

Spina Bifida Guideline

Sexual health and education guidelines for the care of people with spina bifida

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Abstract. Sexual development is not only comprised of the changes to a person's body during puberty; it is a part of social development and should be considered in the context of basic and routine human desires for connectedness and intimacy, beliefs, values and aspirations. As is true for everyone, it is important that individuals with spina bifida have opportunities to acquire developmentally appropriate, relevant and accurate sexual health knowledge. Those with spina bifida need to be able to negotiate sexual desire, intimacy and sexual expression. They also need education about their sexual health and how to limit the negative outcomes of sexual activity related to sexually transmitted infections, unplanned pregnancy or sexual coercion, violence, abuse or exploitation. This article discusses the Spina Bifida Sexual Health and Education Healthcare Guidelines from the 2018 Spina Bifida Association's Fourth Edition of the Guidelines for the Care of People with Spina Bifida using the World Health Organization's framing of sexual health and reviews the literature on sexual health and education for individuals with spina bifida.

Keywords: Spina bifida, myelomeningocele, neural tube defects, sexuality, sex education, sexual health

1. Introduction

Individuals with spina bifida (SB) often develop lower extremity weakness or paralysis, as well as neurogenic bowel and bladder and loss of nerve signals to and from their sex organs [1–4]. The neurologic consequences of SB can alter sexual and reproductive experiences, can impact confidence and self-esteem and hinder relationship building [5–8]. This manuscript will detail the rationale for the guidelines for sexual health and education for individuals of all ages with SB.

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” [9]. Developing a healthy sexuality is important for everyone and depends, in part, on having information to formulate one's attitudes and beliefs about sexual orientation, gender identity, relationships and intimacy [10]. As is true for everyone, it is important that individuals with SB be provided with opportunities to acquire developmentally appropriate relevant and accurate sexual health knowledge and develop and utilize skills for negotiating sexual desire, intimacy and activity. Also it is important to limit negative outcomes of sexual activity related to sexually transmitted diseases, unplanned pregnancy or sexual coercion, violence, abuse or sexual exploitation, regardless of their disability, gender affiliation or sexual orientation. Sexual development is not just physiologic changes of a person's body during puberty (please see Women's and Men's Health Guidelines), it is an integral part of social development and should be considered in the context of basic and routine human desires for connectedness and intimacy, beliefs, values and aspirations.

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1.1. *Sexual health*

Peer-reviewed health literature indicates that individuals with SB have varying levels of satisfaction with their sex lives [11], with approximately half reporting dissatisfaction [12,13]. Initiation of sexual activity in individuals with SB is variable and generally delayed compared to peers without disabilities [7]. Individuals with the lowest lesion levels had the highest chance of finding a partner and engaging in sexual activity [6,7]. Lower lesion levels are also associated with higher sexual satisfaction [8]. In general, having hydrocephalus was predictive of having more problems with sexual function and relationships [12]. Urinary incontinence was associated with altered sexual functioning in multiple studies [6,14,15], although not all [7]. Bowel and bladder incontinence has been demonstrated to interfere with sexual activity [16] such that continence enhances relationship seeking and sexual functioning [17,18]. Both men and women may be advised to catheterize and/or flush their bladders before and after sexual activity to avoid incontinence and infection [19].

Women with SB tend to have normal fertility but require high risk obstetrical care prior to and during their pregnancies, although many with SB do not understand their reproductive potential [5,17,20,21]. Many women with SB when sexually aroused do not have full vulvar engorgement or vaginal lubrication making penetration difficult or painful for some [19]. Some with SB are able to experience orgasms [17]. Most men with SB have altered fertility [22]. Further, the performance of sexual intercourse may be hindered by erectile dysfunction including inability to achieve or maintain an erection for penetration and retrograde, absent or incomplete ejaculation [6,23]. As may be expected, among men, restored penile sensation is associated with improved sexual health and satisfaction [24].

All sexually active individuals are at risk for sexually transmitted diseases and therefore should be counseled about how to reduce their risks [10,25,26]. Confidential family planning services should be made available to individuals with SB in accordance with legal obligations [10,27,28]. Effective counseling is characterized by compassion, respect, a nonjudgmental attitude and using open-ended questions [29]. Vaccination against human papilloma virus has become one of the most successful vaccination programs; due to the efficacy and safety of this vaccine, individuals with SB should receive a full course of this vaccine as children or as adults (up to age 45) if they did not receive it in childhood [30–32].

People with disabilities, including those with SB, are more vulnerable to victimization from sexual violence likely due to a variety of factors including decreased ability to fight an attacker, a desire to please the other person without a complete understanding of the circumstances involved, dependence on others for certain aspects of care, limited communication skills, and increased tolerance of physical intrusion [33]. In general, children with disabilities are nearly three times as likely to be sexually abused as their non-disabled peers and the risks are increased further for children with intellectual disabilities of which some children with SB have [34]. A vast majority of women with developmental disabilities will be sexually assaulted in their lifetimes. The highest risk is among those with mild cognitive impairment [33], a frequent finding among individuals with SB. Compared to respondents without disabilities, young women with physical disabilities are more likely to be the victim of rape (Odds Ratio = 1.49, 95% confidence interval [1.06–2.08]) [35]. While the lifetime reported sexual violence victimization rate is low for men, those with disabilities have three times higher the rate of victimization than men without [33]. The perpetrators of sexual violence against people with disabilities often know their victims well. Nearly one-third were acquaintances or family members and an additional 44% of perpetrators had a history of a care-provider relationship with their victims [33]. In addition to being at increased risk for sexual violence, people with disabilities are at increased risk for other types of violence as well [36,37].

1.2. *Sexual education*

In multiple studies, sexual education, especially as it relates to SB, has been found to be inadequate by persons with SB [6,14,16]. Adolescents with SB are less knowledgeable about sex than their peers [17]. Sex education specifically concerning SB was rarely provided by health care professionals and has been identified as an area for improvement [16,38,39]. Fewer than a quarter of individuals reported that their sexual education was specific to SB [12]. 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 [13]. Both young men and young women wanted more information from their health care providers especially about SB specific sexual education [40]. Young women with SB want increased knowledge of fertility, birth control and hered-

ity of SB [20]. In a qualitative study, the questions and concerns that youth with SB reported fell into 4 themes: romantic relationships, sexuality, fertility/parenthood and the need for more sexual education [16]. A more recent qualitative study identified five themes from people with SB: being perceived as asexual, needing sources for sex education, needing SB-specific sex education, understanding the impact of SB-specific features on sexual engagement, and the perceived relationship between low sexual self-confidence and risk for sexual assault [41].

Inadequate sexual education and access to reproductive services may explain why, when compared to healthy controls, individuals with SB were less likely to use birth control when sexually active [42,43]. There is a need for more sexual counseling for individuals with SB to increase sexual satisfaction and quality of life [13]. The lack of access to sexual health information, training and skill building specific to individuals with SB over their life span contributes to these knowledge gaps and suboptimal outcomes. It is important that individuals with SB 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.

Sexual education and health promotion have proven specifically to benefit youth by combining education with skill development training. Care and education should be delivered through a longitudinal, developmentally appropriate, and culturally sensitive relationship between health care providers and their patients and families [44]. The education should go beyond the basics of anatomy and physiology of puberty and reproduction to incorporate education about gender identity, interpersonal relationships, intimacy, and body image [45]. Developmentally appropriate sexuality education is essential starting early in childhood with parents and health care providers. Helping young children develop a safe, healthy and positive attitude toward self and others is a part of sexual health education. This includes understanding respect, consent and relationship building [46]. Providers should encourage and facilitate family-child communication about sexual health [26,27].

2. Sexual health and education guideline goals

The goals of the sexual health and education guide-

lines were both practical and aspirational. They were to:

1. Optimize sexual health outcomes for individuals with spina bifida.
 - Improve satisfaction with sexuality and sexual relationships.
 - Increase knowledge of sexual health specific to spina bifida.
2. Maximize the ability of adults with spina bifida to participate as desired in meaningful and fulfilling sexual relationships.
 - Provide accurate sexual health education to individuals with spina bifida across their life span.
3. Empower individuals with spina bifida to seek knowledge and skill building regarding sexual relationships.
 - Advance knowledge and comfort of health care professionals to provide sexual health education to individuals with spina bifida.

3. Methods

The Sexual Health and Education working group was formed in 2016 to update the 2006 guidelines entitled “Sexual Development and Function” [47]. Clinical and research experts in the area were identified from the Spina Bifida Association’s Professional Advisory Council [47]. Author 1 served as chair with Author 2 as a member. Collectively Author 1 and Author 2 developed primary, secondary and tertiary outcomes which were approved by the steering committee. With the engagement of the Chairs from Women’s Health and Men’s Health, the scope of the group’s work was determined. Physiologic and reproductive function were determined to be under the purview of the Women’s and Men’s Health group in accordance with the International Classification of Functioning, Disability and Health’s categorization of body function and structures. Knowledge, activities and participation fell under the purview of the Sexual Health and Education group [48]. The working group followed the methodology as described by Dicianno et al [47]. The clinical questions addressed in the literature review and in the guidelines are provided in Table 1.

4. Results

Several of the clinical questions were not answerable from the existing peer-reviewed literature. When spe-

Table 1
Clinical questions that informed the Sexual Health and Education working group

Age group	Clinical questions
0–11 months	<ol style="list-style-type: none"> 1. Is there evidence that prenatal closure impacts sexual function? 2. Is there evidence that discussing the neurologic sequelae of spina bifida improves parent's understanding of sexual health for their infant as they become an adult?
1–2 years 11 months	<ol style="list-style-type: none"> 1. Should the timing of parental sexual education for children with spina bifida differ from that of typically-developing children? 2. Does early sexual education improve sexual health outcomes or social adjustment for children with spina bifida?
3–5 years 11 months	<ol style="list-style-type: none"> 1. What preschool activities promote healthy sexual development for children with spina bifida? 2. How should health care professionals promote developmentally appropriate sexual education for young children with spina bifida?
6–12 years 11 months	<ol style="list-style-type: none"> 1. What should be taught to children with spina bifida regarding sexual health?
13–17 years 11 months	<ol style="list-style-type: none"> 1. What should teens and young adults with spina bifida be taught about sexuality? 2. How can healthy relationships be promoted for teens and young adults with spina bifida?
18+ years	<ol style="list-style-type: none"> 1. How can the ability of adults with spina bifida to engage in meaningful and satisfying sexual relationships be maximized?

cific information about SB was not available, the working group utilized data from other disabilities or from the general population as appropriate to develop the guidelines (see Table 2). When no literature was available, clinical consensus was achieved by the working group. The content of the guidelines focused on providing age and developmentally appropriate sexual education, engaging individuals with SB and their families in the dialogue about developing a healthy sexuality, taking an inclusive culturally responsive approach, making sure that other health needs such as bowel and bladder management are addressed, and offering referrals to subspecialty providers as appropriate [49].

5. Discussion

The Sexual Health and Education Guidelines serve to replace the Sexual Development and Function Guidelines from 2006. These guidelines provide practical actions that the health care provider can take to address the sexual health and education needs of their patients with SB. Counseling and sexual education should be a part of health care for all individuals and should be tailored to the individual's needs.

The working group recommended additional research in the following areas to address the gaps in the literature: the impact of prenatal closure of SB on sexual functioning; the best methods of providing sexual education for individuals with SB; strategies to promote sexual health and well-being for individuals with SB; if sexual education improves safe sex practices for individuals with SB; what factors enhance sexual performance and satisfaction for individuals with SB;

which interventions that are geared toward improving the sexual health of individuals with SB are effective; the relationship between self-esteem, self-image and self-worth with sexual health outcomes for individuals with SB; and the relationship between sexual health and quality of life for individuals with SB. The working group also noted that there are limited condition specific resources for individuals with SB, their families and their health care providers, despite the strong desire for these resources. Additionally, there is little data regarding how socio-cultural factors influence which types of resources are desired and how they would be best presented. Therefore, the working group recommends future efforts focus on the creation of resources that are readily accessible to those who desire them [53].

All individuals, regardless of the presence of disabilities, can benefit from sex and relationship education that supports awareness of developing trusting, nurturing and respectful relationships. Strategies to encourage self-acceptance and autonomy are particularly relevant for people with disabilities [53]. Sexual education should be more than the 'birds and the bees' and should include education around relationship seeking, building and maintaining relationships, desire, communication, self-satisfaction, and sexual practices (including the fluidity of sexual expression and masturbation) [53]. Further, a multidisciplinary team with expertise in sexual functioning with a disability may provide individualized assessments and recommendations [54]. For example, nurses can address hygiene, bowel and bladder management and skin care; sexual health clinicians who are specially trained in sexuality and disability can delve deeply into sexual history and concerns of the individual with disabilities to provide supports and

Table 2
Sexual Health and Education guidelines for providers

Age group	Guideline	Evidence
0–11 months	1. Educate parents and caregivers about the anticipated neurologic sequelae of spina bifida including how sexual functioning may be impacted and that sexuality is a part of life for everyone including individuals with disabilities.	Clinical consensus
1–2 years 11 months	<ol style="list-style-type: none"> 1. Educate parents and caregivers about the anticipated neurologic sequelae of spina bifida including how sexual functioning may be impacted. 2. Educate parents and caregivers that sexuality is a part of life for everyone including individuals with disabilities. 3. Provide factual information to parents and caregivers and encourage them to provide developmentally appropriate sexual education to their children. 4. Explore the parent's expectations regarding their child's sexual development. 5. Explain that sexual exploration is a normal and healthy part of early childhood development. 6. Explain the importance of minimizing the child's risk of sexual abuse through teaching children about their body parts, privacy, who may touch their bodies and what to do if inappropriate touching occurs. 	Clinical consensus as well as [10,44,50,51]
3–5 years 11 months	<ol style="list-style-type: none"> 1. Provide factual information to parents and caregivers and encourage them to provide developmentally appropriate sexual education including appropriate versus inappropriate touching to their children. 2. Explore the parent's expectations regarding their child's sexual development. 3. Explain that sexual exploration is a normal and healthy part of early childhood development. 4. Underscore goal of continence (see Bowel Function and Care and Urology guidelines) for optimal sexual relationships in the future. 5. Review relevant literature that addresses this topic, such as "Bright Futures" and other reports prepared by the American Academy of Pediatrics. 6. Provide education about pubertal development, evaluate concerns or abnormal physical findings and explain the risks of precocious puberty (see puberty guidelines) 	Clinical consensus as well as [10,44,50,51]
6–12 years 11 months	<ol style="list-style-type: none"> 1. Provide factual information to parents and caregivers and encourage them to provide developmentally appropriate sexual education to their children. 2. Review relevant literature that addresses this topic, such as "Bright Futures" and other reports prepared by the American Academy of Pediatrics. 3. Allow the child to ask questions about sexual development and sexuality. 4. Serve as a resource to schools to ensure that children with spina bifida participate in sexual education. 5. Encourage parents to discuss information that their children are receiving about healthy relationships from school, their peers, the media, and social media. 6. Promote skill-building to identify dangerous situations, refuse or break off an attack and summon help. 7. Promote socially appropriate behaviors and social skills. 8. Underscore goal of continence (see Bowel Function and Care and Urology guidelines) for optimal sexual relationships in the future 9. Provide education about sexuality, pubertal development, evaluate concerns or abnormal physical findings and explain the risks of precocious puberty (see puberty guidelines) 	Clinical consensus as well as [10,44,50–52]. Also see: National Guidelines Task Force. Guidelines for comprehensive sexuality education: kindergarten through 12th grade. Reviewers: Gelperin N, Goldfarb ES, Hemich J, Kelly MA, Schoeder E. 2004; http://sexedu.org.tw/guideline.pdf : 1-109.
13–17 years 11 months	<ol style="list-style-type: none"> 1. Acknowledge that sexual health is an important part of life. 2. Discuss healthy relationships in gender-neutral language as the teen years are the time when many achieve self-awareness about sexual orientation. 3. Educate teens about intimate partner violence and sexual assault. 4. Discuss safe-sex practices including non-latex condoms to prevent sexually transmitted infections and unwanted pregnancies. 5. Refer to a women's health provider (i.e., gynecologist, adolescent medicine specialist or family medicine practitioner), if the young woman with spina bifida intends to become sexually active. Refer men to a sexual function clinic if desired. (See Women's and Men's Health guidelines). 6. Ensure that the Guidelines for Adolescent Preventive Services are implemented. 7. Create an environment in which the teen feels comfortable and safe discussing sexual health including being able to speak to the adolescent alone and confidentially. 	Clinical consensus as well as [10, 20,44,50,51]. Also see: National Guidelines Task Force. Guidelines for comprehensive sexuality education:

Table 2, continued

Age group	Guideline	Evidence	
	8. Educate parents by presenting them with factual information and encourage them to provide developmentally appropriate sexual education to their children.	kindergarten through 12th grade. Reviewers: Gelperin N, Goldfarb ES, Hemich J, Kelly MA, Schoeder E. 2004; http://sexedu.org.tw/guideline.pdf : 1-109.	
	9. Encourage parents to discuss information that their children are receiving about healthy relationships from school, their peers, the media, and social media.		
	10. Discuss sexuality routinely and openly during health care visits and acknowledge fluidity of sexuality and gender.		
	11. Allow the teen to ask questions about sexual development and sexuality.		
	12. Serve as a resource to schools to ensure that children with spina bifida participate in sexual education.		
	13. Underscore goal of continence (see Bowel Function and Care and Urology guidelines) for optimal sexual relationships in the future (clinical consensus).		
	14. Provide education about pubertal development and evaluate pubertal development and any abnormal physical findings (see puberty guidelines) [27].		
	15. Educate teens and parents regarding birth control options, pregnancy, genetic risk, and sexually transmitted infection risk associated with sexual activity including non-latex barrier methods (see men's and women's health, and latex guidelines) [15,25–27].		
18+ years	1. Acknowledge that sexual health is an important part of adult life.		Clinical consensus, World Health Organization's definition of sexual health [9] as well as [20]
	2. Take a history of sexual interest, functioning, experience and problems. (see Men's and Women's Health guidelines for information about fertility, reproduction and anatomic functioning).		
	3. Use factual information to educate adults about sexual health including intimate partner violence and sexual assault. Provide guidance about safe sex practices including non-latex condoms to prevent sexually transmitted infections and unwanted pregnancies.		
	4. Refer to a women's health provider such as a gynecologist, adolescent medicine physician or family medicine practitioner. Refer men to a sexual function clinic if desired. (See Women's and Men's Health guidelines).		
	5. Educate about heritability of spina bifida. (See Women's and Men's Health guidelines).		
	6. Create an environment in which the adult feels comfortable and safe discussing sexuality and sexual health routinely and openly during health care visits.		
	7. Refer to support groups and general audience literature regarding disability and sexuality.		
	8. Provide visual samples of items to facilitate discussions, such as female and male condoms, relevant websites, and other online resources.		
	9. Educate about the role of self-examination and routine health maintenance visits (see Men's and Women's Health guidelines).		
	10. Underscore goal of continence (see Bowel Function and Care and Urology guidelines) for optimal sexual relationships.		

therapeutic interventions; occupational therapists can help train individuals in self-care activities, adaptive sexual devices and adaptive clothing; and physical therapists can help address mobility and positioning issues, exertional concerns, range of motion and safety [54].

While the goals of these guidelines are aspirational, it is the belief of the working group that by taking the actions recommended, individuals with SB will be more likely to achieve the desired goals of optimal sexual health outcomes, maximizing the ability of adults with SB to participate as desired in meaningful and fulfilling sexual relationships. These guidelines aim for the empowerment of individuals with SB to seek knowledge and skillbuilding regarding sexual relationships and sexual health

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The Spina Bifida Association has already embarked on a systematic process for reviewing and updating the guidelines. Future guidelines updates will be made available as they are completed.

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Conflict of interest

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