



Striving Towards Better Care for LGBTQ+ People Living with MS

Presented by:
William L. Conte, MD, MS

Marie LeGrand:

Good evening everyone, and welcome to the MSAA's live webinar: Striving Towards Better Care for the LGBTQ+ People Living with MS with Dr. William Conte. I would like to take this opportunity to thank you for joining us this evening. I am Marie LeGrand, Associate Vice President of Mission Delivery, Health Equity, and Education for MSAA and your host for the program.

Before turning it over to our speaker this evening, I would like to take this opportunity to go over a few of the services that MSAA provides and some housekeeping items. 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 from 8:30 a.m. to 8 p.m. Eastern. Additionally, MSAA provides equipment and cooling products designed to improve safety and mobility and to help with heat sensitivity. We also offer an MRI access program to help cover some of the costs for individuals with MS who qualify for assistance. We provide a variety of educational programs such as this, including webinars and on-demand videos, online tools, publications and digital resources. That also includes the Ultimate MS 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 offers support through community connection to help you stay connected with other members of the MS community.

MSAA has also partnered with Talkspace, which is an online mental health service, to create an innovative pilot program for individuals with MS to receive three months of online therapy at no cost. Talkspace connects people to thousands of dedicated providers via secure and confidential HIPPA compliant platform. And to learn more about this and MSAA's programs and services, please visit our website or give us a call to speak with our client services specialists, or you can also send us an email.

As a quick reminder, throughout tonight's program, you will have the opportunity to ask questions by typing them into the chat box. We encourage you to submit questions throughout the program and we'll do our very best to answer your questions during the Q&A portion of tonight's webinar. At the end of the program, we ask that you please complete a brief survey.

Your feedback is extremely important and will help us in developing future programming and content. A link to the survey will also be included in the chat box.

Please note that MSAA strives to provide useful up to date information on matters of concern to people living with MS and their families. This program is for educational and informational purposes only and does not constitute as medical advice. For diagnosis and treatment options, you are urged to consult your physician. Please speak with your healthcare team if you have any questions or concerns.

Tonight, we are going to cover several different topics that Dr. Conte will go into further detail on. Dr. Conte will provide a better understanding about living with MS and how an MS diagnosis and exploration of identity interplay with one another. During this presentation, Dr. Conte will describe differences between sexuality and gender identity and openly discuss health disparities among the LGBTQ+ community. He will also summarize how gender affirming hormone therapy affects people living with MS and factors that influence disease modifying therapy selection.

Without further ado, I'd like to introduce our speaker. Dr. William Conte earned a Bachelor of Science degree in Neurobiology from the University of Florida and graduated from medical school at Loyola University Chicago Stritch School of Medicine. He also completed an adult Neurology residency at Loyola University Medical Center and a fellowship in multiple sclerosis and Neuroimmunology at the University of Chicago. Now, while at the University of Chicago, he also earned a master's degree in Public Health Sciences. Dr. Conte is the head of the MS Center at Methodist Hospitals and an Assistant Professor of Neurology at Indiana University. He has a strong interest in clinical trials and research, and he is focused on providing education on how to improve outcomes for the LGBTQ+ community with MS. Welcome, Dr. Conte.

Dr. William L. Conte:

Thanks. It's great to be here with everybody. I've given this talk a few times, mostly to doctors, but I have adapted them for patients and I've really given this all over the country at this point. So my... Let me just get my screen all situated here.

Okay. So my goal here today is to... So first of all, here's my financial disclosures, which I don't think is really that applicable for today's talk. But really my objectives for tonight is I'm going to talk about sexual orientation, gender identity, and really like the difference between sexual orientation and gender identity, and talk about LGBTQ+ terms, then I'm going to describe the health disparities that LGBTQ+ people face, I'm going to talk about gender affirming hormone therapy and how it affects people with MS. And then talk a little bit about some disease modifying therapies.

So it's kind of like an alphabet soup these days, right, with the LGBTQIA+ terminology. You know, several years ago, people talked about using LGBT as the main term. Then we added the Q, then we added the "+", which I actually think the plus is the most important term here, which I'll talk about in a second, and some people use "IA" or "IA+" to be more inclusive.

So let me just go through some of these terms and tell you about why I think "+" is the most important one. So L stands for Lesbian, which is similar to the G in the sense that it's someone who is sexually or emotionally attracted to someone of the same gender. So "L" being a woman, but some women prefer the term "gay." And then "G" gay, it's men who are sexually or emotionally attracted to other men. But it could be really anybody that is referred to attraction to the same sexual gender. Now the B is bisexual, which is someone who is sexually or emotionally attracted to both men and women or to more than one gender identity.

Now, what's important here with all these, the L, G and B, is that, notice how it says sexually attracted and/or emotionally attracted to both men and women, or men, or women, for the L and the G. So it allows different, you know, I'll talk about this in another slide, there is a spectrum, right? And this sort of alludes to that. Now, the "T" transgender is interesting because this isn't a sexual orientation, this is a gender identity, right? It's someone whose gender identity or expression differs from what is expected based on the sex they were assigned at birth. Some people say male or female, depending on what they're, you know, if they've transitioned or not. But what's nice about the T is that it's really, it's the big spectrum of people. It is highly individualized to the individual.

Now the "Q" is a really important term, it means queer or questioning. So queer is a broad term for anyone who is not straight or cisgender. So sometimes, and especially in this talk, you'll hear me just say, like, queer people, right? That means, it's the shorter way of saying LGBTQ+. Questioning is sort of a newer term that we're using. It's someone who's questioning their sexual orientation or their gender identity, so they're not really sure how to identify themselves presently. And so we include those in the community.

Now, the "I" and the "A" are interesting because these aren't as common as the LGBT term. So intersex is really someone who has the biological traits, this says genetic, hormonal, or anatomical differences that really don't fit into a binary male or female category. A, it stands for a couple of things. It stands for asexual, aromantic or agender. So asexual individuals are someone who just really don't experience, like, either little or any sexual attraction to other people. Aromantic is similar in the sense that it's little or no romantic attraction to others. Then agender individuals are someone you do not have a gender or do not have a strong connection to any particular gender. And like I said earlier, "+" I think is the most important term because this just really includes everybody, right? So the plus means that there's unlimited sexual orientations and gender identities. It's a huge continuum.

So, I'm going to talk about this continuum in a few minutes. But first I'm going to talk about prevalence. So, according to the Williams Institute, about 4.5% of the US population identify as LGBT, which is about 11 million people, 58% are female, 42% are male. And the transgender represents about 0.58% of the US population, which is over a million people actually. Now, on this slide, you'll notice this is now a... there's actually a Gallup poll that was conducted in 2022, which shows Americans in the US who self-identify as LGBTQ+, and this differentiates them. This is percentages by generation.

So you'll obviously see that there's an uptick in people identifying as LGBTQ+ based on the generation and you'll see here earlier on is the Silent Generation, Baby Boomers, Gen X, Millennials and Gen Z. And so there's a couple of interpretations I have of this. So one thing I need to note about this is that they include, versus my previous slide, the Q, so the Q meaning "questioning." So all of these categories include questioning people who aren't sure of their sexual orientation or gender identity. So obviously younger people are going to be more questioning than older people because, you know, they're just not comfortable yet, they're still exploring their sexuality or gender identity. So that's the big important distinction here, because at first glance you might say, oh my gosh, there's more people in more recent times that are up ticking. And you may be thinking, Oh my gosh, there's like an epidemic of queer people happening, right? No, that's not true. So I think the questioning people is a component so that, you know, you see more questioning people in the younger generations.

Secondly, I think it's an important distinction here is that the Silent Generation, especially the Silent Generation, Baby Boomers, there's a huge amount of shame in this population for being queer. And there's a lot of suppressed people that will basically, you know, do anything not to be gay or lesbian. Right? And so you see a lot of these people here, they're married, in a heterosexual relationship and then they come out later in life. So that's an important distinction that I see here. So this is interesting stuff. This is interesting. Now, it is a Gallup poll. So obviously, there's some biases involved in this research. But I think it's interesting stuff.

So I eluded to earlier, I talked about gender identity and sexual orientation. So gender identity, basically, it's your inner sense of your own gender and it may not match your sex assigned at birth, whereas sexual orientation is related to the gender or genders of your romantic and sexual partners. So basically, everybody has a gender identity and a sexual orientation. This is not unique to queer people, heterosexual, cisgendered people, that is their sexual orientation and gender identity. One important distinction is transgender is not a sexual orientation. Alright, so gender identity is separate from sexual orientation. So a transgender person is someone whose gender identity does not correspond to their sex assigned at birth. And a cisgender person is someone whose gender identity does correspond to their sex assigned at birth. And gender expression, which we also... everybody has, is the way a person communicates their gender to those around them, like their appearance or their mannerisms.

So here's the slide I was talking about earlier, about this sort of... the spectrum. So people have developed this "Gender Bear" diagram, which is like, you know, it's like this teddy bear that has all the signs here. So the expression is the whole thing, right? So the gender expression. You have your biological sex, you have your orientation, which is your sexual orientation, and then your gender identity is in your brain. So the gender identity can be binary. It could be a woman or a man or it could be a spectrum in the middle. So this alludes to what I was saying about the plus being the most important thing, is that there's unlimited gender identities and sexual orientations. Same thing with sexual orientation, right? So it could be binary, a woman or a man, or it could be somewhere in the middle, or it could be no one, like in the case of the asexual people.

Sex assigned at birth, it's really three things. It's either female, male or intersex. Obviously intersex is a spectrum in and of itself. And then the gender expression, right? How you express yourself to others, you can be feminine, you can be masculine, or you can be somewhere in the middle. So this is a really beautiful way of looking at this. It's that it is a spectrum no matter what we think, and there really is unlimited sexual orientations and gender identities.

And therefore, for the trans people, gender affirmation is 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. There's social, legal, medical and surgical affirmation. So social affirmation is just changing your names, pronouns, clothes, hair. It's really like more of a social thing, right? And then legal affirmation, which is obviously dependent on the state, unfortunately, and here in the US it's changing your name and gender on official documents. Now medical affirmation is really just basically gender affirming hormone therapy, which is using hormone replacement therapy to sort of align one's body to their gender identity, and then surgical affirmation is actually using surgery to change one's anatomy. And what's nice about this is that it's highly customizable to the individual, right? So not everybody will go through all four steps, some people will just go through one step. And so it is highly customizable.

Ok, so let's shift gears a little bit and talk about health disparities among queer people. So queer people as a minority group, we do face a lot of health disparities. We have higher rates of

disability, higher rates of physical limitations overall poor general health. Now we do see higher rates of HIV amongst gay and bisexual men and transgender women. However, that is changing these days, right? So the incidence of HIV is actually going down amongst gay people, you know, mostly because of the development of prep therapy. So, actually, the highest prevalence is amongst gay and bisexual men and transgender women, but the incidence, which is new cases, we're seeing higher rates amongst heterosexual people these days. We see higher rates of overweight and obesity in lesbian, bisexual women, higher rates of cancer, overall cancer rates, higher rates of cardiovascular disease and overall higher rates of health care utilization, which is a marker of the poor general health.

So why is this? So, I have two theories on this that I talk about. One is adverse childhood experiences, which you see higher rates amongst LGBTQ+ people, and also something called Minority Stress Theory, which I'll talk about, which is basically exposure to anti-LGBTQ+ discrimination, which leads to adverse health outcomes. Okay. Now a lot of this has been studied in other minority groups, but it is applicable to us as well.

So the ACE study, or adverse childhood experience study, was a study that was conducted in the '90s through the CDC and Kaiser Permanente. Kaiser Permanente, if you don't know, was a big healthcare system out in California. It's expanded to other states now, but back in the '90s it was just in California. So they enrolled over 17,000 people and they looked at surveys asking questions about their childhood experiences. So it was given to adults. And then they looked at their current health status and behaviors. But they theorized that the ACEs were either harms that affect children either directly, like abuse and neglect, or indirectly through their living environments.

So what they found is that childhood trauma was very common, and this is not unique to LGBT people, this was just overall in the general population for the 17,000 people. So two thirds of that cohort had an ACE score of at least 1, and 87% of those had more than one. Right? So people usually experience more than one type of trauma. And they found a direct link between childhood trauma and the adult onset of chronic disease, as well as mental health problems. And more types of trauma, like a higher ACE score, increases the risk of health, social, and emotional problems.

So they studied this with MS patients, actually. So there was one study that looked at the ACE study, ACE scores, with MS patients, and they found a higher ACE score led to poor health related quality of life and increased emotional distress in patients with MS at the time of diagnosis and one year follow up. And there was increased anxiety at the one year follow up, which tells to me that these patients had less resilience because of their childhood trauma.

But going back to LGBTQ+ people. So overall this is the rates of the ACE scores amongst queer people. So the average ACE scores for a gay or lesbian person was 2.19, so that means over two, like, more than two childhood traumas. Bisexual people had the most at 3.14. And here's a comparison to other groups, so straight people had 1.60, white people had 1.52, black people 1.69, and Hispanics were 1.80, which I think is really interesting.

Okay, so let's shift gears a little bit. So I'm going to talk about discrimination now. This is Minority Stress Theory, which has been studied extensively in multiple minority groups, and LGBTQ+ people are a minority group. So basically tons of studies have showed that LGBTQ+ discrimination leads to adverse health outcomes. What's interesting about this is that it could be interpersonal discrimination, like bullying, but it also could be structural discrimination such as laws or policies. What's also really interesting about this is that it's linked to health harms, even

for those who are not directly exposed, so just hearing about or witnessing someone being discriminated against or even hearing in the news about laws or policies causes internalized stigma, low self-esteem, expectation of rejection and fear of discrimination. Right? This fear of discrimination is something that's very insidious to these people. And, like I say, it can happen indirectly. So even patients, people coming from like really supportive homes, just hearing exposure to other people causes minority stress.

Okay, intersecting identities, like gender or race or socioeconomic status, may exacerbate the harms. So the more minority groups that one is in, the higher rates of health harms. So, for example, a poor black trans woman, that's multiple minority groups, that's a very concerning group of people that we really worry about who have a lot of health problems.

Anyway, protective factors, this is called Social Support Theory, it's protective against Minority Stress Theory. So things that are protective against minority stress, our peer, community, and familial support, obviously, but you know, I talked about this with other healthcare professionals, is that actually affirming healthcare and social services and inclusive healthcare practices actually helps the patients. It's not like you need to be like someone who's providing hormone replacement therapy, just having an affirming healthcare system actually helps protect against minority stress. So something really important that I advocate for with healthcare professionals.

Okay, so let's talk about MS patients, queer MS patients. So there's not been many studies on the queer MS experience. I have them all listed here. So, let's go through them. So, LGBTQ+ patients were more likely to change MS centers in this one study. Okay? Where it says OR equals 2, that means they were twice as likely to change the MS center in the study. That O.R. means odds ratio. Now LGBTQ+ MS patients also had a lower involvement in LGBTQ+ activities due to their MS status. What that means is that, once diagnosed with MS, queer people withdrew from their queer communities, also vice versa, queer MS patients were less likely to have involvement in MS activities. So that's why it's really important to have MS support groups that are LGBTQ+ focused.

Now in NARCOMS, NARCOMS is a big registry run through the Cleveland Clinic that looks at patient reported outcomes with MS. So according to that database, a big database, about 0.45% of the tables were trans and 4.6% were non-heterosexual, which is similar to that, really that second slide that I presented about the overall prevalence. They did find a similar healthcare utilization between LGBTQ+ people and heterosexuals. Trans people had less discomfort... less comfort discussing sexual health, which I think is a little obvious, and bisexual people had the lowest satisfaction with their care. Okay, So I think it's just interesting stuff, right? So, you know, there's not been... this is it. This is what's been studied with the queer MS experience. Right? And we don't have any studies about their health outcomes with MS.

Ok, so to shift years again, I want to talk about gender affirming hormone therapy in people with MS. All that really gender affirming hormone therapy is, is that you're using hormone replacement therapy to sort of align one's body with your gender. There's two types of gender affirming hormone therapy, there's feminizing gender affirming hormone therapy and also masculinizing gender affirming hormone therapy. So we'll start with feminizing gender affirming hormone therapy, which is really meant to have development of female secondary sex characteristics using estrogens and progesterone replacement. You also want to add a second medicine which will suppress male secondary sex characteristics, which is using like spironolactone and finasteride. Those are the medicines that are usually used for anti androgens.

So there's not been like really much studies, like really any studies looking at the trans experience with MS. So, I kind of pulled from like, at least for estrogen therapy, looking at perimenopausal women. So overall we see worsening of disability for most patients during menopause in women. Therefore, estrogen replacement after surgical menopause has shown beneficial effects, for example, on memory. We also see higher physical quality of life measures in postmenopausal women on hormone therapy. Right? So estrogen replacement therapy, although it does have side effects, we do see higher physical quality of life measures in postmenopausal women who are on hormone replacement.

And then they've looked at this in animals. So EAE is the animal model of MS, it stands for experimental autoimmune encephalomyelitis. It's used in... they do it in mice. So they found that there's actually estrogen receptors on immune cells and they found that there's neuroprotective effects of estrogen replacement in the EAE model of MS. There are some trials ongoing, looking at estrogen replacement in MS patients, this is not specific to trans people. So there's a Phase 2 trial, which is more of a safety trial, looks at giving estrogen replacement plus Copaxone or glatiramer acetate versus placebo it met its primary endpoint of reducing relapse rates. And there's an ongoing Phase 3 trial looking at estrogen replacement plus a variety of disease modifying therapies versus placebo with the primary endpoint looking at cognition or memory problems, measuring with the PASAT test. So this is an ongoing trial that's going on. So hopefully that'll come out soon.

Now, masculinizing gender affirming hormone therapy, it's really easy because you just use testosterone and that basically allows development of male secondary sex characteristics and suppression of female secondary sex characteristics. Now, testosterone and MS has been really studied a lot. So there are neuroprotective effects in MS patients, so it does cross the blood brain barrier, testosterone. It protects spinal cord neurons from oxidative stress and increases something called neurotrophic factors which help protect against damage in the central nervous system. It also decreases microglial activation in the animal model of MS. Microglia are the immune cells that are in the brain.

Okay. And then low testosterone levels has been shown to be a risk factor for MS in males. And basically they've found that low testosterone levels throughout the lifespan is a risk factor for MS. So low prenatal testosterone in men have shown to go on to develop MS, compared to controls. In puberty, we see higher rates of MS in obese males because there's higher rates of androgens to estrogens with obese males. And then in adults, multiple trials have shown that lower levels of testosterone in patients with MS in males compared to controls. It's been across the board.

Okay, my computer is freezing. Okay, so some trials on testosterone. So there was a study that looked at improvement in cognition and slowing of brain atrophy using testosterone replacement. Low testosterone levels has been associated with increased disability scores, as with the EDSS means, and worsening cognitive decline. Now, this is an interesting point, number three, this is actually, this is specific to trans people. So they found a possible association between the male to female transition and development of MS. So basically in this trial, they looked at, as a record linkage trial. Basically what that means is, I think it was in the UK, is that they looked at the co-occurrence on insurance claims between MS and then they also looked at the diagnosis code of gender dysmorphia, meaning like there's a problem with your gender. And they found that there are higher rates of MS in this cohort versus what they thought was to be expected. So there are only four cases that they found MS co-occurring with gender dysmorphia versus there's only supposed to be .6.6 patients. So therefore the relative risk was six fold. So I have a couple of comments about this.

So one is that only four cases of several thousand patients that they've found, I think that's actually pretty good. And the funny thing is about this, one of the funny but serious things, is that... so gender affirmation is actually a medically necessary thing that needs to occur for trans patients. So there's really, really high rates of suicide amongst non transitioned trans people who like aren't able to transition. So it's absolutely a life saving, medically necessary thing that happens. And I think most trans people will take a small risk of getting MS over not transitioning. Right? So I sort of have that issue with this trial, their conclusions about it. It's just that it's still needs to happen. But it's interesting stuff. So the idea is that there is testosterone suppression and therefore it led to MS, that that's what their theory was. But it's just one study. I think more studies need to be conducted. Now. There's an ongoing Phase 2 trial, which is a safety trial looking at testosterone supplementation, looking at a remyelinating effect, which would be great, and also neuroprotection in MS, and they're looking at MRI parameters as the primary outcome. So cool stuff.

So I'm going to touch a little bit on disease modifying therapy selection and then I'm going to open it up to questions. So really the point about this is that one is that not enough research is being done. So a lot of this has to do with HIV patients specifically. So what started me on this path was that I was having conversations with a lot of neurologists and they were like having this impression that patients who were diagnosed with MS who also had HIV, that they should only offer certain disease modifying therapies to them, and those happen to be lower efficacy therapies.

Now, I had an issue with that because why are we excluding the high efficacy therapies from these patients out of fear of the HIV getting worse? And I think what led me to that question, I did a lot self-reflection, is that I think there are two different types of HIV patients. Right? So, there's a patient who's had HIV for many years. They're undetectable on antiretroviral therapy. Normal lymphocytes, normal CD4 count, that's very different than a patient who was recently diagnosed with a high viral load. It's very different. And the problem is, is that most clinical trials just flat out exclude patients who are HIV positive. It's not about the viral level. It's about if they ever tested for HIV positive, they've tested positive for HIV. And I have an issue with that with the pharmaceutical companies, because I think we're excluding a lot of patients from these trials. And therefore it has a downstream effect on the labeling of the FDA approval process. Right? So when you don't study a patient group, you can't see that it works in that group. So all of these disease modifying therapies have exclusions if you're HIV positive.

Not only that, but right now in the clinical trials, and I do the clinical trials, there's no collection about sexual orientation, there's no collection about gender identity. And when we create a new patient in the portal for the clinical trials, it really just says male / female. There's no other option. So I think in order to find that there is a difference with the MS experience amongst queer people we need to collect the data. And I think we're not doing that right now. There's been a shift in recent years to sort of increase representation of minority groups in clinical trials. Right now it's really, the focus has been racial and ethnic groups, but I think we need to do a little bit better and really go deep on 1) socio-economic classes and then 2) sexual orientation and gender identity, I think those are really uncollected.

Let me talk a little bit about the disease modifying therapies labeling. So first of all, oral cladribine, which is called Mavenclad, they actually have on the label, it says contraindicated for use with patients who are HIV positive. It doesn't say anything about the viral load. It just says if they're HIV positive. There's also a warning about simultaneous use with antiviral and anti-retroviral drugs. So the problem with this is that these drugs might interfere with the activation of

Cladribine. But the nice thing about Cladribine is that it's out of your system so quickly. So I think, like, as long as you pause the antiretroviral drugs, you'll be okay. But there is a warning. I mean, it says contraindicated for use with patients who are HIV positive.

Now alemtuzumab, which is Lemtrada, it also says the same thing, contraindicated for use with patients who are HIV positive. Now, I do agree with them on this one, because there is prolonged reduction in the CD4+ lymphocyte count. So I mean it does last a while, the reduction of the CD4 count. So I see the issue with that. I don't really see the issue with cladribine. Anyway.

Now ocrelizumab (Ocrevus), ofatumumab (Kesimpta), and ublituximab (Briumvi) there's a warning for use in patients with "an active infection," whatever that means. Right? So there's arguments for HIV being... it is active, right? I mean, like you're never cured of HIV. However, some people say, including myself, it's turned into a chronic infection. It's probably still active though. So again, the issue is that most clinical trials exclude these patients who are HIV positive. And therefore, when you ask the question to the pharmaceutical companies, what's the data on these, they say they don't have any data, so we just don't know. So it's up to people to try it out in clinical practice. And it may be, you know, it may be the blind leading the blind a little bit, but this is a problem. And the problem is, is that, you know, in 2023, pretty much all the clinical trials for the BTK inhibitors, they're also excluding patients who are HIV positive. And this isn't an old issue. It's still ongoing. So it's not like it's been fixed.

So anyway, I'm going to open it up to questions and answers in a moment. And really, in summary, while you guys are reflecting on questions is thatm what I hope I have taught tonight is that queer people are at higher risk for certain health conditions due to health disparities. And I talked about Minority Stress Theory and the Adverse Childhood Experience study. Gender affirming hormone therapy I do think has benefits in patients with MS, although there is a possible link for development of MS in males undergoing gender affirming hormone therapy, a little more research needs to be done. Certain disease modifying therapies should be using caution with people who are HIV positive, unfortunately, although clinical trials really must aim to improve inclusivity for these patients. So without further ado, I think we have some questions coming in.

Marie LeGrand:

Yes. Thank you so much, Dr. Conte, for a wonderful presentation and coming back and bringing us some updates. We will now take some questions. Just a reminder to please be sure to type in your questions. We did have a few come in prior to tonight's webinar and we'll dive right into this one. So this is around stigma and health disparities for the LGBTQ+ and MS community. So patient surveys show that often members of the LGBTQ+ community receive poor quality of care due to stigma and sensitivity and lack of awareness. And I know you touched on that during your presentation. So how could individuals living with MS who are part of the sexual and gender minority community, self advocate to overcome systemic barriers?

Dr. William L. Conte:

I mean, it's really hard because like on the one hand, self-advocacy is super important for everybody, right? We need to be advocates for ourselves, especially as patients in the healthcare system, because, you know, we all have implicit biases, right? As a patient I have implicit biases, as a doctor I have implicit biases. And so it's... we really should self advocate for ourselves no matter what. You shouldn't be passive about things, but it's really hard because it's like, I struggle as a queer person because like, you know, self advocating is like, why do I need

to self advocate for myself, you know, especially with LGBTQ+ health issues, right? It's really, it gets frustrating, right?

And that's... that kind of goes to show that, like, you know... here's the problem, is that there's a lot of people, like, I'll speak as a healthcare professional now, there's a lot of healthcare professionals that sort of lack awareness of these issues, right? And it's not that they're doing something wrong, it's just that they're just not aware. They just don't know what they don't know. And my experience as a patient in the healthcare system is that, at least by me, I live in Illinois, so it's a pretty opening environment here in the Chicago area, at least I think so. I can't speak for everybody, but at least my doctors, they've been open to having discussions about sort of queer issues. But I don't know if that's for everybody. Right? So some people, some doctors are like, well, why is this important as a neurologist, for example? Well, like I said earlier, the presentation with social support theory, we have, we as health care professionals have an opportunity to sort protect against minority stress for these patients by creating inclusive environments.

So I'm answering this in a roundabout way because there's just not one way to do this. I mean, I think you need to sort of select your healthcare professionals in a safe way. And unfortunately that's not a great way of doing that except for trial and error. I think most queer people will easily realize pretty quickly if they're not in a safe situation with a healthcare professional. But I think I want to defend my colleagues. I do think most of us, as healthcare professionals, are pretty willing to, especially the younger generation, to be open about these things.

Marie LeGrand:

Yeah. And then individuals also have the option if they're not comfortable in having, you know, these discussions with their healthcare provider, they can always go somewhere else.

Dr. William L. Conte:

Yeah.

Marie LeGrand:

Yeah. So if there's someone else that, you know, could be a better fit. So you're not necessarily stuck, you know, for some individuals who may think that they're stuck with perhaps one healthcare provider.

Dr. William L. Conte:

I do want to say, like, it can be exhausting, right? To have to like, you know, change and try, it's like, you know, I wish there was one way of, like, a database of like this is the people you need to go to, but it just doesn't exist, and you know, it can be exhausting. I just want to recognize that and acknowledge that.

Marie LeGrand:

Yeah, Yeah. No, absolutely. Absolutely. So now what advice would you offer to someone who feels nervous and anxious about having conversations with their healthcare provider?

Dr. William L. Conte:

Well, I think you need to be comfortable with your healthcare professional first, right? So like, you know, maybe you don't need to disclose on the first visit, although I would encourage you

to. So what's interesting is that some of the data, especially for trans people, actually, like trans people delay their healthcare due to fear of disclosure. Right? So they will not go to the hospital as quickly. They will not go see, or go to preventative care as quickly because they're fearful of disclosing that they're transgender to their health professional. Not only that, if they do enter the healthcare system, they usually don't disclose right away, which, you know, is important to know for us health professionals, because we need to know if you're on like hormone replacement therapy, things like that.

So it's a huge issue that there's this fear of the healthcare system. I think, because of historically, the healthcare system hasn't been very kind to these people. So I think... what was the question? What advice do I have for...

Marie LeGrand:

Yeah. So yeah, no, that's fine. Yeah, so like, you know, what advice do you have for having, you know, conversations with their healthcare provider?

Dr. William L. Conte:

Well, I think it should be direct. I mean, that's what I do with my doctors. Like, I'm just direct about saying, look, I'm a gay man. This is my health history. I disclose, I mean, I'm not fearful of it. I think it's also location dependent, unfortunately, like I said, I'm in the Chicago area, which, you know, I think, one, there's many doctors in the area if I need to change, but two, I think they're pretty open here. The issue is like if you're in some of the states or the rural areas, you might not, you know, be in a comfortable situation. My advice is really just, I think you should be direct. I don't think you should be shy. And I think you'll realize quickly, almost like a test, if you will, of the doctor or healthcare professional, like if they're going to be a good fit for you.

Marie LeGrand:

Yeah. Yeah. No, that's true. I mean, you can definitely tell from your first, you know, conversation that you have with your provider if this is someone that, you know, you feel you can move forward with, you know, and having like a patient-doctor relationship or not. No, this is wonderful. So now microaggressions, I know you touched on that as well during your presentation. So microaggressions could be manifest in a healthcare setting. So what impact do microaggressions have on the LGBTQ+ community?

Dr. William L. Conte:

Yeah, I think microaggressions are really sneaky. So, if you don't know what microaggressions are, they're sort of these, like... how do I explain it? It's like these, like, sort of implicit, like... it's like with an implicit bias becomes explicit. Like when, when like, for example, like, you know, I use the term "trans people" a lot. When you... let's say a trans person says, this is my, the way you want me to be addressed, but then the doctor doesn't change like the way they address the patient. That's the microaggression. Another microaggression is like you disclose that you're gay and then like the doctor doesn't, like, look you in the eye anymore, or something like that. Those are like microaggressions, right?

Those are just some examples. It could be a lot of more sneaky, though. So how do you deal with them? It's obviously, I think, acknowledging them and also self examining why it's affecting you. And I think just being open about them, too. I think calling out the microaggressions is really important too. You know, one problem is, one thing I lecture about to doctors on this topic is that you always want... I tell doctors you want to approach these patients with an air of

curiosity, but you don't want to be voyeuristic. Does that makes sense, right? You want to ask questions, but you don't want to, you know, keep asking when the patient's becoming uncomfortable or when a boundary has been set. And so I sort of talk to doctors about that, is that there is a fine line between curiosity and voyeurism. And obviously you don't want to cross that line, that line can be very blurry. Does that makes sense?

Marie LeGrand:

That makes complete sense. No, thank you. So we're going to switch gears a little bit and we're going to talk about hormone replacement therapy and MS. What is the relationship between hormone replacement therapy and MS symptoms?

Dr. William L. Conte:

Right. So, I mean, I think a lot of the patients, and this is for cisgendered people, is that we see a lot of problems like memory fatigue and just poor overall quality of life with low hormone levels, and we see with both testosterone and estrogen. And so with estrogen, we obviously see it with post-menopausal women, you have more memory problems. And then when we replace them with estrogen, we see improvement in the symptoms. And it's the same thing with testosterone. So people feel a little weaker with low testosterone levels. So, then when we replace it, they might feel a little more energy.

Marie LeGrand:

Okay, why has my testosterone... okay, so hormone replacement therapy... made my symptoms almost nonexistent?

Dr. William L. Conte:

Yeah, So it's funny because I think... so it's a really complicated topic. And I'm not an endocrinologist, so I don't have the best answer to why this is, but like, I mean, it is a hormone that's important, right? And it's a complex, it's a complex thing, right? So why does testosterone go into the brain? Like, that's weird to me, you know, a little bit, like, and it's... it definitely crosses the blood brain barrier. It causes problems with, like, everything. And so we really... this is a common thing I hear is that when people go on placement... now the problem is, replacement comes with its own risks. These are not risk free medications, but patients do feel better. Now, whether it has a disease modifying effect, I'm not so sure, meaning I'm not sure if it affects the course of MS, but it certainly helps with the symptoms.

Marie LeGrand:

Okay. So now for someone who is transgender, what are some of the challenges that they may experience?

Dr. William L. Conte:

Right. So, I mean, I think transgender people... it's just sort of a misunderstanding of transgender people, overall, these days. I mean, remember, transgender people are just people. Right? And I think, you know, it's obviously... I mean, you just have to put yourself in their shoes, right? Just imagine being in a body that doesn't match your internal gender. Right? And, you know, having body parts that aren't what, that belong to you. Just imagine being in those shoes. And I think we should approach these people with empathy first and foremost. It's just understanding their perspective. I mean, the advice I would give people who are transgender is obviously you want to make sure you're in an affirming healthcare environment, first and foremost, because like I said, the patients that aren't able to transition have very high rates of suicide. And this is really, it's a very concerning group of people.

Marie LeGrand:

Yeah. Yeah. Now, someone did ask prior to the webinar, how do you find a doctor who will treat a trans person with dignity? And I think we touched a little bit on that earlier.

Dr. William L. Conte:

Yeah, it's just like with non trans people who are queer. I mean, you have to... I mean, there's a difference though. I talk to doctors about this subject a lot, and especially neurologists. So I did this presentation at the American Academy of Neurology this year and a couple of people came up to me and were like, Well, why is this important to us? You know, we're not the ones performing gender affirming hormone therapy. We're not doing surgery. We're not, you know, practicing it. And I think we have an opportunity, though... this is what I told them, I told them we have an opportunity for the inclusive care to help support them. And, you know, it's hard to find these people. Right? So as I said earlier, trans people have the higher... they delay their care due to fear of rejection. And there's not a great way of doing this.

Now, I'm working with a student right now, this med student who's got an MBA, and she's doing this... she's trying to create a directory of inclusive practices. So I'm hoping that gets kicked off. And she's trying to do this... practices across the specialties that provide inclusivity. So that's not arrived yet, but I'm hoping for that. Now, there's this one company, well, organization, the Gay and Lesbian Medical Association, or GLMA, they have a directory, but I think you have to pay to get into the directory, so there's obviously some biases there. So... but I think it's mostly people who are like providing HIV care, for example. And then WPATH is another resource. WPATH is an organization that provides standards of care for trans people. It's like a, it's a group of people who have come together and said, this is the standard of care for treating trans people, and they have a directory, but this is people who are actually providing like gender affirmation services. And so it's, it's hard.

Marie LeGrand:

Yeah. Yeah. Now someone was asking about detransitioning. So what about someone who is detransitioning? What... would that affect the MS mistreatment?

Dr. William L. Conte:

Yeah. So one thing about detransitioning. So people, like, at least in the media, are like, oh my gosh, people transitioning, like, what? They're going to regret their choice and stuff. Well, the nice thing about transitioning is that it's so customizable that there is a process for detransitioning. You know, some people, some... this is rare that this happens, but some people down the line sort of like changed their mind or maybe they just didn't realize that they were fitting into this binary group. Maybe they're more of a gender fluid person. And so this is where most people who are transitioned are very happy with with what happened. Anyway, the detransitioning process, I actually think is fine with MS, obviously there might be some hormonal changes which could play a role in some of the symptoms of MS, but I think it's fine. I think it's just you have to watch these pictures a little more closely, but I think people do pretty well.

Marie LeGrand:

Okay. So we'll talk a little bit about HIV and MS, and again, I know you touched on that a bit. So is there a direct correlation between MS and HIV?

Dr. William L. Conte:

Not really. I don't think so. I mean, there's been some theories that having HIV, which creates an immunosuppressive environment, might actually protect against MS, or even that maybe you shouldn't treat people with HIV who have MS. I actually disagree with that second statement, because, you know, we sometimes see patients who have MS contract HIV.

So there's two questions here, is one: is an existing HIV patient less susceptible for developing MS? And then the second question is: is someone who has MS who develops HIV, are they more, like less at risk for relapses? And I just think we just don't know for sure. But HIV does create an immunosuppressed environment. But the thing is, once you treat HIV, you sort of... that gets normalized. So I think these patients definitely... so I only use a direct correlation, I think there maybe some sort of indirect thing that might happen, but it obviously complicates things a little bit.

Marie LeGrand:

Okay. On the topic of HIV and MS, is it true that DMTs could increase the risk of AIDS?

Dr. William L. Conte:

So AIDS being the sort of like the final stage of HIV, I don't think... so, I mentioned earlier the DMT is like... we just don't know for sure how the interaction with HIV and the DMTs work, because it's just not been studied, unfortunately. I don't think... if we're talking about HIV, I don't think they increase your susceptibility to getting HIV. However, if you're... certain disease modifying therapies certainly would lower the CD4 count, so the lymphocyte counts, which could then, you know, I guess make someone more at risk for AIDS, which would be a complication from HIV. But I think as long as you treat the HIV, I don't think it's a problem.

Marie LeGrand:

Okay. So let's talk a little bit about research. So where could research information be found and how do we know about research and clinical trials specific to people living with MS? So we can start with the first part of that question. Where could research information be found?

Dr. William L. Conte:

Well, if we're talking about HIV... or, I'm sorry, LGBTQ+ people, one great resource is the Williams Institute, and I think that's through UCLA is where that's housed. It's just this database, it's a really nice website where it kind of stores all the research studies on LGBTQ+ people, or at least the more important studies. And so I drew a lot of stuff from the Williams Institute. There's also the What We Know Project. I think that one is through Cornell, if I'm correct? So correct me if I'm wrong if I'm not. That one also houses a lot of research. So I think the Williams Institute is mostly like statistics, epidemiology stuff, whereas the What We Know Project is more about the health disparities. So, if anyone is interested in like going through a rabbit hole, go check out those websites. What was the second question?

Marie LeGrand:

And then the second part is how do we know about research and clinical trials specific to people living with MS? So would perhaps their providers have that information apart from the sites that you've mentioned?

Dr. William L. Conte:

Yeah, it's really tough because like some of the healthcare professionals just don't keep up with that stuff, you know, I'm really interested in that. So I definitely keep up with it. But it's so hard, there's so much research going on in the MS world right now. Really. I actually learned statistics

a few years ago that MS, outside of cancer, is the most... it's actually the number one most researched disease state. And I think the asterisk with that, the footnote is that they separated the cancers out. It wasn't just cancer as a whole, which would obviously be number one. It was like... like breast cancer. It's like, okay, but it actually surpasses those disease states, the MS research.

So there's just so much research going on. I think you just have to, you really need to rely on, unfortunately, well, fortunately and unfortunately, some of the foundations. Why I said unfortunately is that then it sort of gets filtered, if you will, the information, it gets filtered through somebody who's doing that, which is good, because then, you know, you can, you know, get the most important stuff, but who defines what's important and what's not important? Does that make sense? That's why I say unfortunately, who's defining that? And so it's really hard. I mean, if you really want to get to the raw data, I would go to the ClinicalTrials.gov website, that houses all clinical trials that are done, at least. Though, this is not just all research, this is just clinical trials for drugs. But they have the old trials up there and the results from them. But that's a lot of... that's an advanced way of looking at it.

Marie LeGrand:

Okay. That's very helpful. So let's talk about mental health. So there is some research evidence on the prevalence of mental health disorders in the community in terms of minority stress, which you touched on as well. So what strategies could they use to cope with a chronic disease and stigma?

Dr. William L. Conte:

So one thing before I ask this question, I want to emphasize is that the research shows that LGBTQ+ people face more mental health problems, but it's not because we are just crazy, right? It's because we face minority stress. We face, you know, adverse childhood experiences that increase our risk of having mental health problems. That's the one important distinction I wanted to make. This is sort of... some of the statistics that come out make it sound like it's just we have higher rates of mental health problems because we're gay. That's not true. It's because of our experience.

And then, so, how to combat that, I think is really looking at support, social support. And, you know, you need to create a village around you, even with non queer people with MS, right? You need the support of the community, you need familial support, hopefully, you need friendships. I think the support groups are really important because as I mentioned, like queer focused support groups, because I mentioned earlier that queer people were more likely to withdraw from... queer people with MS are more likely to withdraw from the queer community, the local queer community when they were when they were diagnosed with the as and also vice versa. They don't participate in MS activities when being queer. So it's really important to have MS focused LGBTQ+ groups. There's not many, not that there needs to be right now. The National MS Society has a virtual one I know of. It's really good. And the MS Foundation just created sort of a, I don't know how to describe it, there's a Facebook group, and there's like a working group that they have. So that's really nice if you can check that out.

Marie LeGrand:

Okay. Okay. No, thank you. Those are very helpful. One question that came in earlier today, so said: "I'm having identity issues. I was a true femme, but since MS, I feel my identity slipping towards left of center and now not sure anymore. Please help a damsel in distress."

Dr. William L. Conte:

Well, I mean, I think this person is really like... I mean, that kind of goes to the point of that, you know, having MS is an identity crisis, right? I mean, this isn't unique to queer people, right? I think people who develop MS, they look at their lives with a different lens after... there's pre-diagnosis and post-diagnosis. I think most patients can commiserate with that. And it does create an identity crisis. I mean, for this person, I would definitely suggest some online resources. Looking at the gender bear, for example. And there may not be a quick answer to this. It may take some introspection over time, some support from good healthcare professionals, maybe some therapists who provide gender affirmation. Those are good resources for this person.

Marie LeGrand:

Wonderful. Wonderful. Well, you know what? We are already at the top of the hour. I know, it just went by so fast as always. So thank you so much, Dr. Conte, for providing us with such informative, you know, information about how MS affects people from the LGBTQ+ community. This has been an amazing and insightful program, so thank you so much once again.

This concludes our webcast. Tonight's webinar was recorded and will be made available on our website. Please visit MSAA's calendar of events for our upcoming webinars and events. On behalf of MSAA, we would like to thank you once again, Dr. Conte, for taking the time and providing us with the tools needed to better understand the impact of an MS diagnosis within the LGBTQ+ community.

And to our wonderful audience, we would like to take time to thank you for joining us this evening. Please take a few minutes to complete the brief survey, which will appear on your screen momentarily and know that we are thinking of the entire MS community and hope that you and your families continue to stay safe. Thank you and have a good night.

Dr. William L. Conte:

Thanks, everybody.