



Living with MS as an LGBTQIA+ Person

Presented by:
William Conte, MD, MS

Yahaira Rivera:

Good evening, everyone. Welcome and thank you for joining MSAA's live webinar "Living with MS as an LGBTQIA+ Person" presented by MS specialist Dr. William Conte. This webinar is part of MSAA's health equity, diversity, and inclusion initiatives. My name is Yahaira Rivera and I'm the Director of Mission Delivery and Program Development for MSAA and I'm your host for the program tonight.

Just a little bit of background about MSAA and some housekeeping items before we get started - as you may know, MSAA is a national nonprofit organization dedicated to improving lives today through vital services and support for the entire MS community. Our services include a national helpline, providing English and Spanish services Monday through Friday, 8:30 a.m. to 8 p.m. Eastern Time; equipment and cooling distribution programs with products designed to improve safety, mobility, and to help with heat sensitivity. In addition, MSAA offers an MRI access program for individuals with MS who qualify for assistance. We also have educational programs, webinars and on-demand videos, online tools, publications and digital resources that includes the just released Ultimate Treatment Guide, which is now available on our website. This interactive guide describes and compares 19 FDA approved MS treatments and will help people living with MS make informed decisions and choices. MSAA also offers support through community connection to help you stay connected to members of the MS community. All of our programs are available to people living with MS nationwide. To learn more about MSAA's programs and services, please visit our web site, mysaa.org or give us a phone call.

During tonight's program, you will have an opportunity to ask questions by typing them into the chat box. We'll do our best to answer your questions during the Q&A portion of tonight's webinar. At the end of the program, we ask if you could please complete a brief survey. Your feedback is important to us, and it helps us in developing future programming and content. A link to the survey is also going to be included in the chat box.

As of friendly reminder, this program is for educational and informational purposes only and does not constitute formal recommendations. If you have specific questions about your diagnosis or treatment, we always recommend that you reach out to your health care provider or physician.

Now, let's talk about our learning tonight. Our learning tonight is going to provide us with a deeper understanding and awareness of the unique needs of the LGBTQIA+ community living with MS. Dr. Conte will define common terms, describe health disparities, and discuss topics

such as hormone replacement therapy and factors that may influence disease modifying therapy selection in MS patients who are part of the LGBTQIA+ community.

Now, without further ado, let me introduce you to our speaker this evening. We are extremely grateful to have Dr. William Conte with us tonight presenting on our topic. Dr. Conte is an MS specialist at the Comprehensive MS Center at Methodist Hospital in Merrillville, Indiana, and he's also an Adjunct Assistant Professor of Neurology at Indiana University in Bloomington, Indiana.

Dr. Conte earned a bachelor degree in neurobiology from the University of Florida. He graduated from medical school at Loyola University, Chicago Stritch School of Medicine, and went on to complete an adult neurology residency at Loyola University Medical Center. Additionally, Dr. Conte completed a fellowship in multiple sclerosis and neuroimmunology at the University of Chicago through a National MS Society Sylvia Lawry Award and earned a Master's Degree in Public Health Sciences.

Dr. Conte believes in customizing therapy to the individual patient with a strong interest in clinical trials and research, he has been the principal or co-investigator on multiple clinical trials and investigator-initiated studies. Dr. Conte frequently lectures on various topics and presents research at national and international conferences. The MS Center at Methodist, which Dr. Conte leads, is recognized as a partner in MS care by the National MS Society. Welcome, Dr. Conte, we are looking forward to your presentation.

Dr. William Conte:

Hi, everybody. Thanks for having me from the MSAA. Really excited to be here tonight. So, you know, this is sort of a new topic that we are... I'm hoping to spearhead continuously talking about LGBTQ+, the needs of the LGBTQ+ community in MS care. These are my disclosures, which I don't think are really pertinent to tonight's topic.

And so, let's just discuss... My goal tonight is really to, sort of, define the terms, define the differences between sexual orientation and gender identity and common LGBTQ+ terms. I also want to describe health disparities that queer people face. I want to describe how gender affirming hormone therapy affects people with MS and also discuss some disease modifying therapy selection consideration.

So, you know, LGBTQ+, LGBT, LGBTQIA, LGBTQIA+, right? There's a lot of letters that I feel like are evolving as the years go on. And so I just want to go down to the basics and sort of talk about of the terms. I don't want to offend anybody that already knows the terms, but I think it's always good just to resummarize things. So, "L", lesbian, is really just a female who is sexually and or emotionally attracted to other females. "Gay" is really the same, but it's a male to male. Bisexual is sexual or emotional attraction to both males or females. And then sometimes people include attraction to transgender people, depending on the person, their own personal preferences. Transgender is an umbrella term for those whose gender is different from the sex assigned at their birth. We'll be talking a little bit more about this. And queer, "Q", that's "queer questioning", so queer is an umbrella term for sexual and gender minorities are not heterosexual or cisgender. So this is just, you know, I like to use the term queer for like, you know, it's a shorthand for the whole community. "Questioning" is a term that refers to people who are unsure or questioning their gender or sexual orientation, so we're inclusive of those people.

"I" is intersex, so this is a little bit more interesting. So it's a variation in sex characteristics that include chromosomes, gonads or genitals, that do not allow individuals to be distinctly identified

a male or female. "Asexual" or an "ally", which is the "A", so asexual is lack of sexual attraction to anyone. An ally is really a person who considers himself a friend to the LGBTQ+ community. And the plus (+), which is really, I think, the most important term here, it's the "others", right? So the "+" really considers that there's an unlimited sexual orientation and gender identities, right? So there is really unlimited types of orientations or gender identity.

So what is the prevalence of the queer community, right? So about 4.5% of the US population identifies as LGBT, that's about 11 million people, and there's more females than males in that. And the transgender is about .5% of the US population, which is actually over a million people. So I mean, we're going to see people like this.

So one important thing I want to talk about is the difference in gender identity and sexual orientation, right? So gender identity is your inner sense of your own gender, it may not match your sex assigned at birth, versus sexual orientation, it's related to the gender, or genders, of your romantic and sexual partners. So everybody has a gender identity and sexual orientation, whether you're queer, whether you're straight, everybody has a gender identity and sexual orientation. And transgender is not a sexual orientation. Okay. So it's a very important thing to remember.

So transgender is a person whose gender identity does not correspond to their sex assigned at birth. And cisgender would be a person whose identity does correspond to their sex assigned at birth. And gender expression is the way a person communicates their gender to those around them, such as appearance or mannerisms. Right? So everybody has a gender expression. So what's an example of this? So, a transgender man would be the assigned sex at birth would be female and the present gender identity would be a man. Okay?

So gender affirmation, which was formerly the term we used was "transition", is sort of a process where a transgender person is able to outwardly express who they are to others. And there's many different types of gender affirmation. So that can be social affirmation, which is like changing a name, pronouns, clothes, hair, it's more of like a social situation, versus legal affirmation, which is changing name and gender on official documents. And there's medical and surgical affirmation. So medical affirmation would be gender affirming hormone therapy, which is aligning one's body to their gender identity, and surgical affirmation is actually using surgery to change one's anatomy. Okay? So we're going to talk a little bit more about that later on in the talk.

One thing I want to start talking about is the health disparities that queer people face. So overall, we face higher rates of overall disability and physical limitations. So it's obviously very concerning for, you know, someone who has MS, because it's an intersection of two types of problems. So there's overall poor general health, high rates of HIV among gay and bisexual men and transgender women. Although HIV is not unique to the queer community, we do face higher rates of it compared to heterosexual and cisgender people. There's higher rates of overweight and obesity in lesbian, bisexual women, higher rates of cancer even, and cardiovascular disease, and overall higher rates of healthcare utilization.

So what are the causes for this? So I have two theories on this. One of the theories is ACEs, or adverse childhood experiences, which are higher among LGBTQ+ people, and then also exposure to anti-LGBTQ+ discrimination leads to adverse health outcomes. So, I'm going to break these down. Okay, so what's this ACE study that I mentioned? So like I said, ACE stands for adverse childhood experiences, and adverse childhood experiences could be direct experiences like abuse or neglect or could be indirect through living environments, like parental conflict, substance abuse or mental illness. So the ACE study was this very large study done

through the CDC and Kaiser Permanente. Kaiser Permanente is like a healthcare system out in California, now is in multiple states. So it was in the mid 90s and enrolled over 17,000 people and basically they asked their adult patients who were enrolled in the study, they gave them surveys, asking about their childhood experiences and then also their current health status or behaviors. So it was first published in '98 and there's been many publications since then.

So what are these definitions? So, you know, of course, abuse is on the survey. So emotional, physical and sexual abuse and also household challenges, but I think was really pertinent to queer people is emotional neglect, basically means someone in your family never or rarely helped you feel important or special. Well, that's like a bold statement, right? What I'm proposing is that you have a closeted queer child who might not feel that they're able to be open to their family, friends, society, and therefore they don't feel important or special. Also, you know, the family doesn't have a source of strength or support, again, supporting a closeted queer person. Obviously, there's exceptions to this generalization that I've made, but I think it's something that a lot of queer people experience. Also, physical neglect I don't think is as pertinent to my conversation.

So, what did they find? So childhood trauma overall was very common. Okay, this is among the whole subject group. So two thirds of the people had a score of at least one, meaning one adverse childhood experience, and 87% of those had more than one adverse childhood experience. So their conclusion was people usually experience more than one type of trauma, and they found a direct link between childhood trauma and adult onset of chronic disease, as well as mental health problems. And more types of trauma, aka a higher ACE score, increased the risk of health, social, and emotional problems.

So this has been studied in MS as well. There was one study that I found. So, they found that a higher ACE score led to poor health related quality of life measures and also increased emotional distress of patients with MS at the time of diagnosis and one year follow up. They also found increased anxiety at the one year follow up for people who had higher ACE scores. So how does this relate to queer people? So overall, they found very consistent rates of higher rates of ACE scores for gay and lesbian people, on average had about two adverse childhood experiences. Bisexual people had about three. So actually it was higher in bisexual people. Just as a comparison, I have some other people, so straight people about 1.6, and I have some racial changes, so white people, 1.5, black people 1.6, and Hispanics 1.8. So higher across the board for queer people. So it was very interesting.

What they found here is that... here's the categories... So, I have some bullets here. So this is the odds ratio. The odds ratio basically means there were three times the odds of someone... So, sexual abuse here. So, sexual abuse has been demonstrated to be pretty consistent with queer youth having higher rates of sexual abuse. So they've found about three times the rate of sexual abuse compared to hetero people. So this is LGB, not trans people, this is lesbian, gay, bisexual people compared to heterosexual people. And then emotional abuse or what I was talking about earlier, 43% of lesbian, gay, bisexual youth had emotional abuse in this study. And this is about trans people. So the take home message here is, you know, double the, basically double the amount of odds of poor mental health for transgender people. 57% of transgender people have poor mental health compared to 34% of cisgendered, lesbian, gay, bisexuals.

Okay. So that's one theory I have. Right? And then the second theory is discrimination. So there's been several hundred studies that have shown evidence that LGBTQ+ discrimination leads to adverse health outcomes. Okay? Now the discrimination can be interpersonal, such as bullying. Okay? And structural discrimination, such as laws or policies. What's very interesting about this is that it doesn't need to be direct discrimination to a queer person. It can be just

exposure to hearing about discrimination. So seeing someone being bullied or hearing about laws or policies being enacted can lead to the health outcomes. So it's linked to health harms, even for those who are not directly exposed. So it causes internalized stigma, low self-esteem, expectations of rejection and fear of discrimination. So this is minority stress theory, which has been applied in several minority groups. And so intersecting identities such as gender, race or socioeconomic status, it says actually it magnifies the harms to the person. So if you think of a... let's use an example of like a trans woman, black, poor person, right? I mean, that's just multiple identities that's going to escalate the harms.

And then protective factors. So good support. So we have peer, community and family support, access to affirming healthcare and social service and inclusive practices. So people have been trying to study how to protect people with minority stress theory, this is all minority groups, and I think these are inroads that we can make.

Okay. So, how does this relate to MS patients? Right? So one thing that I found in this study is... so this was in Italy, I believe, was that queer patients were more likely to change MS centers. Okay? This is the odds ratio is double the amount of patients who are queer versus straight people were more likely to change MS centers. And this is in Italy. Queer people had more... MS patients had lower involvement in LGBTQ+ activities due to their MS status. So my takeaway from this study was that people with the MS disease who were part of the LGBTQ+ community, they isolate themselves from activities in the LGBTQ+ community. So that's an important thing because, you know, as I mentioned on the previous slide, you need peer support to help overcome these obstacles.

Now. NARCOMS, If you don't know what that is, NARCOMS is a registry here in the U.S., it's run by the CMSC in Cleveland Clinic, it's a registry where MS patients contribute to. So in their registry, they... it's really a database... about .5% of patients who have MS were transgender and 4.6% were overall non-heterosexual. And they found actually similar health care utilization between queer people and heterosexual people, trans people had less comfort discussing sexual health, which I think makes sense across all healthcare fields. And bisexual people have the lowest satisfaction with care. So I think this information is very important to help study these things in order to help create a more inclusive environment in the healthcare field for patients. And that's really our responsibility as healthcare professionals.

Ok, so I know that was really heavy stuff that I just talked about. So I want to sort of pivot to something a little bit more positive. So I'm going to talk about gender affirming hormone therapy in people with MS. So what is gender affirming hormone therapy? It's formally called hormone replacement therapy. Okay. So this is actually a gender affirming intervention, right? So it's considered medically necessary for people. And across the board, we see a survival benefit for trans people getting gender affirming hormone therapy. So it's actually a life threatening problem, not withholding gender affirming hormone therapy. There's a recommended criteria for some, but not all surgical treatment. Right? So some people argue that it should be highly individualized based on a patient's goals. So some patients want to get surgery. Other ones want to do gender affirming hormone therapy. Some people want to do both. Some people want to do certain aspects of either one. It's really highly customized to the patient.

So what's the criteria for gender affirming hormone therapy? You need a persistent, well documented gender dysphoria. So that basically means you need to feel sort of out place in your body, versus your sex assigned at birth. But, you need to make a fully informed decision and to consent for treatment. You need to be the age of majority in a given country with additional criteria for younger patients. And if significant medical or mental health concerns are

present, they must be reasonably well-controlled. Obviously, someone is going to have mental health concerns due to gender dysphoria.

So, first I'm going to talk about feminizing gender affirming hormone therapy. So this is really development of female secondary sex characteristics. We use estrogens pretty much across the board for this. You know, they used to use progestogens previously, but that's a little controversial due to, you know, risk benefit.

And this also causes suppression of male secondary sex characteristics. So we give antiandrogens, which is, you know, spironolactone and finasteride. So these are some technical terms that I'm introducing, but basically, these are medications that suppress male secondary sex characteristics. And I mean by that, I mean, like genitalia. Also, it suppresses male hair characteristics on the face, for example, things like that.

And then, so Estrogens and MS. I want to talk about overall estrogen use in MS patients. So overall, we found worsening of disability during menopause in women with MS. Estrogen replacement after surgical menopause, like a hysterectomy, has shown beneficial effects on memory. And this was with premenopausal women, I believe. Higher physical quality of life measures in postmenopausal women on hormone therapy. And then there's also neuroprotective effects of estrogen in mice. So in the EAE model of MS, which is basically the animal model of MS in mice, they found that estrogen receptors are actually on immune cells. So when you give estrogen, there's a protective effect versus too-low estrogen.

There have been some clinical trials in MS with estrogen. So there's a phase 2 trial several years ago looking at estrogen plus Copaxone versus a placebo group. It met its primary end point of reducing relapse rates. So that's very promising. And there's an ongoing phase 3 trial, which is the final phase before drug development, comparing estrogen versus, or plus one of the disease modifying therapies listed below versus placebo with the primary endpoint of cognition or memory problems. Okay. And they're looking at several different disease modifying therapies added on to estrogen. Okay, so this is ongoing.

Ok, so I'm going to shift to masculinizing gender affirming hormone therapy. So this is for using testosterone. Right? So testosterone supplementation is used for this. So this creates development of male secondary sex characteristics and suppressing female secondary sex characteristics. So testosterone in MS is really what entails all this time. Right?

So there has been many studies looking at the neuroprotective effects in MS. So testosterone does cross the blood brain barrier, there's spinal cord neurons, it protects from stress, increases certain factors in the brain to help protect the body, and then also decreases something called microglia in the animal model of MS. So microglia is one of the immune cells in the brain, so it lowers that activation. There's also been evidence that shows that low testosterone levels may be a risk factor for MS in males, in biologic males. And it's been shown that across all types of age groups. So, prenatal, so this is in utero, they found lower ratio of testosterone in men with MS compared to controls. In puberty, obesity in males increases the risk of MS so that because of that there's a higher... So obesity causes a higher conversion of testosterone to estrogen, so there's less testosterone in obese males, for example. And then in adults there's lower levels of testosterone in males with MS compared to controls in multiple trials.

Okay. My computer's freezing. Okay. So there have been some trials on testosterone with MS. Sorry, my computer is just like... there we go! So there was a pilot study looking at improvement in cognition and slowing of brain atrophy with testosterone supplementation. Low testosterone levels is associated with increased EDSS scores, which is the disability score and worsening

cognitive decline. And there's an ongoing phase 2 trial of testosterone supplementation on remyelination (very interesting, right?) in neuroprotection and MS, looking at MRI parameters as the primary outcome.

Okay. So I want to end on talking about disease modifying therapy in HIV positive patients. Like I said earlier, HIV positivity is not unique to the LGBTQ+ population, but it does impact this community more than other communities. So there's a couple of drugs that, you know, actually in the label you're not supposed to use with HIV positive patients, that's Mavenclad, which is oral cladribine, it's actually contraindicated for use with patients who are HIV positive, so you're supposed to screen for that. There's also a warning about simultaneous use with anti-viral and anti-retroviral drugs. So, you know, one thing I want to mention about these things is that what happens in clinical trial development is that, you know, patients aren't totally in a vacuum. Right? So, you know, they want to exclude patients who are HIV positive because, you know, HIV positivity or having HIV can affect something called the lymphocytes. Right? So you guys are all aware of what lymphocytes are, I think, you know, you hear about that probably from your doctor know, let's check your lymphocyte count, so HIV can lower the lymphocytes.

Right? But I think there's, you know, there's different types of HIV patients, really two types in my view. There's a patient who was just diagnosed with HIV that didn't know they had HIV, and they have a low, something called a low CD4 count, which is one of the lymphocytes, high virus in the body, and they're really sick. Right? But then there's a patient who may have had HIV for a very long time and, you know, they're on medicine, really you can't detect any HIV in their blood, they have a normal lymphocyte or CD4 count. And what happens is in these MS clinical trials is that they exclude them all just being HIV positive without any sort of recognition of the different phenotypes or types of HIV. Now, I think we're doing a disservice to patients because then the FDA looks at the clinical trials and says, Well, you didn't study HIV positive patients, so we must put in the label to the doctors that are contraindicated, right?

So it's sort of a controversy, I think that, you know, we're excluding patients from clinical trials and there's this big movement to increase diversity in MS clinical trials, especially racial diversity, but I think we're missing the boat with, you know, with sexual and gender minorities who want to contribute to these clinical trials, but a lot of people are being excluded because of HIV status. So like I said, you know, oral cladribine is contraindicated for HIV positive, same thing with Lemtrada. One trial is interesting because it actually causes a reduction in the CD4 count. So I actually agree that you probably shouldn't have HIV with Lemtrada. Now Ocrevus and Kesimpta are interesting because the label actually says contraindicated for use in patients with an active infection. So, you know, this is more of a legal question, I think. You know, what constitutes an active infection? Now, I argue that a stable HIV positive patient probably is not, that's not really an active infection, like chronic infection. So it gets a little bit complicated just like I said, because of these clinical trials they want studied. And, you know, the thing is, this is not a historical issue, right? So it's 2022 right now, all the phase 3 trials for MS patients for the newer drugs are still excluding HIV positive trials. So I've called on the pharmaceutical companies to help increase diversity in clinical trials. But, you know, I challenge them to keep that effort going.

Okay. So that's basically it. So hopefully I have taught you guys something. So I think it's important to understand the LGBTQIA+ terminology. You know, queer people are also at higher risk for certain health conditions due to health disparities. Hopefully I made that point across. Gender affirming hormone therapy is, I think it is, safe for use in people with MS. And certain disease modifying therapies must be used in caution with people who are HIV positive. But the clinical trials must aim to improve inclusivity for these patients.

I do want to touch on a few resources before we open it up to the question and answer session. So, the Fenway Institute. So, Fenway is a healthcare system for queer people in Boston. It's very famous. But they have a very good health education website, they're really an institute. This is mostly for, I think, healthcare professionals. But it's very good information if any healthcare professionals are listening to this. The Williams Institute, I use some of the statistics from and they keep their website very up to date. The Gay and Lesbian Medical Association advocates for medical equity and treatment for queer people. There is one that I found, the National MS Society LGBTQ+ support group. I shortened the link here. So if you guys want to copy down [tinyurl.com slash these digits](http://tinyurl.com/slash-these-digits), it's much longer, it's nationalmssociety.org/ so, so, so. But if you just go to this website it should forward you, I created a forward link. It's virtual, I think it's based in New York.

The Trevor Project, if there's any young queer people, it's a 24 hour support phone service, sort of like the National Suicide and Crisis Line, which is now 998. But the Trevor Project is really dedicated to young queer people who are in crisis. PFLAG is an advocacy group. It Gets Better is for youth. NAMI is North American Mental... something, it's more for mental health but there's lots of queer resources there. And then here's a website for LGBTQ+ caregivers. Okay? So I think that's basically it for me. We should probably open it up to questions and answers now.

Yahaira Rivera:

Thank you Dr. Conte for such a wonderful presentation and providing facts and information to empower the audience. We do have some questions I would like to go over with you. We received questions during the registration process as well as during tonight's presentation. So talking about stigma and health disparities, we received several questions along those lines. What advice would you offer for LGBTQ+ MS patients who feel nervous or anxious when talking about these topics with their healthcare provider?

Dr. William Conte:

So, I have a controversial opinion on this. I think you should challenge your healthcare professional on this, and I think you should... well, okay, so first of all, I think you need to be open with your healthcare professional. Obviously, that's easier said than done. But we need to know from you what are your challenges, your fears and your lifestyles. But, you know, if you're nervous about talking with your healthcare professional about this, I think there's two types of nervousness here. One, there's fear of being rejected; that your healthcare professional doesn't really, isn't really open to queer people. And I think you should challenge that healthcare professional. And if you don't get a good feedback from them, you should be out of there. Okay, right? So then, you know, you shouldn't be with that healthcare professional.

The second sort of issue is: are they competent in, you know, sort of LGBTQ+ healthcare? Right? That's a little bit more challenging, I think, what would be a good sign? So I still think you should be open with them about it. And a good sign would be their willingness to learn from you or from other resources. So I think you should be open. You know, I'm very, you know, as a patient, I'm very quick to say, you know, look, I'm gay. And even to patients, I'm like, you know, I'm pretty open about it to my patients, just sort of to create a welcoming environment. But that's just me.

Yahaira Rivera:

That's great advice. And knowing that MS is a, it's a chronic disease and requires care, it's important to have that trust and open communication with the physician and your healthcare provider. Thank you, Dr. Conte. Another question that we received during registration is how common is multiple sclerosis within the queer community?

Dr. William Conte:

Yeah, so we just don't know. I mean I, you know, there's very few sites, I did mention in one of my slides about the NARCOMS Registry and I probably should look, but I think it was 4.6%, is what I said, identified as non-heterosexual in the NARCOMS registry. And I think it was about half a percent that identify as trans. So, I mean, lower rates, obviously. The problem with learning about the rates of MS in this community is, one, I think it's there's a bias of patients disclosing their sexual and gender, their sexual orientation or gender identity to the surveyors. Right? So it's obviously lower rates that are reported than actually there are. And also some people, you know, for example, a man who has sex with men, they may not identify as part of the queer community, but yet, you know, they're participating in sort of different behaviors.

Yahaira Rivera:

Thank you. And talking about hormone replacement therapy, we did receive several questions about this topic. What is the relationship between hormone replacement therapy and MS symptoms?

Dr. William Conte:

So yes, so, you know, sort of what we see is... so first of all, these are still being studied, ongoing, and it's obviously a very complex subject matter, you know, especially with estrogens, for example, if you think about even just in heterosexual people, in cisgender people, hormone replacement therapy really depends on whether... are they perimenopausal, postmenopausal, premenopausal? Right? So it depends on that. And then testosterone, I sort of mentioned, helps improve some of the symptomatology depending if there's low testosterone levels. Right? So, you know, with estrogens, there have been studies showing that it increases sort of memory and cognition in certain patients. Right? The question is, what patients would you give that to?

Yahaira Rivera:

How about the TGD hormone? Could that increase their risk of MS?

Dr. William Conte:

So, you know, this is an interesting question. So there's been one study that has shown that a, you know, testosterone... well, giving estrogens and lowering testosterone, giving anti-antigens for someone who's, you know, the sex assigned at birth is a man who's now transitioning to a female, may increase the risk of MS. So there's been one study looking at this. So, and that study, the theory is that low testosterone being suppressed may increase the risk of MS. Now, in that study, there are four cases of MS in trans women and the expected rate was 0.6, I believe. So it's a small number of cases, but there was a discrepancy. So then more information needs to be researched.

Yahaira Rivera:

Definitely. Okay. Thank you, Dr. Conte. And talking about challenges and risks, we received questions of transgender MS patients that they're asking about are there any challenges when choosing a treatment or when going under the hormone replacement therapies, any risks or challenges that they need to be aware of?

Dr. William Conte:

So I propose that, you know, first of all, you need to be with a knowledgeable healthcare professional who is aware of, you know, sort of how to do hormone replacement therapy. I argue that based on the data, it's probably safe for MS patients to undergo hormone replacement therapy. The issue is there's just been no studies on this, so, you know, as more

and more people are open and wanting to become their authentic selves, you know, I think more information will come about. But I propose based on, you know, using the data from, you know, let's say, estrogen replacement for postmenopausal women or perimenopausal women and testosterone replacement. I think it is safe.

Yahaira Rivera:

Definitely. So there is a need of more research so that we can have more information about these topics. But this is a good start. And thank you so much for answering these questions. What about someone who is detransitioning? Would that affect the MS treatment?

Dr. William Conte:

Probably not. I think, you know, again, you still need to treat the MS, right? So like I argue, look, if you're either transitioning or detransitioning, just treat the MS. I don't think you need to modify what you're doing with the MS. Right? You need to be treating the MS effectively. You need to be, you know, using high efficacy therapy and really suppressing the MS disease take down. I say with that, I mean, I just don't know if there is a risk or not about detransitioning, but I don't think there is... if you are being treated for MS.

Yahaira Rivera:

So definitely it's important to have that open communication with a healthcare provider and choosing the right treatment following the treatment for MS and then of course what works for them. And we also have a question about pregnancy. If it's an MS transgendered patient who comes on and off the treatment because of the pregnancy, are there any risks or things to consider?

Dr. William Conte:

So I would treat this as any kind of pregnant patient. You know, if you get ten MS specialists in a room and ask what do you do with pregnancy with MS, you're going to get ten different answers. So, I mean, like it's one of those things that it's highly, I think it's highly personalized what to do for a pregnant MS patient and with treatment options or lack thereof. It just depends. I would again, I would treat this as if it's a cisgender person who just happens to be pregnant.

Yahaira Rivera:

So now we know that you provided information about HIV and MS, and we do have a couple of questions regarding that topic. Is there a direct correlation between MS and HIV?

Dr. William Conte:

So what's been shown... there's been some theories with HIV actually, or HIV treatment helping MS. That antiretroviral treatment might actually lower the risk of relapses. But it hasn't really been fully researched. But there are some theories and it's very scientific and complicated a little bit over my head about, you know, reverse transcriptase and things like that, you know, affecting the relapse rate of MS. So, obviously there's more to MS than relapse rate, there's disability progression, there's MRI activity, brain atrophy. And you know, there hasn't been a clinical trial, a controlled clinical trial, that has been undertaken on this topic. But yeah, there has been some people who have theorized that there's a lower rate with HIV treatment. I'm not so sure about HIV itself. You know, the issue is, HIV is sort of an immunosuppressed state, having active HIV. Like I said, there's been, you know, there's there's two types of HIV patients, like I said, there's a newly diagnosed who is immunosuppressed, and there's one who's had chronic HIV who's well treated. I think those are two different types of patients.

Yahaira Rivera:

Thank you for that. And another question is about advocacy. Could advocacy be useful with the FDA in terms of increasing inclusion for the LGBTQ community in clinical trials?

Dr. William Conte:

So I would argue this is actually a pharmaceutical company issue because, not to blame them, but you know, the FDA, you know, they're the ones who do the review once the results are done. But they are involved in the process when the clinical trials are being run. But ultimately it's up to the sponsor of the clinical trial to set the parameters of the trial within reason. Right? So if there's outliers, the FDA is obviously going to look at that and be like, well, this isn't so kosher. You know, I think, sure, it could be a two pronged approach, you know, advocating with the FDA to help increase this. But I think ultimately, and I've done this, I've challenged the sponsors of these trials to say, well, look, you know, include these patients who, you know... so, lately there's been this push for racial diversity in clinical trials. But it doesn't end with racial diversity. There's more to diversity than just racial diversity, although it's very important to think. And so I think, you know, there's cultural factors involved. And I think we need to sort of start reporting these things in the clinical trials to see if there's a difference between the different groups. Right? So, you know, gender minorities and sexual minorities are not even reported as a baseline characteristic in clinical trials. So it's just, you know, I mean, there's people like that in there, we just don't know.

Yahaira Rivera:

Definitely and to segue to that you're just mentioning about representation, inclusivity - Where could the committee find about research information or opportunities in clinical trials? How can they find opportunities other than through their healthcare provider? Are there any websites or organizations that they can go and find those opportunities?

Dr. William Conte:

Yeah. So, if you really want to get fancy, you can go to clinicaltrials.gov. Now, it's not the most user friendly. I just sort of finally have learned to navigate that. But honestly, all FDA sort of run clinical trials throughout the world are on this website. You go to the website, clinicaltrials.gov, on the right hand side, there's like four boxes and you can select "active", "not recruiting", "inactive", and then you type in multiple sclerosis for the condition. And then there's other stuff that you can sort of type in and that'll show you all the clinical trials. Now the problem is sort of information overload, I think, on that website, right? So, you know, it gets a little complicated. So but I mean, honestly, what's nice about that website is once you click on a clinical trial, you can see who's running it. Like, so, you know, like my clinical trials are on the website and you could see my location there. So, you know, you can actually filter it by your location and see what's in sort of a geographic area for you. So that's probably the best resource other than Googling, which is a little risky to Google, you know, talking to a healthcare professional might not be the best route depending on where you're at because it's just, you know, they just may not know. And then, you know, you're kind of left with not knowing. You know, also, these companies, they have some savviness, you know, if there's a site in your area, it should be popping up in your Facebook, Instagram sometimes as a targeted ad. So I've seen that lately. Sometimes, but I always go to clinicaltrials.gov, I think is probably one of the best resources, even though it's not that user friendly, unfortunately.

Yahaira Rivera:

Thank you. It's an important topic because like we mentioned before, there's the need for more information for the LGBTQIA+ community that is living with MS and if they're aware of those opportunities, then more information and more data to make decisions and to inform the community. Thank you. And what about mental health? Talking about mental health and minority identity is linked to stress. And we know that sometimes because of the systemic

barriers or the stigma or discrimination, just having a diagnosis of MS alone could cause anxiety, depression. And if one belonged to a minority community, that would add up to that. So what strategies could these communities use to cope with this chronic disease and also with stigma?

Dr. William Conte:

So I think it's been studied across all disease states, all minority groups, that a social network is really important. The problem is, in my presentation I mentioned this, was that, you know, queer people who have MS in this one study were less likely to seek out queer advocacy groups. And so it's a catch 22, right? So, you know, you need sort of a village to help you feel supported. But there's a stigma with having a disease in certain communities. And so it gets obviously very complicated. And I think, you know, you'll really see who your true friends are, I think, with certain diseases like MS. And, you know, I would, my advice is you want to be social, you know, you want to make sure your, you know, your health is in check. You want to have a good diet and exercise. And it's really a comprehensive package, I think.

Yahaira Rivera:

Definitely. Thank you for that advice. Having a healthy lifestyle and having definitely a support group and finding that in friends and family and talking about support groups because we know that is important when you're facing and navigating the MS journey. Are there any MS support groups specific to the LGBTQIA+ community?

Dr. William Conte:

Well, there is that one in New York. I don't know how to get it to you guys, but I mean, if you Google, if you go to National MS Society and you Google it, you'll find it. But I put it in my presentation, maybe we can send it out afterwards, I made a tinyURL link in order to direct you to it. But that's the only one I'm aware of, which is... I actually think it's a little problematic, you know what I mean, like, so maybe someone wants to start another one. I'm happy to sponsor it and help out with it. But I think it's important because, like I say, that one study looked at stigma of having MS in the queer community and I think having a MS support group for queer people would be really powerful.

Yahaira Rivera:

Definitely. And Dr. Conte, we also have a question about DMTs. What is the best way to go about understanding side effects of a disease modifying therapy?

Dr. William Conte:

Well, I mean, like, look, any drug is going to have a side effect, right? Aspirin's going to have a side effect. Tylenol has side effects. Right? So, you know, I don't think the, in general, what I tell patients is that, like, we want to take the side effects seriously, but we also, you need to think about the side effects of not treating your MS properly, first and foremost. Right? So I always talk about this like benefit/risk ratio. So like you want a big number, right? So how do you get a big number if you're looking at a ratio? You have.. let's put benefits in the numerator, risks in the denominator, right? So above and below. Right? So obviously a low risk drug is going to give you, you know, a big number, but that doesn't exist. Right? So if a relative risk, then you want a high benefit of the drug and that gets you a big number. What you don't want is low benefit and high risk. But I always encourage patients to think about this concept of if we don't treat your MS properly, you're going to get way more sort of side effects than the drug could possibly give you.

Yahaira Rivera:

Ok. And Dr. Conte, we also have a question about, and I quote, “Do you think the LGBTQ+ community makes itself inaccessible for MS patients, like, for example, at Pride events? How can they advocate for themselves to consider the MS community within the LGBTQ community?”

Dr. William Conte:

Yeah, it's really tough. Like, it's like, you know, like I've said a couple of times now, you know, there's that one study that looked at this, but I think there's this, you know, being part of this community, I think is, you know, myself, there is a stigma on, you know, sort of “being diseased”. And I think that's from, you know, HIV and AIDS. Right? And, you know, unfortunately, the trauma from it. And it's, you know, I think especially among gay men, I don't know if I can speak for, you know, the other ones in the queer community, but, you know, there is this persona of health and beauty. And I think, you know, we've sort of, you know, hit ourselves in the ankle a little bit, or the Achilles, with that. And that, you know, it's a societal thing. You know, I can't fix the world. And I think what we need to do is we need to find that community. And like I said earlier, I think that you'll quickly find out who your true friends are. Right?

And so, you know, this question asked about like Pride events, and, you know, I think it depends on the city again, like here in Chicago, I think they do a pretty good job of creating an inclusive, sort of, family friendly, you know, handicap accessible, Pride Parade experience, I don't know about the actual festival, if it's true about that, but it's tough. It's really tough, I think. I mean, this is not unique to the queer community, it's you know, if you look at, you know, certain cities they're not the most handicap accessible, for example, you know, it's just, it's tough, I think. But it's so important to have that social support, I think. And like I said, you'll quickly find out who your true friends are, for better or for worse.

Yahaira Rivera:

That's right. So knowing the information is important, staying informed, participating in webinars like this one, having an open communication with the healthcare provider, with family members, finding a support system and finding information about clinical trials, all of that is going to help the MS community to make decisions and to have better outcomes. Dr. Conte It looks like we have answered the questions in our time together is coming to an end. If you have additional questions, please reach out to our helpline or email the questions to us and we'll try to share those with Dr. Conte. Is there anything else that you would like to share with our audience? Any advice or takeaways before we bring closure?

Dr. William Conte:

You know, I'm just looking at some of the chat. So it looks like there might be a support group in Oakland. I'm assuming that's queer in MS patients. I wasn't aware of that. So that's great. But again, I mean, now I know of two in the country. I mean, we need more. And then another question, is it advisable or effective to start prep after a disease modifying medicine that supports the immune system? I would say, yes. You know, I think you can do an... well, first of all, it depends what drug you're on. If you're on Cladribine, for example, you're not really supposed to take antivirals with it. But yeah, I say go for it. I mean, because you don't want to, it's like anything, I mean you don't want... infections can worsen MS. So I think prep is okay with MS treatments for most MS treatments. I think that's... we covered everything.

Yahaira Rivera:

I think so, too. Yeah, I think so. I think that we went over all of the questions specific to tonight's topic. On behalf of MSAA, thank you, Dr. Conte, for your time, for providing our audience with insightful and important information, for being part of this conversation alongside with MSAA. To our wonderful audience, thank you for being engaged. Thank you for supporting this program.

We hope that the information brought some clarity to your questions, and we appreciate your support.

This concludes our webcast. Tonight's webinar was recorded and will be made available on our website in the upcoming weeks. Please visit our web site to learn more about MSAA resources and services and also to look at our calendar for upcoming events. And please take a couple of minutes to fill out the survey. Let us know how we did tonight and give us feedback for upcoming events and programing. Know that MSAA is always thinking about the entire MS community and we hope that you and your families continue to stay safe. Thank you so much and have a wonderful evening. Thank you Dr. Conte.

Dr. William Conte:

Bye everybody. Thanks for having me.

Yahaira Rivera:

Bye bye.