

Nutrition for Children with Special Health Care Needs

Module 2: Dietary Intake and Determining Individual Needs

Pre Test

This Pre Test contains 8 multiple-choice questions. It is intended to provide you with some information about material that might require particular attention.

QUESTION 1

What is one LIMITATION of using a food frequency questionnaire to collect information about a child's intake?

- a. it is time-consuming to administer
- b. it often underestimates a child's intake
- c. it does not quantify a child's usual daily intake
- d. the person completing the questionnaire must be highly trained

QUESTION 2

What is one STRENGTH of using a diet history to collect information about a child's intake?

- a. it can provide information about the mealtime environment
- b. it is not time consuming
- c. it does not require much input from parents and caregivers
- d. it provides an accurate estimate of a child's intake

QUESTION 3

TRUE or FALSE: If a child's iron intake is less than the RDA for age, it probably indicates a deficiency.

- a. TRUE
- b. FALSE

QUESTION 4

TRUE or FALSE: The DRIs/RDAs are not useful for children with special health care needs because they are based on data from healthy individuals.

- a. TRUE
- b. FALSE

QUESTION 5

Children with cerebral palsy are often underweight. This is because cerebral palsy:

- a. causes increased energy needs
- b. is often associated with conditions that interfere with an adequate intake

- c. generally predisposes people to being underweight
- d. causes decreased energy needs because of ambulation problems

QUESTION 6

Why is it important to gather information about a child's medication regimen when evaluating his or her intake?

- a. because the child may be receiving inappropriate medications
- b. because complex medication schedules may interfere with mealtimes
- c. because the side effects of some medications can affect appetite
- d. b & c
- e. all of the above

QUESTION 7

You are evaluating 3-year old Sally's food pattern. Her mother describes a typical lunch (see below). Which of the items is inappropriate?

- a. 1/2 sandwich with 1 slice of bread and 3/4 ounce cheese
- b. 1/3 medium banana
- c. 1 small cookie
- d. 16 ounces calcium-fortified orange juice

QUESTION 8

The correct answer to the previous question was d. 16 ounces calcium-fortified orange juice. Why was this inappropriate for 3-year old Sally?

- a. there is no need for Sally to consume calcium-fortified orange juice
- b. 16 ounces of orange juice is an excessive portion for a 3-year old
- c. children should drink milk with meals
- d. orange juice is more appropriate for older children

Introduction

After completing this module, you will have the skills and resources to:

- Obtain accurate dietary intake data
- Understand the methods used to establish recommendations for nutrient intake
- Identify factors that alter nutrient needs

- Evaluate an individual's dietary data

A comprehensive assessment of nutritional status includes examination of growth (using anthropometry), biochemical parameters, clinical indicators, and dietary intake. This module looks at dietary assessment and the estimation of individual nutrient needs.

The first step in dietary assessment is the collection of accurate dietary intake data. [Section 1, Obtaining Accurate Dietary Intake Data](#) examines tools that are useful for collecting information about a child's intake.

[Section 2, Recommendations for Intake](#) reviews the guidelines that are used to estimate an individual child's nutrient needs. First, the intake recommendations for typically-developing children are reviewed. In [Section 3, Factors Affecting Nutrient Needs](#), the effects that some special health care needs can have on nutrient needs are explored.

Finally, in [Section 4, Evaluating an Individual's Intake](#), you will put the process together and evaluate the nutritional intakes of several individuals.

Section 1: Obtaining Accurate Dietary Intake Data

The first step in dietary assessment is the collection of accurate dietary intake data.

There are a number of methods used to collect information about a client's intake. The next few pages review some of these methods...and list strengths and limitations for each method:

- Diet recall
- Food record
- Diet history
- Food frequency questionnaire
- Multiple-pass recall

Diet Recall

Description

Parents or caregivers describe the types and amounts of food eaten in a specified (usually 24 hours) period. The 24-hour diet recall is often used as a screening tool. Food models, measuring cups, and other visual aids can be useful in helping families to estimate portion sizes.

Strengths

- Can be useful during clinic follow-up to measure adherence to dietary recommendations

Limitations

- May not represent a typical day's intake...so may not accurately describe a child's usual intake
- Families tend to forget about (or be unaware of) foods eaten between meals

Food Record

Description

Parents and caregivers record all foods offered to, and eaten by, their child in a specified (usually 3 or 7 days) period. Information to make the record accurate includes detailed portion sizes and methods of food preparation (e.g., baked, sautéed, steamed). It can also be helpful to have families record the time of day that foods were eaten.

Seven-day records are more representative of a child's usual intake than 3-day records. If 3 days are recorded, include one weekend day. It is important to review the completed food record with caregivers to clarify foods and portion sizes.

Strengths

- Provides prospective data
- In general, a good tool to estimate a child's usual energy intake

Limitations

- Errors in portion size estimation are common
- Foods that are added to other foods (e.g., ketchup, jelly, margarine) are often omitted
- Requires time from the family
- Intake recorded may not reflect child's usual intake

Diet History

Description

Parents and caregivers are interviewed to determine a child's usual intake and feeding history. The clinician asks parents about early feeding history (e.g., breastfeeding, type of formula, problems with feeding, introduction of solids) and about the child's current food pattern.

A diet history can be used in combination with a 24-hour recall, food record, or food frequency questionnaire to obtain a fair picture of a child's nutritional intake. Food models, measuring cups, and other visual aids can be useful in helping families to estimate portion sizes.

Strengths

- Provides information about a child's feeding history
- Includes information about intake, feeding skills, and eating environment

Limitations

- Time-consuming
- Interviewer must gain the confidence of the person providing information and be able to evaluate the accuracy and reliability of the answers
- When a diet history is used alone, a child's intake is often overestimated

Food Frequency Questionnaire

Description

Caregivers complete a questionnaire (usually a checklist) that identifies which foods a child eats and the amount of food consumed in a set amount of time (e.g., a day or a week).

Strengths

- Useful as a screening tool for assessing the intakes of groups of people
- Does not require as much time as a diet history or food record

Limitations

- Often overestimates a child's intake
- Does not quantify a child's usual daily intake
- Does not necessarily provide information about specific foods a child eats

USDA Multiple-pass Recall

Description

This interview method consists of 5 steps; the parent/caregiver: (1) lists foods and beverages consumed, (2) answers a series of questions about “forgotten foods” (e.g., beverages), (3) describes when the foods were consumed, (4) describes the amount of each food consumed using the *Food Model Booklet*, a tool with visual aids, (5) responds to a final probe for any other foods consumed.

Strengths

- Has been validated for assessing the energy intakes of groups of children and adults
- Discussion and use of visual aids are appealing to respondents

Limitations

- Has been shown to over- and under-estimate energy intakes of children
- Time-consuming

In addition to evaluation of a child's nutrient intake, a comprehensive dietary assessment includes examination of feeding skills and the types of foods offered and behaviors, relationships, and attitudes toward food. Feeding skills will be covered in Module 3.

The following questions are often useful for eliciting information about a child's food pattern:

- How often does the infant breastfeed?
- How frequently is the infant/child fed?
- How is formula prepared?
- What is the typical meal pattern?
- How much does he eat at one time?
- What supplements are used (energy, protein, enteral, vitamin, mineral)?
- Does the child have food allergies or intolerances, or are there any food restrictions?

A discussion about behaviors, relationships, and attitudes related to food and eating might be started with these questions:

- What foods are preferred? Disliked?
- Can your child communicate hunger? Thirst?
- Who is present at mealtimes?
- Are mealtimes pleasant?
- Describe your child's appetite.
- Is your child interested in eating?
- Do you think your child is underweight? Overweight?
- Do you think your child eats too much? Too little?

Which tool would you use?

You see a 2-year old in clinic. Her weight-for-length is less than the 5th percentile and you are concerned that her dietary intake is inadequate. What is the BEST way to evaluate her usual intake?

- a. 24-hour diet recall
- b. diet history
- c. both of the above
- d. none of the above

The correct response is c. both of the above. A 24-hour recall will provide information about what the child ate in the previous 24 hours, but may not provide information about what the child usually eats. A complete diet history will provide information about the child's usual intake, as well as information about the mealtime environment and the development of feeding skills, but the BEST answer is c.

Section 2: Methods Used to Establish Recommendations for Nutrient Intake

The second step in evaluating an individual's intake is comparing the intake to what is recommended.

Recommendations for specific nutrient intake levels are typically based on the Dietary Reference Intakes (DRIs) published by the Food and Nutrition Board (FNB) of the Institutes of Medicine, The National Academies.

DRIs are based on data from healthy persons over time. Special health care needs can change an individual's needs for specific nutrients.

Recommended nutrient intake levels for children with special health care needs can be made by incorporating what is known about the effects of a specific condition into what is known about the nutrient needs of healthy children (and then monitoring the individual's growth and nutritional status...and adjusting recommendations as needed).

Before we look at the influence of specific conditions on nutrient needs, let's review how the DRIs—the recommendations for healthy groups and individuals—were developed.

The History of the DRIs

Since 1941 in the United States (and 1938 in Canada), recommendations for specific nutrient intakes have existed. In the US, these recommendations were called the Recommended Dietary Allowances (RDA), and in Canada, the term Recommended Nutrient Intake (RNI) was used. For the most part, these recommendations were based on the prevention of deficiency.

In the early 1990s, the approach to nutrient intake recommendations began to change. The current Dietary Reference Intakes (DRI) provide much of the basis for recommended nutrient intake levels in the United States and Canada, and are replacing the RDAs and RNIs.

Some differences between the RDAs (and RNIs) and DRIs:

- Specific data about the safety and efficacy of nutrients in chronic disease are incorporated into the DRIs, including consideration of optimal (rather than minimal) intakes. In the past, only the prevention of deficiency was carefully examined
- Upper limits of intake for specific nutrients are included in the DRIs
- Recommendations for the intake of some food components not traditionally considered to be "essential nutrients" are included in the DRIs
- The DRIs are meant for use with individuals and not only for groups

The DRIs are being released in "sets" as the consensus for each nutrient group is reached. At the time of this writing, DRIs for the following groups of nutrients are available:

- calcium, phosphorus, magnesium, vitamin D, and fluoride
- folate and other B vitamins
- antioxidants (e.g., vitamins C and E, selenium)

- trace elements (e.g., iron and zinc)
- macronutrients (e.g., protein, fat, carbohydrates)

DRI for these groups of nutrients will be released in the future:

- electrolytes and water
- other food components (e.g., fiber, phytoestrogens)

The Current Recommendations—Alphabet Soup

Several new terms are included in the group of Dietary Reference Intakes:

- EAR - Estimated Average Requirement
- RDA - Recommended Dietary Allowance
- AI - Adequate Intake
- UL - Tolerable Upper Intake Level

EAR (Estimated Average Requirement)

- the median intake value that is estimated to meet the requirements of half of the healthy individuals in a specific life stage group; the EAR is used to calculate an RDA
- for assessment of an individual's food pattern, the EAR is the most appropriate reference value; however, it is an average, and thus, 50 percent of individuals could require more than the EAR. An individual's risk for low intake should be carefully considered

RDA (Recommended Daily Allowance)

- the average daily dietary intake level that will meet the requirements of nearly all (97-98%) of healthy individuals in a specific life stage group
- the RDA is not as appropriate for assessing individuals' intakes as the EAR

Why not? If an individual's intake is greater than or equal to the RDA, it is likely that his needs are being met. The converse cannot be assumed, however. That is, if an individual's intake is less than the RDA, it is not necessarily inadequate.

AI (Adequate Intake)

- a recommended intake value that is used when there is not enough information to determine an EAR; based on experimentally derived estimates or approximations of observed intakes of individuals with intakes that are assumed to be adequate
- for nutrients without an EAR or RDA, the AI is the only alternative, and it is expected that the AI for a nutrient is greater than what the RDA would be
- intakes greater than or equal to the AI are likely adequate, but it is difficult to make a conclusion about an inadequate intake based on an AI

UL (Tolerable Upper Intake Level)

- the highest level of continuing daily intake that is likely to pose no risk

Using the DRIs in Clinical Practice

Dietary intake is part of a comprehensive nutritional assessment. The Food and Nutrition Board of the Institutes of Medicine, The National Academies suggests that clinicians also consider the following when evaluating dietary adequacy:

- the types of foods in the individual's diet and usual food patterns
- lifestyle practices that might influence nutrient needs
- anthropometric parameters that might influence nutrient needs
- clinical conditions that affect nutrient needs (this will be covered in more detail later in this module)

It is important to recognize the limitations of each of the DRIs and to select the reference that is most appropriate.

The following criteria may be used when making assessments:

- if an intake is less than the EAR, it very likely needs to be increased
- if an intake is between the EAR and RDA, it probably needs to be increased
- if an intake is greater than or equal to the RDA for many days, it is probably adequate

More information about the development of the DRIs and pdf versions of panel reports and summary panels can be found on this website:
www.iom.edu/project.asp?id=4574.

Which DRI would you use?

You are concerned that a child's vitamin C intake is not adequate. Which DRI will provide the best information?

- UL
- EAR
- RDA

The correct response is b. EAR.

Which situation would be the BEST use of the UL?

- A family is concerned that their child does not consume enough calcium. You compare her estimated calcium intake to the UL.
- You see a child with rickets. You suggest vitamin D supplements equal to the UL for vitamin D in addition to the multiple vitamin that the family has purchased.
- A family gives their 8-year old child a vitamin B6 supplement. You compare her intake to the UL and suggest that the family decrease the amount they are providing, since it is greater than the UL for 8-year olds.

The correct response is c.

Evaluating Portion Sizes

Each child's nutrient needs are different, and individual food patterns vary. The next few pages outline some recommended portion sizes for specific groups of foods.

The suggestions that follow are not necessarily appropriate for all children (and may be inappropriate for some children with medical conditions that greatly affect nutrient needs). They are intended to serve as a general framework that can be individualized based on a child's condition and growth pattern.

This information is summarized in a table in that can be downloaded.

Suggested serving size: Child 1-3 years of age

Grain products

bread - ½ to 1 slice
rice, pasta, potatoes - ¼ to ½ cup
cooked cereal - ¼ to ½ cup
ready-to-eat cereal - ¼ to ½ cup
tortilla - ½ to 1

Vegetables

cooked or pureed - 2 to 4 Tablespoons
raw - few pieces, if child can chew well

Fruit

raw (apple, banana, etc.) - ½ to 1 small, if child can chew well
canned - 2 to 4 Tablespoons
juice - 3 to 4 ounces

Milk

milk, yogurt, pudding - 4 to 6 ounces
cheese - ¾ ounce

Meat, poultry, fish, other protein

meat, poultry, fish - 1 to 2 ounces
eggs - ½ to 1
peanut butter - 1 Tablespoon
cooked dried beans - 4 to 5 Tablespoons

Suggested serving size: Child 4-6 years of age

Grain products

bread - 1 slice
rice, pasta, potatoes - ½ cup
cooked cereal - ½ cup
ready-to-eat cereal - ¾ to 1 cup
tortilla – 1

Vegetables

cooked or pureed - 3 to 4 Tablespoons
raw - few pieces

Fruit

raw (apple, banana, etc.) - ½ to 1 small, if child can chew well

canned - 4 to 8 Tablespoons
juice - 4 ounces

Milk

milk, yogurt, pudding - ½ to ¾ cup
cheese - 1 ounce

Meat, poultry, fish, other protein

meat, poultry, fish - 1 to 2 ounces
eggs - 1 to 2
peanut butter - 2 Tablespoons
cooked dried beans - 4 to 8 Tablespoons

Suggested serving size: Child 7-10 years of age

Grain products

bread - 1 slice
rice, pasta, potatoes - ½ cup
cooked cereal - ½ cup
ready-to-eat cereal - 1 cup
tortilla – 1

Vegetables

cooked or pureed - ½ cup
raw - ½ to 1 cup

Fruit

raw (apple, banana, etc.) - 1 small
canned - ¾ cup
juice - 5 ounces

Milk

milk, yogurt, pudding - 1 cup
cheese - 1 ½ ounces

Meat, poultry, fish, other protein

meat, poultry, fish - 2 ounces
eggs - 2
peanut butter - 3 Tablespoons
cooked dried beans - 1 cup

Suggested serving size: Child 11-18 years of age

Grain products

bread - 1 slice
rice, pasta, potatoes - ½ cup
cooked cereal - ½ cup
ready-to-eat cereal - 1 cup
tortilla – 1

Vegetables

cooked or pureed - ½ cup

raw - ½ to 1 cup

Fruit

raw (apple, banana, etc.) - 1

canned - ¾ cup

juice - 6 ounces

Milk

milk, yogurt, pudding - 1 cup

cheese - 1 ½ ounces

Meat, poultry, fish, other protein

meat, poultry, fish - 2 to 3 ounces

eggs - 2

peanut butter - 4 Tablespoons

cooked dried beans - 1 cup

Section 3: Identifying Factors That Affect Nutrient Needs

It is critical to remember that the DRIs and other recommendations for nutrient intake levels are based on data from healthy individuals. A host of factors, including medical conditions, medications, and atypical growth patterns, can influence the needs of an individual.

This section reviews many of the factors that can influence nutrient needs and describes some specific disorders that are associated with altered needs. This section is presented in three parts:

- influence of medical conditions
- influence of medications
- possible influences of specific conditions

Influence of Medical Conditions

Medical conditions can have an impact on nutrient needs and intake in a number of ways. Some conditions actually alter a child's nutrient needs, while other conditions interfere with adequate nutrient intakes.

Increased nutrient needs

Some medical conditions are associated with increased nutrient needs. For example, children with cardiac disorders or HIV/AIDS-associated wasting often have energy needs that are greater than typically-developing children. Children with athetoid cerebral palsy can have increased energy needs because of energy expended through involuntary movements.

Other conditions may seem to be associated with greater-than-typical nutrient needs. A more accurate description is that the conditions have symptoms that interfere with adequate intakes.

Neurologic problems (e.g., with as cerebral palsy) can cause problems with feeding such as a hyperactive gag reflex or ineffective sucking and swallowing. Likewise, low muscle tone might impair a child's ability to chew and swallow.

Decreased nutrient needs

Children with some conditions (e.g., Down syndrome and Prader-Willi syndrome) are genetically predisposed to being shorter than their typically-developing peers. For many of these children, the adolescent growth spurt is diminished or absent. The energy needs of children with these types of conditions will be lower than what is recommended for typically-developing children. Some syndromes are also associated with decreased metabolic rates.

It is not uncommon for families to forget about a child's short stature and expect him to eat the same amount of food as his typically-developing siblings. Also, if a child had feeding difficulties or was underweight in infancy (which is common with Down and Prader-Willi syndromes), focus on decreasing intake as the child gets older may seem like a "mixed message" to families.

Conditions can also be associated with lower than typical energy needs because of differences in body composition. Children with hypotonia (low muscle tone) have lower basal metabolic needs than children with normal muscle tone. This is one reason for using kilocalorie per centimeter of height (vs. kilocalorie per kilogram of body weight) equations to estimate energy needs of many children with special health care needs.

Problems with muscle coordination and gross motor skills or paralysis will contribute to a decreased level of physical activity...and thus, decreased energy needs. This should be accounted for when estimating an individual child's energy needs.

Altered micronutrient needs

Few medical conditions have a primary effect on an individual's micronutrient needs. There are, of course, a few exceptions, such as Wilson's disease (affects copper status) and other metabolic disorders. For the most part, the primary concerns around altered micronutrient needs are associated with medication-nutrient interactions.

The DRIs for micronutrients are based on the vitamin and mineral needs of individuals with typical energy intakes. Some nutrients are known to be used for energy metabolism and thus, theoretically, requirements for these nutrients are dependent on energy intake. There is not enough evidence, however, to suggest that recommended intakes of these nutrients be adjusted when an individual's energy intake is not typical.

The DRIs (EAR, RDA, AI) remain the best basis for nutrient intake recommendations for children with special health care needs.

Influence of Medications

Medications can influence nutrient needs and can have an influence on intake.

Medication-nutrient interactions can alter an individual's nutrient needs. For example:

- some anticonvulsants interfere with vitamin D metabolism, putting a child at risk for osteomalacia
- some medications cause constipation, making fluid and fiber intake even more critical
- cardiac medication can lead to electrolyte imbalances

From a broader perspective, medications can interfere with an adequate intake in other ways:

- some medications cause nausea and decreased appetite

for children who take a number of medications, timing can be complicated: some medications must be taken with food, others "on an empty stomach;" fitting regular meals and snacks into a complex medication schedule can require creativity

Some medications (and their effects on nutrient needs and intake) commonly used by children with special needs are listed in the next few slides.

Anticonvulsants

Children with seizure disorders (either primary, or related to another diagnosis) often receive anticonvulsant medications.

Nutrition-related side effects can include:

- vitamin D deficiency (e.g., with long-term use of phenytoin, phenobarbital, and carbamazepine)
- folic acid deficiency (e.g., with long-term use of phenytoin)
- possible vitamin B6 and vitamin B12 deficiencies
- carnitine deficiency (e.g., with valproate)
- nausea and vomiting

Laxatives

Many children with hypotonia or neurologic disorders have problems with constipation and require pharmacologic interventions.

Nutrition-related side effects can include:

- potassium deficiency (with long-term use of laxatives that increase peristalsis)

Stimulant Medications

Some children with Attention Deficit Hyperactivity Disorder take stimulant medications.

Nutrition-related side effects can include:

- temporarily depressed appetite and decreased intake
- weight loss or slow weight gain
- slow growth in stature

Effects of stimulant medications on growth have been minimized when children take a “vacation” from the medication (e.g., during summer months). Offering meals and snacks before the medication is administered can also be helpful.

Diuretics

Children with cardiac defects or chronic lung disease often take diuretic medications.

Nutrition-related side effects can include:

- increased excretion of electrolytes (potassium, calcium, sodium, zinc, chloride, magnesium)
- anorexia
- gastrointestinal upset

The effect of diuretics on potassium varies. Some increase excretion; others spare potassium.

Corticosteroids

Corticosteroids are used to treat a number of disorders including asthma and arthritis.

Nutrition-related side effects can include:

- decreased calcium and phosphorus absorption (leading to decreased bone formation and increased bone resorption)
- sodium and water retention
- increased glucose levels (leading to insulin resistance)
- lipolysis and muscle catabolism
- increased appetite or, for some individuals, anorexia
- altered taste
- sore or dry throat

Antidepressants

Antidepressants are used to treat depression. Depression may be a primary or secondary disorder.

Nutrition-related side effects can include:

- increased appetite
- dry mouth
- nausea and vomiting
- constipation
- diarrhea

Antibiotics

Antibiotics are sometimes used prophylactically on a long-term basis.

Nutrition-related side effects can include:

- mouth and tongue sores
- diarrhea
- nausea and vomiting
- altered vitamin K production (with long-term use)

Anti-gastroesophageal reflux disease medications

Used to treat gastroesophageal reflux disease (GERD), most of these medications increase gastric motility.

Nutrition-related side effects can include:

- constipation
- diarrhea
- nausea and vomiting
- abdominal pain and discomfort

Antispasmodics

Some children with neurologic disorders that affect the bladder (e.g., myelomeningocele) take antispasmodic medications.

Nutrition-related side effects can include:

- dry mouth
- constipation
- abdominal pain
- anorexia
- problems with swallowing
- dysgeusia

Influence of Specific Conditions

Possible effects of *some* specific medical conditions on nutrient needs are summarized in this module.

Keep in mind that these are general effects; an individual's nutrient needs may or may not follow what is described. Some general information about each of the following disorders is provided:

- achondroplasia
- autism spectrum disorders
- cerebral palsy
- Down syndrome
- muscular dystrophy
- myelomeningocele
- Prader-Willi syndrome
- Turner syndrome

More information about the impact that specific conditions have on nutritional status is presented throughout this set of modules.

Chondroplasias, e.g., achondroplasia

Description

Chondroplasias are disorders of cartilage growth. Achondroplasia is one type, an inherited problem that involves growth of cartilage in the long bones and skull. Persons with achondroplasia have short limbs, normal-sized trunks, large heads, and small faces and hands.

Possible effects on nutrient needs

Decreased energy needs can lead to problems with overweight and obesity, especially later in childhood:

- short stature makes energy needs (kilocalories per day) less than for typically-developing children

Autism Spectrum Disorders

Description

Diagnostic criteria for autism include problems with verbal and nonverbal communication, ritualistic behaviors, and inappropriate social development. About half of children with autism have some type of cognitive deficit.

Possible effects on nutrient needs

Inadequate nutrient intakes are generally behavior-related:

- food refusal and pickiness can create vitamin and mineral deficiencies; may be related to need for sameness, sensorimotor problems, or other issues related to autism
- disruptive behavior at mealtimes, barriers to an adequate overall intake
- elimination of entire food groups because of special diets (e.g., gluten-free)

Excessive nutrient intakes because of the use of supplements should be addressed

Cerebral palsy

Description

Cerebral palsy (CP) involves chronic, nonprogressive central nervous system (CNS) dysfunction leading to problems with tone and movement. Children with CP make up a very heterogeneous group. Depending on the original insult, this diagnosis has many clinical manifestations, from very mild to very severe neurological involvement. Children with cerebral palsy may or may not be ambulatory and may or may not have mental retardation.

Some children with CP have the spastic or hypertonic type; these children have increased muscle tone. Children with ataxic or hypotonic CP have decreased muscle tone. Dyskinetic, or athetoid, CP is associated with involuntary movements and impairment of purposeful movement; with athetoid CP, muscle tone can be decreased, normal, or increased. Children with mixed CP have more than one type of movement disorder.

Possible effects on nutrient needs

Energy needs may be increased or decreased:

- increased with athetoid CP and hypertonia
- decreased with hypotonia and decreased physical activity

Inadequate nutrient intakes may occur for a number of reasons:

- communication problems that interfere with a child's ability to indicate hunger and thirst
- oral motor problems, including problems with sucking, hypo- or hyperactive gag reflexes, tongue thrust, and lip closure
- impaired motor skills preventing self-feeding
- improper positioning that makes eating difficult
- gastroesophageal reflux (which is higher among children with CP)

Possible medication - nutrient interactions

- anticonvulsant medications

Down syndrome (trisomy 21)

Description

Down syndrome is caused by an "extra" 21st chromosome. Children with Down syndrome often have mental retardation, cardiac defects, and hypotonia (decreased muscle tone). Duodenal atresia (blockage of the intestine) may be present. Oral problems can include oral hypotonia, small oral cavity causing tongue protrusion, and delayed and/or abnormal tooth eruption.

Possible effects on nutrient needs

Inadequate nutrient intakes may be a problem in infancy and early childhood:

- a narrow palate and/or small oral cavity preventing proper sucking and other oral-motor problems including tooth abnormalities
- hypotonia and delayed feeding skill development making feeding difficult
- malabsorption among children with GI malformations

Lower energy needs can lead to overweight and obesity as children get older:

- children with Down syndrome tend to be shorter than typically-developing peers
- hypotonia and muscle coordination problems interfere with physical activity, decreasing energy needs
- less dramatic adolescent growth spurt than typically-developing children

Possible medication-nutrient interactions

- cardiac medications
- many nutritional supplements promoted to families of children with Down syndrome

Muscular dystrophy

Description

Muscular dystrophy is the progressive degeneration of muscle function. The most common is a genetic form called Duchenne muscular dystrophy. Other types include spinal muscular atrophy (SMA), myasthenia gravis, and myotonic dystrophy.

Possible effects on nutrient needs

Inadequate intakes are related to a number of problems that can be associated with muscular dystrophy:

- feeding difficulty related to weak facial muscles and/or improper positioning
- fatigue during mealtime due to feeding difficulties and respiratory problems

Excessive intakes are one reason overweight and obesity are common in later childhood and adolescence:

- decreased physical activity as ability to ambulate decreases
- increased muscle degeneration and changes in body composition

Possible medication-nutrient interactions

- steroid therapy (e.g., prednisone)

Myelomeningocele (Spina bifida)

Description

Myelomeningocele is caused by failure of the neural tube to close completely during fetal development, resulting in a lesion along the spinal cord. The level of muscle weakness and paralysis depends on the level of the lesion (high or low along the spinal cord). Children with myelomeningocele may or may not be ambulatory.

Possible effects on nutrient needs

Inadequate intakes may be a problem in infancy and early childhood:

- problems with feeding, including abnormal gag reflexes and problems with sucking and swallowing, interfere with an adequate intake (more common among children with Arnold Chiari malformation)
- difficulties with positioning and posture, interfering with an adequate intake

Increased needs of some nutrients may be present because of problems associated with the disorder:

- bowel and bladder problems, often making fluid and fiber intakes critical
- pressure ulcers and other problems that are more common among children with myelomeningocele, increasing nutrient (energy, protein, fluid, micronutrient) needs

Decreased energy needs may be due to factors related to the disorder:

- short stature, common among children with myelomeningocele
- smaller muscle mass
- decreased levels of physical activity

Possible medication-nutrient interactions

- anticonvulsants
- medications for neurogenic bladder

Prader-Willi syndrome

Description

Prader-Willi syndrome is a genetic disorder caused by partial deletion of chromosome 15 (paternal) or disomy (maternal). Children with Prader-Willi syndrome have mental retardation and abnormal food-related behaviors. Prader-Willi syndrome is characterized by feeding problems during infancy, and hyperphagia, often resulting in obesity, in childhood and adolescence.

Possible effects on nutrient needs

Inadequate intakes are very prevalent in infancy for individuals with Prader-Willi syndrome:

- difficulty feeding because of problems with sucking and hypotonia

Excessive energy intakes after infancy lead to problems with overweight and obesity:

- short stature contributing to decreased energy needs
- hypotonia and problems with muscle coordination, leading to decreased physical activity levels and decreased energy needs
- hyperphagia and absent satiety cues, leading to excessive intakes
- energy needs (e.g., kilocalories per centimeter) that are lower than those of children without Prader-Willi syndrome

Turner syndrome

Description

Turner syndrome is a genetic defect in females marked by the absence of one X chromosome. Individuals with Turner syndrome typically have ovarian failure, genital tissue defects, heart and circulation problems and short stature.

Possible effects on nutrient needs

Decreased energy needs can lead to problems with overweight and obesity, especially later in childhood and adolescence:

- short stature makes energy needs (kilocalories per day) less than for typically-developing children

Children with Special Health Care Needs...what to consider

When evaluating the intake of a child with a special health care need, consider the effect(s) that the specific condition may have on his intake:

- Does the condition (or medication used to treat the condition) have an effect on the child's nutrient needs?
- Does the condition change the types of foods that the child can eat?
- Does the condition alter the amount of food that the child can reasonably be expected to consume?
- Does the condition have an effect on the amount of time the child can spend at the table? Does this make a smaller intake likely?
- Does the medication or therapy schedule interfere with scheduled meal or snack times?

Section 4: Evaluating an Individual's Intake

This section "walks" you through the decision-making process. The first scenario describes a case and one way to approach the dietary intake data. In the second scenario, you will be asked to make clinical decisions based on the information presented. This section is not scored.

Scenario 1

Jeremy, a 7-year, 4-month old, is referred to you for evaluation of his dietary intake. His family is a little concerned because he is "thin." They note that he has always been "about the same build."

His weight is between the 10th and 25th percentiles, height is between the 25th and 50th percentiles.

You review the records that the family brings to clinic, and plot Jeremy's growth.

Your assessment is that his weight and height remain "in channel" and that his BMI-for-age is acceptable. You explain that Jeremy's growth pattern is within normal limits and that this shows that his energy intake is adequate.

Next, you decide to evaluate Jeremy's intake ... to provide more information about his macronutrient (energy, protein, carbohydrate, and fat) and micronutrient (vitamins and minerals) intake.

Jeremy's parents describe Jeremy's food pattern. He eats 3 meals and 2 or 3 snacks each day. The portion sizes that they describe are appropriate for a child Jeremy's age. You ask them about the mealtime environment, and they tell you that he eats breakfast with his older brother, generally has lunch at school and a snack at afterschool day care. The family eats dinner together most nights, and Jeremy usually eats a snack before bed.

You are confident that the information they are providing is accurate and Jeremy's growth pattern supports an adequate energy intake.

Jeremy's mother says, "Oh, I almost forgot, Jeremy eats applesauce each morning, with breakfast. That is where we put his seizure medication." You are glad she brought this up because you nearly forgot to ask about medications!

Back on track, you remember that there are some medication-nutrient interactions associated with some anti-seizure medications. Specifically, you are concerned about vitamin D and calcium and folic acid.

You decide that you need some specific information about the foods and amounts of foods that Jeremy usually eats in order to assess his vitamin D, calcium, and folic acid intake.

You ask Jeremy's parents if the last few days were representative of what he eats. They tell you that they were on vacation, so his food pattern was unusual. They are

comfortable with your suggestion to keep a food record now that Jeremy's schedule is back to normal.

You receive the food record in the mail and use nutrient analysis software to estimate Jeremy's intake. His energy and protein intake is close to the RDA for age, and his vitamin D and calcium intakes exceed the RDA (but are under the UL). His folic acid intake is less than the RDA (his intake is 120 ug/d and the RDA is 200 ug/d).

You remember that an intake that is less than the RDA does not necessarily indicate a deficiency, but you also remember that long-term anticonvulsant use can lead to a folate deficiency.

You recommend that Jeremy take a small amount of supplemental folic acid, after consulting with Jeremy's neurologist (who prescribed the medication) and primary care physician. You also recommend that Jeremy's intake (and the need for a supplement) be re-evaluated in a year.

Scenario 2

You are asked to see Julie, a 3-year 11-month old with Prader-Willi syndrome. You remember some of the nutrition-related issues common among children Julie's age with this genetic condition. They include:

- a. hypotonia
- b. inadequate intake
- c. short stature
- d. all of the above
- e. a & c only

The correct answer is e. A & C. Both hypotonia and short stature are associated with Prader-Willi syndrome. An inadequate intake is characteristic during infancy because of problems with feeding. By childhood, an inadequate intake is no longer a problem.

You weigh and measure Julie and plot growth. You compare this information to her weight and height at her last clinic visit.

Julie's weight-for-age and BMI-for-age have increased. BMI-for-age was at the 50th percentile eleven months ago; it is now at the 95th percentile.

Julie's height-for-age remains below the 5th percentile on the CDC charts and at the 50th percentile on the charts for children with Prader-Willi syndrome (chart not shown).

Based on Julie's growth pattern, you suspect that Julie's:

- a. BMI is increased because she is about to experience a growth spurt
- b. vitamin and mineral intake is inadequate
- c. energy intake is excessive

- d. energy intake is adequate, but BMI is up because of Prader Willi syndrome

The correct response is c. energy intake is excessive. Although children with Prader-Willi syndrome tend to be overweight, obesity is preventable with a reduced energy intake. Julie's increased rate of weight gain is most indicative of an excessive energy intake.

Julie's family did not bring a food record to clinic. They say that because Julie eats meals at so many different places (e.g., home, Grandmother's, daycare), it is difficult to estimate what she eats.

You explain that you are concerned because she has gained so much weight and that a food record will help you to identify areas to help prevent further gain for a time. You suggest that that they use a notebook that goes with Julie for a week to record what she eats. They agree. What is the next step?

- take a diet history, estimating what she eats when she isn't at home; although this will be incomplete, it will provide some information
- have her parents complete a food frequency questionnaire, add what you think she probably eats
- schedule a follow-up appointment when the food record is received; there is no point in continuing with the interview at this point
- call Julie's grandparents for information

The correct response is a. take a diet history, estimating what she eats when she isn't at home. A food frequency questionnaire will provide information about the types of foods that Julie eats, but will not necessarily provide information about the amount of food she eats. A follow-up appointment once the food record is received is a good idea, but Julia's parents can provide valuable information at this visit.

Since it is evident that Julie's rate of weight gain needs to be slowed, you work with her parents to develop some guidelines for decreasing Julie's energy intake. You explain that you can provide more information once you receive her food record.

The food record arrives and you review it over the phone with Julie's mother. It appears to be complete (items like margarine on toast and drinks between meals are recorded), but her intake is still less than the DRI's Estimated Energy Requirement (EER). With what you know about Prader-Willi syndrome and about Julie's growth pattern, you decide:

- Julie's family has not recorded everything that she eats
- Julie is sneaking food
- Julie's energy needs are actually less than the EER
- none of the above

The correct response is c. In general, the energy needs of children with Prader-Willi syndrome are less than their age-matched peers.

You also evaluate Julie's food record for other nutrients. Her protein intake is greater than the DRI for age, which you decide is not inappropriate. Her intake, with the multiple vitamin supplement she takes, is adequate for vitamins and minerals. You identify some specific areas where the family can make changes (for example, using nonfat milk instead of low fat milk and offering raw vegetables at snacks instead of chips and crackers). You encourage Julie's parents to share this information with Julie's other caregivers.

Finally, you schedule a follow-up appointment with Julie's family to monitor her growth and intake.

Post Test

QUESTION 1

According to the Food and Nutrition Board, if an individual's intake is less than the _____, it very likely needs to be increased.

- a. RDA (Recommended Daily Allowance)
- b. EAR (Estimated Adequate Requirement)
- c. UL (Tolerable Upper Intake Level)

QUESTION 2

Which of the following statements about a 24-hour recall is true?

- a. it provides prospective information
- b. it includes information about a child's feeding history
- c. it requires that the family spend time recording an intake before the clinic visit
- d. it may not represent a typical day's intake

QUESTION 3

In general, what effect does hypotonia have on an individual's energy needs?

- a. increases needs because more energy is expended for each movement
- b. increases needs because of increased muscle mass
- c. decreases needs because of increased muscle mass
- d. decreases needs if children are less active or have decreased muscle mass

QUESTION 4

Which of the following conditions is often associated with increased energy needs?

- a. HIV/AIDS
- b. Down syndrome
- c. achondroplasia
- d. myelomeningocele

QUESTION 5

Scenario 1

You are asked to see Adam, a 4-year 9-month old with autism. While you recognize that all children with autism do not have the same nutrition-related problems, you do remember some issues common among many children with autism. They include:

- a. hypotonia
- b. inadequate intake

- c. short stature
- d. all of the above
- e. a & b only

Scenario 1 - continued

You weigh and measure Adam and plot his growth. His mother has brought an old growth chart, which includes information from when Adam was 3-years of age.

QUESTION 6

Scenario 1 - continued

Adam's mother describes his usual food intake. She says that he is very picky and the only foods that he accepts are warmed milk, fresh squeezed orange juice, tomatoes, French fries, cookies and crackers. She is worried because he is now refusing foods that he used to accept (pizza and hot dogs).

Based on this information, and Adam's growth history, you suspect that Adam's:

- a. energy and vitamin and mineral intakes are adequate
- b. energy and vitamin and mineral intakes are inadequate
- c. energy intake is adequate, but vitamin and mineral intake is inadequate
- d. energy intake is inadequate, but vitamin and mineral intake is adequate

QUESTION 7

Scenario 1 – continued

You tell Adam's mother that his limited intake puts him at risk for several vitamin and mineral deficiencies including zinc, iron, B vitamins and folate. She says that he takes a children's chewable multiple vitamin and mineral supplement daily and shows you the label. You recommend that he continue to take this supplement.

Concerned about his limited intake and the factors that are contributing to it, you ask more questions about:

- a. altered nutrient needs related to autism
- b. food allergies
- c. use of other supplements and medications
- d. meal and snack time behaviors

Scenario 1 - continued

You ask Adam's mother about the mealtime environment. She says that he is offered what the family is eating at meals, but usually refuses to eat. He does not sit at the table with the rest of his family; he will walk around the house with his milk. Between meals, he will go into the kitchen and point at foods that he wants. His mother says that because he used to throw tantrums when she said, "No," she now lets him eat what he wants.

You reassure her that these behaviors are common among children with autism and fit with other behaviors that are associated with autism (for example, the need for a routine).

Adam is already receiving therapy to address behavior problems not related to eating. You suggest that the family work with the therapist to address feeding related behaviors. You provide the therapist with a list of goals:

1. Adam will drink his milk at the table at mealtimes
2. Adam will not have access to food between scheduled meal or snack times
3. Adam will be offered new foods along with foods he already eats

A follow-up appointment is scheduled with Adam and his family to reassess his growth and intake in four months.

QUESTION 8

Long-term use of anticonvulsants can lead to micronutrient deficiencies. Which of the following nutrients is LEAST likely to be affected by long-term use of an anticonvulsant?

- a. vitamin D
- b. potassium
- c. carnitine
- d. folate

For More Information About Obtaining Accurate Dietary Intake Data

Nutrition Questionnaires for Infants, Children, and Adolescents. Appendices A, B, and C in Story M, Holt K, Sofka D, eds. 2002 *Bright Futures in Practice: Nutrition* (2nd ed.). Arlington, VA: National Center for Education in Maternal and Child Health. Questionnaires, along with guidelines for interpreting answers to the questionnaires are included. This publication is available online at <http://www.brightfutures.org> and print copies can also be ordered.

For More Information About Recommendations for Intake

Food and Nutrition Board: Scientific Evaluation of DRIs. This website describes the development of the DRIs and includes pdf versions of panel reports and summary tables. <http://www.iom.edu/project.asp?id=4574>

For More Information About Factors Affecting Nutrient Needs

Medications. Medications. In: Harris AB, Blyler EM, Baer MT. *Nutrition Strategies for Children with Special Needs*. USC University Affiliated Program, Childrens Hospital Los Angeles. 1999. This chapter describes many of the medications that a child with special needs might take, and outlines plans to minimize medication-nutrient interactions.

Medication-nutrient Interactions. Blank S, Harper E. Medication-nutrient interactions. In: Nardella M, et al. *Nutrition Interventions for Children with Special Health Care Needs*. Washington State Department of Health. 2001. This chapter reviews many of the medications (and the medication-nutrient interactions that may be present) commonly used in the treatment of children with special health care needs. To order, contact the Washington State Department of Health, Revenue Section, PO Box 1099, Olympia WA 98504 or visit the Washington State Nutrition for Children with Special Health Care Needs website: <http://depts.washington.edu/cshcnut>. The publication can also be downloaded from the WA DOH website: <http://www.doh.wa.gov/cfh/mch/CSHCNhome2.htm>

For More Information About Evaluating an Individual's Intake

Dietary Reference Intakes: Applications in Dietary Assessment. Institute of Medicine. *Dietary Reference Intakes: Applications in Dietary Assessment*. Food and Nutrition Board. Washington, DC National Academy Press, 2000. This document describes the use of the DRIs in assessing the intakes of groups and individuals and provides some guidelines for interpretation. <http://www.nap.edu/books/0309071836/html> or can be ordered from the National Academy Press at <http://www.nap.edu/catalog/9956.html>

The Food and Nutrition Information Center (FNIC). The FNIC website has information about food and nutrition, including links to nutrient composition information, a searchable nutrient database, dietary guidelines, and food guide

pyramids. FNIC is part of the US Department of Agriculture.
<http://www.nal.usda.gov/fnic>.

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DRI s for Macronutrients. Institute of Medicine. *Dietary Reference Intakes for Energy, Carbohydrate, Fiber, Fat, Fatty Acids, Cholesterol, Protein, and Amino Acids (Macronutrients).* Food and Nutrition Board. Washington DC: National Academy Press, 2002. This report is available on-line: <http://books.nap.edu/catalog/10490.html>.

DRI s for Thiamin, Riboflavin, Niacin, Vitamin B6, Folate, Vitamin B12, Pathothenic Acid, Biotin, and Choline. Institute of Medicine. *Dietary Reference Intakes for Thiamin, Riboflavin, Niacin, Vitamin B6, Folate, Vitamin B12, Pantothenic Acid, Biotin, and Choline.* Food and Nutrition Board. Washington, DC: National Academy Press, 1998. This report is available on-line. A hard copy can be ordered from <http://www.nap.edu/catalog/6015.html>.

DRI s for Vitamin A, Vitamin K, Arsenic, Boron, Chromium, Copper, Iodine, Iron, Molybdenum, Nickel, Silicon, Vanadium and Zinc. Institute of Medicine. *Dietary Reference Intakes for Vitamin A, Vitamin K, Arsenic, Boron, Chromium, Copper, Iodine, Iron, Molybdenum, Nickel, Silicon, Vanadium and Zinc.* Food and Nutrition Board. Washington, DC: National Academy Press, 2001. This report is available on-line. A hard copy can be ordered from <http://www.nap.edu/catalog/10026.html>.

DRI s for Vitamin C, Vitamin E, Selenium, and Carotenoids. Institute of Medicine. *Dietary Reference Intakes for Vitamin C, Vitamin E, Selenium, and Carotenoids.* Food and Nutrition Board. Washington, DC: National Academy Press, 2000. This report is available on-line. A hard copy can be ordered from <http://books.nap.edu/catalog/9810.html>.

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DRI as of 2001. It is available on-line to ADA members at: <http://www.eatright.org>. Login with your ADA number, then follow the links to the Journal.

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Nutrition Strategies for Children with Special Health Care Needs. Harris AB, Blyler EM, Baer MT. *Nutrition Strategies for Children with Special Needs.* USC University Affiliated Program, Childrens Hospital Los Angeles. 1999. This manual provides guidelines for nutrition screening and strategies for ten nutrition-related health concerns. Resources and educational materials are also included.

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