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Episode 21: Sexuality and Spinal Cord Injury  
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On this episode of INside the OUTcomes, we will be talking about sexual and reproductive health within the context of spinal cord injury. My guest is Nicole Sharf, a clinical psychology graduate student in the Chicago School. Nicole works on a Shirley Ryan AbilityLab project focusing on mental health and spinal cord injury funded by the Neilsen Foundation. Her areas of interest are women's health issues, sexuality and rehabilitation. Welcome to the podcast, Nicole.

NICOLE SHARF:

Thank you so much for having me, Sharon.

SHARON:

Can you just start out by talking a little about how spinal cord injury can impact sexual and reproductive health?

NICOLE:

Certainly. So we know that the spinal cord is the main highway for signals between the brain and the body. And this includes sexual response. So things like sensation, desire, arousal, orgasm, ability to maintain erection, all of those things go through the spinal cord injury. And when this communication highway between the brain and the body gets disrupted, so does sexual functioning.   
  
Beyond that, for people with spinal cord injury, sexual functioning is dependent on things like an individual's level and completeness of their injury, their muscle movement and their mobility. Other medical co-morbidities that they may have, like diabetes, high cholesterol, depression, substance use, etc. The age at which they were injured and how sex and intimacy looked in their life prior to injury.   
  
And that kind of, I think, leads me into the different psychosocial changes that we do see following an injury. Right. There can be self-esteem and body image issues. There are changes in relational dynamics between an individual in their partner and also at the individual level themselves, how they feel about being a sexual person. Questions of, am I desirable? Am I lovable? Like there's so many expectations that individuals with spinal cord injury face as they approach sexuality following their injury.

SHARON:

And what are some of the common myths around sexuality and spinal cord injury.

NICOLE:  
  
Common things around sexuality and spinal cord injury are I think the fact that sex does not end after spinal cord injury. People can and do have rewarding sex lives and it might look a little bit different. It might mean adapting and exploring with your partner or independently, but it is possible. It's really about redefining what intimacy means.   
  
So for men, men can have psychogenic or reflexive genic erection so triggered by things like what they see or physical touch or imagery depending on the injury, one or both of these things might be possible. And then for women with spinal cord injury, they can achieve orgasm with pelvic innervation or direct clitoral stimulation.   
  
I think another common misconception is that women with spinal cord injury can't become pregnant once menses resume following injury. Women can naturally become pregnant. They can carry and deliver a baby post injury through sexual intercourse or IVF. But there are possible complications that can arise, including things like autonomic dysreflexia, blood clots, increased spasticity and UTIs. So it's really important to have open communication with your provider as you do pursue pregnancy.   
  
I do really quickly want to touch on the [pregnancy decision making tool](https://spinalinjury.pregnancywithdisabilities.org/) established by researchers at the University of Michigan for people with spinal cord injury who are considering starting a family. And it was made for people with spinal cord injuries who are thinking about starting a family. And it asks individuals a series of questions, kind of guiding them through to help them make the best possible choice for their situation.  
  
SHARON:

I want to go back a little bit to some challenges that people face in terms of accessing health care and accessing care around reproductive health. Can you talk a little bit about that?

NICOLE:

Certainly. I think that what we see within rehabilitation is when individuals are first injured, sex and reproductive health isn't so front of mind right there. They're more so focused on getting through the rehabilitation process. And so as a result, topics of sexuality and reproductive health are just overlooked or not really emphasized during inpatient rehab. But by the time individuals with spinal cord injury get back into their communities and they're working through adjustment, they notice that there's a significant lack of resources around these things.

SHARON:

Could you talk a little bit about access in terms of like the physical barriers that people might face when they go to an office?

NICOLE:

Certainly. And that's actually something that got brought up in our focus groups as well. Physical access to facilities can be a barrier for individuals with spinal cord injury. Engaging in their routine screenings poses barriers when medical equipment is not made in mind. For a person with disability, like access to a mammogram or having a cervical pap smear. I also wanted to highlight that outside of women with spinal cord injuries, men with spinal cord injuries experience gaps in reproductive health care to accessing their routine screenings, managing STDs or low testosterone levels. Those can be impacted for men with spinal cord injuries as well.

SHARON:

What are some things that people with a spinal cord injury can do to improve their sexual satisfaction?

NICOLE:

There are so many interventions and things that people with spinal cord injury can do. I would say that the first thing is, change your mindset. The brain is said to be the largest sex organ. So with that comes many possibilities. Understanding intimacy more broadly beyond physical intercourse is going to be important for a person with spinal cord injury and persons with disability. Rewriting an individual's sexual narrative for their self or for their partner. This could look like looking at arousing images, sharing fantasies, engaging in role play, and igniting all of the senses and finding and experience with other parts of the body that can facilitate a pleasant sexual response. Our erogenous zones aren't only limited to the genitals, so it kind of takes a little bit of being creative and exploring your body in a different way.   
  
Sexual devices and vibrators are also methods that individuals can use to improve their sexual satisfaction following injury. But just be aware that the use of vibrator can put an individual at the risk of getting autonomic dysreflexia. So definitely consult with your health care provider before use. Other devices include special wedges, a Hoyer Lift for positioning. And there is also something called an Intimate Dider device, which is popular amongst people with spinal cord injuries.   
  
I also quickly want to touch on lubricants. So use of water based lubricants can really be helpful in improving sexual satisfaction. Using a tens unit and vaginal inserts for women, and then for men who may encounter erectile dysfunction. The use of vacuum pumps, penile rings, vibrators or options including penile implants or medications like Viagra and Cialis, all are ways of improving sexual satisfaction following injury. Pelvic floor therapy to working with a pelvic floor therapist on these things can be extremely helpful, as well as speaking with the sex therapist.

SHARON:

So, Nicole, you are a lead author on a recent publication in the journal *Rehabilitation Psychology* that reported on some research with focus groups of people with spinal cord injury and clinicians who work with people who have spinal cord injury. So can you talk a little bit about the findings of that research? I know that out of the focus groups, some themes emerged. So can you start with that?

NICOLE:

Yes, certainly. So our focus groups were comprised of 16 people with spinal cord injuries. We had ten females and six male participants, eight rehabilitation clinicians and four psychologists. We identified three themes from our qualitative analysis that highlighted psychosocial adaptation in the context of sexuality, intimacy and sexual reproductive health. And we also ended up looking at the similarities and the differences in how people with spinal cord injury viewed these issues compared to their rehabilitation clinicians. The themes that came out of our findings included one where we looked at the effect of spinal cord injury on relationships with non-injured partners. The second theme pertains to sexual self-esteem, encompassing anywhere from gender role adaptation to body image concerns. And our third theme explored challenges in sexual and reproductive health care. Looking at things like family planning, accessing specialized care, and health care provider competence.

SHARON:

So I know that from the focus groups you gathered narratives from participants. Can you share a couple of the things that participants said about each of these themes that were uncovered?

NICOLE:

So thinking about our first theme, we identified, that there was an impact on sexual relationships with sexual and intimate relationships with non-injured partners following injury. And we noticed amongst women in our study specifically, that they had experienced both internalized ableism as well as partnered, ableism. Internalized ableism occurs when people with disabilities internalize or adopt negative attitudes, beliefs, stereotypes about their disability or disabilities in general, which can fuel feelings of shame, insecurity and diminished self-worth as well. And so we really saw this in the context of relationships. One female participant in our study had said the following” “My husband left when I had my accident. He didn't want to be responsible for a cripple. And so that sort of set me into this feeling that I don't know who I am. I mourn the loss of the marriage, obviously, while dealing with this catastrophic incident, and then wondered, would anyone ever find me attractive again? I can't hold my bladder. I use a catheter. I walk. Not really at all. And I'm a mess. Who am I?”

Then we uncovered issues of partnered ableism stemming from this population as well, which occurs when the perpetuation of ableist attitudes and behaviors by non-injured partner reinforce power imbalances, undermines autonomy and the contributions of the partner. A female participant with spinal cord injury in our study said the following: “My ex-fiancé stayed with me after the accident and he would brag to me left and right about all the people that would come to him and tell him how phenomenal he was for staying with me as if I did anything to this man other than break my back. And there's nothing more frustrating than being like I'm the stable one. I was always the stable one.” So these quotes elicit definitely some cognitive dissonance, right? And we're seeing that ableism, is pretty pertinent and present across our participants.

Correct. Referred there.

SHARON:

What were some other things that people said in relation to some of the other themes that you found?

NICOLE:

So for our second theme of sexual self-esteem, we noticed that our focus group participants experience significant gender role adaptation following their injury. And what this means is that the ability to engage in gendered behaviors and roles can often be compromised by changes in physical appearance and bodily functions, which could influence how a person expresses their femininity or expresses their masculinity. One of our female participants stated: “I came back from what was this horrible event, and I started to feel like a person again and a woman too. I lost that woman because I lost the ability of my bladder to be independent. And that's a big, crushing blow as a person.” A male participant stated” “I was a sixth grade football coach, a hunter, liked to shoot guns. Now I can't even hold a pencil. It was a struggle at first, and I wanted to teach my children how to do things, how to cast a lure, tie a bait on, or how to properly hold a pistol. But as I go on and as I grow, I don't care. I willed my ass out on the basketball court and helped with basketball this year. I can't even do anything, but I don't care.” So kind of showing that adjustment and their adaptation experience from initially being injured all the way through.

Now, our final theme pertains to challenges in sexual and reproductive health care. Participants with spinal cord injury shared their experiences of seeking parenthood irrespective to the views of their health care clinicians and in reproductive health care settings. They reported experiencing challenges, having their needs met and advocating for themselves, the majority of the time feeling silenced by stigma or bias. One participant in our study noted: “Working with the health care industry and having children with a spinal cord injury is not easy. They don't understand. I've talked to nurses who have asked me how I'm going to care for my kids and have threatened to call social services on me. So, I mean, that does a lot to your mental health.”

SHARON:

What other findings were reported in the paper based on the focus groups?

NICOLE:

So I think I mentioned that access to specialized care was a significant finding as well. Referrals to an OB GYN who specializes in serving individuals with spinal cord injuries, let alone mobility disabilities in general, is really hard to find. And it presents a really big challenge for women with spinal cord injuries. So that's one thing. I mentioned this earlier as well, like engaging in typical preventative health measures, engaging in mammograms, cervical screenings, all of that becomes a really huge ordeal. And not having the proper resources available in medical settings poses barriers. So that was discussed predominantly by rehabilitation clinicians and psychologists.

And the clinicians in our study also acknowledged their own gaps in knowledge and expressed that training and resources on sexual health after spinal cord injury for individuals working with this population would prove invaluable. And one psychologist in particular also described her experience of working with an individual, of working with a transgender individual who's going through a transition of whether to change their sexuality, making a transition from going to male to female, and how there's a significant lack of resources for transgender folks with spinal cord injury, let alone the in the LGBTQ plus community as a whole. This finding in particular poses a really fruitful area for research for this field as a whole.

SHARON:

So what can someone do? Someone who has experienced a spinal cord injury and just has questions about sexuality and reproductive health and is just looking for some resources to get started? Where can someone like that go?

NICOLE:

That's a great question, Sharon, and a really important one, too.

The first thing that I would tell someone is to bring up their sexuality and reproductive health concerns with their health care provider or someone that they feel comfortable sharing it with. That person should at least be able to place a referral for this individual who is seeking to learn more information. Maybe that's talking with a sex educator or a therapist or someone who has expertise in this area. Other resources include two websites. The first is MSKTC which stands for Model Systems Knowledge Translation Center. They have awesome and informative [factsheets](https://msktc.org/sci/factsheets) about pregnancy, sexual health, intimacy, all of these things following injury. And another great website too is [Spinal Cord Injury BC](https://scisexualhealth.ca/). Their website is specifically about sex and intimacy and reproductive health following spinal cord injury. They have key topics like sexuality like women's health, men's health, bowel and bladder, contraception and relationships. So really a plethora of resources available on their websites and on these websites. They even to link additional resources, including videos, books, peer stories and clinical resources that would be really, really helpful for someone who's wanting to seek more, seek out more information about sexual and reproductive health after spinal cord injury.

SHARON:

Well, thank you so much, Nicole, for being on the podcast. I will be sure to link those resources in the show notes to this episode. Again, thanks so much for being with us.

NICOLE:

Thank you for having me.

SHARON:

This has been INside the OUTcomes: A Rehabilitation Research Podcast. This podcast is produced by the Center for Rehabilitation Outcomes Research at Shirley Ryan AbilityLab and is funded by the National Institute on Disability, Independent Living and Rehabilitation Research. This is your host, Sharon Parmet, signing off.