Discussing sexuality in the context of spina bifida in relationships

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Young adulthood

- Time of significant life transitions
  - increased independence
  - identity development
  - body image changes
  - forming peer and romantic relationships

Neinstein et al, 2009
Surprise! Disabled people have sex

A Toronto couple is working to educate disabled people who may have been kicked out of high school sex ed classes, as well as the able-bodied.
Sexuality

- Sexuality: capacity for sexual feelings; person’s sexual orientation or preference; sexual activity
- Young people with SB report no significant difference in sexual interests
- But, may face challenges when engaging in relationships and sexual activities
  - Sensation
  - Motor impairments
  - Incontinence
  - Stigma
Literature to date

- 67% of young people with SB reported worries about intimate relationships (Sawyer & Roberts, 1999)
- People with SB aged 15-35 yrs with urinary incontinence sig. less likely to be sexually active compared to those without incontinence (Cardenas, 2008)
- General sex education considered adequate
- Specific to SB lacking (Verhoef et al, 2005)
How do young people with SB think about and discuss their sexuality with their sexual and romantic partners in the context of their disability?

- Young adults aged 16-25 years with self-reported SB
- Recruited through a provincial SB&H organization
- English speaking
- Could provide their own informed consent
- Did not have to have had a sexual relationship

- 11 participants (8 female, 2 males, 1 transgender)
  - 2 identified as homosexual, 1 as bisexual and 8 as heterosexual
## Participants

<table>
<thead>
<tr>
<th>Pseudonym</th>
<th>Age</th>
<th>Gender</th>
<th>Diagnosis</th>
<th>Hydrocephalus</th>
<th>Mobility</th>
<th>Day bladder control</th>
<th>Night bladder control</th>
<th>Sexual orientation</th>
<th>Romantic relationship</th>
<th>Sexual relationship</th>
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<tr>
<td>Stacey</td>
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**Bladder control:**
1 = No control (no bladder control, dependent on clean intermittent catheterization at all times).
2 = Some control (has the ability to sense bladder distension and some control. Uses clean intermittent catheterization as well).
3 = Complete control (has the ability to sense bladder distension and no incontinent episodes. No use of clean intermittent catheterization).

CA = community ambulatory (mobility includes either no assistive devices or uses forearm crutch); FTM = transgender male; lipo = lipomyelomeningocele; MME = myelomeningocele; non-A = noncommunity ambulatory (mobility primarily with wheelchair use); SBO = spina bifida occulta.
1. Importance of disclosure

It doesn’t matter, so why would I ever bring it up? (Kevin, 24)

2. Worries about disclosure

○ Timing

Yeah, it’s an intricate part of who I am therefore it has to be part of the romantic relationship (Cameron, 24)

I do not tend to bring it up to people until I’ve gotten very close to them. And even then, I find that I tend to not bring it up until absolutely necessary (Rachel, 20)

○ Fears of rejection

I expected people to freak out about the incontinence. No-one ever did, but I always expected it (Lewis, 24)

I could have an issue with incontinence. It’s less awkward to have a conversation beforehand (Lewis, 24)
3. Impact of disclosure

It made me feel better that someone could accept me for all these things [that] I don’t necessarily accept (Ashley, 18)

Treat me like I’m normal, but there’s certain things you’re gonna have to do different (Jackie, 16)

He was just like, “Oh cool.” And basically anything that I was really, like, worried about telling him about myself, like either sexually or, you know, just things about myself, he would just be like, “Oh that’s really interesting” (Rachel, 20 yrs).
Lack of preparation

- Often excluded from sex education classes
- Some general sex education (parents, online, friends etc).
- BUT- Not SB specific

As a girl, you never really know that you can explore your own desires and pleasures...just hearing it from anybody would have just been huge (Rachel, 20)

It was something that I was worried about. Will [incontinence] affect me getting romantic relationships? Will I not be able to have romantic relationships because of this? (Rachel, 20)
Discussion

◦ Rejection (or fear of rejection) part of everyday life BUT can be heightened when a disability is involved
◦ Integrating disability and sexual identities can be challenging (East and Orchard, 2014)
◦ Incontinence is a key concern when considering relationships
◦ Participants who became more comfortable with their “disclosure script” also identified this deepened intimacy.
What can HCPs do?

◦ Provide support to help develop understanding of spina bifida ➔ helps develop confidence in communicating this to others

◦ ➔ provides the foundation for communicating their needs in later romantic and sexual relationships

◦ Discuss sensation, self-exploration, incontinence

◦ Help young people develop a ‘script’ that they can feel comfortable using with partners
Future work

◦ Evaluating educational interventions for HCPs
◦ Exploring impact of sexual orientation on information needs
◦ What else?
Thank you!

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