Sexual Dysfunction
2010 Rare Neuroimmunologic Disorders Symposium
Presenter: Wanda Castro-Borrero, MD, UT Southwestern

Transcription from presentation available at https://youtu.be/tU47LRa2ovg

[00:00] [Dr. Greenburg] So yesterday we could rate it as PG-13 now it is time for our rated “R” lecture. This is I gave ever one a warning ahead of time Dr. Wanda Borrero would be talking about sexual dysfunction and sex which is a healthy thing and after Transverse Myelitis and ADEM there is often a lot of changes that happen in the human body sexually both physically and emotionally and a variety of other ways and this has real implications so this is let’s put it into perspective this is the Rare Neurological Symposium this is depending on how you count things this is the fifth the forth and the tenth it’s been happening every decade and we are bringing people from all over the country and the 10 hours of lectures and different things this is one of the things that we make sure we talk about because often in the doctor’s office it doesn’t get discussed and it’s always the same thing over and over again in my experience, “How about your pain, let’s talk about your Rituxan, your CellCept, your interferon, your depression and is there anything else? And there is silence usually the spouse is looking at the other spouse and I say, “Is it sex?” And somebody shakes their head yes. It doesn’t get discussed in the doctor’s office especially after these events, it has to be discussed and Doctor Castro-Borrero I say has taken an interest in sex from the neurological and medical perspective and has been devoting time in the clinical and the research side trying to sort out why do things change and how do we make it a better part of our life. So, I will turn the stage over to Dr. Castro-Borrero and when she is done I will be in the other room shall release you for a break and she is going to limit that break because we are trying to make up a little bit of time but you will walk out of here happy that is the worthwhile trade off so –

Wanda

[02:05] [Dr. Wanda Castro-Borrero] Good morning, I always said as Dr. Greenburg said this is my area of interest so there might be things that I don’t know and why this has become my area of interest is like he said most of the patients if you don’t ask the physician is not going to talk about it and with the limited amount of time we have in the clinic well this is one of the last things we discuss. My main problem is when I was putting this together is to get everything in 30 minutes. okay when I give talks for physicians and patients it about an hour and with questions we can go over so I try to make everything shorter, you have a lot of slides we are not going to go over all of them, I try to summarize them you have all the slides here except for one okay and then we can go over it, so let’s start.

[03:00] So I usually like to start with this thought [Slide says “Everyone is a sexual being... It is natural for everyone to desire affection and intimacy.” Frederick Foley, PhD] Dr. Foley has done a lot of research and sexual dysfunction in the MS population and I think it is very true everyone is a sexual being, it is natural to desire affection and this is not only sex because sex is just part of this big sexuality thing, we want to feel love have someone in our live that express that affection so one thing I want you to take home today is maybe you might not have a sexual life as everybody else have maybe you cannot have an erection you cannot have penetration but still you can fulfill that desire of being loved.

[03:50] So just a little bit about what happen in the brain this is not only for MS this is for any of the rare neurological disorders like NMO, ADEM and Sarcoidosis any of them that would have any lesions in the brain or spinal cord all of these things will apply to it. Parts of the brain that are really, areas of the brain
that I think that are very important that causes some of the problems in sexual dysfunction in our patients is if you see the left anterior cingulate cortex you know most of the lesions in MS patients are periventricular you have seen those coming out of the ventricle, right? So that is where your cingulate cortex is. So that area will take some of the sexual desire, so I explain to some patients when you have a lot of lesions here it is kind of expected that there is going to be some issues with sexual desires and libido and then when I showed the MRI’s to the patients they were like “Maybe that’s what’s going on so it is not necessarily that I am not interested in my partner anymore.” Another area that is important is the hippocampus because that will motivate sexual drive. The periaqueductal gray when you look at it in MS patients there is always a small lesion there and that is an important relay center for sexual stimuli. So, we know that sexual dysfunction is not only in the mind because of depression because of the stress that is going on because of the lesions that you have in your brain and spinal cord.

Then we need to have a very well-balanced system so this is not only neurological your endocrine system should be addressed make sure that it is working properly, vascular system also needs to be addressed and then physiological factors sometimes depression can become very important for patients when they don’t have a lot of desire for sex.

Then we have five neurotransmitters that are very important when we are talking about sexual dysfunction. Dopamine and norepinephrine are the ones that promotes the sexual drive and serotonin is going to inhibit sexual function, what is interesting is most of the patients will be on some type of SSRI antidepressant right? Lexapro, Celexa, Prozac, Pascale and all of this is going to affect the serotonin level and I think there is in the slides that you have there is a pretty good study that shows that SSRI’s can affect any part of the sexual function everything and then I can tell you later what we can do for that.

Then sexual dysfunction is not something that is not going to cause disability, right? We all know that it’s, and that is why insurance companies do not cover any medications for sexual dysfunction because they don’t feel that it is a real medical problem. The issue is like psychologically is a big, big concern okay people that have a more fulfilled sexual life or intimate life they will be happier. Back at home in Porto Rico we make fun if someone get very grouchy at the office in the morning okay last night they spent the night in the doggy house or there was no sex last night, we all talk about things like that and probably here in the states they make comments about that and probably here in the states they make comments about that as well. So, we know that when people have a fulfilled intimate life they are happier and that is important.

So this was and I apologize because I don’t have the reference here but this was in a study and they show that in MS sexual dysfunction is five times higher than in the population and also in all the chronic diseases is the one with higher percentage of sexual dysfunction. Then in the female population it is about 22% in the general population but in the MS females it can go up to 75% with the most common complaint is decreased libido. In the male population in the country in the male population it is 21% and 85% for the MS population, and what is interesting is erectile dysfunction is the most common cause but it is very closely followed by decreased libido on some of the male patients when they come into the clinic it takes a little bit longer for them to tell that there is a problem. Usually when they come into the clinic for their first visit I ask is there any problem with sexual function and they say no the second visit I ask again and they say no the third visit finally they will admit it, with the female it is sometimes more easier to get to that.

Okay so how we make a diagnosis, I think this is a multidisciplinary approach, why? Because not everything is MS not everything is Transverse Myelitis not everything is that. So, we need to make sure
that the patient said: “I have a problem.” After the patient said I have a problem something that would be nice is that they fill out the Multiple Sclerosis Intimacy and Sexual Questionnaire. This is and I don’t have a copy here but I can make copies for all those who are interested. It is about 19 questions and you grade in the last 6 months from 1, 2, 3, 4, 5, been always to one being almost never. Different, for example I have a great sexual life or I feel adequate with my partner I feel not attractive anymore and you rate those. What is interesting about the MS-ISQ-19 is you can classify the type of sexual dysfunction that you have ok and I’m going to go to that couple of minutes. Basically, there are 3 types of sexual dysfunction, primary which is direct effect of the demyelinating lesions in the brain and spinal cord. Secondary which is basically symptoms because of the symptoms or of the medications you are taking and then tertiary which would be physiological. And there is treatment for each of them so we know what’s the main problem so we can address that specifically, so I think that is a great tool and each of them can only be used in MS patients.

Then we need to have so urology, some OB/GYN interaction we need to do some labs, and these are just baseline free and total testosterone and this is either females or males we need to check prolactin levels we need to check LH and FSH and sex hormone binding group also it is important to do a fasting cholesterol panel and a fasting glucose because not everything is demyelinating lesions.

We also need to make sure the patient stops smoking, we know that smoking is not good for MS but also smoking is going to make sexual function problems. We also need to make sure the stress, depression and all this other stuff is addressed. And this I already told you there are three types of dysfunction and what are the most common complaints in females? Usually it is decreased desire. Then some of the female patients come to the office and they tell you: “Well but that is not bad I have a lot of friends that my age and they have two or three kids and they work and they said they don’t think about sex and I said the question is were they like that before? You know. Were you like that or was this something that just happened, and it’s important to verify that. Decreased vaginal lubrication is a big, big problem, so patients need to use a lot of lubricants. Then also there could be pain on penetration and they can be anorgasmia as well.

In the males one of the most common thing is erectile dysfunction, there is also decreased libido, they can be anorgasmia and just to let you know problems with anorgasmia are not that common but when that happens it is very difficult to treat there is no FDA approved medication for that. I have been trying to get nasal oxytocin because there are some studies about it, this medication was discontinued by the FDA a few years ago and we have been unable to find it, you can get it from Europe or Canada but at least patients are having issue trying to get it from there but for anorgasmia that’s the only thing that I have read that maybe helpful.

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Then secondary sexual dysfunction we know fatigue is a big issue, so fatigue is going to be a implication for sexual dysfunction. Spasticity, we know that in specific positions they are going to have extensor spasms and they’re going to lock and those legs are not going to move for a while so we need to avoid those positions, we need to treat a spasticity before sexual activity. Bowel and bladder incontinence, we have patient that can have bladder incontinence or bowel incontinence when they are having sexual intercourse and that becomes very embarrassing very stressful they don’t want to have sex so we need to talk about all these things so we can try to do to make it better.

Then medications, patients that have problems with their bladder they are probably going to be on anticholinergic, what Doctor Lamott was talking about, and this is going to cause a lot of vaginal
dryness so these patients are going to need a lot of lubrication. Also, anti-depressants SSRIs as I told you Paxil, Celexa, and Lexapro these are going to affect every type of sexual dysfunction, so there is a very nice study which shows if you give Wellbutrin, this is the drug that we use the most in our clinic, Wellbutrin 150 milligrams daily can counter act the effect of SSRI’s in sexual dysfunction. So, you will see most of my patients are going to be on a combination of Wellbutrin and SSRI.

[14:33] Tricyclic antidepressants like Amitriptyline or Triptyline those are not used for depression but they are used for pain and they can also effect sexual dysfunction. Baclofen is also medication that is use for Spasticity that can cause some erectile dysfunction so some of the patients that has this problem I recommend to switch them to Tizanidine for example or any other anti-spastic medication.

[14:59] Then the anti-fatigue medications Amantadine is not used a lot but those patients that use it can have any type of sexual dysfunction but in erectile dysfunction, anorgasmia, decreased libido. Also, amphetamines and this is dose dependent is at a high dose patient can have problems with sexual function but at a low intermediate dose it can be beneficial.

[15:27] Then this was, these are quotes from patients about what the problems are related to sexual functioning some of them think that disabled people are not sexually attractive and I tell my patient that you are still the same person that you were 10 or 20 years ago it might be a little bit different and you may have to do thing a little bit different but you are the same person even though you may have gained ten or 20 pounds your still attractive you just have to work with that self-esteem.

[16:04] Another thing that they said is there partner doesn’t find them attractive and this is the interesting one because when you have both of them in the clinic and you ask, that is not true. So, they haven’t talked between each other and this happens a lot couples don’t talk about this and then you get this period ds you have in your own mind he doesn’t like me anymore, she doesn’t like me anymore but that’s not really what is going on.

[16:30] And then this is another one: “I cannot be both a caregiver and a lover.” And the National MS Society and addressed this as well and they call it the “caregiver dilemma”. So, what they recommend is that patient that needed a bath or a change or a cath or do any of these things they recommend that they hire someone or that ask someone else other than the spouse or partner that they do those functions so it is an easier transition.

[16:56] And this is the most common one: “with everything else that is going on, the kids, work, the last thing on my mind is sex.” Hear I just want to tell you that MS and I just have the statistics for MS is one of the most chronic diseases with the highest rate of divorce. We don’t know why, okay. It could be because of the financial strain of the chronic disease it could be the uncertainty of the MS but I think that sexual dysfunction has a role here as well. And I think if the patient and their partner talk about this maybe we can salvage some couple and some marriages.

[17:40] And so basically for the tertiary sexual dysfunction this is just thoughts that the patient has the role changes and performance and changes in society cultural beliefs and that is very, very important the financial strains as well.

[17:59] Taboo, if you are coming from a very Catholic Hispanic Porto Rican family at sixteen you were going to be a nun in a seminary you shouldn’t be talking about this today, okay. My family would be very surprised that I am doing this but I think we need to talk about it, it is important it is very important.
back in the seventies at home nobody talked about sex you didn’t see anything on TV now kids are more exposed to these things so I think we need to start talking about these problems.

[18:38] So how we treat sexual dysfunction so basically, it’s going to be a lot of trial and error and we need to do a lot of stuff. One of the things that might be helpful is education and this could be a sexual counselor talking about sexual positions talking about what other things you can do to fulfill intimacy. Medications you have to review those medications try to use new medications to see if they will help with sexual dysfunction. You also can treat any systemic illness if you have problems with cholesterol, diabetes those need to be addressed you need to make sure you have your revelation with urology your OBGYN, hormones are okay you don’t need any supplements testosterone or any estrogen supplements and patients need to think there might need some need to use some sexual device maybe a vibrator or something else that can help and I am going to talk about that as well.

[19:39] So Eros, Eros is the first and only device or even medication because there is no medication approved for female sexual dysfunction. This is the little device that is battery operated it has three levels this is the suction this area is placed to the clitoris and this causes the suction it has a low, medium, and high level. I expect, and this is the study that I really want to do in our clinic I had at least 20 patients to use this device and see if it works in MS. It has been studied with patients with diabetes and it has been studied with patients with radiation because of cervical cancer so I think it will be a promising tool. [She points to a picture that says: Noninvasive, non-pharmacological, battery powered mechanical device, that when activated by the woman herself or her partner, creates a gentle vacuum over the clitoris to increase blood flow to the genitalia. Improving vaginal lubrication, increasing genital sensation and augmenting orgasmic ability.]

[20:26] I do believe that patients with MS are going to be needing a higher power I don’t think the lower level or mid-level is going to be enough. And this is something in the studies improves everything, not only improves lubrication engorgement of the area also improves desire, orgasm and sexual pleasure overall. So, I think if this works in MS patients this is going to be a great device. It is not covered by insurance and it costs about $300.

[21:02] Then this is something that we recommend for our patients and it is the wall power vibrator, the Eroscillator is one of them but there are others. Usually patients that were able to achieve an orgasm before MS or Transverse Myelitis they will be able to achieve an orgasm with this. The problem that I have in some patients is that they don’t want to use it and I have couples that it is the females or the males the patient or the partner that doesn’t want to use it, okay. And here again it is communication it’s not that you are going to achieve an orgasm without your partner it is just something to help you to get there with both of you. So, the Eroscillator it is about $130 you can buy it online. Then lubricants are very, very important I think female patients should have a good stock of lubricates because you will need it.

[22:00] Then male sexual dysfunction. We divided treatment in two areas: Invasive and non-invasive. So, the non-invasive will be physiotherapy and you can use the Viagra, Cialis, and Levitra and some people say that probably that doesn’t work because if you look at why patients will have problems with erection in MS, Transverse Myelitis, or ADEM it might not be helpful but the truth is it does help in most of our patients it’s not 100% but it is helpful, the problem is not predictable. And seeing this when you see those commercials when they say every moment can turn into a moment and you have to be prepared and really in patients with sexual dysfunction it has to be a plan activity I’m going to go over
that as well. You can it’s not going to be just this moment you have to plan there are a lot of things going on and I always recommend going a date once a month, once a month you have that plan.

[23:14] So we can use for males that vacuum erection device that is non-invasive and probably a little bit invasive. Testosterone supplementation, body mapping. And then in the invasive type you can do injections of Edex or Alprostadil you can also do the suppositories and you can also have a prosthesis. And this is basically a picture of the prosthesis with the little pump to pull it up and down.

[23:52] So the erection device the vacuum I haven’t had any good response from patients I don’t think male patient would like to use this and when they talk about it the say I would rather put an injection than do this but this is an option, okay. Maximum duration is about 20 to 30 minutes, you can put the device over the penis create the vacuum and pull it out and then put the ring at the end. Of course, you are closing the blood flow there so you are going to have some pain, bruises, and hematoma in the area those are real side effects but if the problem is erectile dysfunction it may help it’s not 100% either.

[24:36] These are then injections and you have I think more pictures about this you can use monotherapy like CAVERJECT or Edex which is just prostaglandin E1 or you can send it to a compounded pharmacy and then you can add papaverine, phentolamine and atropine. I usually like to start with 5, 10 or 20 milligrams, I think 5 milligrams is not going to help MS patients or Transverse Myelitis so you can just start with 10 or even 20 if you are going to get some benefit it’s going to be 20 or higher.

[25:15] So here is where you get the injection so you have to tell the patient that it has to be on the side the because the majority of the nerves are at the top of the penis and the lower part so it has to be on the side and it is a very small needle patient said it’s not uncomfortable the ones that have done the injections but once again it has to be the high dose the low dose will not be helpful and sometimes this has to be done in combination with Levitra, Cialis or other medications.

[25:48] This is the suppository and basically you just insert it and push the plunger let it rest for about 30 minutes then you can have sexual activity.

[26:05] Body mapping is something that is recommended by the National MS Society and I recommend that every patient that has some type of problem with Transverse Myelitis or lesions in the brain take a little bit of time to do this. The main problem when you do this is that the body has changed and all of you know that your body has changed. So now areas that had given you pleasure now might be painful so how you avoid that you just have to figure it out again and maybe areas that have given you no pleasure in the past now that is the area that we need to discuss about. So basically, the recommend you take 15 to 20 minutes, the first time you do it by yourself, be in a room and start touching all the parts of your body and you can change the stroke, you can change the pressure and the length you are in each area. And they said the first time do it by yourself the second bring your partner into the situation so you can do it together. So, this is just to figure out which areas are okay and which areas are so painful you don’t want to be touched at all.

[27:13] Then masturbation and sexual aids okay and I always talk about this and it’s interesting when you talk to the patients they will bring this up. I had a patient that said, “Oh doctor Castro I had to buy a vibrator because my hand with the tremor is so bad I cannot use it anymore.” And I say, “okay, that is good.” So, there are different devices that you could use. Masturbation by yourself you’re by your
partner oral sex will be best in females with some type of sexual dysfunction once again there is culture beliefs and other thing so you have to discuss with your partner if oral sex maybe a possibility.

[27:54] Sexual aids, there is going to be specific sites like disabilities-r-us.com that have these sexual aids and this one here the Hitachi magic wand I have a patient that swears that it is the best one. What is good about this website as well is they have chat rooms so patients can talk to each other, they can bring any problems any issues they can talk about what they are using so I think it is and they have resources so you can by different things there as well. This vibrator here (Points to Ultraviolet vibrating egg) might not be as good as the Eroscillator because it is just battery operated so for patients who have problem with dexterity this is the larger thing you can hold in your hand and it’s going to be a little bit better so they have different things for different problems.

[28:57] So how we treat secondary dysfunction, physicians need to look at the medications to look at the medications the patients are on doesn’t cause any problems and if it does cause any problems then we can switch to something else or we can get some type of help to diminish the side effects of this type of medication. We also need to treat depression we need to treat Spasticity, pain, bowel, bladder incontinence and important smoking cessation, that is a big, big issue.

[29:30] Go on a date at least once a month, this needs to be planned, okay why we need to plan we need to take the medications if the problem is erectile dysfunction we need to take the medications, injections, tablets. If the problem is Spasticity, we are going to take the anti-Spasticity medications 30 to 45 minutes before planned sexual intercourse so it is at its peak. If you need, if you have problems with energy you need to take your Provigil, Adderall, Ritalin at least 30 minutes before so it’s at its peak before you are planning it. You need to empty your bladder you need to empty your bowels if possible. You also need to drink a lot of ice cold beverages so you don’t get dehydrated, Uhthoff's meaning you are not going to get symptoms when you are overheated after having sex. So, all of this need to be addressed that what I said it needs to be planned. And if you have children get someone to take care of them that night.

[30:34] Then psychosocial counseling I recommend that if you send patients you send someone who is certified, someone that knows what it’s doing, someone that has some experience with these conditions, and they can teach them some sexual stimulation techniques, positions as well. One big thing is communications if you don’t talk to your partner if you don’t learn about the disease about what the problems is you cannot do anything to fix it, okay and also you need to make sure can we talk today can we talk tomorrow, do we need some books, what we need to do to learn more about this. Tell your partner I don’t like this and be honest it’s not like whatever I just need it not to past some of the female patients it’s just something I have to do it’s my duty as a wife, no it’s not. So, you have to be there you have to be conscience if it is not giving you any pleasure just say it lets try something else.

[31:40] Sexual position it’s important because as I told you before some sexual positions can trigger spasms then when you are in pain when you’re in the spasm the moment is ruined at that point so we have to start over. So, there is nothing for MS patient for positions. This is from COPD patients I think are appropriate for MS patients the person with MS should be the one laying down. [She points to a picture of a couple in the missionary position] but also this type of position would be also helpful [She points to a picture of a couple she is on her back with her legs over her partner laying on his side] you don’t do a lot but you are still some pleasure and getting some pleasure from this not like you just lay there. So, these are four and there were six but I think the other two were more acrobatic ones and I
thought it was not for MS patients at all. They were in a chair and standing up and I am like I don’t know how you can conserve any energy doing that so I said I am going to take those out I don’t think those will work. But I think these four [The other two positions are one with the man on his back and the woman sitting on him facing away straddling him. The other the woman is facing down and the man on her back.]

[32:55] And I think one more thing you can do with your partner is go and by a book and there are many books about sexual positions and you can just start trying them and look at things you think maybe helpful. And then during sexual intercourse there is going to be problems with adductor spasms, extensor spasms, bowel incontinence, bladder incontinence, energy conservation so we need to address all of this. Talk to your partner that it’s very, very important if you have bowel and bladder problems make sure you self-cath before sexual intercourse make sure you empty your bladder make sure if it is possible that you try to have a bowel movement. And since this is going to be planned you can take your MiraLax the night before or that morning or you can take your Dulcolax or a Dulcolax suppository before you can do all this to make sure you don’t have a problem so it’s not going to be a problem so you are not going to be embarrassed.

[33:53] Talk to your physician and physician should talk to their patients as well as your doctor about checking your medications we can do any switch of medications and then consider a sexual therapist or counselor. Optimize treatment with Spasticity use it 30 to 45 minutes before this is something Dantrolene is a medication use for spasms we don’t use it a lot in MS patients it is use mainly used in spinal cord injuries. But Dantrolene has the benefit to decrease the extensor spasms before intercourse. So, the patient, if this is the problem Dantrolene maybe the medication that you want to try.

[34:35] Time sexual activity with the pickup in energy, express your love in other forms you can kiss you can cuddle you can massage you can do other stuff you can still feel love and that you love your partner and you don’t need to go have sex and I have couples and they have been living like that and they are very happy and they are doing well so I think this is mainly communication and keep yourself well hydrated with cold beverages. And that is it. It was not really “R” rated and I am not really an overexposed thing I just want to talk a little bit about it.