



“Don’t ignore what your body is telling you”

Optimizing sexual satisfaction for women with spina bifida

Courtney Shepard Streur, MD, MS

Christine Schafer, BS

Valerie Garcia

Elisabeth Quint, MD

David Sandberg, PhD

Claire Kalpakjian, PhD

Daniela Wittmann, PhD, LMSW

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Background

- Women with spina bifida have sex
- High reported incidence of sexual dysfunction
 - Why?
 - How can it be improved?

Methods

- Qualitative Study
- Study population: 25 women with spina bifida
 - Ages 16-52 (mean age 27.1, SD 8.1)
- Individual semi-structured interviews
- Outcomes: overlapping themes of women's perspectives
- Analysis:
 - Grounded theory
 - Interviews analyzed by 3 independent reviewers
 - Consensus on themes was reached

Results

7 Themes:

1. Fear of rejection with resulting difficulty setting boundaries and risk of coercion
2. Conflict about spontaneity versus self-care in sexual encounters
3. Concern about incontinence during sex
4. Trial and error in learning optimal sexual positions
5. Decreased genital sensation
6. Safety considerations during sex
7. Advice women wished to share with other women

Fear of rejection with resulting difficulty setting boundaries

I feel like there's always a risk of embarrassment for me in that there's always a chance my partner's not going to be understanding.



Fear of rejection with resulting difficulty setting boundaries

They took advantage of [me] and I took it as love and that was not love... I didn't realize at the time that [was] what they were doing, I was just looking for love no matter how I could get it.



Conflict about spontaneity versus self-care

Not always do I go cath myself beforehand because that really does suck when it comes to my quality of life... how do you tell somebody, “Hold on. I gotta go catheterize my bladder and then we can have sex.”



Concern about incontinence

I'm constantly worried about the incontinence happening. I'm always worried that I'm going to get distracted during sex worrying about that too much.

Concern about incontinence

The bowel—there's really nothing I can do about that because it seems to have a mind of its own so I just pretty much pray.



Trial and error in learning optimal sexual positions

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

Trial and error in learning optimal sexual positions

I have very good upper body strength so I can move myself around with my arms mostly.”



Decreased genital sensation

So not like 100% numbness but there is a little bit of numbness.

Decreased genital sensation

You know it's hard for me to know if I have low sensation and like people will ask do you have low sensation in your vagina? Well, I don't know. I've had the same sensation I've always had."

Safety considerations

I had to find non-latex condoms which most stores don't have.

Safety considerations

I have to worry about if my legs are together or on top of each other too long, I have to worry about skin breakdown

Advice women wished to share

You just have to be willing to try new things.

I would make sure it was a person I could trust and knew the problems I had.

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

We have a lot of toys and that's super useful if my back's not feeling great one day.

Conclusions

- Women with spina bifida are sexual beings
- Physical *and* psychosocial factors lead to diminished sexual satisfaction
- Providers should routinely address these concerns

Thank you!
