Specific nutritional care in children

Maintaining good nutritional status in cerebral palsy

J. Hulst (NL)
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<th>Role</th>
<th>No relevant conflicts of interest to declare</th>
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Learning objectives

- Know and recognize the nutritional disorders in children with cerebral palsy
- Be aware of possible interventions to correct these disorders
- Know how to assess nutritional status in children with CP
CP – Gross Motor Functioning Classification Scale

GMFCS Level I

GMFCS Level II

GMFCS Level III

GMFCS Level IV

GMFCS Level V

Heterogeneous group
CP – type

Heterogeneous group
The problem CP

- Number of patients with CP is rising
- US 100,000 children
- Approx 90% of children survive into adulthood
- Life expectancy related to gross motor function and feeding


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 gastrooesophageal reflux disease, constipation and dysphagia are also very frequent in this population and impact quality of life and nutritional status. There is currently a lack of a systematic approach to the care of these patients. With this report, ESPGHAN aims to develop uniform guidelines for the management of the gastroenterological and nutritional problems in neurologically impaired children.

METHODS: Thirty-one clinical questions addressing the diagnosis, treatment, and prognosis of common gastrointestinal and nutritional problems in neurologically impaired children were formulated. Questions aimed to assess: 1) the nutritional management including nutritional status, identifying undernutrition, monitoring nutritional status, and defining nutritional requirements; 2) to classify gastrointestinal issues including oropharyngeal dysfunctions, motor and sensory function, gastroesophageal reflux disease, and constipation; 3) to evaluate the indications for nutritional rehabilitation including enteral feeding and percutaneous gastrostomy/jejunostomy; 4) to define indications for surgical interventions (e.g. Nissen Fundoplication, oesophago-gastric disconnection) and finally 5) 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 two 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.
Background

- 30-85% of children with CP have feeding and swallowing problems (depending on GMFCS)

  • Spectrum of associated clinical conditions:
    - Respiratory infections
    - GE reflux
    - Chronic aspiration

Result:
Inadequate intake => short and long term effects

Reilly and Skuse 1994
Dahlseng et al Dev Med Child Neurol 2012
Background (2)

Associated with

- Undernutrition
- Growth failure
- Poor bone health
- Micronutrient deficiencies

Goals of the management:

- Maintain good nutritional status
- Improve quality of life for both the child and family
Prevalence of undernutrition

North American Growth in Cerebral Palsy Project

- 66% stunted
- 44% low fat store
- Correlates with CP severity
Consequences of undernutrition

- ▼ Cerebral function
  - Reduced potential
  - Reduced responsivity
  - Withdrawal/irritability

- ▼ Immune function
  - ▲ Infection (chest, UTI)

- ▼ Circulation time
  - ▼ Healing (esp. pressure sores)

- ▼ Respiratory muscle strength
  - Weak cough
  - More chest infections

- Micronutrient deficiencies
- Growth failure
More consequences.....

Undernutrition/low fat stores in NI children

- ↑ hospital admissions and doctor’s visits
- ↓ participation in school activity and family activities
- ↓ quality of life

Stevenson RD et al. Pediatrics 2006;118(3):1010
Multiple reasons for inadequate intake can be present in children with CP

Parental stress
- Parent-child interaction
- Family relationships

Poor general health
- Respiratory illness
- Hospital admissions

Developmental profile
- Gross and fine motor ability
- Cognitive ability
- Receptive and expressive language delay
- Social communication difficulties
- Visual impairment

Gastrointestinal problems
- Gastro-oesophageal reflux
- Delayed gastric emptying
- Chronic constipation

Oro-motor dysfunction
- Jaw instability, thrust and retraction
- Over-bite
- Tonic biting
- Abnormalities of tone in lips, cheek and tongue
- Tongue thrust
- Poor tongue laterisation

Inappropriate seating
- Poor truncal support
- Sub-optimal head position

Neurological impairment
- Reduced mobility level
- Abnormal muscle tone, spasm, contracture
- Head control
- Movement control/dystonia
- Uncoordinated swallow

Pain
- Gastro-oesophageal reflux
- Constipation
- Uncomfortable seating

Environmental factors
- Distracting visual/auditory stimuli
- Limited communication opportunities

Sub-optimal fat deposition
- Decreased triceps skinfold thickness

Poor growth
- Weight
- Height
- Head circumference

Behavioural and emotional factors
- Fear, sensory issues, negative past feeding experiences
- Frustration

Andrew, Parr, Sullivan, ADC 2011
Oral motor dysfunction & feeding inefficiency

- Oro-pharyngeal incoordination
  - Slow rate of feeding
  - Prolonged feeding times
  - Spillage (>50%)
  - Unsafe swallow

- Vomiting
- Early satiety
- Behaviour disturbance
  - Food refusal
Other problems contributing to feeding difficulties

- Visual or other sensory impairments
- Dental problems (up to 90%)

María Teresa Abeleira, et al
Orthodontic Treatment in Children with Cerebral Palsy, 2016
IDENTIFY UNDERLYING CAUSES IN ORDER TO GIVE AN OPTIMAL INDIVIDUALIZED NUTRITION ADVICE
How to approach nutritional management in NI children?

ESPGHAN WG suggests that nutritional evaluation and management should be performed by a **multidisciplinary team** ideally including a physician, dietitian, nurse, speech therapist, physical therapist, psychologist and occupational therapist (LoE Moderate, GoR strong)
Multidisciplinary assessment

• Consider oropharyngeal dysfunction in all children with CP even when no obvious clinical signs are present

• Assessment of comorbidity

• Assessment of eating, drinking and swallowing difficulties

⇒ Necessary for deciding route and type of feeding

• NICE guideline, Cerebral palsy in under 25s: assessment and management, 25-1-2017
• ESPGHAN guidelines 2017, submitted
Multidisciplinary assessment (2)

• Determine safety, efficiency and enjoyment of eating and drinking

1. Taking a relevant history

2. Observation in a normal mealtime setting
   - oral resistance?
   - lack of energy and endurance to do the work of eating?
   - Any oral-motor disabilities present?

NICE guideline, Cerebral palsy in under 25s: assessment and management, 25-1-2017
Multidisciplinary assessment (3)

- Sometimes additional investigations needed
  - e.g. Videofluoroscopy or fibroscopic endoscopy in specialized center

  Oral-motor function
  Poor lingual function
  Delayed swallow reflex
  Poor pharyngeal peristalsis

  Swallow safety
  aspiration
  penetration

*NICE guideline, Cerebral palsy in under 25s: assessment and management, 25-1-2017*
Actual involvement of health care professionals

Study Sullivan et al. Dev Med Child Neurol 2000

• Oxford feeding study (n=271):
  • nearly 2/3 of caregivers reported that their child had never had feeding and nutritional status assessed
  • Only 17% of children had contact with dietician in previous 12 months
  • Only 27% speech therapist
  • Only 17% occupational therapist
Assessment of nutritional status
Predictors of nutritional status: I. Growth

- Growth = sensitive indicator of whether energy needs are being met
- CP specific charts – WFA, HFA, BMI-FA
Growth is a sensitive indicator of whether energy needs are being met. CP specific charts – WFA, HFA, BMI - FA.

GMFCS II

GMFCS V
Predictors of nutritional status:

II. Body composition

- Calculation of body fat from 2 skin folds correlates with Fat mass (TBW) \((Stallings 1995)\)

- TSF < 10\(^{th}\) centile identifies 96% of malnourished CP \((Samson-Fang, 2000)\)
Assessment of nutritional status: antropometry

- Weight
  - Difficult to perform
  - Methods: wheelchair scales, sitting and hoist scales
Assessment of nutritional status: antropometry

- Height
- Alternative height measurements – segmental length
- Sliding calipers

Knee-heel length (KH)  Tibia length (TL)

Growth assessment: Segmental Lengths

- Growth charts available for select ages
- Estimated height: \( H = (2.69 \times KH) + 24.2 \)
- Potential errors
  - Extrapolating to other ages
  - Extrapolating to other conditions
  - Calculating growth velocity (combines errors)
  - Calculating BMI (squares the error)
Assessment of nutritional status: anthropometry

Finding a low weight or BMI does not necessarily mean a low fat mass, but can also imply a low muscle mass, but high fat mass

Assess fat and lean mass!

Clinical look: fat deposition?

- Skinfold thickness measurements (SFT)
  - Easy, repeatable
  - More direct measure of body fat
  - Interpretation

- ESPGHAN guidelines 2017
- Samsung-Fang 2000
- Kuperminc et al. Dev Med Child Neurol 2010
SFT in CP

- Altered distribution
- More stored centrally
- May not reflect total body fat

Skinfolds interpretation

Slaughter equation (1988):

\[
\% \text{ Body fat} = 1.21(\text{tsf}+\text{ssf}) - 0.008 \ (\text{tsf}+\text{ssf})^2 - 1.7
\]

CP specific equations (Gurka):

- Overall correction +12.2
- Additional correction for males, severe GMFCS, Black race, Pubertal status

Oeffinger DJ, et al DMCN 2014;56(5):475-8
% BF from SFT with CP specific equations similar to % BF from DEXA

Gurka, MJ et DMCN 2010
Assessment of nutritional status in CP: more than weight (and height)

- Nutritional status should not only be based on weight and height
- SFT measurements should be a routine component of NA
- Include routine measurements of knee height or tibia length to assess linear growth
- CP-specific growth charts should not be used to identify undernutrition
Red flags warning signs of undernutrition in NI children

Identification of undernutrition based on the interpretation of anthropometric data:

- WFA z-score < -2
- TSF thickness < 10th centile for age/sex
- Mid-upper arm fat or muscle area <10th percentile
- Faltering weight and/or failure to thrive
- Physical signs of undernutrition such as decubitus, skin problems, poor peripheral circulation

LoE moderate, GoR strong
Bone health: aspects of nutritional care

- GMFCS IV/V at risk for low serum Vitamin D
- Need 800-1000 IU/day Vitamin D
- Rickets is infrequent, but fracture rate is high (4% annual incidence)
- G-tube feeds may not deliver RDA micro-nutrients

Dietary Considerations in Osteopenia in Tube-Fed Nonambulatory Children with Cerebral Palsy. Duncan et al CLIN PEDIATR 1999 38: 133
- 58% for calcium
- 68% for phosphorous
- 74% for Vitamin D
Assessment of Bone Mineral Density (BMD)

- BMD measurement by DXA difficult in CP:
  - Joint contractures
  - Scoliosis
  - Hip dysplasia
  - Metallic implants
- Can use distal femur for DXA in CP
  - Z scores correlate with fracture history
Monitoring micronutrients and bone health

Recommendations:

Use of DXA scans to measure bone mineral density as part of nutritional assessment in NI children (LoE moderate, GoR weak)

Assessment of micronutrient status (e.g. vitamin D, iron status, calcium, phosphorus) as part of nutritional assessment of NI children (LoE moderate, GoR strong)
How often should nutritional status be monitored?

ESPGHAN WG suggests that NI children have

- anthropometry performed at least every 6 months
- micronutrients checked annually
- Bone health: not mentioned
Nutritional intervention

Principles of nutritional support

- Parenteral nutrition
- Enteral feeding
- Oral nutritional supplements
- Nutritional counseling
Case  Sam, 8 year old boy

- CP after neonatal asphyxia
- GMFCS level IV
- Scoliosis
- Feeds orally, about 45 minutes per meal, total >3h per day
- Worries about nutritional status, referred for gastrostomy placement by pediatrician

⇒ W: - 2.5 SD
⇒ H: not performed
⇒ No deterioration over time
Case Sam

Should we go on with gastrostomy placement or not?
Case  Sam, 8 years old

Low weight

Additional measurements:

- segmental tibia length: -2 SD
- SFT of biceps and triceps: 0 SD on curve of typically developing children

Further assessment

- No serious GI morbidity
- Improvement expected in mealtime duration by optimizing positioning and adjustment of food structure and use of ONS

=> NO GASTROSTOMY, follow-up
Low weight or BMI alone is not enough to decide on start of tube feeding!
A measure of body composition should be taken into account!
In case of feeding problems: early feeding via tube feeding/ gastrostomy does not have to be the first step! Make an individualised plan together with patient/parents
Interventions to improve eating, drinking and swallowing: possible steps (1)

• Modify food and fluid texture and flavours
  • Thickeners
  • Pureeing

• Improve positioning when eating

• Optimize feeding techniques
  • Pacing
  • Spoon placement

NICE guideline, Cerebral palsy in under 25s: assessment and management, 25-1-2017
Interventions to improve eating, drinking and swallowing: possible steps (2)

- Use of specialized feeding equipment
- Strategies for developing oral motor skills => improve function of lips, cheeks, tongue and pharynx
- Optimise mealtime environment
- Implement strategies for managing behavioural problems & communication
- Train people involved in the care of the child

*NICE guideline, Cerebral palsy in under 25s: assessment and management, 25-1-2017
Bell KL J Clin Nutr 2013*
Interventions to improve eating, drinking and swallowing: possible steps (3)

- Increase of energy content of oral feeding: additional fat/oils, dry milk powders
- ONS
Route of feeding

- Adequate Oral Motor Skills & Low Risk of Aspiration?
  - Yes: Oral Feeding
  - No: Enteral Tube Feeding
    - Short Duration of Feeding
      - Yes: Nasogastric or Nasojejunal Tube
      - No: Gastrostomy Tube

- Adequate Weight Gain, or Linear Growth, or Time to Feed
Important

Consider enteral tube feeding before the development of undernutrition
Gastrostomy in CP

PREVALENCE of gastrostomy placement, N = 1295

- Study in 6 countries, GMFCS level IV and V

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<td></td>
<td>n</td>
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Wide variation!  

Dahlseng et al Dev Med Child Neurol 2012
Outcomes of EN

Enteral feeding leads to increase in:

- Weight
- Weight-for-Height
- Muscle and fat
- Peripheral circulation
- Immune function
- Cognitive ability
- General well-being
- Improved caregiver QoL
Why decision for gastrostomy-tube placement should be taken carefully....
Invasive procedure with minor and major complications

- Granulation tissue
- Site infections
- Tube migration
- Buried bumper
Overfeeding risk

- Immobile children with CP have low physical activity
- G-tube feeding with high calorie feeds can lead to obesity
‘Apart from the actual bearing and suckling of children, there is no act which better epitomises the maternal role than the preparation and serving of food’

Newson & Newson, 1970
G-TUBE: DECISION MAKING

- Based on net balance between advantages and disadvantages
- In order to promote best interest of individual patient
- Emotionally difficult for parents due to negative caregiver perceptions – fears

Espghan guideline, 2017
Time should be taken to inform and educate parents and to help them in decision making
Nutritional advice CP: calorie and protein intake

- Use dietary reference standards for typically developing children in the absence of validated energy requirements; recognise that these may overestimate energy needs.

- Regular monitoring of body weight and fat mass provides the best indicator of energy requirements

- Use the dietary reference intake for protein in typically developing children
  - Supplementary protein intake in specific clinical situations e.g. decubitus ulcers or children with a very low calorie requirement
Goal of nutritional intervention

- Reach possible growth potential considering underlying disease
- Avoidance of obesity
- Aim for:
  - Weight at 50th centile WFH for children with normal activity
  - Weight at 25th centile WFH for wheel-chair bound children
  - Weight at 10th centile WFH for bedridden children

What feed to use?

- **Infants**: human milk, standard infant formula or nutrient dense infant enteral formula as clinically indicated

- **Over 1 year**: standard (1.0 kcal/mL) polymeric age-appropriate formula + fibre

- **Poor volume tolerance**: high-energy density formula (1.5 kcal/ml) + fibre

- **Maintenance of enteral tube feeding after nutritional rehabilitation in immobile NI children**: low-fat, low-calorie, high fibre, and micronutrient replete formula.

- **GOR, gagging and retching**: try whey-based formula
Take home messages

- High prevalence of undernutrition, growth impairment, poor BMD and micronutrient deficiencies
- Monitoring of nutritional status and growth is essential in children with CP
- Nutritional care for children with CP should take place in a multidisciplinary team
- Consider enteral tube feeding before undernutrition occurs
- Gastrostomy feeding is the preferred route for long term EN
- Involve parents in the decision making about gastrostomy
Thank you for your attention!

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Home diets

- ESPGHAN recommends caution if pureed food is used for enteral tube feeding in NI children
  - nutritional adequacy and safety

- BDA does not recommend the administration of liquidised food via enteral feeding tube
  - risk to nutritional adequacy
  - feeding tube blockage
  - risk of gastric infection.
  - risks to infants aged <6 mo
  - jejunal fed patients
Hydration

Careful attention be paid to hydration status, as NI children are at risk of dehydration for a variety of reasons:

- Inability to communicate thirst
- Drooling
- Unsafe swallow