Nutritional Assessment of Children with Medical Complexity

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SickKids®

I (we) would like to begin by acknowledging the land on which SickKids operates. For thousands of years it has been the traditional land of the Huron-Wendat and Petun First Nations, the Seneca, and most recently, the Mississaugas of the Credit River. Today, Toronto is home to Indigenous Peoples from across Turtle Island. SickKids is committed to working toward new relationships that include First Nations, Inuit, and Métis peoples, and is grateful for the opportunity to share this land in caring for children and their families.

Art by Emily Kewageshig

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Outline: Assessment of Children with Medical Complexity

- Who are Children with Medical Complexity (CMC)?
- Nutritional Assessment:
  - Anthropometrics
  - Feeding disorders
  - Nutritional requirements
  - Biochemical assessment
  - Bone health

Children with Medical Complexity (CMC)

Individuals with:

- Presence of ≥1 complex chronic conditions; often multisystem & severe
- Significant functional limitation requiring technology (e.g. feeding tube)
- High health care utilization from different providers
- Caregiver identified high health care service needs

Account for <1% of all children but significant health-spending

Dewan & Cohen, 2013

Children with Medical Complexity: GI/Nutrition Sequale

Chronic problems in 80-90% of children with CP or other neurological impairments (NI) include:

- Malnutrition
- Feeding disorders
- Gastroesophageal Reflux Disease (GERD)
- Constipation
- Delayed gastric emptying
- Diarrhea

Chong, 2001; Marchand et al., 2006; Sullivan, 2008; Penagini et al., 2015

Gastrointestinal Issues: Symptoms

GI Issue	Symptoms affecting oral feeding
GERD	Pain or discomfort part way through feeds Feeds well at beginning of feed but limits intake Vomiting may or may not be seen
Delayed Gastric Emptying	Decreased hunger Nausea, Gagging Vomiting- sometimes hours after a feed
Constipation	Decreased hunger Nausea, Gagging Vomiting Abdominal pain
Diarrhea	Malabsorption Dehydration

Marcus & Breton, 2013

Nutritional Assessment of CMC

Anthropometrics

- Head circumference (birth to 24 months)
- Weight
- Recumbent length (<2 years) & height (>2 years if ambulatory)
- Segmental length
- Weight-for-Height z-scores (WHZ)
- Body Mass Index (BMI)
- Mid-arm circumference, triceps skinfold, mid-arm muscle mass

Nutritional Assessment of CMC

Segmental Measurements

- Techniques available for estimating stature from segmental measurements
  - Knee height
  - Upper-arm length
  - Tibial length
- Measurements should be made by trained practitioners who understand methods & limitations
- Some require specialized equipment

Academy of Nutrition and Dietetics, 2016

Equations for estimation of stature from segmental measures in children with CP (birth-12 years)

Segmental Measure	Equation to estimate stature (S) (cm)
Upper arm length, UAL*	S = (4.35 x UAL) + 21.8
Tibial length, TL	S = (3.26 x TL) + 30.8
Knee height, KH*	S = (2.69 x KH) +24.2

*Requires special equipment

Samson-Fang & Bell, 2013

Nutritional Assessment of CMC

Weight-for-Height z-scores (WHZ)

- Z-scores provide more meaningful context to growth and nutritional status than percentiles in all children

- WHZ can be used in children under 5yo;
  - WHO reference ranges available online
    - Weight-for-length/height (who.int)

- WHZ ≤ -3 indicates severe wasting

Nutritional Assessment of CMC

Body Mass Index (BMI)

- In neurotypical children BMI can be considered an alternative to direct measure of body fat
- Validity in children with CMC is questionable as there are differences in body composition
  - Altered bone mass
  - Altered muscle mass
- Use of predictive equations to determine height should not be used in calculating BMI

Academy of Nutrition and Dietetics, 2016

Samson-Fang & Bell, 2013

Nutritional Assessment of CMC

Skinfold Measurements

- Standard methods for measurement
  - Triceps
  - Subscapular
- Mid-arm circumference, mid-arm muscle mass
- Reference data available based on healthy children
- Interpret with caution
  - Children with NI may store fat centrally with low adipose deposits peripherally

Academy of Nutrition and Dietetics, 2016

Nutritional Assessment of CMC

Growth Charts

- ESPGHAN recommends using WHO growth curves
- Previously it was recommended to use both the WHO growth curves in conjunction with disease-specific growth charts when available
- Disease-specific curves are growth *references* with limitations
  - Small sample size
  - May be based on children already suffering from malnutrition

ESPGHAN, 2017

Feeding Disorders

- Heterogeneous set of problems characterized by:
  - Food refusal
  - Inadequate caloric/nutritional intake
  - Oral-motor deficits
  - Swallowing dysfunction
  - Gastrointestinal issues
  - Growth failure
  - Behavioral issues

- Causes may be complex & multi-factorial (medical-behavioral)

Lefton-Greif, 2008; Marcus & Breton, 2013;

Miller, 2011; Penagini et al, 2015; Silverman 2010

Feeding Disorders

Common Etiologies Associated with Feeding Disorders:

- Prematurity
- Neurologic disease
- Gastrointestinal Issues
- Genetic syndromes
- Cardiac anomalies
- Respiratory conditions
- Anatomical anomalies
- Psychosocial/behavioral

Lefton-Greif, 2008; Miller 2011; Tutor & Gosa, 2012

Oral-Motor Issues

- Poor oral motor control
  - ⬇ intake
  - ⬆ aspiration risk
- Liquids are difficult to manage
  - Loss of liquid from front of mouth
  - Premature escape of bolus into oro-pharynx ⍰ aspiration risk
  - Often better with bottle feeding
- Purees easier to manage
- Immature chewing skills
  - Oral motor skills correlate with developmental level & not chronological age

Marcus & Breton , 2013

Clinical Signs of Swallowing Issues

- Coughing/choking with oral feeds
- Change in voice quality during oral feeds
- Poor secretion management
- Sudden, significant drop in oxygen saturation with oral feeds
- Sudden, significant drop in heart rate with oral feeds
- Resistance to oral feeding
- Recurrent chest infections
- Recurrent unexplained fevers

Is aspiration from above or below?

Marcus & Breton, 2013; Miller, 2011; Tutor & Gosa, 2012

Behavioural or Physiological?

- Is it behaviour or an adaptive response?
- Feeding refusal is usually related to underlying physiological issue
- Can become an aversion with repeated negative experiences
- Behavioural issue/aversion cannot be addressed until underlying physiological issue is resolved

Nutritional Requirements of CMC

Altered Energy Needs

- Spastic CP may grow with average energy as low as 60-70% of Dietary Reference Intake (DRI)

- Most children with NI have **decreased energy needs** compared to healthy children, even with spasticity

- Total Energy Expenditure is affected by
  - Type of neurological involvement
  - Muscle tone (spasticity or hypotonia)
  - Activity level (non-ambulatory versus ambulatory)

Marchand et. al, 2009

Nutritional Requirements of CMC

Estimating Energy Needs

- Recommended use of WHO equation and an activity factor of 1.1 x Resting Energy Expenditure (REE)
- Use the following equations to determine REE*

Age Range (years)	Males (kcal/d)	Females (kcal/d)
0 – 3	60.9W – 54	61.0W - 51
3 – 10	22.7W + 495	22.5W + 499
10 – 18	17.5W + 651	12.2W + 746

*Use as a starting point and titrate feeds based on weight response

World Health Organization, 1985; Marchand, 2009

Nutritional Requirements of CMC

Fluids

- Usual maintenance requirements may not be appropriate
- ⬆ requirements due to excessive losses
  - Drooling
  - ++ Sweating
- ⬇ requirements for patients with inactivity and muscle wasting
- Typically, 75-100% of maintenance may be adequate and can be adjusted based on clinical status

Nutritional Requirements of CMC

Protein

Patients are at risk for protein insufficiency

- Are often already protein-wasted, due to inactivity and poor dietary intake
- Low energy requirements/intake = low protein intake
- Are at high risk for pressure ulcers, already have them
  - Inflammatory sequelae

Nutritional Requirements of CMC

Protein

- No guidelines have been developed for protein requirements in children with disabilities

- Start with an estimation using the RDA/DRI
  - US National Pressure Ulcer Advisory Panel recommends (adults):
    1.25 – 1.5 g/kg

- Consider using high-protein formula
  - Higher-protein and adult formulas
  - Combination of adult & pediatric formulas
  - Addition of protein modules

Nutritional Requirements of CMC

Micronutrients

- Prevalence of micronutrient deficiencies between 10-55%
- High risk for deficiencies of:
  - Iron
  - Zinc
  - Copper
  - Vitamin D
  - Carnitine
  - Folic Acid
  - Vitamin B12

- Recommendation to provide DRI for micronutrients

ESPGHAN, 2017

Lab Markers for Nutrition Assessment of CMC

- Urea, creatinine, electrolytes & glucose
- CBC, hemoglobin, mean corpuscular volume, ferritin, iron
- Calcium, magnesium, phosphate
- Albumin or total protein
- Liver enzymes
- Vitamins A, B12, D, E, folic acid
- PTH
- Zinc
- **C-Reactive Protein (CRP)**

ESPGHAN, 2017

Lab Markers for Nutrition Assessment of CMC

Children on long-term jejunal feeds:

- Asses 1-2 times/year:
  - Serum Cu + ceruloplasmin
  - Selenium
  - CBC+MCV/ferritin/STR/iron
  - Zinc
  - CRP
  - Albumin

Broekaert et al., 2019

Bone Health in CMC

- Decreased bone mineral density noted in ~60% of children with NI
- Fragility fracture prevalence: 20% in non-ambulatory children with CP
- Dietary Ca, PO4, Vitamin D are below DRI in 50-80% of children with NI
- Risk Factors:
  - Limited ambulation
  - Increased anticonvulsant therapy
  - Limited sun exposure
  - Prematurity
  - Long term PPI use
  - Underlying condition, co-morbidities

Coppoloa et al., 2009; Fehlings et al., 2011; Marchand et al., 2009

Bone Health in CMC

- Yearly labs
  - Ionized Ca, PO4, 25-OHD, PTH, ALP, urinary calcium/creatinine ratio
- Supplement Ca intake to DRI
  - Monitor for complications (nephrocalcinosis/stones)
- Supplement 800-1000 IU of Vitamin D per day

Fehlings et al., 2011

Nutritional Assessment of Medically Complex Children with Neurological Impairment

1) What are their underlying issues? For example, what is the medical diagnosis? GERD? Developmental age/feeding ability

2) **Growth History**
   a. Weight change velocity (g/day) compared to normal
   b. Growth curve
      - Proportionate weight/length
      - Use disease-specific growth charts in conjunction with WHO curves when possible
   c. Alternative methods of measuring anthropometrics
      - Knee-height
      - Tibia length
      - Upper arm span
      - Skinfolds
   d. Consider WHZ in children under the age of 5 years
   e. Recognize that children with neurological impairment grow differently than children without neurological impairment

3) **Nutrition Requirements**
   a. Fluid
      - Often adequate with 75-100% X maintenance
      - Consider insensible losses (e.g. sweating, drooling)
   b. Energy
      - Often adequately provided by 0.9-1.1 x REE calculated by WHO equation
      - Safely titrate energy up or down by 10% to affect change

WHO Equation for calculating REE:

Age Range (years)	Males (kcal/d)	Females (kcal/d)
0 – 3	60.9W – 54	61.0W - 51
3 – 10	22.7W + 495	22.5W + 499
10 – 18	17.5W + 651	12.2W + 746

*W=weight in kg

   c. Protein
      - Minimum DRI for age
      - Optimally aim for 1.25-1.5 g/kg/day
      - May need to use modules to meet requirements
   d. Micronutrients
      - Use the DRI for age for micronutrients
      - 800-1000 IU per day vitamin D for non-ambulatory patients
      - Use bloodwork to ensure adequate intake

4) **Ins/Outs**
   a. Emesis
      - Can inform you about GERD symptoms, prompt need for formula, schedule, or tube type change
   b. Stool
      - Constipation can impact feed tolerance
      - Loose stools may suggest malabsorption
   c. Urine output
      - Can indicate hydration status (aim for 4-6 wet diapers per day)

5) **Supplements/Medications**

6) **Bloodwork**
   a. Bone health labs should be monitored yearly
   b. Other micronutrient labs should be considered annually depending on tube and intake

7) **Recommendations**

Stay Tuned…

- Join us for the next core competency on reccommendations to manage nutrition in children with medical complexity

September 7th, 2023

ESPGHAN, 2017; Johnson et al, 2015; Soscia, 2021; Gallagher et al, 2018

Recommended Reading:

SOCIETY PAPER

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

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