



Guidelines for the Care of People with Spina Bifida

Nutrition, Metabolic Syndrome, and Obesity

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We thank the work of the 2018 Workgroup Members: Amy C McPherson, PhD, (Chair); Lorry Chen, RD; Joseph O'Neil, MD, MPH; Kerri A Vanderbom, PhD

Introduction

Good quality nutrition is important for everyone. Individuals with Spina Bifida experience unique challenges related to varied dietary intake across the lifespan.¹ This is typically due to a complex interplay of medical and social factors². Children with Spina Bifida who have a latex allergy may limit intake of fresh fruits and vegetables due to cross-reacting foods (See Latex Guideline). Those with the Chiari II malformation may have an aversion to textured foods.³ For many individuals with Spina Bifida, the negative impact of bowel and bladder accidents may lead some to restrict hydration and dietary intake, especially during the daytime.⁴ Altered eating habits can lead to constipation, skin breakdown, osteoporosis, anemia, metabolic syndrome, and other secondary conditions.⁵ It is therefore critical to work with children, families and adults with Spina Bifida to emphasize the importance of healthy nutrition and a varied diet on overall health and wellness, while understanding their daily concerns and living context.⁶

Most children with Spina Bifida follow typical growth patterns until they are approximately four years of age. After that, increased fat mass (versus lean mass) has been found when compared with children without Spina Bifida.⁷ In addition, children and adults with Spina Bifida often have shorter stature, secondary lower limb paralysis or orthopedic complications. The increased fat mass combined with a shorter stature often leads to body weight being categorized as overweight or obese⁸. Although higher weights do not automatically confer poor health⁹, excess fat mass or where excess fat is distributed may increase risk of outcomes such as metabolic syndrome, cardiovascular disease and type II diabetes.¹⁰ Girls with Spina Bifida diagnosed with premature puberty may experience weight gain.¹¹ Sleep apnea can result from excess body fat or changes in weight over time¹². Carrying excess body fat may further challenge mobility and self-care tasks.¹³ It is important for people with Spina Bifida to understand the possible risks associated with both poor nutrition and excess body fat and for health care professionals to discuss these topics using a collaborative, strengths-based approach (see both Health Promotion Guidelines and Physical Activity Guidelines).



Body Mass Index (BMI, based on an individual's height and weight) is an imperfect assessment of body composition, in part because it does not account for fat and lean tissue.¹⁴ In addition, there are challenges to obtain height and weight measurements to calculate BMI or there can be variability in the techniques used. Use of length or arm span versus a standing height is often used when a person is unable to independently stand.¹⁵ Difficulties obtaining these variables (weight and height, length or arm span) may arise in busy clinics due to privacy, clothing, and shoe variations, and changes with braces and wheelchair attachments. Furthermore, the space, personnel and equipment needed can create additional challenges (e.g., two staff to obtain an arm span, wheelchair scale vs. standard scale). The combination of these issues can result in BMIs that do not accurately reflect the body composition of the patient. Finally, BMI is not a direct measurement of health. However, BMI is often calculated at clinical encounters to track an individual's BMI trajectory *over time* and can guide the discussion of appropriate nutrition and weight management strategies. The appendix accompanying these guidelines summarizes anthropometric measurement techniques that can be used with individuals with Spina Bifida.

The aim of these guidelines is to provide the best available evidence for promoting healthy nutrition and weight in people with Spina Bifida across the lifespan. The guidelines also provide suggestions for how health care professionals can approach positive weight-related conversations, facilitate shared decision-making, as well as provide strategies for preventing obesity-related co-morbidities and optimizing independence and self-care throughout the lifespan.

Outcomes

Primary

1. Maximize and support wellness through the lifespan.

Secondary

1. Reduce and prevent secondary conditions related to poor nutrition and overweight/obesity.

Tertiary

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

0-11 months

Clinical Questions

1. What nutritional support should be provided when infants with Spina Bifida first go home from the hospital?
2. What guidance on breastfeeding and/or use of breast milk should be given to



parents of infants with Spina Bifida?

Guidelines

1. Assess weight, height, and occipital frontal head circumference¹⁶ at every clinical encounter¹⁷. (see Appendix)
2. Ensure that the family's nutrition plan is followed closely by primary care provider(s):
 - Refer the family to community nursing and other support groups to ensure close monitoring of the child's growth and whether there are issues with feeding and elimination. (clinical consensus)
 - Connect the family with the Spina Bifida specialist clinic nearest them. (clinical consensus)
3. Discuss feeding options at pre- and post-natal timeframes with parents and caregivers. Provide evidence-based information and guidance for formula and breast-feeding, share resources available for each option, answer questions and support the decision that fits the family's desires and abilities.
4. Formula selection for non-breastfed infants can be guided by the care team. Selecting the most appropriate formula may depend on a variety of factors including gestational age, growth, development and tolerance.
5. If breastfeeding is the preferred option, additional considerations and discussion points should be considered, including:
 - Discuss with them that ideally, infants with Spina Bifida should be breastfed or given breast milk exclusively for the first 6 months. Infants should continue to have breast milk for a year or more, as with all neonates.¹⁸
 - Share the evidence-based benefits of breastfeeding: Breastmilk provides significant health benefits for all infants, but especially for those with congenital challenges, who may require added support for wound healing with early surgical intervention, nutritional challenges, and higher risks of infections. More specifically, breastmilk contains immunoglobulin A (IgA), lysozymes and lactoferrin that provide protection against infections requiring hospitalization. Nutrient bioavailability in breastmilk provides an added benefit for neurocognitive development with docosahexanoic acid (DHA)¹⁹
 - Feeding breastmilk may impact the infant's microbiome and future impact over time needs further study (Dudley 2024).
 - Provide resources such as lactation consultants that are available to support breastfeeding or to troubleshoot challenges that may be encountered
 - Parental knowledge of breastfeeding benefits may be known; however, initiation of breastfeeding may be especially challenging due to the infant's complications shortly after birth and an even greater supportive environment than usual may be necessary to encourage breastfeeding.²⁰

- Inform the mother that if the child's spinal surgery precludes immediate breast feeding, it may be possible to pump breastmilk to feed the child until it is possible to transfer him or her to her breast.²¹
- Support the mother to begin expressing breast milk within the first few hours of delivery if she is able and willing to do so by offering information on the benefits of breastmilk and support equipment as necessary.²⁰
- If the mother wants to breastfeed, support them to pump frequently (eight to 10 pumping sessions per 24 hours for the first seven-10 days) to ensure enough breastmilk will be available once infant has surgery.²¹
- Advocate for babies to be hospitalized in close proximity to their mothers to facilitate breastfeeding if possible.²²
- Provide mothers with information about accessing breast milk banks and planning for situations where she cannot provide it herself.²³
- Encourage mothers to nurse their child in a flat position for 5 days following surgery to reduce pressure on the wound to avoid a cerebral spinal fluid leak.²⁴
- Provide the mother with information about breastfeeding equipment options that can help meet the individual needs of the child with Spina Bifida (e.g., different types of propping pillows, nipples, nipple shields, bottles, pumps, latex-free equipment).²¹
- Incorporate a lactation consultant to be a resource for the mother. Consider having these discussions before the birth of the child.
- Mention that 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,^{2, 21}
- Support mothers in consulting with feeding specialists to recommend the appropriate thickener for their breast milk to prevent aspiration, given that typical baby cereals often have a negative enzymatic reaction.²⁵
- Suggest breastfeeding or non-nutritive sucking (finger or pacifier) as ways to provide comfort to the infant and assist with pain management for acute procedures, such as injections.²⁶
- Highlight that the baby's transition from drinking breastmilk to eating solid food can cause constipation.²⁷ Hypotonia related to the condition may impact the transition to solid food intake.² Recognize additional anticipatory guidance and nutritional consultation may be beneficial during this timeframe.
- Close multi-disciplinary follow-up is indicated for infants with slow weight gain, growth limitations or conversely, fast gains.

1-2 years 11 months

Clinical Questions

1. What evidence-based information on nutrition and obesity prevention & management can be provided to parents?

2. What is the best way to manage constipation with diet for this age group?
3. How can providers communicate with parents about the benefits of a varied diet in an understandable and non-judgmental manner?
4. What are the best methods to provide anticipatory guidance focused on parental feeding, i.e., recognizing hunger cues, providing a diverse range of foods from all food groups with multiple attempts, to promote varied dietary intake.

Guidelines

1. Assess weight and height at every clinical encounter to track over time¹⁷. (Clinical consensus, see Appendix)
2. Measure occipital frontal head circumference until 2 years of age¹⁶ (see Appendix)
3. Support families to establish health-promoting food behaviors within their family. Tailor the advice to the family context as appropriate.
 - Start introducing a range of appropriate foods as early as possible to get them integrated into food preferences. It may be harder to do so later, when food preferences are more entrenched.²⁸
 - Recognize that children with Chiari II malformation may have sensitivity to different food textures.³
 - Consider that families with lower incomes may experience food insecurity.¹ Explore their ability to access additional resources to ensure sufficient nutrition.
 - Encourage parents and caregivers to provide as varied a diet as possible. Specific types of energy-dense foods that are high in fat and have a low water content (e.g., cookies, chips, nuts) can be part of a varied diet in moderation. Over restriction can lead to over-eating of those foods when they become available.²⁸ Therefore, varied dietary intake is important.
 - Caution parents against using food solely as a reward/ positive reinforcement, which can create a difficult relationship with food that is hard to break later on and may lead to altered eating behaviors.^{28, 29} Provide parents with other strategies for positive reinforcement rewards such as praise, stickers, and small toys. (clinical consensus)
 - Educate families on the importance of consuming a varied diet and how it affects the whole body.⁶
 - Provide guidance to families that promote authoritative feeding behaviors,³⁰ responding to hunger and satiety cues of the child. Parents provide options and determine times of eating, child autonomously determines what and how much they eat.
 - Discuss that some fluid and food choices used to help ensure hydration and bladder/bowel function are not necessarily the right choices for weight management (e.g. chocolate milk, juice, and sports beverages). Encourage hydration by drinking water).³¹

4. Speak with parents about nutrition in terms of their child's health and growth.
 - Provide regular opportunities for parents to discuss any concerns about their child's weight, growth and/or eating behaviors.³² A trusting therapeutic relationship can greatly facilitate an honest and open discussion.³³
 - Partner with parents to identify and address specific nutritional challenges that the family is facing.³³
 - Discuss that a limited diet and reduced activity may lead to constipation, skin breakdown, osteoporosis, anemia, and other problems in all children, including those with Spina Bifida.⁵ Additionally, mention that children with Spina Bifida have less calorie-burning tissue (lean body mass) and a lower rate of burning calories (metabolic rate).^{8, 34}
 - Show parents the trajectory of a child's weight and height, BMI (or other measures of growth and adiposity), if appropriate. Use a growth chart as a visual aid, without referring to growth cut-offs developed for typically developing children or using just one datapoint.¹ A steeply-increasing trajectory would warrant proactive discussions of current feeding/eating behaviors and activity levels.³³
 - Increase accuracy of measurements taken within the clinic through the use of calibrated equipment and proper technique, and use the same techniques each time to ensure consistency between data points (see appendix)
 - Highlight the importance of parents modeling healthy behaviors to their children from an early age.^{20, 28, 35, 36} Encourage the whole family to get involved in healthy living activities³⁷, not just the child with Spina Bifida.
 - Discuss that children with Spina Bifida, especially those who are non-ambulatory, who undertake low levels of physical activity and have higher body fat levels or contractures, are at increased risk for bone fractures.³⁸ Encourage physical activity and healthy lifestyles (See Physical Activity Guidelines)
 - Explain the multifactorial influences of decreased resting energy expenditure, higher incidence of surgeries, although healing needs may be confounded by social issues such as living in food deserts or financial constraints².
5. Provide guidance on maintaining good bowel health.
 - Explain that increased fiber in the child's diet will add bulk to the stool and make it easier to pass. Sources of fiber include fruit, vegetables, and whole-grain bread and cereals.⁵
 - Daily fiber intake can be estimated using either an age-based or weight-based approach applying the same guidelines that are recommended for all children.³⁹ Using the child's age + 5 rule or multiplying 0.5 grams of fiber per kg of body weight up to 35 grams per day provides an estimate of needs. Adding adequate amounts of soluble fiber (water absorbing for softening and frequency of stool) and insoluble fiber (non-water absorbing for

- bulking stool) in fruits, vegetables, nuts and legumes will also be beneficial.^{40,41}
- Recommend that if the child is constipated, parents should increase fiber intake slowly over two to three weeks by adding one new high fiber food every two to three days. Increasing fiber too quickly can make constipation worse or cause gas, cramping, and diarrhea.⁴²
 - Recommend more fluids, especially water and non-caloric fluids, which will also soften the stool and help with constipation. Follow the daily Maintenance Fluid Requirements (24 hour period) Calculation⁴³:
 - 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
 - Discuss bowel health in relation to the child's broader continence goals to reduce the risk of incontinence episodes and subsequent family disengagement (clinical consensus)
 - Further guidance can be found in the Bowel Function and Care Guidelines.
6. Screening for dyslipidemia (fasting lipid profile) is recommended every two years from 2 years of age if the child's BMI is above 95th percentile or a family history of dyslipidemia/early cardiovascular disease and/or morbidity in first- or second-degree relatives is present⁴⁴
7. Have nutrition and weight-related resources available to share with youth and families.
- Confirm that information is evidence based and at the appropriate literacy level.
 - Provide consultations with appropriate specialists as needed, e.g., registered dietitians.

3-5 years 11 months

Clinical Questions

1. What evidence-based information on nutrition and weight management can be provided to parents?
2. What is the best way to manage constipation with diet for this age group?
3. How can providers communicate with parents about the benefits of a varied diet in an understandable and non-judgmental manner?
4. What are the best methods to provide anticipatory guidance focused on parental feeding, i.e. recognizing hunger cues, providing a diverse range of foods from all food groups with multiple attempts, to promote varied dietary intake.

Guidelines

1. Conduct annual assessments of weight, height, or alternative height (e.g., arm span or recumbent length), and track BMI over time, looking at trends rather than single data points. (clinical consensus, see Appendix)
2. Discuss general nutrition principles with all families and highlight the importance of healthy behaviors for the entire household.
 - Provide regular opportunities for parents to discuss concerns with their child's weight, growth, and/or eating behaviors.³² A trusting therapeutic relationship can greatly facilitate an honest and open discussion.⁴⁵
 - Explain that most children with Spina Bifida follow typical growth patterns until they are four years of age. After that, increased fat mass (versus lean mass) has been found when compared with children without Spina Bifida.^{2, 7}
 - Discuss that linear growth or height will also be slower than peers without Spina Bifida due to paresis or paralysis of lower limbs⁴⁶, which also reduces calorie requirement.
 - Show parents the trajectory of a child's weight and height (or other measures of growth and adiposity). Use a growth chart as a visual aid, without referring to growth cut-offs developed for typically developing children.¹ A steeply-increasing trajectory would warrant discussions about current feeding/eating behaviors and activity levels.³³
 - Discuss with parents, if relevant, that BMI is an imperfect indicator of health in most individuals with Spina Bifida and especially in children with Spina Bifida due to difficulties measuring height and body composition.³⁴
 - Consider monitoring other measures of adiposity, such as waist circumference.⁴⁷ (see Appendix)
 - Highlight that early eating patterns and relationships with food are critical for ongoing good nutrition through the lifespan.³²
 - Provide guidance to families that promote authoritative feeding behaviors³⁰, responding to hunger and satiety cues of the child. Parents provide options and determine times of eating, and the child autonomously determines what and how much they eat.
 - Emphasize the broad benefits of a varied diet and physical activity, offering strategies to enable the child to incorporate healthy lifestyle behaviors appropriate to their abilities.⁴
 - Discuss that some fluid and food choices to help ensure hydration and bladder/bowel function are not necessarily the right choices for weight management (e.g., chocolate milk, juice, and sports beverages).³¹
 - Consider that nutritional challenges may arise from other circumstances including food intolerances, allergies, food selectivity and/or medical complications such as gastrointestinal reflux, constipation, neurogenic bladder or medication interactions.²
 - Highlight that children with Spina Bifida, especially those who are non-ambulatory, who undertake low levels of physical activity, and who have

- higher body fat levels or contractures, are at increased risk for bone fractures. Recommend a diet with adequate calcium and vitamin D, after a child turns 4 years of age, when calcium needs increase to 1000 mg daily.³⁸ To achieve these goals, approximately 3 (8 ounce) cups of low fat milk are suggested or a combination of 2 cups of low fat milk and one cup of low fat yogurt. Alternative calcium foods are necessary to incorporate into the diet if a child avoids dairy based foods due to allergies, intolerance, or acceptance.
- Consider that families with lower incomes may experience food insecurity.¹ Explore their ability to access additional resources to ensure sufficient nutrition.
 - Provide guidance to families that promote authoritative feeding behaviors,³⁰ responding to hunger and satiety cues of the child. Parents provide options and determine times of eating, child autonomously determines what and how much they eat.
3. Provide guidance on maintaining good bowel health.
- Explain that increased fiber in the child's diet will add bulk to the stool and make it easier to pass. Sources of fiber include fruit, vegetables, and whole meal or whole grain bread and cereals.⁵
 - Daily fiber intake can be estimated using either an age-based or weight-based approach applying the same guidelines that are recommended for all children.³⁹ Using the child's age + 5 rule or multiplying 0.5 grams of fiber per kg of body weight up to 35 grams per day provides an estimate of needs. Adding adequate amounts of soluble fiber (water absorbing for softening and frequency of stool) and insoluble fiber (non-water absorbing for bulking stool) in fruits, vegetables, nuts and legumes will also be beneficial.^{40, 41}
 - Recommend that if the child is constipated, parents should increase fiber intake slowly over two to three weeks by adding one new high fiber food every two to three days. Increasing fiber too quickly can make the constipation worse or cause gas, cramping, and diarrhea.⁴²
 - Recommend more fluids, especially water and non-caloric fluids, which will also soften the stool and help with constipation. Follow the daily Maintenance Fluid Requirements (24 hour period) Calculation⁴³:
 - 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
 - Discuss bowel health in relation to the child's broader continence goals to reduce the risk of incontinence episodes and subsequent family disengagement (clinical consensus)
 - Further guidance can be found in the Bowel Function and Care Guidelines.

4. Screening for dyslipidemia (fasting lipid profile) is recommended every two years if the child's BMI is above the 95th percentile or a family history of dyslipidemia/early cardiovascular disease and/or morbidity in first- or second-degree relatives is present.⁴⁴
5. Have nutrition and weight-related resources available to share with youth and families.
 - Confirm that information is evidence-based and at the appropriate literacy level.
 - Provide consultations with appropriate specialists as needed, e.g., registered dietitians.

6-12 years 11 months

Clinical Questions

1. What information do schools and communities need to know about the special dietary and adapted equipment needs of students with Spina Bifida to help children eat and access food independently?
2. What parenting strategies can encourage a varied diet for the whole family?
3. What is the best way to manage constipation with diet for this age group?
4. Are children with Spina Bifida at higher risk for obesity-related comorbidities?
5. Should screening for metabolic complications of obesity be performed in children aged 6-12 years with Spina Bifida?

Guidelines

1. Conduct annual assessment of weight, height or an alternative height (e.g., arm span or recumbent length) and BMI, looking at trends over time rather than single data points. Alternative measures to consider could include segmental limb lengths and/or seated height.² It is important to be consistent in measurement assessment so that they can be tracked over time (clinical consensus, see Appendix)
2. Consider monitoring other measures of adiposity or body composition² monthly/annually and track the trajectory.⁴⁷ (see Appendix)
3. Conduct annual assessment of blood pressure/percentiles to monitor for pre-hypertension and hypertension. (clinical consensus)
4. Highlight dietary needs specific to living with Spina Bifida.
 - Discuss the importance of consuming fiber and water to manage bowel and bladder health. Sources of fiber include fruits, vegetables, whole-wheat or whole grain bread and cereals. A mix of each along with regular fluids, will help avoid constipation.⁵
 - Advise limiting sugary drinks such as juice, chocolate milk, and sports beverages.^{48, 49}
 - Discuss that children with Chiari malformation may have a sensitivity to

- different food textures.³
- Recommend that the child have access to food purchasing and preparation spaces. (clinical consensus).
- Recommend a diet with adequate calcium and vitamin D for children with Spina Bifida to avoid fractures due to osteoporosis.³⁸
 - Examples of food to include in the diet include milk, yogurt, and cheese, canned fish (e.g., salmon or sardines) and fortified food options such as some juices, cereals or plant-based milk alternatives.
 - If supplements are being used or recommended, provide consultation with a registered dietitian for proper dosing.
 - Refer clients to the National Center on Health, Physical Activity, and Disability <http://www.nchpad.org>), which provides advice on nutrition and physical activity for persons with disabilities, including Spina Bifida.⁵⁰
- 5. Provide families with nutritional information tailored to their circumstances.
 - Take into account a family's geographical location, ethnicity, access to food, and other biopsychosocial factors when providing dietary education.⁵¹
 - Consider that adults and families with lower incomes may experience food insecurity and limited access to diverse dietary options.¹ Explore their ability to access additional resources to ensure sufficient nutrition.
 - Caution parents about finding reliable sources of nutrition information and being cautious of social media advertising for supplement products.²
 - Incorporate culturally relevant practices into meal planning and food choices that foster acceptance and life-long habits for medical nutrition therapy practices.²⁰
 - Encourage parents to include their children from an early age to participate in grocery shopping and food preparation, as appropriate to their age and ability.⁵²
 - Suggest parents let their children choose a new food (e.g., a fruit or vegetable) to try. Involving children in choices can lead them to increased independence and interest in their foods. Repeating their exposure to varied options can help them increase their acceptance and enjoyment of them.⁵³
 - Involve children in discussions about healthy lifestyles in order to explore their understanding, perceptions, and priorities regarding nutrition.³³ If appropriate, ask parents to identify one or two small, nutrition changes that they feel they could integrate into their daily life.⁵⁴
 - Celebrate any successes, such as drinking more water, introducing a new fruit or vegetable, cutting back on sugary drinks, and having regular mealtimes. Focus upon the strengths of the family.³³
 - Highlight the importance of parents modeling healthy behaviors to their children from an early age.^{28, 35, 36} Encourage the whole family to get involved in healthy living activities³⁷, not just the child with Spina Bifida. Balance technology usage with physical activity⁵⁵.

- Emphasize to parents the importance of eating patterns related to portion sizes and avoid enforcing that a child has to finish all of the food on the plate or providing food as a coping strategy for boredom.²⁰
 - Connect with the school to develop a plan around eating and optimizing nutrition.^{20, 55}
 - Identify community supports available for the patient and their family. However, understand that lack of engagement in these supports is often related to busy family schedules and multiple medical appointments and not simply “non-compliance”.⁵⁵
 - Provide guidance to families that promote authoritative feeding behaviors,³⁰ responding to hunger and satiety cues of the child. Parents provide options and determine times of eating, and the child autonomously determines what and how much they eat.
 - Highlight that children with Spina Bifida, especially those who are non-ambulatory, who undertake low levels of physical activity, and who have higher body fat levels or contractures, are at increased risk for bone fractures. Recommend a diet with adequate calcium and vitamin D.³⁸ especially when a child turns 9 years of age and their calcium needs increase to 1300 mg daily.³⁸ To achieve these goals, approximately 4 servings of low fat dairy. Alternative calcium foods are necessary to incorporate into the diet if a child avoids dairy based foods due to allergies, intolerance, or acceptance.
6. Screening for diabetes (fasting glucose, HbA1c or oral glucose tolerance test) every two years is recommended in children 10 years of age or older, or at the onset of puberty if it occurs at a younger age, with a Body Mass Index (BMI) over the ≥85th percentile and have one or more additional risk factors including^{56, 57}
 - i. family history of Type 2 Diabetes Mellitus (T2DM) in a first- or second-degree relative,
 - ii. high-risk ethnicity,
 - iii. maternal history of gestational diabetes
 - iv. acanthosis nigricans,
 - v. hypertension,
 - vi. dyslipidemia or
 - vii. polycystic ovary syndrome (PCOS).
 - viii. Use of obesogenic psychotropic medications
 7. Currently there is no consensus on screening for lipid disorders in children and adolescents. The US Preventive Services Task Force has determined that there is insufficient evidence for screening in asymptomatic children or adolescents less than 20 years of age. Other organizations including the National Heart, Lung, and Blood Institute’s Expert Panel on Integrated Guidelines for Cardiovascular Health and Risk Reduction in Children and Adolescents, the American Academy of Pediatrics’ Bright Futures program, and the multi-society Guideline on the Management of Blood Cholesterol recommend selectively

screening children with a family history of cardiovascular disease or dyslipidemia or other risk factors (e.g., family history of dyslipidemia/early cardiovascular disease and/or morbidity in first- or second-degree relatives, history of diabetes, hypertension, or smoking in childhood) as early as age 2 years. They also recommend universally screening children aged 9 to 11 years and again at ages 17 to 21 years. Encourage families to discuss any concurrent risk factors that are present.⁵⁸

8. Provide guidance on maintaining good bowel health.

- Explain that increased fiber in the child's diet will add bulk to the stool and make it easier to pass. Sources of fiber include fruit, vegetables, and whole meal or whole grain bread and cereals.⁵
- Daily fiber intake can be estimated using either an age-based or weight-based approach applying the same guidelines that are recommended for all children.³⁹ Using the child's age + 5 rule or multiplying 0.5 grams of fiber per kg of body weight up to 35 grams per day provides an estimate of needs. Adding adequate amounts of soluble fiber (water absorbing for softening and frequency of stool) and insoluble fiber (non-water absorbing for bulking stool) in fruits, vegetables, nuts and legumes will also be beneficial.^{40, 41}
- Recommend that if the child is constipated, parents should increase fiber intake slowly over two to three weeks by adding one new high fiber food every two to three days. Increasing fiber too quickly can make the constipation worse or cause gas, cramping, and diarrhea.⁴²
- Recommend more fluids, especially water and non-caloric fluids, which will also soften the stool and help with constipation. Follow the following daily Maintenance Fluid Requirements (24 hour period) Calculation⁴³:
 - 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
- Discuss bowel health in relation to the child's broader continence goals to reduce the risk of incontinence episodes and subsequent child/family disengagement (clinical consensus).
- Further guidance can be found in the Bowel Function and Care Guidelines.
 - Have nutrition and weight-related resources available to share with youth and families.
- Confirm that information is evidence-based and at the appropriate literacy level.
- Provide consultations with appropriate specialists as needed, e.g., registered dietitians.

13-17 years 11 months

Clinical Questions

1. What is the most effective protocol to approach diet and nutrition goals in annual Spina Bifida clinic visits?
2. What are biggest barriers to varied nutrition for children with Spina Bifida in this age group?
3. What self-management skills and resources related to varied nutrition should be provided for children with Spina Bifida?
4. What is the best way to manage constipation with diet?
5. Are children with Spina Bifida and obesity at higher risk for metabolic syndrome?
6. Should screening for metabolic complications of obesity be performed in children aged 13-17 with Spina Bifida?

Guidelines

1. Conduct annual assessments of weight, height, or alternative height (e.g., arm span or recumbent length) and BMI, while acknowledging the limits of BMI. (clinical consensus, see Appendix)
2. Consider monitoring other measures of adiposity or body composition⁴⁷ (see Appendix) and plot the trajectory over time.
3. Conduct annual assessment of blood pressure/percentiles to monitor for pre-hypertension and hypertension. (clinical consensus)
4. 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 minimize skin breakdown, and increase activity and endurance.⁸
 - Discuss that children with Spina Bifida, especially those who are non-ambulatory, who undertake low levels of physical activity, and who have higher body fat levels or contractures, may have lower energy needs²⁰ are at increased risk for bone fractures. Recommend a diet with adequate calcium and vitamin D.³⁸
 - Examples include milk, yogurt, and cheese, canned fish (e.g., salmon or sardines) and fortified food options such as some juices, cereals or plant-based milk alternatives.
 - If Vitamin D or Calcium supplements are being used or recommended, provide consultation with a registered dietitian for proper dosing.
 - Provide regular opportunities for teens to discuss any concerns with their weight, growth and diet.³² A trusting therapeutic relationship can greatly facilitate an honest and open discussion.³³
 - Identify the teen's priorities and negotiate goals that meet those priorities as well as the parent's and clinician's goals.⁵⁹
 - Use a strengths-based approach that highlights their nutritional achievements and celebrates successes.³³
 - Discuss with parents, if relevant, that the Body Mass Index (BMI) is an

- imperfect indicator of health and presents increased challenges in children with Spina Bifida due to difficulties measuring height and body composition.³⁴ Instead, show the child and parents the trajectory of the child's weight and height (or other measures of growth and adiposity) on a growth chart as a visual aid. Do not refer to growth cut-offs developed for typically developing children.¹ A steeply-increasing trajectory would warrant proactive discussions of current feeding/eating behaviors and activity levels.^{20, 33}
- When discussing weight with older children and youth with Spina Bifida, it's important to avoid using fear-based approaches. Instead, consider having supportive and individualized conversations that explore how weight may impact their health and daily functioning. Depending on the person's specific situation, this might include:
 - Moving and transferring may become more difficult, which may also reduce independence and self-care activities.⁸
 - Increased pressure on the skin when seated for long periods of time (such as when using a wheelchair) may result in skin breakdown⁶⁰
 - Weight gain alongside existing scoliosis or kyphosis may result in additional breathing problems.⁵
 - It's also important to recognize that higher weight does not necessarily mean poor health.
 - Monitor for disordered eating habits that may require additional clinical support for positive intervention related to healthy eating.^{20, 61}
 - Highlight the benefits of exercise training (including aerobic and strength training) for cardiorespiratory endurance, muscle strength and mobility.^{62, 63}
 - Refer clients to the National Center on Health, Physical Activity, and Disability (<http://www.nchpad.org>), which provides advice on nutrition and physical activity for persons with disabilities, including Spina Bifida.⁶⁴
5. Consider the broader literature for all older children, given that there is little evidence specifically for teens with Spina Bifida. For instance:
- Understand that eating habits generally worsen for all individuals as they move from childhood into the teen years and become more autonomous.⁶⁵
 - Emphasize the positive health benefits of breakfast and eating fruits and vegetables.^{36, 66} Skipping breakfast and low fruit and vegetable consumption is common in teens.⁶⁷
 - Recommendation of 5 servings of fruits and vegetables daily. Provide information on serving size and options to increase consumption, e.g., frozen or canned options (ref).
 - Consider that food insecurity and lower socioeconomic status can be related to less varied diets.⁶⁸ Explore their ability to access additional resources to ensure sufficient nutrition.
 - Emphasize that the family setting remains important for teens. Parental

- modelling, dietary intake, and encouragement are all associated with fruit and vegetable consumption among teens.³⁶
 - Some children with SB may have disruptions in appetite regulation hormones such as leptin and ghrelin, making satiety more challenging, although this requires further study.⁶⁹
6. Discuss opportunities for teens to participate in nutrition-related activities and develop knowledge and skills, including:
 - Identifying the teen's knowledge level about healthy eating habits. (clinical consensus)
 - Encouraging the family to identify roles that the teen can play as part of daily life, such as meal planning, shopping, and food preparation.⁷⁰
 - Encouraging teens to select a new food to try, which can encourage broader food preferences.⁷¹
 - Identifying the teen's existing strengths and resources regarding nutrition and how they can be built upon to reach their goals.⁷²
 7. Screening for diabetes (fasting glucose, HbA1c, or oral glucose tolerance test) every two years with a Body Mass Index (BMI) over the $\geq 85^{\text{th}}$ percentile and have one or more additional risk factors including^{44, 56}
 - family history of Type 2 Diabetes Mellitus (T2DM) in a first- or second-degree relative,
 - high-risk ethnicity,
 - maternal history of gestational diabetes
 - acanthosis nigricans,
 - hypertension,
 - dyslipidemia
 - polycystic ovary syndrome (PCOS).
 - use of obesogenic psychotropic medications
 8. Currently there is no consensus on screening for lipid disorders in children and adolescents. The US Preventive Services Task Force has determined that there is insufficient evidence for screening in asymptomatic children or adolescents less than 20 years of age. Other organizations including the National Heart, Lung, and Blood Institute's Expert Panel on Integrated Guidelines for Cardiovascular Health and Risk Reduction in Children and Adolescents, the American Academy of Pediatrics' Bright Futures program, and the multi-society Guideline on the Management of Blood Cholesterol recommend selectively screening children with a family history of cardiovascular disease or dyslipidemia or other risk factors (e.g., family history of dyslipidemia/early cardiovascular disease and/or morbidity in first- or second-degree relatives, history of diabetes, hypertension, or smoking in childhood) as early as age 2 years. They also

recommend universally screening children aged 9 to 11 years and again at ages 17 to 21 years. Encourage families to discuss any concurrent risk factors that are present.⁵⁸

9. Provide guidance on maintaining good bowel health.
 - a. Explain that increased fiber in the child's diet will add bulk to the stool and make it easier to pass. Sources of fiber include fruit, vegetables, and whole-meal or whole grain bread and cereals.⁵
 - b. Daily fiber intake can be estimated using either an age-based or weight-based approach applying the same guidelines that are recommended for all children.³⁹ Using the child's age + 5 rule or multiplying 0.5 grams of fiber per kg of body weight up to 35 grams per day provides an estimate of needs. Adding adequate amounts of soluble fiber (water absorbing for softening and frequency of stool) and insoluble fiber (non-water absorbing for bulking stool) in fruits, vegetables, nuts and legumes will also be beneficial.^{40, 41}
 - c. Recommend that if the child is constipated, parents should increase fiber intake slowly over two to three weeks by adding one new high fiber food every two to three days. Increasing fiber too quickly can make constipation worse or cause gas, cramping, and diarrhea.⁴²
 - d. Recommend more fluids, especially water and non-caloric fluids, which will also soften the stool and help with constipation. Follow the following daily Maintenance Fluid Requirements (24 hour period) Calculation⁴³:
 - 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
 - e. Discuss bowel health in relation to the youth's broader continence goals to reduce the risk of incontinence episodes and subsequent youth/family disengagement (clinical consensus).
 - f. Further guidance can be found in the Bowel Function and Care Guidelines.
10. Have nutrition and weight-related resources available to share with youth and families.
 - a. Confirm that information is evidence-based and at the appropriate literacy level.
 - b. Provide consultations with appropriate specialists as needed, e.g., registered dietitians.

18 + years

Clinical Questions

1. How do nutrition issues vary by different demographics (e.g., age, geography,



level of lesion, economic status, race and ethnicity, gender, etc.) among adults with Spina Bifida?

2. What considerations should be given to nutritional intake when adults with Spina Bifida are taking medications to address other health concerns?
3. What is the best way to manage constipation with diet?
4. Are adults with Spina Bifida who have obesity at higher risk for metabolic syndrome?
5. Should screening for physiologic complications of obesity be performed in adults with Spina Bifida?

Guidelines

1. Conduct annual assessments of weight, height, or alternative height (e.g., arm span or recumbent length), and calculate BMI. (clinical consensus, see Appendix)
2. However, explain that BMI has decreased accuracy for people with paralysis, who have lowered ratios of fat to lean muscle tissue⁷³ and that looking at the trajectory over time may be more useful.
3. Consider monitoring other measures of adiposity and tracking over time to establish a trajectory.⁴⁷ (see Appendix)
4. Conduct an annual assessment of blood pressure/percentiles to monitor for pre-hypertension and hypertension. (clinical consensus)
 - Tailor the discussion around varied nutrition to the adult's context. Recognize that there is individual variation in independence, cognitive ability, and medical complexity that might impact nutritional patterns.²
 - Consider that adults and families with lower incomes may experience food insecurity.¹ Explore their ability to access additional resources to ensure sufficient nutrition.
 - Refer clients to the National Center on Health, Physical Activity, and Disability (<http://www.nchpad.org>), which provides advice on nutrition and physical activity for persons with disabilities, including Spina Bifida.⁶⁴
 - Identify who requires information about a varied diet (i.e. the adult with Spina Bifida, the caregiver, the attendant, the family member, or others).¹
 - Explore the adult's existing access to cooking options and food preparation areas. (clinical consensus)
 - Involve a social worker or disability organization representative who can speak to adults about available local, state, and federal nutritional benefits such as the Supplemental Nutrition Assistance Program (SNAP), farmer's market vouchers or coupons, and other sorts of food vouchers that are available for eligible individuals.^{74, 75}
5. Provide information about potential interactions between nutrition in foods and medications.
 - Highlight that some medications, such as corticosteroids, have side-effects

- including weight gain, increased appetite, high blood pressure and a higher risk of developing osteoporosis or diabetes.⁷⁶
- Provide information about specific foods and beverages that may interact with medications, such as anti-hypertensive, anticoagulant, or corticosteroid medications.⁷⁷
 - Encourage adults to disclose any prescribed, over-the-counter or complementary and alternative medications they are taking to all of their health care professionals, including pharmacists. (clinical consensus)
 - Emphasize the importance of reading medication labels to identify any dietary contraindications.¹ If this is difficult, discuss other ways that the adults could find out about potential contraindications, such as making the medication labels available in a larger font or asking the pharmacists for assistance.⁷⁸
6. Have nutrition and weight-related resources available to share.
 - Confirm that information is evidence-based and at the appropriate literacy level.
 - Provide consultations with appropriate specialists as needed, e.g., registered dietitians.
 7. Screening for abnormal blood glucose is indicated as part of assessing cardiovascular risk assessment in adults aged 40 to 70 years who have a BMI > 25 kg/m². Individuals who have a family history of diabetes, have a history of gestational diabetes or polycystic ovarian syndrome, or are members of high-risk racial/ethnic groups may be at increased risk for diabetes at a younger age or at a lower body mass index. Clinicians should consider screening earlier in persons with one or more of these characteristics.⁷⁹
 8. Screening for dyslipidemia (fasting plasma profile) is recommended for men ≥ 40 years of age, and women ≥ 50 years of age or postmenopausal. Adults with the following risk factors should be screened at any age: Current cigarette smoking, diabetes, arterial hypertension, family history of premature coronary heart disease, family history of hyperlipidemia, high risk ethnicity (individuals of First Nations or of South Asian ancestry), or the presence of rheumatoid arthritis, systemic lupus erythematosus, psoriatic arthritis, ankylosing spondylitis, inflammatory bowel disease, chronic obstructive pulmonary disease, chronic HIV infection, chronic kidney disease, abdominal aneurysm, or erectile dysfunction.⁸⁰
 9. Provide information on changes individuals with a uterus commonly experience around peri/menopause, including adipose tissue accumulating in the abdominal area, increased cardiovascular risk, and decreased bone density.⁸¹ Although there is currently no evidence that individuals with Spina Bifida experience menopause earlier than those without Spina Bifida,⁸² anticipatory advice around calcium intake and other biopsychosocial factors that can impact health at this time of life is suggested (clinical consensus).
 10. Address change in calcium and vitamin D requirements, including calcium decreasing to 1000mg/day starting at age 19.



Research Gaps

1. Evidence-based guidelines for weight-management, obesity prevention, and obesity treatment specific to children and adults with Spina Bifida.
2. Accurate assessment of body composition in a standardized and accessible manner.
3. Growth curves and weight classification cut-offs specifically for children and adults with Spina Bifida.
4. Evidence about the energy needs of people with Spina Bifida across the lifespan that is based on their mobility methods.
5. Whether children and adults with Spina Bifida are at higher risk for metabolic syndrome or other weight-related co-morbidities.
6. Whether screening for physiological complications of obesity should routinely be performed in children and adolescents with Spina Bifida.
7. Evidence for the role of weight management interventions in the prevention of metabolic syndrome.
8. The safety profile and effectiveness of surgical and pharmacological weight-loss or metabolic interventions in individuals with Spina Bifida.



Appendix:

BMI and Body Composition Measurements

Detailed instructions on anthropometric procedures can be found in the Anthropometry Procedures Manual from the National Health and Nutrition Examination Survey (NHANES) on the Centers for Disease Control and Prevention website:
https://stacks.cdc.gov/view/cdc/50334/cdc_50334_DS1.pdf

Weight: Weigh clients with light indoor clothing but without shoes/socks/slippers. Ask the person to remove any heavy or excess clothing, braces and any heavy items from their body and the wheelchair (if using a wheelchair scale). If the individual is able to stand safely, a calibrated scale can be used to obtain weight. If the individual is unable to safely stand, use a digital chair or wheelchair scale. Subtract the weight of the chair or wheelchair from the total weight to provide the individual's weight.

Height: Measure to the closest millimeter with a portable stadiometer or length measuring board. For infants, use a securely mounted horizontal measuring board with a fixed head piece and horizontal backboard, and an adjustable foot piece.

For children under 4 years of age:

1. Ask the parent or guardian to remove the child's clothes except for diapers or underpants
2. Ask an assistant to support the child's head while you position the feet and ensure that the head lies in the Frankfort horizontal plane
3. Apply gentle traction to bring the top of the head in contact with the fixed head piece.
4. Secure the child's head in the proper alignment by lightly cupping the palms of your hands over the ears.
5. Align the child's legs by placing one hand gently but with mild pressure over the knees.
6. With the other hand, slide the foot piece to rest firmly at the child's heels. The toes must point directly upward with both soles of the feet flexed perpendicular against the acrylic foot piece. To encourage the child to flex the feet, run the tip of your finger down the inside of the foot.



If a person can stand unaided:

1. Assist the person to stand with his/her back against a wall-mounted height scale (stadiometer) with heels together and eyes looking straight ahead (Frankfort plane)
2. Adjust the horizontal arm of the scale until it sits on top of the person's head
3. The person's height is indicated by the position of the scale arm
4. Record measurement in centimeters

If a person cannot stand, measure the child's length (recumbent):

1. Ask the person to lie on a length board, face or front upward
2. Position the person so that the feet are touching the footboard together, the shoulders are relaxed and touching the baseboard, arms at sides, legs straight and knees together, and the crown of the head is touching the headboard

Where a measuring board is unavailable and/or for people with severe contractures, measure segmental length:

1. Ask the person to lie on the measuring board (or examination table), face or front upward
2. Measure from head to neck (just above shoulder)
3. Measure from shoulder to hip
4. Measure from hip to knee
5. Measure from knee to ankle bone
6. And measure from ankle bone to bottom of foot
7. Add measurements together and record in centimeters
8. For people with scoliosis, measure both sides of the body

Other methods to assess height

Where height/length is challenging to assess, alternative methods have been shown to be useful, including arm span ⁴⁶ and ulna length ⁸³.

Arm Span

1. Extend both arms outward (each arm abducted to 90 degrees)
2. Using two assessors, measure posteriorly from fingertip to fingertip using a metal rod or flexible tape measure
3. Record measurement in centimeters

Ulna Length Measurement (Segmometer)

1. Have the individual sit with their left forearm resting comfortably on a table. Their palm is flat on the table, facing downwards, with the fingers extended outward.
2. Support and position the arm in pronation with 90 – 110 degrees of elbow flexion
3. Palpate the distal tip of the ulna styloid process (the prominent bone of the wrist) and mark lightly with a pen.
4. Place the tips of the segmometer or the anthropometer adjacent to both points (tip of the elbow and tip of the ulna styloid process).
5. Measure in centimeters, to the nearest millimeter (e.g. 19.7 cm) to obtain ulnar length in centimeters
6. Complete the following calculation for height ⁸³:
 - Male: height (cm) = (4.605 x ulna length in cm) + (1.308 x age in years) + 28.003
 - Female: height (cm) = (4.459 x ulna length in cm) + (1.315 x age in years) + 31.485

Body Mass Index (BMI): BMI should be calculated using both height and length as kilograms per meter squared (kg/m²).

A child or adolescent's BMI should be graphed on a sex-specific BMI for age graph and classified using Centers for Disease Control and Prevention cut-offs. Underweight = < 5th percentile, healthy weight = 5th to < 85th percentile, overweight = 85 to < 95th percentile, class 2 obesity = ≥120% to <140% of the 95th percentile or a BMI ≥ 35 kg/m² to <40 kg/m², whichever is lower based on age and sex, and class 3 obesity = ≥140% of the 95th percentile or BMI ≥ 40 kg/m², whichever is lower based on age and sex.⁸⁴

BMI for adults is classified as underweight = BMI < 18.5, healthy weight = 18.5 to 24.9, overweight = 25 to 29.9, obese = 30 to 34.9, class 2 obesity = 35 to 39.9, and class 3 obesity = 40 or greater.⁸⁵

Occipital head circumference (up to two years of age)¹⁶

1. Ask the parent/caregiver to hold the baby over their shoulder or sit with the baby in their lap

2. Place the head circumference tape around the child's head so that the tape lies across the frontal bones of the skull; slightly above the eyebrows; perpendicular to the long axis of the face; above the ears; and over the occipital prominence at the back of the head
3. Move the tape up and down over the back of the head to locate the maximal circumference. Tighten the insertion tape so that it fits snugly around the head and compresses the hair and underlying soft tissues.
4. Measure the circumference to the nearest 0.1 cm.

Waist circumference:

1. Ask the patient to place him/herself in the following manner:
 - Clear the abdominal region
 - Feet shoulder-width apart
 - Arms crossed over the chest
2. It is suggested to kneel down to the right of the patient in order to measure waist girth
 - Palpate the patient's hips to locate the top of the iliac crest
 - Draw a horizontal line halfway between the patient's back and abdomen
3. Place the measuring tape horizontally around the patient's abdomen (*to work comfortably, it is suggested to wrap the tape around the patient's legs and then move up)
4. Align the bottom edge of the tape with your marked point
5. It is recommended to use a measuring tape with a spring handle, such as the Gulick measuring tape, in order to control the pressure exerted on the patient's abdomen
 - Gently tighten the tape around the patient's abdomen without depressing the skin
6. It is suggested to request the patient to relax and breathe NORMALLY (abdominal muscles should not be contracted)
 - Ask the patient to take 2 or 3 NORMAL breaths
 - Measure from the zero line of the tape to the nearest millimeter) at the end of a NORMAL expiration
7. Note the lesion level and/or any bulky masses, liposuction incision marks or spinal curvature.

8. Waist circumference ≥ 102 cm (40 inches) in men and ≥ 88 cm (35 inches) in women are at an increased risk of developing health problems.⁸⁶

Waist circumference in supine

1. Ask the patient to lay down and place him/herself in the following manner:
 - Clear the abdominal region
 - Arms crossed over the chest
2. Palpate the patient's hips to locate the top of the iliac crest
 - Draw a horizontal line halfway between the patient's back and abdomen
3. Complete steps 3-6 as indicated above

*If iliac crest cannot be located, measure smallest part of abdomen

Skinfold Thickness

1. Ask the patient to remove their shirt if comfortable and clear the abdominal region
2. Begin with right arm placed at a 90 degree angle and request that the patient places his/her arm across the abdomen, with the palm facing inward

Triceps:

- Along the midline on the back of the triceps of the right arm, determine the midpoint located between the top of the acromial process (top of shoulder) to the bottom of the olecranon process of the ulna (elbow)
- Pinch the skin to create a vertical skinfold with the thumb and forefinger about 0.5 inches from the measurement site
- Release the calipers on the skinfold three times for 1 second each and record the measurements

Subscapular:

- Ask patient to place arm behind his/her back
 - The skinfold should angle 45 degrees from horizontal, in the same direction as the inner border of the scapula
 - Release the calipers on the skinfold three times for 1 second each and record the measurements
3. Use the Slaughter equation to calculate the estimated body fat.⁸⁷

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