Management of Sexual Dysfunction

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[00:00:05] **Dr. Frederick W. Foley:** Sexual dysfunction is widespread in adults, in the adult US population. So, if you have a physical illness, well, then the prevalence of it tends to go up. When we talk about sexual dysfunction with neuroimmunological illness -- and I just want to let you know upfront, almost all my work has been done in MS -- we have to conceptualize it a little bit differently. And the way I conceptualized it was that we have primary, secondary, and tertiary sexual dysfunction. Primary sexual dysfunction occurs as a result of disease-related changes in the CNS that directly impair sexual feelings and/or response.

[00:00:44] So, if you have lesions in your sacral area of your spine, that will cause sexual dysfunction. That's an example of a primary sexual dysfunction. Secondary sexual dysfunctions occur as disease-related physical changes or medical or pharmacological treatments that indirectly affect sexual feelings or response. For example, if you're taking an SSRI antidepressant, there's a good probability you're going to have sexual dysfunction, or if you have fatigue, significant fatigue, there's a good chance that you're going to have a sexual dysfunction. Those would be examples of secondary sexual dysfunctions.

[00:01:23] Tertiary sexual dysfunction refers to the psychological, social, and cultural issues that interfere with sexual feelings or response, such as body image concerns, for example, would be an example of a tertiary. When we look at the epidemiology of sexual dysfunction in MS, our study found that 68% of a large US sample of almost 6,000 patients reported persistent sexual dysfunction. So, it's pretty common, and other studies in the MS literature show similar kinds of problems. So, when we look at the neurology of the sexual response, it's no wonder that so many people with MS or other neurological conditions would have sexual dysfunction because the neurology of the sexual response is very complex, as you can see from the slide.

[00:02:15] Especially spinal cord lesions in the sacral and lumbar areas are highly associated with sexual dysfunction, but the thoracic segments of the spine also can be involved in it. So, different areas of the brain are involved in different aspects of our sexuality. Also, there are other medical conditions that can cause sexual dysfunction: cardiovascular disease, hypertension, other vascular diseases, hyper/hypothyroidism, drug or alcohol abuse, trauma, etc. So, there are many, many different things that can add to the mix on top of the neuroimmunological condition.

[00:03:09] So, what I ask health care providers to do is, ask about sexual functioning. Many health providers don't ask about it, and it's very important that they do. But a recent study found that 84% of MS patients would like to be asked about their sexuality by their MS health care provider, but only 15% of MS doctors report discussing or asking about sexuality with their patients. And the most common reason for not doing so was a fear of crossing personal boundaries. So, it's important for patients and caregivers to bring it up to the doctors, because physicians have said that, "If the patient brings it up, I will discuss it with them. That way I won't be crossing any boundary with the patient."

[00:03:58] Speak up about it when you go see your health care provider. Also, some MS health care providers feel that they don't have adequate medical education on the topic. So, on this topic, how do we talk about sex, and with whom can we talk about it? Not only do physicians and health care providers have difficulty talking about sex, but our patients do and the general population does. And so, we encourage partners to structure their talks about sex if they're nervous about it, agree on when and where it's most comfortable to talk about sex. We encourage people to use educational books, handouts, and videos to initiate the discussion.

[00:04:47] My office was full of self-help books on sexuality and technical books on sexual dysfunction, and I guess, it was no wonder my kids were always interested in coming into my office when they were growing up. But also, when you're having that discussion, it's important to not accuse, or criticize, or blame your partner. Use 'I feel' language or 'I would like' language, not like 'You should' language or 'You don't' language when you're talking about it. And expect that some sexual requests will be rejected. Remember, this does not mean rejection of you as a person. And be aware that sexual feelings and preferences change just as daily symptoms can change and fluctuate.

[00:05:34] And we encourage people to use non-verbal communication assertively. Take his or her hand and show how you like to be touched, and don't expect your partner to do anything unless you explicitly ask them or show them. In other words, no mind reading. And above all else, do not expect perfection. This was a study that we did a number of years ago, and these are the obstacles endorsed by health care providers in addressing sexual function. So, these were the reasons that they wouldn't ask.

[00:06:10] Some examples of primary sexual dysfunction is: less feeling or numbness in the genitals, loss of libido can be from primary reasons, less intense or pleasurable orgasms or climaxes, or inadequate vaginal wetness or lubrication in women, or difficulty getting or keeping an erection for men. So, for men, erectile dysfunction is the most common reported sexual problem that men in the general population have and men with illnesses have. But the good news for men is that, erectile dysfunction can be managed. Virtually every man who has erectile dysfunction can be given an erection today. The medicines and technologies have advanced, and so, there's a lot of hope out there for men.

[00:07:03] There's, of course, the PDE5 inhibitors, beginning with sildenafil, which was the first FDA-approved one. Now there are quite a few others. There are some others that can be used, but they're not FDA-approved in the United States for erectile dysfunction. In terms of medical management: well, there's a vacuum erection device. So, basically, this device, you place a tube over the penis and then remove the air from the tube with either a battery-driven or hand pump, and that causes an erection. And then, a band is placed around the base of the penis to hold the erection for sex. And there's pretty high patient satisfaction with this device.

[00:08:09] There's also intracavernosal injection therapy that is available. In order for the PDE5 inhibitors to work, like the sildenafils of the world, you have to have the ability to get an erection. What those medicines do is they help you maintain an erection. So, if the neurology isn't intact to be able to initiate an erection, you can use intracavernosal injection therapy. Now, when I talk to my patients about this, a lot of men get blanched

at first, “Inject my penis?” And I reassure them that, “Look, you can use an autoinjector, that you don't have to see the needle. It's not a big needle. And, also, it feels like the flick of a rubber band, just a momentary sting.”

[00:09:04] And I refer them to a urologist who can help them, teach them how to do it, and titrate the dose in the office, because when it comes to erections, you can have too much of a good thing. If you have an erection that lasts four hours or longer, well, all the oxygen in the penis will be used up, and the tissues will start decaying. So, that constitutes a medical emergency, and that's why a urologist helps the patient titrate the dose of the injection therapies. There are also intraurethral suppositories that can be used and some topical medications that can be tried. And for all of these things are not useful or helpful, there's penile prostheses that can be surgically implanted in the penis that will enable you to get an erection.

[00:10:02] And then, of course, there's just regular sexual aids, like vibrators and other kinds of sex aids. And perhaps one of the most important aspects of this is education, informing people of what's available, and getting people to talk to each other about it. This is just a cartoon of the intracavernosal therapy and the urethral suppositories that are sometimes used. So, switching over to women for a moment. Women have almost as much erectile tissue as men do. The clitoris is the only obvious external part of the erectile tissue, but if you can see here, there's a large wishbone shape to erectile tissue for women that is contained within the labia.

[00:10:59] And one of the more common sexual dysfunction symptoms in women is loss of libido. So, we teach women and their partners how to cope with the loss of libido, and how to establish a new framework for intimate communication when your sex drive isn't there. And also, help them deal with the grief, with the loss of the sex drive itself on an emotional basis. And then, teach them how to reestablish sensual and sexual pleasure, even in the absence of libido. And one of those ways we do that is by teaching them to do a body-mapping exercise: teaching them to get in a safe, comfortable setting, remove their clothing, and begin by touching the top of the head and systematically move down the body.

[00:11:50] So, one partner is the giver, and one partner is the receiver. And so, with neuroimmunological disorders, the body changes frequently. The sensations change in the body, so it's a way of getting to re-know your body well. And so, when you're in the receiver position, you have to be completely selfish and just direct your partner to do what feels good to you. And then, we have you switch, and you'd be the giver, and then the other person be the receiver. And the giver's job is to just follow the instructions of the receiver and alter the touch to maximize pleasure. Initially, when we do this, it's important not to attempt to attain an orgasm, because attempting to obtain an orgasm puts pressure on the process.

[00:12:42] You want to just experience this process and not put pressure on it. When I've given couples instructions to do this, a lot of times they come back and say, “Dr. Foley, we cheated. We went for the orgasm.” I say that, “That's your prerogative.” Okay. And if loss of libido is due to a secondary sexual dysfunction like fatigue or tertiary dysfunction like depression, treatment of those underlying symptoms will frequently restore libido. And sometimes, you have to trade libido and physical desire for closeness and pleasure, for the intimacy that is associated with those intimate physical behaviors.

[00:13:26] There are no meds approved to manage primary sexual dysfunction in women with neuroimmunological disorders. There's only a couple of drugs that are approved to treat women with hypoactive sexual desire disorder who are premenopausal. They're not approved for MS or other neuroimmunological disorders. You could try the PDE5 inhibitors. There's one small study that was done in MS that was randomized controlled, but it didn't indicate a great deal of improvement for the women in the trial. But some women, some of my patients, have tried some of it, and some of them say it works. I don't know if that's a placebo effect.

[00:14:10] But from a biological standpoint, the same mechanisms that cause an erection in men also cause the clitoris and the erectile tissue in women to expand, but the jury is still out on how well it works. And there are other treatments for women. There's a clitoral vacuum pump, which is similar to the vacuum pump for men, except it's placed over the clitoris. There's vibrators and sexual aids, water soluble lubricants, Kegel exercises, which we'll talk a little bit about, PFMT, which we'll talk about, TTNS, which we'll talk about, and emphasis on intimacy and communication.

[00:14:56] This is just a picture of the clitoral vacuum pump for women, and you can see the soft area, the top of the slide is what's placed over the clitoral area. And one small study in women with MS had marginally improved sexual function scores from it. There's also a transcutaneous tibial nerve stimulation and pelvic floor muscle training. In TTNS, a small needle is inserted near the ankle to stimulate the tibial nerve, or electrodes replaced externally over the nerve. Because when the tibial nerve is stimulated, impulses travel to the nerve roots in the spine to block abnormal signals from the bladder and prevent spasms. In PFMT, it consists in the repetition of one or more sets of voluntary contractions of the pelvic muscles, such as Kegel exercises do this.

[00:15:55] By building the muscles' volume, it elevates the pelvic floor and pelvic organs and has been associated with improved sexual functioning. For example, this study in MS, which used the supervised pelvic floor muscle training, found that it significantly increased desire, arousal, lubrication, orgasm, and satisfaction after 12 weeks of practice. So, these results were clinically meaningful and significant. For the TTNS training, there was a study published with 35 women with sexual dysfunction, and these were women with MS. It wasn't randomized, but they had comparable demographics and clinical characteristics for both groups. And both groups improved significantly on this, the TTNS group and the PFMT group.

[00:16:56] So, there were no differences in improvement between the groups. There's a little preliminary evidence for aquatic exercise. It's 60 female MS patients randomized to aquatic exercise or an active control group. Both aquatic groups improved sexual function scores on desire, arousal, and orgasm, but not on lubrication, satisfaction, or pain. We use an intimacy-based sexuality in our work. But we're not only interested in the erotic aspects of the relationship, but the essential aspects of the relationship as well. Holding hands, other types of touching that does not involve erotic acts, and also the special person aspects of the relationship. If a couple is in a relatively long-term relationship, we want to enhance all these areas: the special person, the sensual, and the erotic aspects of the relationship.

[00:17:59] And we like to use an intimacy-based model of looking at the female sexual response cycle, where we're looking at all of these factors that can be involved in their sexuality. And this was just a quote I found that I like, "The orgasm gap exists in heterosexual women because traditional models of penis and vagina sex simply don't work for most of us. Most women need clitoral stimulation to achieve orgasm, but we often need more than that. We need for our heads to be in the right place, to feel sexy, safe, and desired, and our bodies and vaginas warmed up and put in the mood. It's a whole process."

[00:18:48] And sometimes men and women have different aspects of what needs to be present for all of those dimensions: the special person aspects, the erotic aspects, and the sensual aspects. Sometimes men use the erotic aspects to open up more emotionally and feel closer. And sometimes for women, the emotional closeness may come first in order for them to open up to the more erotic aspects of the relationship. And there are great resources out there for women and couples: Mind The Gap by Dr. Karen Gurney; it focuses on intimacy and desire within a relationship as a whole, and there's a sex ED platform online called beducated.com; it offers quite a few courses in adult sex education with explicit sex guides.

[00:19:48] Okay. These are just some examples of secondary sexual dysfunction items. And fatigue is a big problem in neuroimmunological disorders. I know in MS, it's one of the most frequent and disabling symptoms. So, I just want to tell you a little story on that about a couple that I treated. They were relatively young, in their mid-thirties. She had MS. And at the end of the day, she was just exhausted. They both worked full time and had a couple of kids that were in elementary school. And so, they came to see me for a consultation. They hadn't had sex in over a year. When I asked them why that was. She said that, "Well, I'm busy all day. I work. After the kids are in bed, I'm totally exhausted."

[00:20:52] I asked her, "Have you ever thought of trying to be a morning person when it came to sex?" And she said, "Oh, no, no. That wouldn't work. I work first then play in life." So, I sent them home. I said, "I just want you to think about it. I want you to be open and brainstorm about this, about how to get your sex life back." And they came back to me a couple of weeks later, smiling. And I said, "Oh, okay. Something looks different here." And they told me they realized they both worked pretty close to home. And on Fridays, they were able to negotiate extended lunch hours with their respective employers.

[00:21:35] And so, they used that time to come home. The house was quiet. The kids were in school. She still had energy. Her fatigue hadn't kicked in badly yet. And they said to me that they didn't always start making love on Friday. The first Friday, they just sat together. But they said that it re-established intimacy, and they know that MS was going to throw them more curveballs down the road. But they felt very empowered by this, and they felt if they could handle this symptom, then they can handle others.

[00:22:07] And so, I'm going to just stop the share there because I see my time is up and just say that in our studies, and we published several studies on this topic, we found that education alone significantly improved sexual dysfunction in men and women with MS. So, getting materials from your organization on sexuality and sexual function, reading about it, or asking your health care providers for help with this, and education about it, we found in our studies, led to significant improvement in this area. Thank you very much.

[00:22:58] **Dr. Carlos A. Pardo:** Thank you, Dr. Foley. That was great. I need to confess that I am one of those practitioners that sometimes skips the question about the sex life. I need to acknowledge that. But, actually, it's a very important part in our medical practice.

[00:23:15] And as a health care provider, I believe that mental health depends on many factors. Sexuality is one of them. Dr. Foley, that was great. Thank you very much for your participation. We hope that next year, you are able to come in person and chat a little bit more about sexuality in rare neuroimmunological disorders.

[00:23:36] **Dr. Frederick W. Foley:** Thank you. I would be honored to.