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

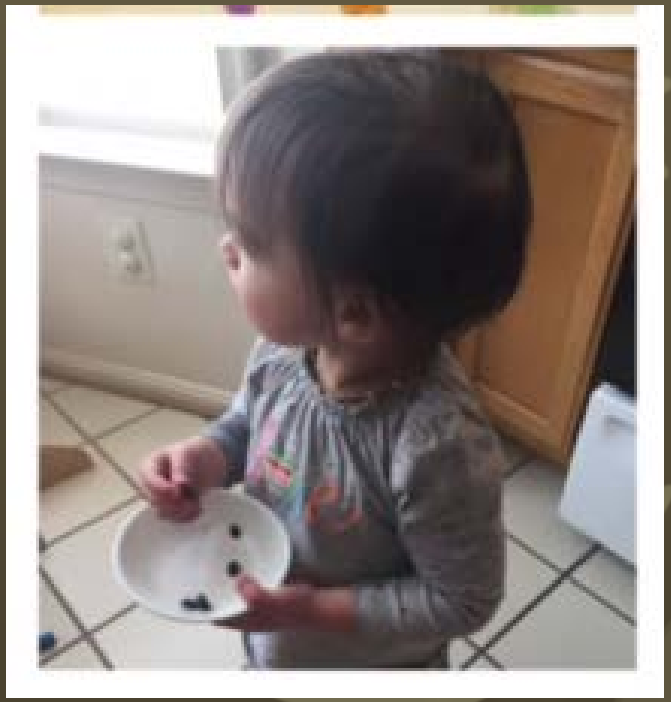
Reflux/Emesis

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

The Team : Social Work

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

Anthropometry

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

Treatment
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

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. :')