Sexual Function in Females with Spina Bifida

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Overview

- Sexuality and sexual activity in women with spina bifida
- Special considerations in addressing sexual health
- Sexual satisfaction?
- Family planning
SEXUALITY AND SEXUAL ACTIVITY
Online international survey of 119 women

- Sexual Identity:
  - 99% of women identified as female

- Sexual Orientation:
  - 85% heterosexual (lower than general population)
  - 3% homosexual
  - 10% bisexual (higher than general population)
  - 1% asexual
  - 2% other
Who is sexually active?

- Older
  - Mean age: 17
- Lower level of lesion
- Continent
  - Or no difference?
- No hydrocephalus
- Live independently

2. Sawyer SM and Roberts KV, Deve Child Nuerol 1999
3. Lassmann J et al, J urol 2007
But...

• There are sexually active women with spina bifida who are younger, have high levels of lesion, are incontinent, have hydrocephalus, and who do not live independently\(^1\)
• 90% would like to get married, 76% would like to have children\(^2\)
• 5% of women have talked to a doctor about sex\(^3\)
• 74% of youths with SB rate their knowledge of sexual health and SB as “poor” or “extremely poor”\(^2\)
  • “Can I pass SB on to my partners by having sex with them?”

EVERYONE needs education

1. Lassmann J et al, J urol 2007
2. Sawyer SM and Roberts KV, Deve Child Nuerol 1999
SPECIAL CONSIDERATIONS
Some basics
Precocious Puberty

• 15% by age 8
• Hydrocephalus increases risk

...I remember the first time I had my period [at age 8]... I thought I was bleeding to death.

36 year old female
Other basics

• Lubrication
  • Some women do not excrete vaginal lubrication
• 4-5 \textit{mg} of folic acid daily
  • Requires a prescription

• Contraception
  • No latex condoms!
  • Seizure medications may decrease efficacy of oral contraceptives
    • Also increased risk of birth defects with certain seizure medications
Incontinence
I’m constantly worried about the incontinence happening. I’m always worried that I’m going to get distracted [during sex] in worrying about that too much.

35 year old female
If he’s touching my stomach I have to worry about the urostomy pouch, is it gonna leak or become disconnected?

52 year old female
I sometimes urinate when I orgasm.

22 year old female
Urinary Incontinence During Sex: Recommendations

- Empty bladder/urostomy bag before sex
  - Decreases spontaneity
  - Incontinence still may happen
- Use mattress protectors
- Place chucks pads under sheets to be discrete
- Warn partner before
Even though I have control over my bowels, sometimes during sex I don’t.

52 year old female
The bowel– there’s really nothing I can do about that because it seems to have a mind of its own so I just pray.

35 year old female
Fecal Incontinence During Sex: Recommendations

• Watch diet before sexual activity
• Empty bowels before sex
  • Especially if anal penetration
• Mattress protector
• Wipes
• Warn partner before
Positioning
Positioning

Judging by how I’m feeling that day I’m like this position is a yes or a no.

32 year old female
Positioning

- Considerations:
  - Scoliosis
  - Back pain
  - Hip pain or instability
  - Limited mobility
  - Limited ability to bend
  - Osteoporosis
  - Weight gain
  - Pelvic organ prolapse
Positioning

• Be aware of limitations
• Avoid any painful position
  • Inform partner if hurting
• Different positions may be better different days
• Consider using assistive devices
• Seek advice of a physical therapist or other expert
Positioning: General

Mostly it’s been missionary. Laying on my stomach is good.

35 year old female

This show ain’t gonna happen with me standing up.

29 year old female
Sex used to really hurt... until I started doing it what they call “doggy style”... That’s how my gynecologist explained it after looking at my anatomy... I have [pelvic organ] prolapse.

27 year old female
When I was younger I was smaller but now I’m heavier so I really don’t feel comfortable being on top of somebody. I like side by side... scooting all the way to the edge of the bed for the woman is another good position.
Sensation
Nerve innervation
Sexual Sensation

- 80% of women have some genital sensation
  - Rare if lesion above L2
- 37% of women experienced an orgasm

Sawyer and Roberts, Dev Med Child Neurol 1999
I can feel and everything but it’s like certain parts of my... private area like I don’t feel it 100%.

24 year old female
...if I’m walking a lot or if I’m sitting for a long period of time, then I’ll have more numbness than usual and then obviously I don’t enjoy it.

24 year old female
Sexual Sensations: Recommendations

• Experiment

• Map out sensation and inform partner
  • Often increased above level of lesion
Sexual Sensation: Recommendations

For me with spina bifida I think that anal sex is how I get off versus vaginal. I guess anal and oral.

27 year old female
Sexual Sensation: Recommendations

And hey, if you can’t orgasm, at least you can make yourself feel good.

22 year old female
Sexual Satisfaction
How satisfied are women?

• Limitations:
  • No validated survey instruments for women with spina bifida
  • Small populations studied
  • Nuances hard to elucidate from surveys
  • Results may vary by:
    • Most recent experience
    • Current partner (supportive vs. not)
    • Opportunities
    • Confidence
How satisfied are women?

- Studies do suggest women may have some sexual dysfunction

Improving (Partnered) Sexual Satisfaction

• Build confidence
  • Affirming partner
• Selectively choose a partner
• Give feedback
  • Seek satisfaction for both
• Seek advice and counseling
When I first met my husband I up front said I have a lot of medical issues, he said I don’t care. And then the relationship started to go into more of an intimate level and I said I have to tell you things are not “normal.” And he just looked at me and said we’ll figure it out.

36 year old female
Sexual Sensation: Give Feedback

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...

29 year old female
At one point I actually went and I saw a physical therapist who gave me a position. It would have been helpful much earlier in my life.

30 year old female
FAMILY PLANNING (Briefly)
Family Planning

• The number of women with SB having babies is increasing! However...

• Too many providers assume:
  • Women are not sexually active
  • Women cannot have babies
  • Women should not be mothers

• As a result:
  • Few women use birth control
  • Many think they cannot get pregnant
  • Women have unintended pregnancies
  • Women have difficulty accessing information and finding supportive providers
Family Planning

• Having babies is very important to most women with spina bifida
• Fertility is normal for most
• Important to discuss the possibility of becoming pregnant with women starting in adolescence
  • Also offer contraception
I’ve always, always wanted to be a mother ever since I was little.

27 year old female
Family Planning

- Many adolescent and adult women with spina bifida are unaware they can become pregnant\(^1\)
  - Assume they cannot because of their spina bifida
  - Providers tell them they cannot

- Unintended pregnancies occur in this population!
  - 3 women in a study of SB youths ages 14-23\(^2\)
  - 5/25 women in a study of SB women\(^1\)
    - 5/6 of pregnancies in this study

- Women value provider’s willingness to help them reach their sexual and reproductive health goals over their experience and expertise in the area\(^1\)

1. Streur CS et al, Disabil Health 2019
2. Sawyer SM and Roberts KV, Deve Child Nuerol 1999
Medical doctors looked at me for years and always told me that I would never bear a child, ever.

27 year old female
Unintended pregnancy at age 18
Conclusion

• Women with SB have sex and babies
  • Even if not currently sexually active, majority interested in having a partner and having babies one day

• Addressing sexual and reproductive health for these women can:
  • Improve their sexual satisfaction
  • Promote positive relationships
  • Reinforce their identity as sexual beings
  • Help women dream and plan for the future
  • Prevent unintended pregnancies

• You don’t need to be an expert to start talking!
Thank you!

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