SPINA BIFIDA ASSOCIATION

Guidelines for the Care of People with Spina Bifida

Men's Health

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Introduction

Until recently, adult sexual function in men and women with Spina Bifida had not been widely considered, as many born with this condition did not live to adulthood. Even after the advent of modern medical breakthroughs like ventriculoperitoneal shunting, intermittent catheterization, and urinary diversion increased quality of life and longevity, many adults with Spina Bifida continue to be cared for by pediatric specialists well into adulthood. Similarly, urologic issues that affect adults are often ignored.

It is clear that sexual function is altered in a majority of men with Spina Bifida, as male sexual organs are innervated by the distal spinal cord which is often impaired by Spina Bifida. Evidence suggests that young adults with Spina Bifida generally feel under informed about sexual health, with nearly one third of respondents stating that they were not provided appropriate information related to how Spina Bifida can affect sexual function)[1-3] Additionally, traditional points of emphasis in men's health care, such as prostatic hypertrophy and cancer, have not been addressed in this population. The health care community now widely accepts the need for a better understanding of the specific issues that men and women with Spina Bifida face regarding sexuality, fertility, and aging reproductive organs.

This document will review the following men's health topics:

- Male sexual function
- Male fertility considerations
- Prostate cancer screening and treatment

The purpose of these guidelines is to: 1) highlight the existing evidence regarding the male sexual health in Spina Bifida, 2) make recommendations based on existing data and expert opinion, and 3) emphasize research gaps and areas for additional opportunities to improve the health of men with Spina Bifida.

Sexual Function: Outcomes

Primary

1. Optimize sexual function and fertility in men with Spina Bifida.

Secondary

1. Evaluate and characterize penile and genital sensation.
2. Evaluate and characterize erectile function.
3. Evaluate and characterize orgasmic and ejaculatory function.
4. Maximize fertility potential of men with Spina Bifida, if desired.
5. Ensure sexual education and safe practices (Sexual Health and Education Guidelines).
6. Determine the sexual activity and interest in men with Spina Bifida.

Tertiary

1. Describe known therapies for decreased genital sensation, erectile/orgasmic/ejaculatory dysfunction, and infertility.
2. Assess the impact of fertility and sexual function on the quality of life in men with Spina Bifida.

Men's Health Guidelines begin at age 6-12 years 11 months

6-12 years 11 months

Clinical Questions

1. Are there strategies to promote healthy self-identity and avoid sexual abuse?
2. When should a testicular exam be conducted for boys with Spina Bifida?

Guidelines

1. Provide anticipatory guidance regarding sexual function and its potential challenges. (clinical consensus)
2. Conduct an annual scrotal exam that documents testicular position, size, consistency, symmetry, and presence or absence of masses. (clinical consensus)
3. Access and document genital sensation (penile, scrotal) and Tanner staging annually.[4-6]
4. Offer human papillomavirus (HPV) vaccination per Centers for Disease Control and Prevention and American Academy of Pediatrics guidelines, if appropriate.[7-8]

13-17 years 11 months

Clinical Questions

1. When should a testicular exam be conducted?
2. What is the prevalence of decreased penile/genital sensation?
3. What is the prevalence and nature of erectile dysfunction?
4. What is the best way to inquire about and assess sexual dysfunction?
5. What is the understanding of normal sexual function as well as Spina Bifida-related alterations in boys with Spina Bifida?
6. At what age or developmental level should sexual function and fertility evaluation be offered?
7. Are boys with Spina Bifida in this age group aware of contraceptive techniques, specifically the availability of latex-free condoms? Are latex-free condoms as effective as latex-containing condoms? Are there alternative methods of barrier contraception for this population?

Guidelines

1. Conduct an annual scrotal exam that documents testicular position, size, consistency, symmetry, and presence or absence of masses. (clinical consensus)
2. Access and document genital sensation (penile, scrotal) and Tanner staging annually.[4-6]
3. Instruct men about monthly testicular self-examinations (TSE). (clinical consensus)
4. Initiate open-ended conversations with boys age 13-17 with Spina Bifida about their knowledge of normal sexual function when the provider deems that the boy is developmentally ready, or when there is evidence of sexual curiosity and experimentation in their medical history.[9-12] (clinical consensus) (Sexual Health and Education Guidelines)
5. Educate patients that sexual function may be altered as a sequela of Spina Bifida.[10- 11,13] (clinical consensus)
6. Provide information about safe sexual practices and genetic risk factors.[14] (clinical consensus) (Sexual Health and Education Guidelines)
7. Offer human papillomavirus (HPV) vaccination per Centers for Disease Control and Prevention and American Academy of Pediatrics guidelines, as appropriate.[7-8]

8. Characterize and document erectile function when it becomes developmentally appropriate. Providers may use the International Index of Erectile Function (IIEF) or Sexual Health Inventory for Men (SHIM).[9,15] (clinical consensus)
9. When relevant, characterize and record orgasmic and ejaculatory function.[10,13,16] (clinical consensus)

18+ years

Clinical Questions

1. What is the prevalence of hypogonadism (abnormal testes and/or testosterone levels) in men with Spina Bifida?
2. What is the prevalence of decreased penile/genital sensation in men with Spina Bifida?
3. What is the prevalence and nature of erectile dysfunction in men with Spina Bifida?
4. What is the best way to inquire about and assess sexual activity in men with Spina Bifida?
5. What is the understanding of normal sexual function as well as Spina Bifida-related alterations in men with Spina Bifida?
6. What is the best way to inquire about sexual function, including nocturnal emissions, non-genital stimulation, masturbation, and oral and genital contact?
7. How much does sexual function influence the quality of life in men with Spina Bifida?
8. Are men with Spina Bifida aware of contraceptive techniques, specifically the availability of latex-free condoms? Are they as effective as latex-containing condoms? Are there alternative methods of barrier contraception for this population?
9. What are the paternity goals and outcomes in men with Spina Bifida?
10. What is the optimal approach to men with Spina Bifida desiring an infertility evaluation?
11. How much does fertility and paternity influence the quality of life in men with Spina Bifida?

Guidelines

1. Conduct annual scrotal exam that documents testicular position, size, consistency, symmetry, and presence/absence of masses.[4-6]
2. Assess and document genital sensation (penile, scrotal) yearly[4-6]
3. Instruct patients on monthly testicular self-examination (TSE) to age 40 (clinical consensus)[17-18]
4. Inform patients that sexual function and reproductive capacity may be altered as a sequela of Spina Bifida.[10-11,13,16,19](clinical consensus)
5. Provide information about safe sexual practices and genetic risk factors.[14] (clinical consensus) (Sexual Health and Education Guidelines)
6. Refer the man to a urologist with expertise in male sexual function if he expresses concern regarding sexual dysfunction or an exam suggests impaired sensation or function of the genitalia. (clinical consensus) Similarly, it is recommended to make an appropriate referral to a specialist in male sexual function and/ or male infertility if he expresses concern related to orgasmic or ejaculatory function. (clinical consensus)
7. Characterize and record erectile function, orgasmic and ejaculatory function when relevant. (clinical consensus)
8. Explain to men with Spina Bifida that phosphodiesterase inhibitors are first-line pharmacologic treatments for erectile dysfunction. Men should be offered these treatments and instructed on their use if they do not have contraindications. (clinical consensus)
9. Employ open-ended questions to explore the man’s interest in paternity and concerns about the hereditability of Spina Bifida. Offer genetic counseling and infertility evaluation when questions about these topics arise.[11] (clinical consensus)

10. Educate men about the risk of heritability of Spina Bifida for their offspring and offer their female partners additional supplementation with folic acid to reduce the risk. (clinical consensus) (Women's Health Guidelines)

Research Gaps

1. There is a need to characterize sexual function and interest among men with Spina Bifida.
2. There is a lack of understanding about the impact of sexual dysfunction on quality of life among men with Spina Bifida.
3. There is a need to characterize the incidence and etiology of hypogonadism in men with Spina Bifida.
4. Mechanisms should be developed and standardized to assess and monitor penile/genital sensation in men with Spina Bifida.
5. The prevalence and nature of penile/genital sensation based on the type and level of lesion in men with Spina Bifida needs to be characterized.
6. There is a need to understand the prevalence and nature of erectile dysfunction in men with Spina Bifida.
7. Validated questionnaires for erectile, ejaculatory, and orgasmic dysfunction specific to men with Spina Bifida or other congenital neuropathies are needed.
8. The extent of the effect of sexual dysfunction (erectile, ejaculatory, and orgasmic), decreased genital sensation, and fertility concerns on quality of life in adult men with Spina Bifida remains uncharacterized.
9. There is a lack of mechanisms and tools to assess young men's and men's developmental readiness to discuss sexual function and interest.
10. There is a lack of information on the prevalence of infertility, and mechanisms to treat infertility in men with Spina Bifida are undefined.
11. The impact of infertility and paternity on the overall quality of life in men with Spina Bifida is unknown.
12. Information is needed on the use, safety, and need of latex-free condoms in men with Spina Bifida.
13. Research is needed to determine whether early sensation is predictive of future male sexual function.
14. Information is needed to determine the best strategies to promote anatomical awareness and a healthy self-identity, and to avoid sexual abuse.
15. There is a need to improve the characterization of paternity goals and outcomes in men with Spina Bifida.

Prostate Health: Outcomes in Men 18+

Primary

1. Address urologic cancer screening criteria specifically for adults.

Secondary

1. Achieve optimal use of prostate-specific antigen (PSA) testing.
2. Follow advanced screening considerations of adult males with Spina Bifida.
3. Follow treatment considerations for adults with prostate cancer (PCA) and Spina Bifida.

18+ years

Clinical Questions

1. How should men with Spina Bifida be screened for PCA?
2. What additional testing could be offered to men to appropriately screen them for PCA, such as genomic testing and MRIs? When are these appropriate?

3. Are there specific recommendations for antibiotic prophylaxis for transrectal ultrasonography (TRUS) biopsy in a man with chronic bacteriuria?
4. Are PSA norms established for men who perform intermittent self-catheterization?
5. How should men be evaluated and counseled for treatment after a diagnosis of PCA is established?

Guidelines

1. Do not offer PSA testing to men with a life expectancy of less than 10-15 years or to men who are <55 and >69 years of age unless they are at elevated risk for prostate cancer based on family history.[20]
2. For men between the ages of 55-69 with neuropathic bladder and chronic bacteriuria with at least 10-15 years life expectancy, the value of PSA alone as a screening tool is low. Discuss and offer PSA and digital rectal exam (DRE) testing as appropriate.[20]
3. If a biopsy is recommended, consider using MRI-guidance, transperineal technique, and pre-treat men with culture-specific antibiotics prior to biopsy.[21-23]
4. Consider waiting for fPSA normalization and tPSA nadir, typically about 12 weeks, before determining whether a biopsy should be performed based on elevated PSA in men with congenital neuropathic bladder on ISC who had a recent urinary tract infection.[25-30]
5. Adequately assess pre-treatment bowel, urinary, and sexual function to guide counseling about treatment options for prostate cancer.[31] (clinical consensus)
6. Prior to decision-making for treatment of prostate cancer, men with Spina Bifida may benefit from adjunct testing to fully characterize the risks of various treatments (e.g., cystourethroscopy to evaluate the external sphincter or urodynamics to evaluate bladder storage function).[31] (clinical consensus)

Research Gaps

1. The question of PSA cutoff for biopsy has not been clearly elucidated in any population.
2. Incidence of screening in men with Spina Bifida is unknown.
3. No studies have been conducted to investigate outcomes after treatment for prostate cancer in men with Spina Bifida.
4. Determine the effect of intermittent self-catheterization on prostate-specific antigen testing.
5. Define the role of digital rectal exams on cancer screening in men with Spina Bifida.

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