, phosphorus, vitamin D
• Biphosphonates: reduces bone turnover and bone resorption

Increased Risk of Fracture

Drug-Nutrient Interactions

- Anticonvulsant meds alter Vitamin D and calcium metabolism

- **Holick et al:** recommended that institutionalized patients on at least 2 antiseizure meds receive 1000 IU vitamin D/day to maintain serum 25(OH) D levels within range of 25-45 ng/ml
  - This should prevent the osteomalacia and vitamin D deficiency associated with antiseizure medications
Micronutrient Status Monitoring

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

- Reported to occur in 60-75% of children with neurological impairment, leading to complications such as hemorrhoids, fecal obstruction or anal fissures¹

- Attributed to:
  - Decreased muscle tone
  - Decreased physical activity
  - Lack of fluid/fiber
    - Fiber and fluid intakes are inadequate in 53% of NI children²
  - Certain medications (phenytoin, baclofen, and anticholinergics) may exacerbate

### Dietary Fiber

<table>
<thead>
<tr>
<th>SOLUBLE</th>
<th>INSOLUBLE</th>
</tr>
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<tbody>
<tr>
<td><strong>Examples</strong></td>
<td><strong>Function</strong></td>
</tr>
<tr>
<td>Inner Pea Fiber, FOS, Inulin</td>
<td>• Fermentation and its effects</td>
</tr>
<tr>
<td>Soy Polysaccharide, Outer Pea Fiber</td>
<td>• May alter absorption (glucose, fat)</td>
</tr>
<tr>
<td></td>
<td>• Prebiotic effect</td>
</tr>
<tr>
<td></td>
<td>• Add bulk to stool</td>
</tr>
<tr>
<td></td>
<td>• Helps manage stool consistency and frequency</td>
</tr>
</tbody>
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Prebiotic Fiber

• Food ingredients that selectively stimulate a limited number of bacterial species for the benefit of the host
  • Resistance to upper GI digestion
  • Selectivity of fermentation
    • Promotes growth of beneficial bacteria in colon
  • Production of the SCFA butyrate
Prebiotic Fiber

• Supports colonic health
• Association w/improved cardiovascular health
• Supports bone health
  • can increase uptake and deposition of minerals (calcium/magnesium) into the bone
• Anti-inflammatory effects
  • Production of SCFA has anti-inflammatory effect in colon

Insoluble Fiber

• Common types:
  • Cellulose
  • Hemicellulose
  • Lignin

• Poorly fermentable

• Key functions
  • Promotes more favorable stool consistency
Nutritional Management of Constipation

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

• Evaluation the nutritional needs of these patients is complex:
  • Impaired nutritional status can affect health, healthcare cost and quality of life
  • Issues can include malnutrition, GE reflux and oral motor dysfunction
  • Standard growth charts and alternative anthropometric measurements are recommended as part of nutritional assessment for this population

• EN is indicated in many of these patients
  • Lower energy density formula, whey-based formulas or energy dense formulas with fiber or may be recommended for some
  • Protein adequacy is important to support LBM

• Nutrition-related issues can include:
  • Delayed GE, impaired motility, feeding intolerance: protein source may influence
  • Osteoporosis: supplementation and bisphosphonates to manage
  • Constipation: fiber/prebiotics and additional fluid can be beneficial
Questions?

Nutrition-related resources and tools are available from Nestlé Nutrition Institute: www.nestlenutrition-institute.org

Visit the New and improved MyCE site at MyCEeducation.com
Offering CE to dietitians and nurses