Sexual Health and Education
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Introduction

As stated by the World Health Organization, “Sexual health is a state of physical, emotional, mental and social well-being in relation to sexuality; it is not merely the absence of disease, dysfunction, or infirmity. Sexual health requires a positive and respectful approach to sexuality and sexual relationships, as well as to the possibility of having pleasurable and safe sexual experiences, free of coercion, discrimination, and violence. Sexuality is a central aspect of being human throughout life and encompasses sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy, and reproduction.”¹

The ICF model includes a biopsychosocial approach to disability and functioning that allows for the incorporation of environmental and personal factors that are specific to the individual with a health condition.² It is helpful to look at sexuality for individuals with spina bifida from a more positive perspective that focuses on reaching one’s “ability” rather than “disability” associated with the variable health conditions that include spina bifida. This perspective necessitates the inclusion of environmental modifications and support for personal factors that improve knowledge, skills and allowing for the integration of personal autonomy and individuation.

Sexuality education and health promotion has proven to specifically benefit youth by combining education with skill development training that enables youth to discuss and use condoms with their sexual partners. Research has shown that knowledge alone is not sufficient to induce behavioral change.³ Interventions “need to influence the proximal cognitive determinants of decision-making and goal enactment as specified by social cognitive theories” as well. Young people are less likely to have unprotected sexual intercourse if they have acquired a variety of social skills relevant to dealing with romantic and sexual relationships ⁴ This has implications for the prevention unplanned pregnancy and the transmission of HIV and other sexually transmitted infections

Advocates of Youth, is an organization that “envisions a society that views sexuality as normal and healthy and treats young people as a valuable resource.” This organization has reported on various research evaluations documenting how comprehensive sex education programs “can help youth delay the onset of sexual activity, reduce the frequency of sexual activity, reduce the number of sexual partners, and increase condom and contraceptive use.” http://www.advocatesforyouth.org/publications/1487

(Kent, Davies, Deverell, & Gottesman (1990) discussed skills acquired through “social rehearsal” that enables one to practice terms and approaches for talking with a partner
about their sexual views while “negotiating” romantic relationships.” Such explicit negotiation can allow for better assessment of a partner’s views and can establish a cooperative approach to negotiating a romantic relationship without sexual intercourse or with safer sex.”

It is important for individuals with spina bifida be provided with opportunities to acquire relevant and accurate sexual health knowledge; develop and utilize skills for negotiating sexual desire, intimacy and activity that supports healthy sexuality while limiting negative outcomes of sexual activity related to sexually transmitted infections, HIV transmission, unintended pregnancy or sexual exploitation.

From the ICF perspective, the mental and physical functions that relate to the sex act are coded under body functions (b640) and include arousal, penile sensation and erection, clitoral erection, vaginal lubrication and sensation, ejaculation and orgasm. While individuals with spina bifida have similar sexual desire scores (the mental functions related to arousal), sexual dysfunction was reported by a vast majority of individuals with spina bifida. Sexual dysfunction as it relates to how the body parts/systems function falls under the purview of the guidelines for men’s and women’s health. In addition, procreation functions (b660) that deal with fertility are addressed by the guidelines for men’s and women’s health. The issue of creating and maintaining a relationship of a sexual nature (d7702) falls under the domain of participation as does following safe sex practices as a part of looking after one’s health (d570). Sexual education, as a part of the environment is coded e5858. The topics of having sexual relationships, including performing the sex act, and sexual education are under the purview of these guidelines.

The peer-reviewed health literature indicates that individuals have varying levels of satisfaction with their sex lives, with approximately half reporting dissatisfaction with their sex lives. While sexual satisfaction and intimacy are directly related to quality of life, this is rarely studied and in one study, being sexually active did not result in differences in life satisfaction. Sexual activity in individuals with spina bifida is delayed and often limited compared to the desire for sexual relationships among individuals with spina bifida. Individuals with the lowest lesion levels had the highest chance of finding a partner and engaging in sexual activity. And having lower lesion levels was associated with sexual satisfaction. Women with hydrocephalus were less likely than women without hydrocephalus to be sexually active. In general, having hydrocephalus was predictive of having more problems with sexual function and relationships. Urinary incontinence was associated with altered sexual functioning in multiple studies, but not all. Bowel and bladder incontinence has been demonstrated to interfere with sexual activity, such that continence enhances sexual functioning. As may be expected, restored penile sensation is associated with improved sexual health and satisfaction. A study of 30 men (18 with spina bifida, 12 with spinal cord injury, age range 13 to 55 years) with low –spinal -lesions ( below L1) that underwent the ToMAX procedure, surgery that connects the dorsal nerve of the
penis to intact ipsilateral ilioinguinal nerve, 24 of 30 (80%) patients had restoration of penile glans sensation. The men reported better sexual function (p=.22) and increased satisfaction (p=0.004). Improved sensations help them manage urinary incontinence with resultant improvement in personal hygiene and independence. Study authors reported “most patients felt more complete and less handicapped with their penis now part of their body image” and reported “more open and meaningful sexual relationships with their partners.” (Overgoor 2013)

The receipt of sexual education, especially as it relates to spina bifida has been found to be inadequate in multiple studies. Adolescents with spina bifida are less knowledge about sex than their peers. Sex education specifically concerning spina bifida was rarely provided by health care professionals. Parents and caregivers have also need accurate and timely information on sexuality for their children, adolescents and young adults and increased comfort in discussing sexual health with family members. Fewer than a quarter of individuals reported their sexual education was specific to spina bifida. In a study by von Linstow, less than half of the subjects reported that their sexual education at puberty was useful and one-third lacked knowledge about how their sexual functioning was impacted by their disability. Both young men and young women wanted more information from their health care providers especially about spina bifida specific sexual education. Young women with spina bifida want increased knowledge of fertility, birth control and heredity of spina bifida. In a qualitative study, the questions and concerns that youth with spina bifida reported fell into 4 themes: romantic relationships, sexuality, fertility/parenthood and the need for more sexual education. Inadequate sexual education may be why compared to individuals with cystic fibrosis and healthy controls, individuals with spina bifida were less likely to use birth control when sexually active. Women with physical disabilities report inadequate sexual health education and lack of understanding regarding birth control options. There is a need for more sexual counseling for individuals with spina bifida to increase sexual satisfaction and quality of life. The lack of access to sexual health information, training and skill building specific to individuals with (spina bifida) neural tube defects over their life span contributes to these knowledge gaps and suboptimal outcomes.

Overall 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
  o Maximization of ability of adults with spina bifida to participate as desired in meaningful and fulfilling sexual relationships
  o Elimination of sexual abuse/assault of individuals with spina bifida
  o Accurate information regarding fertility and reproductive health options
  o Awareness of sexual desires and the ability to communicate these to others before and during intimacy

PRENATAL/INFANCY
Clinical Questions
• Is there evidence that prenatal closure impacts sexual function?
  o 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?
  o 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}

Guidelines
• Nurture the foundations of healthy intimacy.\textsuperscript{26}
• Educate parents/caregivers about the anticipated neurologic sequelae of spina bifida including how sexual functioning may be impacted.
  o Based on expert opinion

TODDLER (1-3 YEARS)
Clinical Questions
• Should the timing of parental sexual education for children with spina bifida differ from that of typically developing children?
  o 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?
  o There is no evidence on this topic.-benefit of open communication and theoretical benefit in this area

Guidelines
• Educate by providing factual information and encourage parents to provide developmentally appropriate sexual education.27
• Discuss sexuality routinely and openly during health care visits.27
• Explore expectations of the parents regarding their child’s sexual development.28
• Nurture the foundations of healthy intimacy.26
• Explain that sexual exploration is a normal and health part of early childhood development.26

PRESCHOOL (3-5 YEARS)

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

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

SCHOOL AGE (6-11 YEARS)

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

Guidelines
• Promote continence (see Guidelines for bowel and bladder management)
• Promote functional independence (see self-care and mobility guidelines)
• Maximize bone health to decrease fracture risk later in life (see Endocrine Guidelines)
• Optimize range of motion in lower extremities (see mobility guidelines)
• Educate by providing factual information and encourage parents to provide developmentally appropriate sexual education\(^\text{27,28}\)
• Discuss sexuality routinely and openly during health care visits\(^\text{27}\)
• Allow the child to ask questions about sexual development and sexuality\(^\text{26}\)
• Address pubertal development and perform Tanner staging\(^\text{26}\)
  o Refer to endocrinology if precocious puberty\(^\text{33,34}\) is identified.
• Serve as a resource to schools\(^\text{27}\) to ensure children with spina bifida participate in sexual education.
• Encourage parents to discuss health relationships and information children are receiving from school, peers, the media and social media\(^\text{26}\)
• Promote skill building to identify dangerous situations, refuse or break off an attack and summon help\(^\text{32}\)
• Promote socially appropriate behaviors and social skills\(^\text{28}\)

TEEN AGE (12-18 YEARS) and YOUNG ADULT

Clinical Questions
• What should teens and young adults with spina bifida be taught about sexuality?
  o There is no specific literature on this topic.
  o Developmental appropriate education should occur. Individuals with disabilities may need modification to their sexual education\(^\text{27,28}\)
• How can healthy relationships be promoted for teens and young adults with spina bifida?
  o There is not specific literature on this topic.
  o Same as for peers with inclusion of opportunities for skill building in addition to having knowledge
Guidelines

• Acknowledge that sexual health is an important part of adult life.
• Discuss healthy relationships in gender neutral language as the teen years are time when many achieve self-awareness about sexual orientation.26
• Educate youth and young adults about intimate partner violence and sexual assault.27
• Promote skill building to identify dangerous situations, refuse or break off an attack and summon help.32
• Discuss safe sex practices including non-latex condoms.26-28
• 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.
• Create an environment in which the teen or youth feels comfortable and safe discussing sexual health.26
• Promote continence (see Guidelines for bowel and bladder management)
• Promote functional independence (see self-care and mobility guidelines)
• Maximize bone health to decrease fracture risk later in life (see Endocrine Guidelines)
• Optimize range of motion in lower extremities (see mobility guidelines)
• Educate by providing factual information and encourage parents to provide developmentally appropriate sexual education.27,28
• Encourage parents to discuss health relationships and information youth are receiving from school, peers, the media and social media.26
• Discuss sexuality routinely and openly during health care visits.27
• Allow the teen or youth to ask questions about sexual development and sexuality.26
• 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
• Address pubertal development and perform Tanner staging.26
• Serve as a resource to schools 27 to ensure children with spina bifida participate in sexual education.
• Promote self-esteem and empowerment.
• Promote socially appropriate behaviors and social skills.28

ADULT

Clinical Questions

• How can the ability of adults with spina bifida to engage in meaningful sexual relationships that are satisfying be maximized.
  o As described in the introduction, continence is associated with improved sexual health.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.

**Guidelines**

- Acknowledge that sexual health is an important part of adult life.
- Educate adults about intimate partner violence and sexual assault.
- Provide guidance about safe sex practices including non-latex condoms.
- Refer to women’s health provider (gynecologist, adolescent medicine, family practitioner) if woman with spina bifida intends to become sexual active.
- Create an environment in which the individual feels comfortable and safe discussing sexual health.
- Promote continence (see Guidelines for bowel and bladder management)
- Promote functional independence (see self-care and mobility guidelines)
- Maximize bone health to decrease fracture risk (see Endocrine Guidelines)
- Optimize range of motion in lower extremities (see mobility guidelines)
- Discuss sexuality routinely and openly during health care visits.
- Promote self-esteem and empowerment.
- Refer to support groups and lay-literature regarding disability and sexuality.
- Provide visual samples of items (female/ male condoms; use website/online resources for discussions

**RESEARCH GAPS**

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

**REFERENCES**


Added references: Kirby, Shaalam, Overgoor