Sexual Health & Education

Amy Houtrow, MD, PhD, MPH, Chair
Michele Roland, MD
Outcomes

• Primary Outcomes
  • Optimization of sexual health for individuals with spina bifida
  • Provision of a safe and confidential environment for the exchange of reproductive health and sexually information between a patient and their health care provider(s)
  • Awareness of sexual harassment/abuse/assault and actions to take if victim

• Secondary Outcomes
  • Improved knowledge of sexual health among individuals with spina bifida

• Tertiary Outcomes
  • Maximization of ability of adults with spina bifida to participate as desired in meaningful and fulfilling sexual relationships
  • Elimination of sexual abuse/assault of individuals with spina bifida
  • Accurate information regarding fertility and reproductive health options
  • Awareness of sexual desires and the ability to communicate these to others before and during intimacy
Prenatal/Infancy (through age 1 year)

Clinical Questions

• Is there evidence that prenatal closure impacts sexual function?
  • There is no literature regarding sexual functioning after prenatal closure. The existing literature regarding urologic functioning does not demonstrate improvements with prenatal closure.\textsuperscript{22-24} Given the innervation pattern, one could hypothesize that prenatal closure does not improve sexual functioning.

• Is there evidence that discussing the neurologic sequelae of spina bifida improve parents’ understanding of sexual health for their infant as they become an adult?
  • There is no evidence specific to parents of infants, but a majority of parents felt that they had inadequate knowledge about sexuality as it relates to spina bifida in a study of a single center in the 1990s.\textsuperscript{25}
Prenatal/Infancy (through age 1 year)

Guidelines

1. Nurture the foundations of healthy intimacy.²⁶
2. Educate parents/caregivers about the anticipated neurologic sequelae of spina bifida including how sexual functioning may be impacted.
   • Based on expert opinion
Clinical Questions

• Should the timing of parental sexual education for children with spina bifida differ from that of typically developing children?
  • Developmentally appropriate sexual education for all individuals is recommended,\textsuperscript{27} including for those with disabilities.\textsuperscript{28}
  Parents are identified as the primary source of sexual education for young children.\textsuperscript{27,29}

• Does early sexual education improve sexual health outcomes or social adjustment for youth with spina bifida?
  • There is no evidence on this topic.-benefit of open communication and theoretical benefit in this area
Toddler (1-3 years)

Guidelines

1. Educate by providing factual information and encourage parents to provide developmentally appropriate sexual education.

2. Discuss sexuality routinely and openly during health care visits.

3. Explore expectations of the parents regarding their child’s sexual development.

4. Nurture the foundations of healthy intimacy.

5. Explain that sexual exploration is a normal and health part of early childhood development.
Preschool (3-5 years)

Clinical Questions
• What preschool activities promote healthy sexual development for children with spina bifida?
  • There is no specific literature on this topic. Bowel and bladder incontinence has been identified as a barrier to successful sexual relationships.\textsuperscript{11,15}
  • There is limited evidence that children with physical disabilities are at increased risk for abuse.\textsuperscript{30,31}
• How should health care professionals promote developmentally appropriate sexual education for young children with spina bifida?
  • There is no specific literature on this topic.
  • Use of mirrors during early childhood for genital exploration
  • Encourage early self-care of bowel and bladder incontinence as this is a factor identified /linked to sexual difficulties and avoidant relationships.
  • Bright Futures and other American Academy of Pediatrics reports address sexual education.\textsuperscript{26-28}
Preschool (3-5 years)

Guidelines
1. Promote continence (see Guidelines for bowel and bladder management)
2. Promote functional independence (see self-care and mobility guidelines)
3. Maximize bone health to decrease fracture risk later in life (see Endocrine Guidelines)
4. Optimize range of motion in lower extremities (see mobility guidelines)
5. Educate by providing factual information and encourage parents to provide developmentally appropriate sexual education.²⁷,²⁸
6. Discuss sexuality routinely and openly during health care visits.²⁷
7. Explore expectations of the parents regarding their child’s sexual development.²⁸
8. Nurture the foundations of healthy intimacy.²⁶
9. Explain that sexual exploration is a normal and health part of early childhood development.²⁶
School Age

Clinical Questions
• What should be taught to school aged children with spina bifida?
  • There is no specific literature on this topic.
  • Bright Futures and other American Academy of Pediatrics reports address sexual education.\textsuperscript{26-28}
  • Specific and accurate names for genital anatomy and function
• How can children with spina bifida be protected from sexual abuse?
  • There is no specific literature on this topic.
  • Children should be educated about how to identify dangerous situations, how to say no or stop an event and summon help.\textsuperscript{32}
School Age

Guidelines

1. Promote continence (see Guidelines for bowel and bladder management)
2. Promote functional independence (see self-care and mobility guidelines)
3. Maximize bone health to decrease fracture risk later in life (see Endocrine Guidelines)
4. Optimize range of motion in lower extremities (see mobility guidelines)
5. Educate by providing factual information and encourage parents to provide developmentally appropriate sexual education.²⁷,²⁸
6. Discuss sexuality routinely and openly during health care visits.²⁷
School Age

Guidelines continued

7. Allow the child to ask questions about sexual development and sexuality.26
8. Address pubertal development and perform Tanner staging.26
   • Refer to endocrinology if precocious puberty33,34 is identified.
9. Serve as a resource to schools 27 to ensure children with spina bifida participate in sexual education.
10. Encourage parents to discuss health relationships and information children are receiving from school, peers, the media and social media.26
11. Promote skill building to identify dangerous situations, refuse or break off an attack and summon help.32
12. Promote socially appropriate behaviors and social skills.28
Clinical Questions

• What should teens and young adults with spina bifida be taught about sexuality?
  • There is no specific literature on this topic.
  • Developmental appropriate education should occur. Individuals with disabilities may need modification to their sexual education.  

• How can healthy relationships be promoted for teens and young adults with spina bifida?
  • There is not specific literature on this topic.
  • Same as for peers with inclusion of opportunities for skill building in addition to having knowledge.
Teenage Guidelines

1. Acknowledge that sexual health is an important part of adult life.
2. Discuss healthy relationships in gender neutral language as the teen years are time when many achieve self-awareness about sexual orientation.26
3. Educate youth and young adults about intimate partner violence and sexual assault.27
4. Promote skill building to identify dangerous situations, refuse or break off an attack and summon help.32
5. Discuss safe sex practices including non-latex condoms.26-28
6. Refer to women’s health provider (gynecologist Adolescent Medicine specialist or Family Medicine practitioner), if young woman with spina bifida intends to become sexual active.
7. Create an environment in which the teen or youth feels comfortable and safe discussing sexual health.26
Teenage Guidelines continued

8. Promote continence (see Guidelines for bowel and bladder management)
9. Promote functional independence (see self-care and mobility guidelines)
10. Maximize bone health to decrease fracture risk later in life (see Endocrine Guidelines)
11. Optimize range of motion in lower extremities (see mobility guidelines)
12. Educate by providing factual information and encourage parents to provide developmentally appropriate sexual education.27,28
13. Encourage parents to discuss health relationships and information youth are receiving from school, peers, the media and social media.26
14. Discuss sexuality routinely and openly during health care visits.27
Teenage Guidelines continued

15. Allow the teen or youth to ask questions about sexual development and sexuality.26
16. Define questions that patient may have to ensure that their concern or question is addressed as well; if they express no question explain common questions others have had.
17. Address pubertal development and perform Tanner staging.26
18. Serve as a resource to schools 27 to ensure children with spina bifida participate in sexual education.
20. Promote socially appropriate behaviors and social skills.28
Clinical Questions

• How can the ability of adults with spina bifida to engage in meaningful sexual relationships that are satisfying be maximized.
  • As described in the introduction, continence is associated with improved sexual health.\textsuperscript{15}
  • Orthopedic deformities and mobility limitations may require creativity to find an effective and comfortable position for sexual intimacy.
  • Encourage self exploration that facilitates partner communication before and during intimacy
Adult

Guidelines
1. Acknowledge that sexual health is an important part of adult life.
2. Educate adults about intimate partner violence and sexual assault.
3. Provide guidance about safe sex practices including non-latex condoms.
4. Refer to women’s health provider (gynecologist, adolescent medicine, family practitioner) if woman with spina bifida intends to become sexual active.
5. Create an environment in which the individual feels comfortable and safe discussing sexual health.
6. Promote continence (see Guidelines for bowel and bladder management)
Guidelines continued

7. Promote functional independence (see self-care and mobility guidelines)
8. Maximize bone health to decrease fracture risk (see Endocrine Guidelines)
9. Optimize range of motion in lower extremities (see mobility guidelines)
10. Discuss sexuality routinely and openly during health care visits.
12. Refer to support groups and lay-literature regarding disability and sexuality.
13. Provide visual samples of items (female/ male condoms; use website/online resources for discussions
Research Gaps

- Studies of the performance of the sexual act among individuals with spina bifida to identify barriers and factors that enhance performance and satisfaction.
- Studies of interventions that are geared toward improving the sexual health of individuals with spina bifida.
- Studies of the relationship of sexual health and quality of life.
- Studies investigating how and when to provide sexual education for individuals with spina bifida.
References


References


References


References


References


References


