



MIGRAINE WORLD SUMMIT

INTERVIEWS WITH WORLD-LEADING EXPERTS

TRANSCRIPT



LGBTQ MIGRAINE CARE DISPARITIES

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Introduction (00:05): If we look at some of the most marginalized in our community — trans people, trans people of color, people of color, lesbians — people that aren't part of privileged groups outside of the LGBTQ community tend to have greater disease burden across the spectrum, migraine disease, as well as others. So we really have to look at this as a health disparities discussion. And why is it that the most marginalized of us are experiencing the — experiencing worse health outcomes?

Lisa Horwitz (00:37): New studies show that more than 50% of people in the LGBTQ community experience migraine. What these studies do not show is why this group has such a high percentage of migraine. Do the stressors of life as LGBTQ contribute to this high percentage? Do practitioners have enough training to effectively diagnose and treat this community? How can patients effectively advocate for their care? Joe Coe from the Global Healthy Living Foundation is here to explore these questions and more, about migraine in the LGBTQ community. Joe, welcome to the Migraine World Summit.

Joe Coe (01:14): Thank you so much, Lisa, for having me. I'm delighted to talk about this issue with you today.

Lisa Horwitz (01:19): We are so excited to have you here. Reading the study that over 50% of people in this community suffer from migraine — that is even more than the percentage of women, which we generally think [of] as the largest group. Why, in your opinion, do you think so many people in your community are suffering from migraine?

Joe Coe (01:43): That's a really deep and complicated question, but if I was to boil it down to the most simple way of looking at it, it's because the world isn't fair. We face systemic oppression and discrimination, sometimes are rejected by our families because of who we are as LGBTQ people. So, the increased stress and trauma that a lot of us in our community face, I would imagine impacts migraine disease, as well as multiple chronic illnesses in the LGBTQ community.

Lisa Horwitz (02:17): Specifically regarding migraine diagnosis and treatment in LGBTQ community, what do you think are the greatest unmet needs?

Joe Coe (02:27): I think we have to look at the LGBTQ community in its rich diversity. So, we're not a monolith. I'm a gay white man that has a lot of access in this world; I am able to navigate health systems; I have an employer that understands my disease. If we look at some of the most marginalized in our community — trans people, trans people of color, people of color, lesbians — people that aren't part of privileged groups outside of the LGBTQ community tend to have greater disease burden across the spectrum, migraine disease as well as others. So we really have to look at this as a health disparities discussion. And why is it that the most marginalized of us are experiencing the — experiencing worse health outcomes?

Lisa Horwitz (03:17): Do you think it's because of lack of access [to] care or lack of practitioners willing to serve these patients?

Joe Coe (03:26): On the practitioner side, it's important for people to see that there are LGBTQ neurologists and primary care physicians and nurse practitioners. On the access side, migraine might not be the biggest concern for an LGBTQ patient. It might be, if you're trans, getting your hormone treatment; it might be, if you're HIV-positive, making sure that you're getting your HIV medication. So we really need to look at the LGBTQ community as a whole and say, how are we going to — once folks come in the door for hormones or HIV medication or for other forms of



LGBTQ-affirming care at LGBTQ clinics, for example — how are we also talking to them about migraine? Are we bringing this up if we're hearing that they have headaches? Are we not brushing it off that it's, quote-unquote, "just stress," and it's something that should be normative or normalized in our community? So I think it's a really important discussion. It's multifaceted and we need a multifaceted approach to really solve the issue.

Lisa Horwitz (04:28): You mentioned trans patients might be coming in searching for hormone treatments, and many times, for many people, hormone fluctuations can trigger attacks or be a main driver of migraine. So it does seem like an area that would be a good starting point for practitioners to maybe address this issue in clinical care.

Joe Coe (04:51): And I've heard anecdotally — I'm on the board of our LGBTQ center here in Rockland County, New York, and we fortunately are able to partner with a health system and manage or coproduce or cocreate this health clinic for our community here. And I've heard from folks that work in that clinic, in that space, that there are studies and there's thought that if you bundle medication — so if a person is coming for hormones, something that affirms their identity that they need to live, to survive, to feel like their whole self and truly who they are; if you are looking at other chronic diseases, you might not be managing your blood pressure because it's not top of mind; you might not be managing your migraine as much because it's not top of mind. But that thing that cuts at you, that cuts at your identity? People are going to do what they need to do to get their hormones.

Joe Coe (05:47): So we need to look at when people are doing that, how are we talking to them about chronic disease like migraine, and are we having discussions around treatment? And I think the point that you bring up, Lisa — and I'm no expert here; there are so many smarter people on trans issues than I am; it's not my lived experience — I think that there is a lot that can be said there about affirming people's, just, lived experiences and seeing them as a person. And then I think that we can have these greater discussions around healthcare in general.

Lisa Horwitz (06:20): Tying into seeing people in the LGBTQ community as people, it seems like such a simple concept, but we know it's not easy for everyone to do. Do you think that this other-ism keeps patients away from going to the doctor to seek any sort of medical treatment?

Joe Coe (06:39): Oh, without a doubt ... If you feel like you're going to be shamed or questioned about who you are as a person, you're not going to live that indignity and seek care. We know that people are delaying treatment to routine wellness visits because their primary care physician isn't affirming of their identity or sexual orientation. So we really need to do a lot of work as a culture, as a society, to embrace the fact that lesbian, gay, bisexual, transgender, and queer people are 100% fully human. We are your neighbors; we are your friends; we're the people that are doing good in this world, and you need to see us like that and not as some politicized "other" that's trying to do whatever the people that want to oppress us say we're doing — which really, I don't understand, but it does keep us from getting the care that we need because: Why deal with another form of discrimination?

Lisa Horwitz (07:39): Yeah, it sounds exhausting, trying to get help from someone and then feel like you have to come in armed for battle just to defend your existence.

Joe Coe (07:48): I hear so many stories of people, that their partners aren't taken seriously if they're in a same-sex relationship, or that their identity isn't affirmed if they're trans or nonbinary. And these are fundamental things that are so simple for us to do. Ask someone what



their preferred pronouns are at a medical setting, and that changes just the feeling of the — when you're filling out that initial form, that, "Wow, I might not have to have this battle so, I could use my energy to get the care that I need to get." And we all know living with chronic diseases, we have limited energy and bandwidth to deal with all of this stuff, so, make it easier for folks: Be affirming; be uplifting. It's really not that hard to treat people with dignity and respect.

Lisa Horwitz (08:39): You said that you have not experienced as many difficulties as some other people in your community. Did you have a hard time finding treatment and care for your own migraine?

Joe Coe (08:51): I definitely did. I didn't realize that I had a hard time finding treatment and care for migraine for many years until I started to do this work professionally and realized that I was settling when I shouldn't be. So I like to think of it as: When we think of migraine, as a culture, we think of it — and this is how I thought of it — I was like, "It's a really bad headache. It knocks me out for a couple of days; I have to go in the dark; it's something that people in my family experience; it's a part of life. It's part of my existence."

Joe Coe (09:26): I am shocked to this day, although I know it's not the case, when people say they don't have a headache every day. I lived for so long with a headache every day. It wasn't a horrible headache. It was just a headache and — "just a headache" — it was there: It was like white noise in the background, very muted for most days, unless it was a full-on migraine attack, and then, those were the days that I would be really impacted. I didn't realize that I was settling for subpar treatment until I started to listen to professionals; hear the work of the Migraine World Summit; work at the Global Healthy Living Foundation; do all these things and encounter all these people that are, like: There's all these other options out there. I thought it was just a headache. And I thought as a guy — and I think that played more into the issues with me and delaying treatment. I thought it wasn't that bad; I don't really see myself in the migraine community, so I never was drawn to learning more; I never felt like it was a priority in my life. It was always something that was there, but not the primary thing.

Joe Coe (10:30): Discrimination in other aspects of my life as an LGBTQ person was very much there. So, I dealt with that discrimination in my school, discrimination in my community, and all of those issues, but I didn't connect how that might be also feeding into the intensity of my migraine attacks. And it was why I was so excited when I heard the research of Nicole — Dr. Nicole Rosendale, who did this study through a research network called The Pride Network, and it was called — it's a long name; researchers do amazing work, which sometimes ... really long things — it's "Migraine, Migraine Disability, Trauma, and Discrimination in Sexual and Gender Minority Individuals." And she was one of the, either the leading principal investigator or coprincipal investigator, but I got to speak with her on my podcast *Talking Head Pain*.

Joe Coe (11:24): And I was getting chills because I was like, "Wow, they're talking about how trauma impacts the LGBTQ community and migraine." And so many of us are traumatized by society: Either we're bullied in school; or our families are not supportive; or we're stressed that we're going to get fired from our job; or we think that the Supreme Court's going to overturn marriage equality. All of these issues contribute to a daily bombardment of our soul and our spirit, and that has to impact how we feel. And it's so refreshing that things that we know as a community — of course, heterosexism, homophobia, and transphobia is making us sick — but now we have researchers that are starting to say, "Yeah, it really is," and that validates the experience in a different way.



Lisa Horwitz (12:19): You brought up so many things I want to break down from that answer. So, we started off by talking about how it took you a while to really accept that you were part of this community — the migraine community — and I know a lot of our viewers, myself included, felt the same way: "This is a headache. I have it under control." So I love that you share that you felt this other-ism. I think that we get so used to the daily pain that we forget how severe it really is and therefore hold back on pushing for more treatment or pushing to see a specialist. Did you find that was kind of what happened with you?

Joe Coe (13:02): I kind of just settled. I was being treated by a really — my primary care physician, who's great. But he wasn't up-to-date on some of the newer medications, because he is treating so many different things as a primary care physician. You can't expect them to be experts on everything. So I was doing OK with him. And I think what really helped me get to a place where I am now, where I'm much better managed, is that I said to myself, "I'm worth the time and energy it's going to take to get to whatever I could try to get to. I don't know if it's going to be 100%, 95%, 80%, but I'm worth that battle." Because I was at 60 or 70%, and I was OK with the passing grade at 70%. I was like, "All right, I'm working; I'm getting through my life; I'm doing most of the things that I want to do." I didn't have this conversation with myself consciously, but this is, in retrospect, how I must have thought and came to this. I was doing OK; I was getting by.

Joe Coe (14:08): Now I'm doing so much better, and it's a passion of mine, and I know my organization's, to reach the people that are just getting by, because there are so many options now. It's really, really inspiring and hopeful that we have such great innovation. We have headache specialists; we have nurse practitioners who are specializing in headache medicine; we have primary care physicians who are doing that; we have patient advocacy groups that can support us.

Lisa Horwitz (14:38): Do you feel that healthcare in terms of mental health and dealing with these stresses is a key to helping LGBTQ treat their migraine?

Joe Coe (14:51): Mental health is a difficult topic. I'm a big believer that it's an art, and it's ... we need better access to providers; we need insurance companies to cover it. We need people that are not going to do damage to our community, because mental health providers can come in with their own biases, and mental health historically hasn't been used positively towards us.

Lisa Horwitz (15:21): So even this is a stressor, thinking — I'm not in the LGBTQ community and I think, "Oh, I can go see a therapist to help me manage my stress." And to you, you see that as another form of possible stress or damage.

Joe Coe (15:36): Oh yeah. The first thing I think about when I'm interviewing therapists for myself: "Am I going to have to educate them on LGBT issues?" Because if I am going to have to do that, that's not going to work out. And that might not be what I want to talk about, right? I could have that totally under control, and that's not what I want that therapeutic relationship to be. But unfortunately, if you have a clinician who isn't affirming or supportive of the LGBTQ community, it could do a lot of damage — a lot of damage. There have been therapists that have done a lot of damage to my community. There are also amazing therapists that help us get out of really difficult moments that are doing amazing work. So I wouldn't paint a broad-brush stroke and say, "It's what's going to work." It'll work if we have caring, empathetic, culturally competent therapists that are able to address the multifaceted nature of our identities and how that may or may not impact our health.



Lisa Horwitz (16:43): So, coming back to talking about treatment specifically about migraine, how can people in the LGBT community ensure that they are not getting subpar care? How can they stand up for themselves in a doctor's office? How can they research care providers beforehand to be able to tell if it's a good fit for them?

Joe Coe (17:08): So, I'm very blunt: We'll never be able to ensure that we're not going to be mistreated by anyone. We could do things that can increase the likelihood that we might not be, but we live in a culture that views us as "less than," that we are having to debate our existence. We're worried, like I said, about the Supreme Court saying that we're second-class citizens. So we can't ensure that we don't have the power to — what we do have the power to, is to support each other, to share resources. If we know that there are providers that are affirming, let people know that there are providers that are affirming. Look in your local community for LGBTQ centers and clinics. There are many ... both, just educational support centers that don't provide healthcare services, and LGBTQ-specific health clinics. The likelihood that you're going to get better care and resources from your local community who's on the ground, understanding who the providers are, is much greater. So, make friends or reach out to those folks and look at [what] the national organizations are doing — the Human Rights Campaign, or if you're talking about mental health, the Trevor Project. Reach out to organizations that are doing the work on the ground.

Lisa Horwitz (18:33): How do you keep patients encouraged to keep finding a new physician even after they've had multiple bad experiences?

Joe Coe (18:45): You're worth the time and energy. You deserve to be respected by your healthcare provider. Full stop. That's hard for some of us to hear — that we deserve to be respected — because in many ways we're not. But we deserve that, and we deserve to feel better. And unfortunately, the world is still not where it needs to be. Like I said earlier, the most marginalized of us are dealing with the greatest burden of this, so we also need to support each other as a community: Come together; understand that people are coming to us — if we're an organization, if you're a healthcare provider — with a lot of, for lack of a better word, baggage. And we have to unpack that, and we have to provide space for people to feel secure and safe enough to share some really deep, painful lived experiences, in order to get to the place where we need to be.

Lisa Horwitz (19:46): I'm thinking of parents in the community, raising children who might be coming against this struggle. I'm assuming your advice to these parents seeking care for their children is the same thing: Reach out to the local communities in your neighborhood to figure out who would be good providers. Do you have any other additional words of advice for parents who are working with children who have migraine and may be in the LGBTQ community?

Joe Coe (20:13): Love your children.

Lisa Horwitz (20:16): No. 1: Love your children. Yeah, that's great advice.

Joe Coe (20:19): It's simple, but so many of our parents don't. My parents did, but I know so many don't, and it's something that we take for granted — that feeling like you're part of a family, that could make a big difference. There are groups for parents, both locally and nationally. One group is called PFLAG; it stands for Parents and Friends of Lesbians and Gays ... and the name has evolved ... to be more inclusive, I know they do amazing trans work in local



communities as well. And again, reach out to your local Pride and LGBTQ centers and find out where they recommend you to go as a parent.

Joe Coe (21:02): Understand that as a parent who isn't part of our community, you'll never experience our lived experience. And that's somewhat unique to this form of marginalization, because the parents aren't going to be in the same position to say, "I live that; I experience that; I know what it's like to be gay." My parents don't know what it's like to be gay. So, I think that empathy, but not trying to force it, I think is really important. And young people know when young people are feeling loved and respected — in our homes, in schools, in communities, and religious settings. So it's really just making that environment, as adults, where we're saying we're not going to create an environment that is harming our LGBTQ youth.

Lisa Horwitz (21:56): I love that. I see so many parallels between — not to demean the experience of LGBTQ — but there's so many people, and our friends and family and coworkers, who don't understand migraine, and they'll never fully experience what we go through. So imagining having to deal with both of these parts of your humanity being disbelieved or pushed aside. It's truly a struggle; it sounds like a real struggle.

Joe Coe (22:24): I've always felt that chronic disease, LGBT issues, oppression — they're all rooted in the same thing. It's power dynamics, it's who's believed, who's respected. So that statement, Lisa, isn't that far off. I think that the invisible nature, a lot of times, of both things: Being LGBTQ, sometimes people know; sometimes they don't, unless you tell them. Migraine, sometimes they might know; sometimes they won't, unless you tell them. So I think that invisible nature, the stigma, I think there is...there's a lot to be explored there.

Lisa Horwitz (22:57): This leads perfectly into my next question, which is: Why is it so important for less visible groups impacted by migraine, such as men, LGBTQ, and BIPOC, to be represented within this community?

Joe Coe (23:13): I think it will change if people get care or not, if people want to be part of something bigger than themselves, which can really create positive change individually. I think it's our responsibility to look at where we have control and power in our lives, and our organizations, and our institutions to create that change. And not just do it because it's the buzzword; do it because it's important, and it's lifetime work. It's not something that we're going to solve in a year. It's not something that we're going to solve with one initiative. It's something that we have to solve with intense culture change. And that starts at the top, and it starts with all of us when we have power to make that change. So I think that it's so important for folks like myself and others in my community to see and hear that there are LGBTQ people that are living this experience — that you're not alone, that your trauma, your pain, whatever you're feeling, is real and it's not OK. It's not fair; it's not right, and there are people that will work with you to fight that.

Lisa Horwitz (24:27): Representation matters. It always seems to come down to: Representation matters.

Joe Coe (24:33): One thing about representation: It has to be real.

Lisa Horwitz (24:35): There is a lot of virtue-signaling going on in the world right now as opposed to true representation.



Joe Coe (24:41): Oh, I so agree. And people know: People in the LGBT community know, people in the BIPOC community know, people that are marginalized know when an organization is doing the work, and when an organization isn't doing the work and is saying they're doing the work. I think it's important for all of us to do a lot of soul searching and say: Where do we have the power to impact change to make it so that 50% — as you said, Lisa, in the beginning of this interview — of LGBTQ people that live with migraine are going to not have that be the reason why they're not getting treatment? Because we know — you know, I know — that there's going to be a ton of other barriers for getting treatment and getting migraine disease under control. We can't make being lesbian, gay, bisexual, transgender, another one of them. That's not acceptable, in this day and age, in our country and in our world.

Lisa Horwitz (25:42): So lastly, I want to ask you: What is different for you now than 10 years ago when you think about your life with migraine?

Joe Coe (25:51): Oh wow, so much. I don't have a headache every day, which — I didn't realize how big that was. And because of newer medications and because I was able to get a healthcare team that included a cardiologist and a neurologist, you know — so I was able to see specialists; prior, I was not — I am on different treatments that have enabled me to exercise more, to appreciate and enjoy life more. And what blows my mind is: I didn't know what I was missing. And I think that's really what is hard for some folks. And this isn't everyone's experience, but we're so used to surviving. If we're LGBTQ, we're used to surviving. How do we envision a world without heterosexism and homophobia? That's mind-blowing. As a migraine patient, how do we envision a world without migraine pain? That, I didn't know was mind-blowing, but it was.

Joe Coe (26:54): And what are we missing? It's hard for people to grasp that because we're so used — we're able to understand when something's being taken away from us; we feel it. But what we might get by putting the energy and effort forward? That's a harder sell. So we need to really decide for ourselves where we want to be, and is this OK. So I'm in such a different place. I have bad days. I had a bad day a couple days ago, and I made it a point to post it on social media, because I've been — I post a lot of the good days, which, it's important to be positive, and all the things that I'm doing, and the exciting personal records that I'm achieving at the gym. But I had a really bad migraine attack the past weekend, and I said, "You know what? I want people to see this, because I don't want them to just think that everything is OK all the time."

Lisa Horwitz (27:48): I think it's really important that you are sharing the bad days, if only to illustrate that this is a disease without a cure, but it can be managed. And as our listeners just heard, it took years for you to find the right adjustment and the right number of doctors. So I always like to just reemphasize to everyone: Keep trying; it can get better. Your first experience doesn't have to be your ending sentence of your treatment, because this is such an insidious disease that slowly — it's like you said before, you boil the ocean one degree at a time, and that's kind of how migraine can slowly take over your life: One little inconvenience, or symptom, at a time until you don't realize how dysfunctioning you really are.

Joe Coe (28:40): Oh, totally. And I think that kept me from exercising, from getting into a place where I wanted to be. So I said, "What's the worst that will happen to me? I'll have a migraine attack. That's bad, but I have a migraine attack anyway, so I'm going to try this. I'm going to work with people." And it was rough getting off of the older medications, getting onto the newer ones. I'm able to do things that I never thought 10 years ago I could do, and in large part it's because I'm better managed with my migraine.



Lisa Horwitz (29:12): That is great news. Joe, I want to thank you so much for today's interview. We've covered a wide array of topics. Where can we learn more about what you're doing or follow your work?

Joe Coe (29:24): In a couple of places. First, my organization is Global Healthy Living Foundation, and that's GHLF.org. And I also host a podcast about headache and migraine called Talking Head Pain. That's on Apple, Spotify, and you can also find that at talkingheadpain.org.

Lisa Horwitz (29:44): Are there any resources you'd like to recommend to our audience?

Joe Coe (29:49): On talkingheadpain.org, there's a resource library; there are audio guides around migraine disease; there are also some episodes particularly focused on the LGBTQ community, both from the research perspective and patient-provider perspective. So definitely check out the catalog at talkingheadpain.org.

Lisa Horwitz (30:12): Well, today we have discussed how the LGBTQ community has extra obstacles with receiving medical care and diagnosing migraine. We can all agree that the first step forward is acceptance and kindness, and patients should reach out to their local LGBTQ communities for resources on finding practitioners and friendly physicians in their area. Thank you again, Joe.

Joe Coe (30:36): And thank you, Lisa, and the Migraine World Summit for continuing this important dialogue. I want everyone to leave this interview knowing that you're loved, that someone out there loves you, that you are important, that you're valued, and that you deserve respect.