SEXUAL AND REPRODUCTIVE HEALTH IN PEOPLE LIVING WITH SPINA BIFIDA

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Who are we?

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  • Mother
  • Woman living with Spina Bifida
Disclosures

• Linda and Courtney
  • None

• John
  • Association with:
    • Centers for Disease Control and Prevention
    • Spina Bifida Association (Board of Directors)
Break-Out Session Goal

• Equip you with the knowledge and confidence to start talking to adolescents and adults in your clinics about sexual and reproductive health.
Overview

• How Spina Bifida impacts sexual function for men and women
  • Neurobiopsychosocial framework
  • Ways to optimize function
• How Spina Bifida impacts women’s reproductive health
• “How I talk about sexual health”
• Group Discussion
• Q&A/Discussion Time with 2 adults living with SB
Why this discussion?

- What do adolescents and adults do?
  - They think about love.
  - They think about sex.
  - Disability does not eliminate basic human needs
Neurologic
Psychologic
Biologic
Social
Men’s Health
Men’s Health

Workgroup Members: Hadley Wood, MD, FACS (Chair); Dominic Frimberger, MD; John S. Winer, MD

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. 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

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
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. © 2018 Elsevier Inc.
Sexual Response Phases

Desire → Excitement → Plateau → Orgasm → Resolution / Reflection
Sexual Response Phases

Desire → Excitement → Plateau → Orgasm → Resolution / Reflection

Impacted by abnormal innervation
Sexual Response Phases

Desire → Excitement → Plateau → Orgasm → Resolution / Reflection
Men’s Sexual Desire

• Little impact by SB
• May be lower if sexually inactive
• Little impact by other factors – hydrocephalus

Sawyer SM and Roberts KF, Dev Med Child Neurol 1999
Choi EK et al, Urology 2017
Lassmann J et al, JUrol 2007
Rosen RC et al, Urology 1997
Gamé X et al, Urology 2006
Lee NG et al, J Pediatr Urol 2015
Verhoef M et al, Arch Phys Med Rehabil 2005
Gamé X et al, J Pediatr Urol 2014
Sexual Response Phases

Desire → Excitement → Plateau → Orgasm → Resolution / Reflection
Males

T11-L2
Psychogenic Erections

S2-S4
Reflexogenic Erections
Erections with Spinal Cord Lesions

- Reflexogenic Erection
  - Induced by physical stimulation
  - Requires intact sacral reflex arc (S2-S4)

- Psychogenic Erection
  - Induced by psychic stimulation
  - Lesions below L2

- “Mixed Erection”
  - Lesions below L2 and above S2
Men’s Health

• Erectile Function
  • Most can achieve erection – 56-95%
  • Quality of erections diminished in 13-71%
  • Correlated with level of lesion
    • Ambulation?
    • Hydrocephalus?
    • Penile sensation?

Choi EK et al, Urology 2017
Gamé X et al, Urology 2006
Verhoef M, Dev Med Child Neurol 2004
Predictors of Erectile Function

• Lower level of lesion increases likelihood of achieving erection
  • 33-50% thoracic level
  • 71-84% lumbar level
  • 83-100% sacral level

Treatment of Erectile Dysfunction

• Palmer (Chicago) 1999-2000 – Sildenafil
  • Study of 15 men - 80% improvement in IIEF
• Szymanski 2017 – online survey
  • 25/69 used PDE-5 inhibitors
    • 76% reported improved erections
    • 56% reported improved intercourse

Palmer JS, Kaplan WE, Firlit, J Urol, 2000
Ejaculation

**T11-L2**

**Ejaculation**: First phase (sympathetic) – peristalsis of vas, SVs, prostatic smooth muscle and closure of bladder neck

**S2-S4**

**Ejaculation**: Seminal fluid creation (parasympathetic), pelvic floor contraction for projectile ejaculation/semen release (somatic)
Ejaculatory Function

• Ability to ejaculate – 50-88%
• Nocturnal emissions – 52%
• Ejaculate without erections - 5-13%
• Quality of ejaculation diminished in many
  • “weak”, “dribbling”, retrograde
• Correlated with level of lesion

Sawyer SM and Roberts KV, Dev Med Child Neurol 1999
Choi EK et al, Urology 2017
Game X et al, Urology 2006
Verhoef M, Dev Med Child Neurol 2004
Predictors of Male Ejaculatory Function

- Improved with lower levels of lesion

Treatment of SB Ejaculatory Dysfunction

• No known research-based treatment
• Reflections of several men:
  • “Last longer”
  • “Better at satisfying a partner”
Treatment of Ejaculatory Dysfunction in Men with SCI

- Often for fertility purposes (obtaining semen)
  - Electroejaculation
  - Penile vibratory stimulation
    - Sometimes used at home
- PDE5i may improve ejaculation

Lombardi G et al, J Sex Med 2009
Other Male Arousal Treatment- Learning from SCI

• “Body Mapping”
  • Genitalia, head/neck, torso/arm/shoulder most stimulating
  • New areas of arousal at or above the level of lesion

Men’s Health: Treatment

• What can one do for abnormal penile sensation?
• TOMAX procedure – 1st described 2013
  • Tomas DeJong & Max Overgoor
  • Nerve re-routing – ilioinguinal (L1) to pudendal

Overgoor et al, J Urol, 2013
Men’s Health: Treatment

• TOMAX procedure
  • Unilateral procedure
    • Penile sensation gained in 24/27 men
    • 5 gained ability to get erection by tactile stimulation
    • Improved stiffness and sex satisfaction scores
  • Bilateral procedure performed
• Performed at one center in US

Sexual Response Phases

Desire → Excitement → Plateau → Orgasm → Resolution / Reflection
Men’s Health

• Orgasmic Function
  • Ability to achieve orgasm – 20-67%
  • Correlated with penile tactile sensation
Treatment of Male Orgasmic Dysfunction

- Non-medical treatment
  - Longer foreplay
  - Addressing fatigue, depression as well as pain, spasticity
  - Body mapping sensitive areas
  - Mindfulness

Soler JM et al, J Sex Med 2008
Stoffel JT et al, World Journal of Urology
Sexual Response Phases

Desire → Excitement → Plateau → Orgasm → Resolution / Reflection
Men’s Health: Paternity

• Cardenas (Seattle) 2008
  • 15% without hydrocephalus; 1/25 with HC

• Decter (Hershey) 1997
  • 7/10 with L5/sacral SB – all amb w/o HC
  • 1/39 w/ higher lesion attempted – success

• Laurence (Wales) 1975
  • 9/11 married men – 23 offspring
    • None with MMC
Men’s Health: Fertility

• What can we learn from SCI world?
  • Miami Project to Cure Paralysis – Male Fertility
  • 533 men – 7 injured prior to age 12y
    • All (3) injured before age 10y – azoospermia
    • Two injured at 10 and 11.6y – oligospermia
    • Two injured at 11.9 y – normospermia

  • NORMAL NEURAL INPUT AT EARLY AGE MAY BE REQUIRED FOR NORMAL SPERMATOGENESIS
Women’s Health
Sexual Response Phases

- Desire
- Excitement
- Plateau
- Orgasm
- Resolution / Reflection
SB Sexual Desire

• Normal or near-normal

Sawyer SM and Roberts KF, Dev Med Child Neurol 1999
Choi EK et al, Urology 2017
Lassmann J et al, JUrol 2007
Rosen RC et al, Urology 1997
Gamé X et al, Urology 2006
Lee NG et al, J Pediatr Urol 2015
Verhoef M et al, Arch Phys Med Rehabil 2005
Gamé X et al, J Pediatr Urol 2014
Sexual Response Phases

- Desire
- Excitement
- Plateau
- Orgasm
- Resolution / Reflection
Females

- **T11-L2**
  - Psychogenic arousal

- **S2-S4**
  - Reflexogenic arousal
  - Sensory to genitalia
SB Female Arousal and Lubrication

• Arousal
  • No to mild impairment

• Lubrication
  • 0-14% experience problems
  • Many women unsure

Verhoef M et al, Arch Phys Med Rehabil 2005
Lassmann J et al, Jurol 2007
Choi EK e tal. Neurourol Urodyn 2018
Female Arousal Treatment

• “Body Mapping”
  • Identify areas of increased sensitivity
  • Often at or just above level of lesion
  • Other common areas:
    • Head/neck and torso
    • Some areas sensitive to vibratory sensation

• Longer foreplay
• Use of water-based lubrication

Sexual Response Phases

- Desire
- Excitement
- Plateau
- Orgasm
- Resolution / Reflection
Female Orgasm/Sensation

- 0-47% experience “problems with orgasm”
  - Many unsure if they orgasm

Sawyer SM and Roberts KV, Dev Med Child Neurol 1999
Verhoef M et al, Dev Med Child Neurol 2004
Verhoef M et al, Arch Phys Med Rehabil 2005
If I’m walking lot or sitting for a long period of time, then I’ll have more numbness than usual.
Treatment of Female Orgasmic Dysfunction

- Map out most sensitive areas of body
  - Often just above level of lesion
- Longer foreplay
- Use of sex aids
  - Vibratory stimulation
  - Gentle vacuum (Eros device)
- Try other forms of sex
  - Anal
  - Oral

Alexander M and Rosen RC, J Sex and Marital Therapy
Kreuter M et al, Spinal Cord 2011
Streur CS et al, J Sex Med 2020
Sexual Response Phases

Desire → Excitement → Plateau → Orgasm → Resolution / Reflection
Psychosocial Considerations

- Confidence
- Sexual abuse and coercion
- Societal stigma of people with disabilities as asexual
- Difficulty finding sexual health care
Sexual Confidence

• Impacted by:
  • Overall self-confidence
  • Body image
    • Often poor
    • Concern about abdomen, legs, chair, buttocks (SB)
  • Perception of “ability” compared to those without disabilities
  • Negative experiences with partners
  • Surgical scars
  • Incontinence

• May be difficult to set/enforce boundaries

Bailey KA et al, Healthy Psychol Open 2016
Streur CS et al, J Sex Med 2019
When I was younger I felt very ashamed of my body and as I’ve grown up that hasn’t changed a whole lot.
Sexual Abuse/Coercion

- Women with physical disabilities at 4x the risk of sexual abuse
  - Also at increased risk of intimate partner violence

Casteel C et al, Inj Prev 2008
I just felt so alone and I wanted that feeling, I don’t think I really wanted sex, I wanted someone to love me.

I was just trying to satisfy a person, so if it hurt me it didn’t matter.
Sexual Health Care

- Lack of providers
- Stigma
So why are you here?

For birth control.

But what do you mean?

Well, because I don’t like having babies.

But you’re in a wheelchair. You can’t stand.

Do you stand when you have sex?

Streur CS et al, J Sex Med 2019
Managing Partner Relationships

- Encourage emotional support and intimacy with partner
- Seek sexual pleasure of the partner
- Open communication—feedback, experimentation, problems
- Trial and error
  - Recognize this can be frustrating for some
- Use a variety of sexual behaviors/expressions
  - Long foreplay
  - Massage
  - Use aids, fantasy, experimentation
- Peer mentorship programs, sexual health counselors, physical/occupational may be beneficial if open/honest

I genuinely believe that I have a better sex life than most of my friends because I have to communicate what I need during sex and that has made it a lot easier for me to communicate what I want as well.
Sexual Knowledge in SB

• Sexual knowledge is lower for most w/ SB

• Sexual functional assessment should be part of transition care for adolescents and regular care for adults

• History

• Discuss increased risk of sexual abuse

• Discuss STI and contraception

• Discuss latex-free products
How to Discuss Sexual Health With Girls and Young Women With Spina Bifida: A Practical Guide for the Urologist

Courtney S. Streur, David E. Sandberg, Claire Z. Kalpakjian, Daniela A. Wittmann, and Elisabeth H. Quint

OBJECTIVE
To provide urologists with a practical guide for how to provide sexual health counseling to girls and women with spina bifida.

METHODS
The recommendations and research of several sources were synthesized to create this guidance, including clinical guidance from the Spina Bifida Association and American College of Obstetricians, the current literature on the sexual health of girls and women with spina bifida, and the multidisciplinary experience of the authors.

RESULTS
Sexual health education should be viewed by urologists as a continuous discussion, starting in early childhood and gradually building through adolescence. Developing a plan for when and how to bring it up, utilizing parents as educational partners, identifying who will provide the detailed one-on-one counseling if not the primary urologist, establishing a referral network for specialized care (eg, adolescent gynecologist, physical therapist, or sex therapist), becoming familiar with how spina bifida impacts sexual health, and being prepared for challenges are key to providing these girls and women with competent sexual health education. Urologists should also screen for abuse at each visit and be familiar with reporting and resources for when abuse is identified.

CONCLUSION
This guidance can serve to direct urologists in providing competent sexual health education to girls and women with spina bifida. This will ensure these girls and women receive the basic education they need, and that they can be referred to appropriate sexual health experts as indicated.

Women’s Reproductive Outcomes
Methods – Two Studies

• Study of Reproductive Health and Women with Early Onset Disabilities
  – Semi-structured interviews of 41 women including 7 with spina bifida
  – Have a physical disability or health condition that affected their ability to walk or to use their arms or hands at the time of their pregnancies.
  – Disability onset before puberty

• Study of Pregnancy in Women with Physical Disabilities
  – Semi-structured interviews of 25 women including 1 with spina bifida
  – Women ages 18-55 with onset at any age
  – Have a physical disability or health condition that affected their ability to walk or to use their arms or hands at the time of their pregnancies.

• In both studies, women were recruited through email lists, social media, and snowball sampling
Increase in Births

Evidence suggests that the percentage of women with disabilities who are giving birth is increasing.

– Among with spina bifida, births increased by 56% between 2003 and 2013 (Shepard, 2018)
– In California, percentage of women who gave birth more than doubled between 2000 and 2010 (Horner-Johnson, 2017)

Research Questions

• What information do women get about sexual and reproductive health (SRH) and their right to sexual expression from family, health professionals, and other sources
• Barriers and unmet needs for reproductive health care
• Impact on women’s decisions about reproductive health
Information about Puberty

“Menstruation was kind of a surprise as this came on, you know . . . we just went and got what I needed. Nobody ever really explained like tampons to me, the changes in my body.”

“We were pretty open. . . I think growing up in the hospital and having to be so open about so many different things having to do with my body, it just didn’t seem like a big deal to me.”

Women had a range of information about the onset of puberty

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"My parents were always of the mentality that I could do whatever I wanted in any aspect of my life whether it be having a family or working or higher ed or whatever."

"I just honestly think that she never thought I would get pregnant. My body, it was so different, you know?"

Families vary in messages they give disabled children about sex.
Care Coordination

I went to see a high risk OB and they immediately got in contact with my urologist and my neurosurgeon to make sure that everybody was on board... during pregnancy and during delivery.

I grew up in the X city and all of the surgeries I had had done happened at the same hospital that she was born so all of my doctors that had done my other surgeries were involved in the planning of what if I needed a C-section.

Care was coordinated with other specialists during pregnancy and delivery
My doctors were not planning a C-section because I’ve had some other surgeries in my abdominal area and they were afraid of excess scar tissue and things like that. They said, “If we need to do one we can but we don’t want to plan to do one.”

“It looked like someone had poured a jar of rubber cement in there.’

It was necessary to consider the impact of previous surgeries.
I had an anesthesia consult about two months before she was born... They did tell me that I couldn’t get an epidural because of my back... but I did get IV pain medication.

Q: “Did you meet with an anesthesiologist ahead of time?”
A: “No. Not ahead of time but just when I was in there. . . . I wish I had known more options for pain, for managing the whole situation.

Approaches to anesthesia were inconsistent
“My OB was great. But I also think, you know, things only happened the way they happened because we planned ahead.”
Conclusion

• Messaging from families and the information that women had about puberty and pregnancy varied
• Although there was care coordination among the small number of women involved in this study, there was room for improvement in some aspects of care
• Planning ahead and management were key
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References


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