Feeding and Nutritional Challenges for Young Children with Chronic Illness

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Goals of Nutrition in the Care of Children with Chronic Illness

The child will achieve and maintain:

- A safe and efficient means of nutrition support
- Ideal body weight
- Kcal/protein/nutrient/fluid intake to satisfy needs

Family/caregivers will:

- Identify and access appropriate resources
- Demonstrate knowledge and skills to comply with team recommendations

Community caregivers will:

- Participate collaboratively in coordination of care
Chronic Diseases of Childhood

Asthma
Cystic Fibrosis
Diabetes
Obesity and Overweight
Malnutrition
Developmental disabilities
Cerebral Palsy
Consequences of low birth weight and prematurity
Mental illness
Pediatric Feeding Disorders

Include a wide range of problems that interfere with normal eating activities and result in inadequate caloric or nutritional intake, resulting in compromise of the child’s growth and development.
Incidence of Pediatric Feeding Disorders

25-35% in typically developing children
33-80% in children with developmental delay

Feeding disorders are complex and most feeding problems have a combination of physiological and environmental or emotional causes

Severe feeding problems are noted:

- Children: 3-10%
- Children w physical disabilities: 26-90%
- Children w medical illness/prematurity: 10-49%
Factors Related to Feeding Problems

Structural/Anatomic Abnormalities
   TE Fistula, esophageal atresia, strictures, etc.

Physiologic abnormalities
   GI motility problems, GERD, dumping syndrome, short gut syndrome, etc.

Neurological Conditions
   CP, ID/dev delay, cranial nerve dysfunction, musculoskeletal disorder, ASD,

Behavioral Issues
   Psychosocial difficulties, negative feeding behaviors, rumination, emotionally based difficulties (phobias, depression, conditioned emotional reactions, etc.)
Factors Related to Feeding Problems

Cardiorespiratory Problems
Metabolic dysfunction
  genetic and metabolic syndromes

Gastrointestinal conditions
  GI medical conditions
  food allergy, celiac disease, hereditary fructose intolerance

General Medical Conditions
  prolonged hospital stays (ICU), lung disease, cancer, renal, skin disease

Oral motor dysfunction
  oropharyngeal dysphagia, cleft palate, Pierre-Robin sequence, dev delay
Factors Related to Feeding Problems
Kidney Disease

Altered/Decreased taste sensitivity
- Accumulation of uremic toxins
- Micronutrient deficiencies (Zn)
- Decreased number of taste buds

Reduce appetite and oral intake
- GER/emesis
- Uremic anorexia
- Unpalatable diet due to restrictions of sodium, potassium and phosphorus
The Team Approach

Pediatric Feeding Problems are bio-behavioral conditions in which biological and behavioral aspects mutually interact, and both need to be addressed to achieve normal feeding.

Most children have a behavioral component to their complex feeding problem, regardless of concurrent physical factors.

Understand the needs of the child as a whole and in the context of his family.
The Team Approach

We all wear many hats .... sometimes simultaneously!

Medicine: Physician and Nurse
Oral Motor: OT and SLP
Behavior Psychology
Nutrition
Social Work

Decide what information to gather and how best to share it so that it is meaningful to all team members
The Team: Medicine

Medical stability
Reflux/Emesis
Constipation
Medications
Other medical conditions and complications
The Team: Oral Motor Therapist

Occupational and Speech Therapist

Assure child’s safety for eating and drinking by mouth
Recommend appropriate drink and solid texture consistencies
Offer input about oral intake target, based on the child’s oral motor status
Recommend safe bolus size and drink presentation
Suggest therapeutic feeding techniques
Monitor swallowing skills and safety during meals throughout the admission
Perform MBS when needed
The Team: Behavior Psychology

Why Don’t They Eat?

- Condition aversion
- Lack of experience
- Lack of appetite
- Hypersensitivity
- Reinforcement of behavior incompatible with feeding
Psychosocial Impact on the Family

Parental depression or anxiety
Marital stress
Helplessness/hopelessness
Negative communication patterns between the parents/child, in/out of mealtimes
Sibling jealousy
Financial stress
The Team : Nutrition

Meeting the Nutrition Needs of the Team

Establish appropriate volumes and portion sizes for meals

Adjustment of tube feeding schedules to optimize oral feeding sessions

Determine appropriate use of kcalorie boosters and supplements

Ensure that the team is educated on meeting special needs of each patient (allergies, metabolic disorders, etc.)
The Team : Nutrition

Meeting the Nutrition Needs of the Family

Provide nutrition education to enable the family to meet the nutritional needs of their child
Aid the family in establishing a feeding schedule which takes into consideration their home, school, and therapy needs
Instruct the family about age-appropriate portion sizes and menu planning
Assist families in obtaining community resources
Nutritional Considerations

A B C’s
Anthropometry
Biochemical
Clinical
Dietary
Eating Habits
Anthropometry

GROWTH!

Utilize WT/HT or BMI (z-scores)

Goals should be aimed at maintaining adequate fat and muscle stores to endure illness or surgery while facilitating daily physical care and management

- Age
- Actual versus expected rate of growth
- Use population specific data if available
- Analysis of longitudinal points
- Adequacy of fat and muscle stores
- Daily physical care and management
- Level of physical dependence
Brain Growth/Development

By 2 years of age, the brain is about 80% of the adult size.

By 6 years of age, 95% of the brain volume has been achieved

The pre-school years (i.e., 1–5 years of age) are a time of rapid and dramatic postnatal brain development, i.e., neural plasticity, and of fundamental acquisition of cognitive development i.e., working memory, attention and inhibitory control.

Also, it is a time of transition from a direct maternal mediation/selection of diet-based nutrition to food selection that is more based on self-selection and self-gratification
Growth in Chronic Kidney Disease

Protein-Energy Malnutrition
Salt Wasting
Renal Osteodystrophy
Corticosteroids
Acidosis
Decreased expression of growth hormone receptor
Impaired signal transduction of the GH receptor
Decreased production of IGF-1
Decreased activity of IGF
Biochemical

Nutrient Needs

Fluid Needs

Electrolytes

Lab values
Clinical

Associated deficits
Vomiting/reflux
Dysphagia/oral motor dysfunction
Muscle tone and positioning
Influence of repeated illnesses
Dehydration
Bowel habits – treat constipation
Dietary

Texture
Liquids
Energy Needs
Food Allergies
Tube Feedings
Food selectivity/refusal
Eating Habits

Feeding Skills and safety

Social Environment

Access to community resources

Psychosocial implications
General Mealtime Strategies for Families

Set a feeding schedule and routine
Limit length of mealtimes
Avoid all day grazing/snacking
Have family members model good eating behavior
Involve the child in meal preparation
Reinforce positive eating behavior
Begin with small portions and serve with preferred foods
Treatment
Behavioral Strategies during
Intensive Feeding Program

Texture/Bite Fading
Non-removal of spoon
Physical guidance
Reinforcement
Representation
Bite placement
Modeling
Self-monitoring
Exposure
Treatment
Approaches to Maximize Nutritional Intake

Provide appropriate texture, solid and liquid, for skill level

Provide small frequent meals if indicated

Provide jaw control, other facilitative techniques, and adaptive equipment to improve oral-motor function

Provide a consistent, conducive environment for meal time

Optimize positioning

Kcalorie Boosters

Multivitamin/mineral supplementation

Provide supplemental tube feedings if necessary
Treatment
Tube Feedings

Why Tube Feed?
Poor growth
Protection of airway
Inability to consume adequate calories
Hypermetabolism
Abnormal GI tract

Choice of Tube
NG for short term (less than 2-3 months), ability of care giver to pass tube
GT for long term, with or without Nissen fundoplication
Duodenal or jejunal feedings
Treatment
Tube Feedings

Schedule

- Continuous overnight
- Daytime bolus feedings with or right after oral meals
- Combination

Avoid overfeeding which will suppress appetite

Weaning

- Pre-emptive tube cuts for those who are well nourished
- Set goal volume at meal, provide remaining food via g-tube
Benefits of Nutritional Intervention

The child has the strength and endurance to fully participate in therapy programs

Allows for achievement of optimal growth potential

Improved health with decreased episodes of illness

Reduced stress on the family
Case Study

Sent: Wednesday, February 25, 2015 10:02 PM

To: Miller, Patricia

Subject: 100% again!

Ok, I promise I'm not going to email you every time Casey goes a whole day without a tube feed but I think this is worth mentioning.

Today she had scrambled eggs with feta and cantaloupe for breakfast. She enjoyed it so much that she asked for more. She ate TWO eggs (egg whites with a drop of yolk), two tbsp of feta, and two small servings of cantaloupe!

For lunch she had a tiny turkey wrap (3") with mustard and mayo, half of a Cheez It, 3/4 of a Nilla wafer, and 4 blueberries as an afterthought.

I'm telling you all this in great detail because THIS IS NORMAL EATING!!! These are normal foods that a toddler should be able to bite and chew and swallow...and she's biting and chewing and swallowing them! It's jaw-dropping!

Over the course of the rest of the day she had a fruit pouch, 4 oz of yogurt, some freeze dried yogurt fruit bites, and garden pasta bake for supper. She chowed down on penne, carrots, zucchini, and tomatoes!

I've emailed her nephrologist to ask for a lab slip because we have no idea how her kidneys will tolerate the electrolytes and we're probably going to have to do frequent labs for a while until we figure out a diet that works for her, but what a wonderful problem to have!!!

Please feel free to use this email and the attached photo when working with families of children like Casey. I never thought we'd see the day. :')