NUTRITION and OBESITY

SPINA BIFIDA HEALTHCARE GUIDELINES

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OUTCOMES

• **Primary**: Maximize and support wellness through the lifespan, defined as “*Individuals living life to their fullest potential*” [1] (p. 162).

• **Secondary**: Reduce/prevent secondary conditions related to poor nutrition and higher weights.

• **Tertiary**: Support the development of client/caregiver knowledge, self-management skills and self-efficacy related to nutrition and dietary habits.

Infancy

**Clinical Questions:**

1. What follow-up support should be provided when infants with spina bifida first go home from hospital?

2. What guidance on breastfeeding and/or use of breast milk should be given to parents of infants/newborns with spina bifida?

**Guidelines:**

1. Ensure family is followed closely by primary care provider(s):
   
   • Refer to community nursing and other community supports to ensure close monitoring of growth, feeding issues and elimination.
   
   • Connect family with the spina bifida specialist clinic nearest them.
2. Provide guidance and support on breast-feeding both pre- and post-natally:

- Infants with spina bifida should ideally be exclusively breastfed or given breastmilk for the first 6 months, with continued breastfeeding for a year or more, as with all neonates [2].
- Pre-natal counselling should be provided in advance of delivery about:
  - The need to begin pumping breast milk early (within 6-12 hours of delivery) and
  - The need to pump frequently (8-10 pumping sessions per 24 hours for first 7-10 days) to ensure supply is available once infant has surgery [3].
  - That the mother will have to pump breastmilk to feed the infant before transferring the infant to her breast if surgery precludes immediate breast feeding.
- Give mothers information about accessing breastmilk banks and planning for situations where she cannot provide it herself [4].
- Encourage mother to nurse the infant flat for 5 days to reduce pressure on the wound to avoid a cerebral spinal fluid leak [5].
- Provide the mother with information about breastfeeding equipment options to meet individual needs of the infant with spina bifida (e.g., different types of propping pillows, nipples, bottles, pumps, latex-free equipment, supplemental nursing systems) [3].
- Severe Chiari malformation may affect successful latching and coordination of sucking, swallowing, and breathing- a referral to a lactation consultant should be made if mothers continue to experience challenges [3].
- Breastfeeding or non-nutritive sucking (finger or pacifier) may provide comfort to the infant and assist with pain management for acute procedures (e.g. injections) [6].
- The transition from breastmilk to solid food can be a point of constipation- identify and avoid commonly constipating foods if possible (e.g. white rice, under-ripe bananas, cheese).
Toddler

Clinical Questions:

1. What evidence-based information can be provided available to parents on nutrition and overweight/obesity prevention & management?
2. How can the benefits of a healthy diet be communicated to parents in an understandable manner?

Guidelines:

1. Support family to establish healthy food behaviours/food relationships with their child by communicating what is known about parental feeding practices:
   - Early eating patterns and relationships with food are critical for ongoing good nutrition through the lifespan [7].
   - Start introducing healthy foods as early as possible to get them integrated into food preferences- it may be harder later on when food preferences are more entrenched [8].
   - Recognize that children with Chiari malformation may have a sensitivity to different food textures.
   - Habitual provision of unhealthy foods can lead to a cycle of more requests and consumption of unhealthy foods: early healthy feeding practices can help avoid this [9]. However, overly restricting food, especially energy dense foods, which are high in fat with a low water content (e.g. cookies, chips, nuts) can lead to over-eating of those foods when available [8]. Therefore a balance is needed.
   - Using food as a reward/ positive reinforcement can create an unhealthy relationship with food that is hard to break later on and may lead to undesirable eating behaviours [7, 8]. Provide parents with other strategies for positive reinforcement rewards such as praise, stickers, small toys etc.
   - Maintaining bowel and bladder function may be prioritized by families over nutritional status; therefore educate families on the importance of consuming a
balanced diet on the whole body [10].

- Fluid/food choices to ensure hydration and bladder/bowel function are not necessarily the right drinks/food for weight management (e.g. chocolate milk, juice, sports beverages). Encourage consideration of non-caloric fluids for hydration (e.g. water, club soda, crystal lite).

2. Talk to parents about nutrition in terms of their child’s health and growth:

- Provide regular opportunities for parents to discuss any concerns with their child’s weight, growth and/or eating behaviours [11]. A trusting therapeutic relationship can greatly facilitate a honest and open discussion [12].

- Poor eating habits and reduced activity may lead to obesity, constipation, pressure sores, osteoporosis, anemia, and other problems. Children with spina bifida also have less calorie burning tissue (lean body mass) and a lower rate of burning calories (metabolic rate), which also puts them at high risk for obesity [13, 14].

- The trajectory of child’s weight/height can be shown to parents on a growth chart as a visual aid, without referring to weight/growth cut-offs developed for typically developing children [12]. A steeply increasing trajectory would indicate that overweight or obesity may be a concern and warrant proactive discussions of preventative strategies.

- Highlight the importance of parents modeling healthy behaviours to their children from an early age [8, 15, 16] and encourage the whole family to get involved in healthy living activities [17], not just the child with spina bifida.

- Discuss that children with spina bifida are at increased risk for bone fractures, especially those who are non-ambulatory, who undertake low levels of physical activity and have higher body fat levels or contractures [18].

Preschool

Clinical Questions:
1. What evidence can be provided on the best nutritional method(s) to prevent, treat, and manage overweight/obesity?
2. How is constipation best managed?

Guidelines:
1. Weight-management interventions specific to spina bifida are lacking. However, the following principles should be communicated:
   - Provide regular opportunities for parents to discuss any concerns with their child’s weight, growth and/or eating behaviours [11]. A trusting therapeutic relationship can greatly facilitate a honest and open discussion [12].
   - Emphasize the broad benefits of healthy eating and physical activity, offering strategies to enable the child to incorporate healthy lifestyle behaviours appropriate to their level of ability [19].
   - Early eating patterns and relationships with food are critical for ongoing good nutrition through the lifespan [7].
   - Fluid/food choices to ensure hydration and bladder/bowel function are not necessarily the right drinks/food for weight management (e.g. chocolate milk, juice, sports beverages).
   - If relevant, discuss that Body Mass Index is an imperfect indicator of health in all young people, and especially children with spina bifida (due to difficulties measuring height and different body composition) [14].
   - The trajectory of child’s weight/height can be shown to parents on a growth chart as a visual aid, without referring to weight/growth cut-offs developed for typically developing children [12]. A steeply increasing trajectory would indicate that overweight or obesity may be a concern and warrant proactive discussions of preventative strategies.
   - Discuss that children with spina bifida are at increased risk for bone fractures, especially those who are non-ambulatory, who undertake low levels of physical activity and have higher body fat levels or contractures [18].
2. Provide guidance on maintaining good bowel health:

- Increase fiber in the child’s diet—this will add bulk to the stool and make it easier to pass. Sources of fiber include fruit, vegetables, wholemeal bread and wholemeal cereals.

- Increase fiber slowly over two to three weeks if the child is currently constipated. Add one new high fiber food every 2-3 days. Increasing fiber too quickly can make the constipation worse or cause gas, cramping and diarrhea [20].

- Aim to meet daily fiber guidelines for all children [21]:
  
  - 1-3 years: 19g
  - 4-8 years: 25g
  - 9-13 years: Female: 26g; Male: 31g
  - 14-18 years: Female: 26g; Male: 38g

- Giving more fluids, especially water and non-caloric fluids, will also soften the stool and help with constipation. Daily Maintenance Fluid Requirements (24 hour period) Calculation [22]:
  
  - 100 mL/kg for the first 10 kg body weight
  - + 50 mL/kg for the next 10 kg body weight
  - + 20 mL for every kilogram of body weight over 20 kg

- Encourage the child to use the toilet as soon as s/he feels the urge to go.

- Timed toilet times may also encourage consistent emptying [20].

- Physical activity can also help stool move through the bowel and prevent constipation [20].

- Medication, devices or surgical intervention may be needed to help children to have predictable, regular, soft bowel movements.

Schoolage

Clinical Questions:

1. What information should be provided about the special dietary needs and
adapted equipment needs of students with spina bifida to independently eat/access food at school or in the community?

2. What parenting strategies can encourage a balanced, healthy diet for the whole family?

Guidelines:

1. Highlight dietary needs specific to spina bifida:
   - Discuss the importance of fiber and water consumption to managing bowel and bladder health. Sources of fiber include fruit, vegetables, whole meal bread and whole meal cereals. A mix of each will help avoid constipation.
   - Regular fluids are also needed to ensure the fiber can leave the body.
   - Advise parents to limit sugary drinks such as juice, chocolate milk, sports beverages.
   - Recognize that children with Chiari malformation may have a sensitivity to different food textures.
   - Ensure child has access to food purchasing and preparation spaces.
   - To avoid fractures due to osteoporosis, children with spina bifida should be maintained on a diet with adequate calcium and vitamin D

2. Provide families with nutritional information tailored to their circumstances:
   - Take into account geographical location, ethnicity, access to food etc. when providing dietary education.
   - Encourage parents to include children from an early age to participate in grocery shopping and food preparation, appropriate to their age and ability.
   - Suggest parents let their child help choose a new healthy food to try. Involving kids in choices can lead to increased independence and interest over their foods, learn about healthy choices, and repeat exposure to healthy options can help to increase acceptance and enjoyment [23].
   - Involve children in discussions about healthy lifestyles to explore their
understanding, perceptions and priorities [12].

- If appropriate, ask parents to identify 1-2 small healthy nutrition changes that they feel they can integrate into their daily life.
- Celebrate any successes (e.g. drinking more water, introducing a new fruit or vegetable, reduction in sugary drinks, regular meal times etc.). Focus upon strengths of the family [12].
- Highlight the importance of parents modeling healthy behaviours to their children from an early age [8, 15, 16] and encourage the whole family to get involved in healthy living activities [17], not just the child with spina bifida.
- Discuss that children with spina bifida are at increased risk for bone fractures, especially those who are non-ambulatory, who undertake low levels of physical activity and have higher body fat levels or contractures [18].

Teenage

Clinical Questions:

1. What is the most effective protocol to approach the diet/nutrition goals and information included in yearly spina bifida clinic visits?
2. What are biggest barriers to healthy nutrition for young people with spina bifida?
3. What self-management skills and resources related to healthy nutrition should be provided for individuals with Spina bifida

Guidelines:

1. Provide opportunities for teens and parents to talk about their priorities and concerns regarding nutrition and weight:
   - Discuss how nutrition can play an important role in helping individuals with spina bifida maintain a healthy weight, minimize pressure sores, and increase balance and endurance.
   - Discuss that children with spina bifida are at increased risk for bone fractures,
especially those who are non-ambulatory, who undertake low levels of physical activity and have higher body fat levels or contractures [18].

- Provide regular opportunities for teens to discuss any concerns with their weight/growth/diet [11]. A trusting therapeutic relationship can greatly facilitate a honest and open discussion [12].
- Identify the teen’s priorities and negotiate goals that meet their priorities as well as parent and clinician goals [24].
- Use a strengths-based approach, highlighting their nutritional achievements and celebrate small successes [12].
- If relevant, discuss that Body Mass Index is an imperfect indicator of health in all young people, and especially teens with spina bifida (due to difficulties measuring height and different body composition) [14].
- Instead, show teen the trajectory of their weight/height on a growth chart as a visual aid, without referring to weight/growth cut-offs developed for typically developing children [12]. A steeply increasing trajectory would indicate that overweight or obesity may be a concern and warrant preventative strategies.
- Avoiding the use of scare tactics, discuss potential negative consequences of higher weights for teens with spina bifida, as it relates to their circumstances:
  - Moving and transferring may become more difficult, which may also reduce independence and self-care activities
  - There can be increased pressure on skin, which may be more vulnerable to ulcers if person is seated for long periods of time (e.g. in a wheelchair)
  - If there is existing scoliosis or kyphosis, higher weights may cause additional breathing problems if lungs cannot inflate sufficiently
- Highlight decreased energy expenditure if physical activity is decreasing (e.g. teen is spending increasing time in a wheelchair).

2. Although there is little evidence specifically for teens with spina bifida, consider the broader literature for teens:
• Eating habits generally worsen as children move into the teen years and become more autonomous [25].
• Skipping breakfast and low fruit/vegetable consumption is common in teens [26]. Emphasise the positive health benefits of both [16, 27].
• Lower socioeconomic status can be related to poorer diets [28].
• Family setting remains important for teens: Parental modelling, dietary intake and encouragement are all associated with teens’ fruit and vegetable consumption [16].

3. Discuss opportunities for the teen to participate in nutrition-related activities:
   • Identify teen’s knowledge level around healthy eating habits.
   • Encourage family to identify roles for the teen in meal planning, shopping and food preparation as part of daily life.
   • Selecting a new healthy food to try can encourage broader food preferences.
   • Identify teens’ existing strengths and resources and how they can be utilized to reach their goals [29].

Adult

Clinical Questions:
   1. How do nutrition issues differ by different demographics for adults with spina bifida?
   2. What considerations should be given to nutritional intake when people with spina bifida are taking medications to address other health concerns?

Guidelines:
   1. Although there is little evidence specifically for people with spina bifida, some considerations:
   • Adults and families with lower incomes may experience food insecurity (e.g. access to enough food for an active, healthy life)[30].
   • Refer clients to National Center on Health, Physical activity and Disability
• Many adults require quite low intakes of calories to avoid obesity
• Explore who needs the information about healthy food (i.e. individual with SB, caregiver, attendant, family member etc.). Identify who is purchasing and/or preparing the food.
• Discuss existing access of food preparation area and cooking options (i.e. do they only access to a microwave).
• Involve a social worker or disability organization representative who can speak to patients about available local, state, and federal nutritional benefits (e.g., Supplemental Nutrition Assistance Program (SNAP) benefits, food vouchers, farmer’s market bucks, etc.) that are available for eligible individuals [31, 32].

2. Provide information about potential interaction of nutrition and medication
• Highlight that some medications (e.g. cortico-steroids) have side-effects, that include weight gain, increased appetite, high blood pressure and higher risk of developing osteoporosis or diabetes.
• Provide information about specific foods and beverages that may interact with medications, such as anti-hypertensive, blood-thinning, or cortico-steroid medications.
• Encourage patients to disclose any prescribed, over-the-counter or complementary and alternative medications they are taking to all of their healthcare professionals, including pharmacists.
• Emphasize the importance of reading medication labels to identify any dietary contra-indications. If this is difficult, discuss strategies that may help (e.g. larger font, asking the pharmacists for assistance) [33].

Other

Clinical questions:
1. How are food/ nutrients best measured in children and adults with spina bifida? How often is it measured and addressed? How is it followed up?
2. What evidence is there about age of onset of overweight/obesity?
3. How can nutritional guidance developed for people without disabilities be adapted for those with spina bifida?
4. What nutritional supplements should be recommended to people with Spina bifida across the lifespan?

Guidelines:
1. Use National Food Guidance with specific serving sizes of different food groups (e.g. Food Pyramid or Canada’s Food Guide) as guidance for assessing food intake and nutrient adequacy in diet.
   • Tailor serving sizes based on a child’s growth pattern.
2. Most children with spina bifida follow typical growth patterns until they are 4 years of age. After that, increased fat mass (vs lean mass) has been found when compared with children without spina bifida [34].
   • Linear growth or height will also be slower than peers due to paresis or paralysis of lower limbs [35], which also reduces calorie requirement.
   • As children with spina bifida get older, serving sizes should be monitored as those using wheelchairs will be less mobile than their peers and so will require far less energy consumption. However, there are no definitive guidelines around calorie requirements for children with spina bifida.
3. Use the GRAID domain methodology to adapt evidence-based nutrition guidelines, programs, or policies to be inclusive of individuals with disabilities, including spina bifida [36, 37].
4. The following nutritional supplements should be discussed:
   • To avoid fractures due to osteoporosis, children with spina bifida should be maintained on a diet with adequate calcium and vitamin D based on gender and age, and supplementation of both should be advised if dietary intake does not
• People who have spina bifida themselves are more likely to have children with spina bifida. A woman with spina bifida who is planning to get pregnant should talk with her doctor about getting a prescription to take 4,000 µg (4.0 milligrams) of folic acid one month before pregnancy and during early pregnancy [38].

Key research gaps
1. Evidence-based guidelines for weight-management, obesity prevention and obesity treatment for those with SB for children with SB aged birth to 20 years old.
2. Assessment of body composition in a standardized and accessible manner (e.g. DXA for all isn’t realistic)
3. Evidence about the energy needs of people with spina bifida at different ages and who use different mobility methods.
4. Growth curves and weight classification cut-offs need to be developed specifically for people with spina bifida.

Resources (not evidence-based):
• Nutritional considerations for adults with spina bifida: http://www.nchpad.org/777/4145/Nutrition~Spotlight~~~Nutritional~Considerations~for~Adults~with~Spina~Bifida
• Growing up with spina bifida: http://fpg.unc.edu/sites/fpg.unc.edu/files/resources/reports-and-policy-briefs/NCODH_SpinaBifida.pdf
• Living with spina bifida: Young adults: https://www.cdc.gov/ncbddd/spinabifida/adult.html
• Medical Home Portal: Spina bifida:
  https://www.medicalhomeportal.org/diagnoses-and-conditions/spina-bifida
References

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