SPINA BIFIDA ASSOCIATION

Sexual Function in Men with Spina Bifida

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Disclosures

- None

GUIDELINES FOR THE CARE OF PEOPLE WITH

SPINA BIFIDA

SPINA BIFIDA ASSOCIATION

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

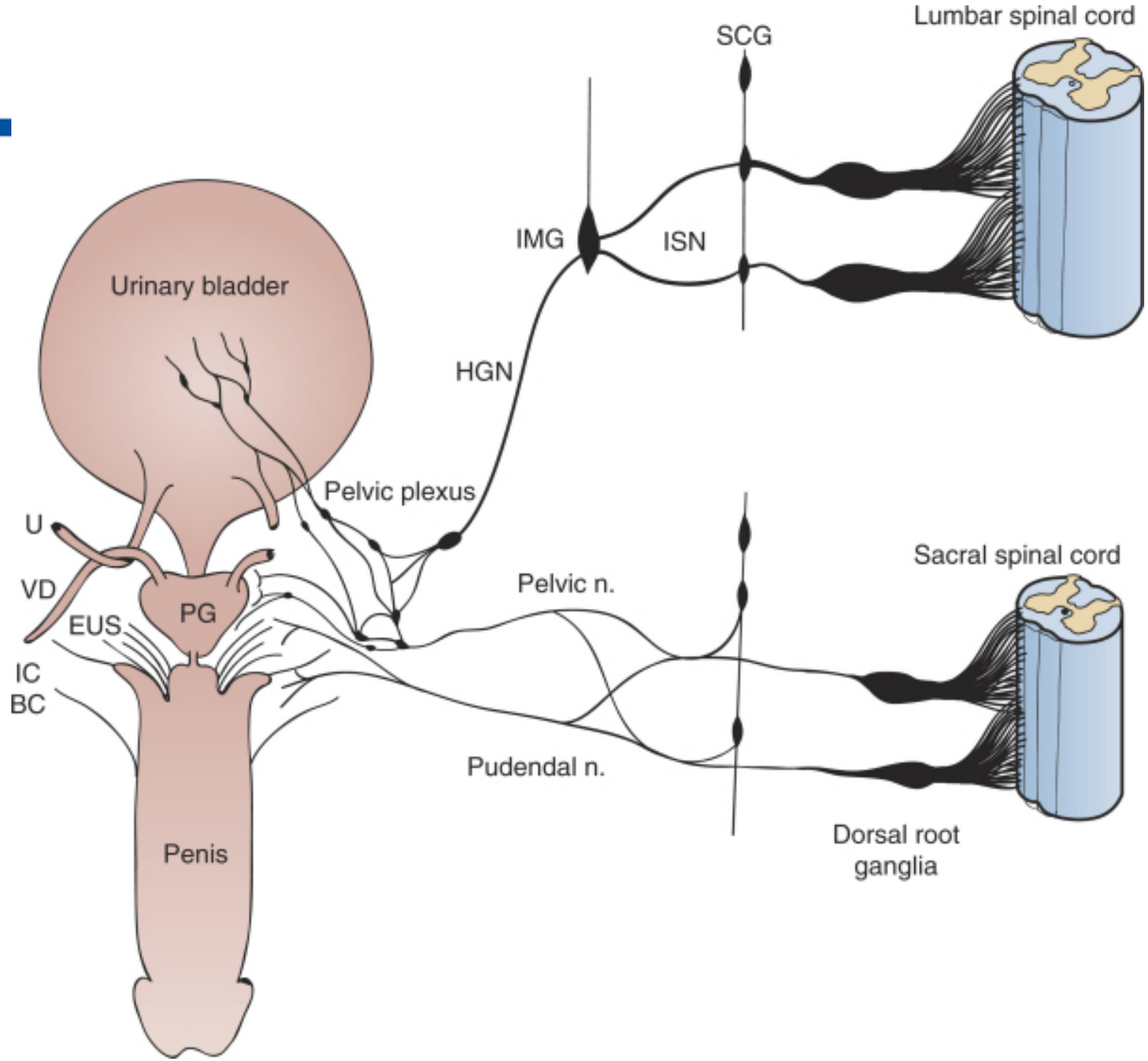
UROLOGY

Urologic Congenitalism

Spina Bifida Health-care Guidelines for Men's Health

John S. Wiener, Dominic C. Frimberger, and Hadley Wood

Spina bifida has traditionally been regarded as a pediatric health issue with little regard to adult consequences of the disorder. The congenital neurologic and urologic anomalies, as well as sequelae of bladder management, can have a profound impact on adult male sexual function. Abnormalities in testicular descent, development, and function; fertility; penile sensation; erectile function; ejaculatory function; and orgasmic function are common. Prostate cancer has been diagnosed in men with spina bifida, but little data are available to guide screening, diagnosis, and treatment efforts. The Spina Bifida Association has supported development of guidelines for health care providers to address male health issues in individuals with spina bifida throughout their lives. UROLOGY 116: 218–226, 2018.


Lumbar spinal cord
SCG
IMG
ISN
HGN
Urinary bladder
Pelvic plexus
U
VD
EUS
PG
IC
BC
Penis
Pelvic n.
Sacral spinal cord
Pudendal n.
Dorsal root
ganglia

Topics

- Cryptorchidism
- Hypogonadism
- Fertility/Paternity
- Penile Sensation
- Erectile Function
- Ejaculatory Function
- Orgasmic Function
- Sexual Knowledge
- Sexual Interest & Activity

Cryptorchidism in Spina Bifida

- Multiple studies from multiple nations show incidence of 15-23% in boys w/ SB
- May be influenced by genitofemoral n. (L1-2)
- AUA Cryptorchidism Guidelines
  - Examine testicles at least annually
  - If malposition, surgery recommended at 6-18 months

Hypogonadism in Spina Bifida

- **Hypogonadism = testicular dysfunction**
  - **Make sperm**
  - **Make testosterone**
- **Multiple studies from multiple nations show significant proportion of men with SB have small testicles**
- **Smaller proportion have low testosterone levels**

Hypogonadism in Spina Bifida

- **Two studies showed that men with SB had:**
  - **Small and/or soft testicles**
  - **Low testosterone / elevated FSH**
  - **Only 5/9 w/ motile sperm; most abnormal morphology**
  - **Biopsy - Poor or no spermatogenesis (5/16 normal)**
- **Testicular examination is important**

Reilly, AUA Annual Meeting, 1992

Hulting, Dev Med Child Neurol, 2000

Male Fertility in Spina Bifida

- **Hutling 2000 4%**
- **Cardenas 2008 15% but only 1 w/ HC**
- **Decter 1997 70% L5-S1 – all amb w/o HC**
  Only 1/39 higher tried

Penile Sensation in Spina Bifida

- **Penile sensation is via S2-4**
  - **Thus, sensation is dependent on neurologic level**
- **How is sensation mediated?**
  - **Fine touch – A-beta fibers**
  - **Pain/thermal – C fibers – erotic sensation**
  - **How does one test???**
- **Decreased sensation is associated w/ ED**

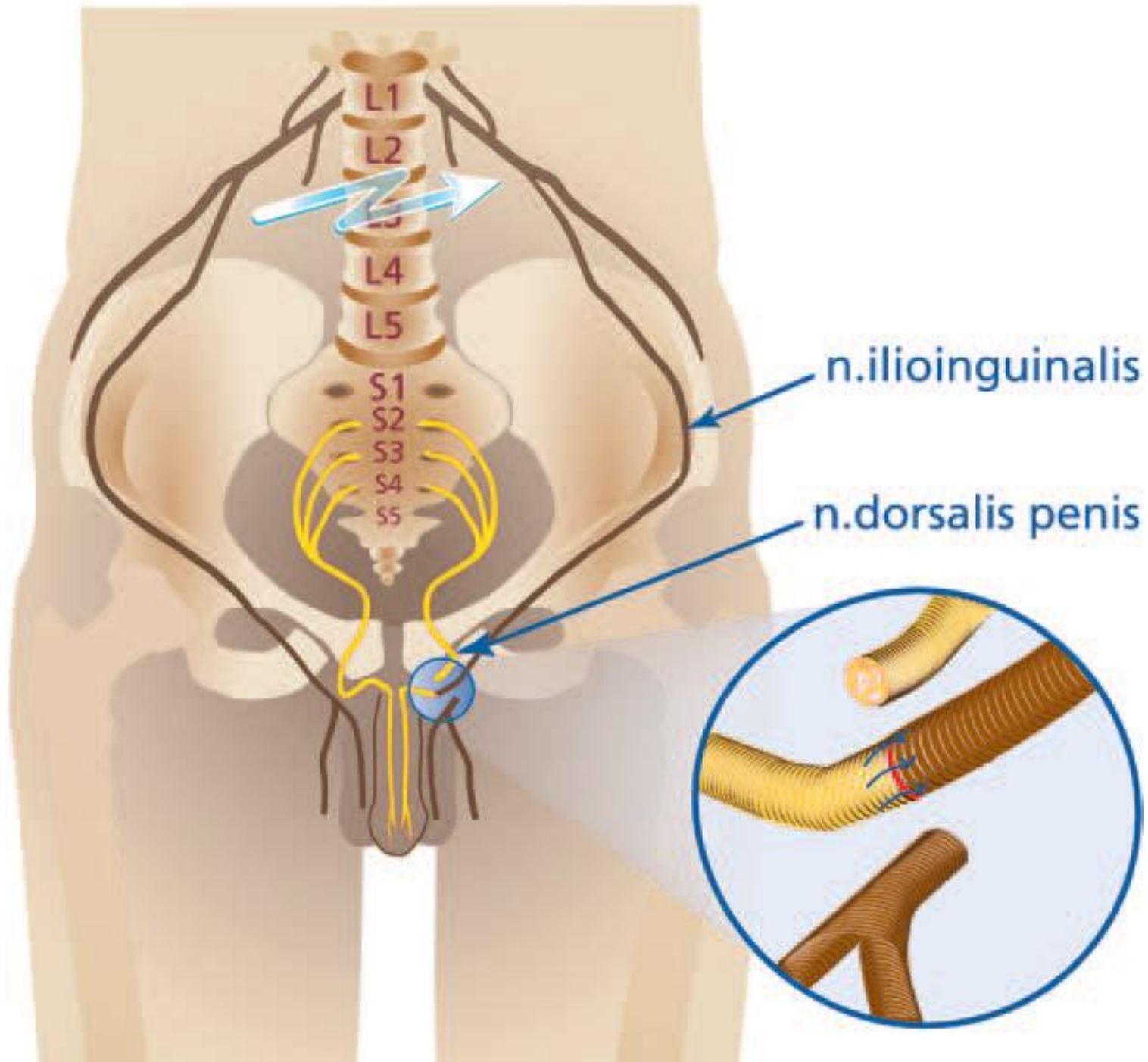
Penile Sensation in Spina Bifida

- Sandler/Worley (NC) 1996 – 20% normal
- Gatti (Parma) 2009 –
  - 7% normal in L2 SB and above
  - 53% normal in L3-5 and sacral SB
- Verhoef (Utrecht) 2005 – 27-32% “less genital sensitivity than desired”

Penile Sensation in Spina Bifida

- **What can one do if it's abnormal?**
- **TOMAX procedure – 1st described 2013**
  - Tomas DeJong & Max Overgoor
  - Nerve re-routing – ilioinguinal (L1) to pudendal

Overgoor et al, *J Urol*, 2013


L1
L2
L4
L5
S1
S2
S3
S4
S5
n.ilioinguinalis
n.dorsalis penis

Penile Sensation in Spina Bifida

- **TOMAX procedure**
  - **Initial study**
    - **Penile sensation gained in 24/27 men**
    - **5 gained ability to get erection by tactile stimulation**
    - **Improved stiffness and sex satisfaction scores**
  - **Performed at one center in US**

Overgoor et al, *J Urol*, 2013
Overgoor et al, *Plast Reconstr Surg*, 2014
Jacobs et al, *J Sex Med*, 2013

Erectile Function in Spina Bifida

- **Well-described research instruments**
  - **IIEF/SHIM – not validated in SB**
    - **Focus on intercourse in past four weeks**
- **Online survey – 2017 – only 41% reported sufficient firmness for intercourse**
- **Most report inability <u>to maintain erections</u>**
  - **Likely related to decreased sensation**
  - **Shiomi (Nara, Japan) 2006 – 26 men**
    - **85% had erections by AV stimulation**
    - **54% had rigidity with tactile stimulation**

Erectile Function in Spina Bifida

- Treatment
  - Palmer (Chicago) 1999-2000 – Sildenafil
    - 80% improvement in IIEF
  - Szymanski 2017 – online survey
    - 25/69 used PDE-5 inhibitors
      - 76% reported improved erections
      - 56% reported improved intercourse

Erectile Function in Spina Bifida

- Review
  - Ask about it
  - Use non-validated instruments?
  - Options
    - Constriction ring – non-latex
      - Be sure to remove
    - Vacuum pump
    - PDE-5 inhibitors
    - Injection therapy
    - Surgery? - TOMAX / penile prothesis

Ejaculatory Dysfunction in Spina Bifida

- Like ED, survey tools suboptimal
  - Hard to assess retrograde ejaculation by history
- Semen emission may be altered
  - 73-88% report ejaculation
    - Higher than normal erections or orgasms
    - Most report dripping and not w/ orgasm
      - Szymanski 2017 – only 17% forceful
- Should ask/discuss implications

Orgasmic Dysfunction in Spina Bifida

- Even fewer reports - six
- No unified definition – limited tools
- 20-66% of men reported orgasm
  - Likely related to penile sensation

Sexual Knowledge in Spina Bifida

- **Sexual functional assessment should be part of transition care for adolescents and regular care for adults with SB**
- **History taken without family present**
- **Discuss STI and contraception**
- **Discuss latex-free products**

Sexual Knowledge in Spina Bifida

- **Discuss increased risk of SB in offspring**
  - **One estimate 1:23 – no difference M vs. F**
    - **Prior to folate supplementation**
  - **Recommend folate 4000 µg daily for 1-3 months prior to conception & through 1st trimester**

Sexual Activity/Interest

	Ever Sexually Active	Sexually Active in Past Yr.	Sexually Active in Past Mo.	Desired Sexual Contact	Desired Children
Lassman, 2007	24%				70%
Verhoef, 2005		22%		70%	
Sandler, 1996	27%			100%	
Game, 2006			40%		
Szymanski, SPU 2017	75%*				
	*91% masturbation 62% vaginal intercourse 35% anal intercourse				

Sexual Activity/Interest

- **Identity**
  - **96% male**
  - **1% each – female, transgender, other**
- **Orientation**
  - **92% heterosexual**
  - **7% homosexual**
  - **2% bisexual**

Szymanski, *SPU* 2017

So don’t make assumptions…

Sexual Activity/Interest

- **Urinary & fecal incontinence during sexual activity (M + F)**
  - **Rarely broached in medical literature**
  - **Preliminary findings from online survey**
    - **65% experience urinary incontinence**
    - **45% experience fecal incontinence**
    - **More common in women**
    - **More common in those with baseline UI**

Szymanski, *AUA* 2018

Men's Health

- **Good Problem to Have**
  - **We have succeeded in getting boys to manhood**
  - **Focusing on quality, not just quantity, of life**
  - **Treating men with SB like able-bodied men**
  - **Allowing men to achieve their dreams**

- **Make Time**
- **Ask**
- **Ask**
- **Listen**
- **Listen**
- **Exam**
- **Refer when necessary**

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