Disability Visibility Podcast

Episode 27: Chronic Pain

Guests: Alecia Deon and Sarah Blahovec

Host: Alice Wong

Transcript by Cheryl Green

For more information: https://disabilityvisibilityproject.com/podcast/

Introduction

[radio static, flipping stations, landing on voices singing]

LATEEF MCLEOD: This is the Disability Visibility Podcast with your host, Alice Wong.

[hip-hop beat transitions to mellow music]

ALICE WONG: Howdy, partner! Welcome to the Disability Visibility Podcast, conversations on disability politics, culture, and media. I'm your host, Alice Wong. Today's episode is about chronic pain with my guests Alecia Deon and Sarah Blahovec. I interviewed Alecia previously for Episode 14 on emergency preparedness, and the conversation continued about her experiences getting prescription medications and accessing healthcare as a person with sickle cell anemia. You're gonna hear about about that in this episode. In the second half, Sarah shares some of the major misconceptions about living with pain and recent efforts by pharmacies and the government to limit prescription painkillers. Both Alecia and Sarah describe the stigma and shame that some pain patients face and the numerous hurdles they encounter when seeking pain treatment. There are also lots of things to think about when it comes to supporting pain patients without being ableist toward people with substance abuse issues who also need care. Are you ready? [electronic beeping] Away we go!

ELECTRONIC VOICE: 5, 4, 3, 2, 1!

Alecia's Introduction

ALICE: OK, so, Alecia, thank you so much for being on my podcast today. Why don't you tell me a little bit about yourself and where you're from?

ALECIA: Thanks for having me. I'm I'm so happy to be here with you. So, I was born in Jamaica. I immigrated here when I was younger, and I have sickle cell anemia. I connected with your work on Twitter, trying to find more voices for this particular experience. And I think I'm trying to connect more with being disabled and what that means for me, given my culture, given my background and my history. And I've found a lot of spaces to bring all of myself into, as a disabled person who's also black and also queer and also these other intersections. So, it's been pretty fulfilling to step into another space and say wow, I have a voice here, and people actually care what I'm going through. And I never had that before.

[bubbly electronica]

Emergency preparedness and stockpiling medications

ALICE: You recently experienced recently experienced Hurricane Irma. Where we you in relation to the path of Hurricane Irma, if you don't mind?

ALECIA: So, I think it was within the last couple of hours, right before it really hit, that it changed path. But we were kinda directly in its path, and it switched from the East coast of Florida to the West coast of Florida. So, coming up through the Keys, Key West, and then Miami. And I live in the county right above Miami. So, that would've been a direct hit for us.

ALICE: One thing that people always say that I read in a lot of these emergency preparedness literature: They say oh, stockpile your medications.

ALECIA: [laughs] That's the funniest thing I've ever heard, honestly.

ALICE: I know. That's what they actually said, like they say, "Always have an extra supply of medications." I'm like, are you on Medicaid? I don't think so!

ALECIA: [laughs] OK? That's the first issue, first of all. [laughs] And it's the issue of when I actually have a prescription, when I'm need, and I go to Walgreens to fill my prescription and, say, they don't have the medication. And so, I try to go to another Walgreens, and they flag my account and say, "This person has been to more than one Walgreens within whatever time period." And I don't know who is watching that, like who in the federal government is watching that, but the way that narcotic medication, all of these, the way it's tracked, I can't even get it when I need it, OK? And in normal condition, in my everyday life, I can't get my stuff when I'm in need of it. So, to say, "stockpile for an emergency," that's impossible. That's ridiculous. Absolutely not. [laughs]

Being labeled a drug seeker when you're in pain and being dismissed by white doctors

ALICE: Yeah, and also I think the other, with opioids or narcotics, you get labeled as a drug seeker, when you're just trying to get it refilled. Could you speak a little bit about that in terms of just the real amount of work it takes just to get what you need?

ALECIA: You know, I think that is one of the hardest things that I have to endure. And so, for example, this past weekend, I was all happy. I was feeling good, feeling pretty good. And I get all cute and say, you know, I wanna go sit at Starbucks and get some work done. I go to grab for my keys, and my right hip literally just gives out on me, and it feels like it is disintegrating. And within like a minute, I'm in excruciating pain. I have to hobble back to my bed, try to drink some water, try to lay down, get a heating pad, do what I can. I'm by myself at home. I don't have access to anything. Even if I was to try to call Uber and all of these things, I have to get up and walk.

And when I go to the hospital, the amount of times I've been in an emergency, and I've had doctors who are primarily white male doctors look at me like I'm not actually in pain and treat me like I'm not actually in pain and treat me like I'm there seeking drugs when I'm visibly, literally screaming my head off. There have been times where when that pain, when it hits 10, I mean, there's no me sitting still. Most times I try to stay still just so I don't aggravate my body anymore and cause any more pain, potentially. But I'm screaming my head off. And they're looking at me like I'm lying.

And the last time I remember, I had a blood clot in my lungs, and it's like 2:00 am in the morning, and I'm at home. I lay down, and I say, OK, let me just try to go to sleep. I think I took some pain medication. And most of the times when by the time the pain is that bad, I take prescription medication, and it feels like I took a Tylenol. There's no relief, no help at all. So, I say, OK, let me lay down and try to go to sleep, sleep it off maybe. I lay down. I can't find a comfortable position. I can't, I feel like I can't breathe. And I'm like, OK, let me just go to the emergency room. And the doctor says to me, "You know, well, we are going to treat you. You don't have to cry like that." I was so incensed and furious. It's just like how dare you take away a basic human emotion from me when I'm actually in pain, you know?

And there's research to show that as a black person, when you go into an emergency room, and you're seen by one of these doctors, that white folks believe that we experience less pain. And all of this being tied to our history in this country. And so, that history is brought into my face and brought into my experience when somebody sees me visibly in pain, visibly uncomfortable, screaming my head off, and they would say, "Oh, you don't have to do all of that. We're gonna treat you." And it's minimizing. It's insulting. It's so many things, and it kind of just feels like it's tearing at my humanity. And I have to not only deal with the fact that I'm in pain, but now I have to deal with the fact that you also just took a jab at my humanity, and now I have to figure out a way to not internalize that.

That's kinda what I did on the weekend. I didn't wanna go to the emergency room because I didn't have the mental capacity to deal with the doctors.

[pensive music]

Giving real medical care versus social control of black disabled bodies

ALECIA: There's a clinic that I go to, sickle cell clinic that I go to when pretty much they treat you for the day, and then you're able to go home. Or if the situation is too severe, then they keep you. But having access to that has been really helpful. But my issue comes in with are you actually trying to help me and give me access to resources, or are you trying to control me and control the way I take care of myself and the way I treat myself?

ALICE: Yeah. You have to follow the rules or—

ALECIA: Mmhmm. Exactly.

ALICE: So much of that is surveillance and also a disciplining of behavior and bodies. And also, again—

ALECIA: I knew you would get me! I love you. You're great. [laughs] 'Cause you start to feel guilty. You start to feel guilty like you're doing something wrong, like you shouldn't do this. You should just obey the rules and do it the way they want you to do it. And it's like no, that's not helpful for me. It's not working.

ALICE: Well, these are all means of social control—

ALECIA: Mmhmm, absolutely.

ALICE: —over disabled bodies, over black disabled bodies. This is again about criminalizing the experiencing of pain, which is really enraging because people with chronic pain, they just don't get the same, I don't know, why don't you tell me, I guess. I mean, what are the thoughts about the way that it's just not seen as, it's not taken as seriously?

ALECIA: Right. Yeah, I think it’s the, you know, because I can’t verify for myself. And because we don’t trust people, especially marginalized people, which you know, is the issue, that that silencing, we don’t trust marginalized people to be able to give voice to what they’re experiencing. So, I don’t know if that’s, like you’re saying, part of the criminalization. I don’t know what that is. But it’s not until the doctor can verify for himself that I’m in a sickle cell crisis, or they get the blood test results back, and they can see, oh, well, this number shows that this is what’s going on. So, it’s more likely that she’s telling the truth. But the fact of seeing me crying and screaming, I can’t even have anyone touch my body how much pain I’m in, and you know, that’s not good enough for you.

[pensive music]

Taking care of your spirit and soul

ALICE: How do you deal with that in terms of just picking yourself up and going forward and surviving another day? But how do you take care of your spirit? How do you make sure that you remember to love yourself even though so many messages around you harm you?

ALECIA: You know, I think that’s always the center of my message anytime I get the opportunity to talk to other people with sickle cell. It’s always, “Don’t forget to take care of your soul. Don’t forget to take care of your spirit.” Because every time I see a doctor, and they make those insinuations and treat me in a way that I don’t deserve to be treated, especially as a person who’s seeking help for a chronic issue that’s documented, that you know is a fact, and you know how painful it is. [sighs] it’s really, really hard to move forward thinking about what I’ve gone through, just mentally, outside of the physical pain, just the mental strife I’ve had to deal with taking care of myself and my spirit and my soul in these other intersections as well as these other issues, that’s my primary goal. No one will take my humanity from me. I’m like, I will not allow you to rob me of that. I’m here because I’m in pain, and I don’t care if you believe me or not. Either treat me or let me go somewhere else where I can be treated.

You learn to stop apologizing. You know, I didn’t cause this on myself. Even if I did, [chuckles] I didn’t cause this on myself; it’s genetic. You know that it’s painful. There should be more resources for us. But because of the perception that oh, this is a black issue, you know, I feel so tied to that. And there are times when I really sit down, and all of it really hits me. And it hurts, it hurts, it aches. Because I’m just a human being, you know? There’s a suffering that is just inherent in the fact that I’m a sick person, and I have this illness. But then there’s the suffering that other people have caused me because of the way that they view me, because of the way that they speak to me, and because of how they treat me. So, I think it’s a very, very important place to get to for people with sickle cell, people with disabilities in general, to not let this system destroy your soul and destroy your spirit. You’re beautiful. You are amazing. You are here. I think my commitment to not being silent anymore, because I’m very tired of everybody else trying to tell me what I’m going through.

ALICE: Thank you so much for talking with me today.

ALECIA: Thank you so much for doing this. I feel like this is so special for disabled people, for myself, especially in a moment where I'm saying I'm tired of being silent, and I'm tired of not being heard. Just the opportunity to do this with you has been amazing. Thank you so much for reaching out. I love you so much.

[upbeat electronica]

Sarah's Introduction

ALICE: So, Sarah, thank you so much for joining me on the podcast today.

SARAH: Oh, thank you for inviting me.

ALICE: Sarah, why don't you go ahead and introduce yourself.

SARAH: OK. My name is Sarah Blahovec. I am the Disability Vote organizer for the National Council on Independent Living, and I'm also a blogger and independent activist for disability rights. I have Crohn's disease, which is a chronic illness. So, a lot of my extracurricular, outside of work activism is on chronic illness and chronic pain. Which, I just wanna preface first with recognizing that chronic pain and chronic illness are not the same thing and not even necessarily the same community. I happen to have both. Some people may be chronically ill without pain. Some may have pain from their disability but not have chronic illness. So, I know I tend to get a little bit murky there with blending them together, but they can be very discrete at times. It just happens in my case that they both affect me.

Sarah's pain and pain medications

ALICE: Great. Thank you so much. Since this episode is about pain, do you mind describing the kind of pain you've experienced in the past and present and what you do for pain relief?

SARAH: I've had a lot of complications from Crohn's that are not necessarily related to my primary condition but are related to symptoms, of side effects of my immunosuppressant medication. So, I've had a lot of different types of pain in the past. For about five years, I had chronic infection issues that were at the skin level. So, I would have to get really painful surgery that would just involve local anesthetic and draining of really large infections. Last year, I had one that was, it took four weeks after the surgery to drain, and it was a very, it was possibly the most severe skin infection I had had. But beyond that, I had a PICC line for two months, and I also had and still have chronic pain, hip pain.

Now, I've been out of remission for about a year, hopefully getting better now. It seems to be a little bit on an upswing. And I'm lucky enough to say that my pain is controlled well. I use Tramadol, which is not an opioid; it's a synthetic opioid. So, it's consider a little bit lower level, and it isn't as difficult to get or difficult for doctors to prescribe. And I've been on that for quite a few months now. And I also have inflammatory bowel disease induced arthritis. So, I tend to have a lot of pain in particularly my joints in my knees and my hands. So, I am on, again, it's not an opioid at this point, and it has been working moderately well.

Acute pain versus chronic pain

ALICE: What are some of the most, I guess, frustrating aspects of being in pain? And for those who don't understand, what is the difference between acute and chronic pain?

SARAH: That is something that actually is kind of unclear because in terms of policies lately, there's been a lot of changes in terms of prescription policies for what is considered acute pain compared to chronic pain. And they are not very clear on that; they tend to consider essentially end-of-life pain and cancer pain as chronic pain. In reality, it's really a lot more than that.

For me, for months I could not get out of bed until I had Tramadol in my system for at least an hour because the abdominal pain and joint pain was so severe, I just couldn't get up. And whenever you have this on a daily basis, people think you just get used to it. But it's not something you really get accustomed to being in pain all the time. It saps away your energy and your focus. It makes it just difficult to get through your day-to-day tasks. It can take me twice as long on a bad pain day to do something that it would take on a regular day.

For acute pain, generally they would consider that, for me at least, something like whenever I've gone through these surgeries. But the thing is, is even acute pain—in my definition—can last for a very long time. I had been on painkillers for months for the pain in my, the really bad pain in my hip. Pain is not something that you can say, "Oh, after seven days, it's chronic" or something like that. A lot of people with chronic pain are sometimes diagnosed with acute pain because they have flares of symptoms. And so, the doctor will say, "Oh, this flare is acute compared to the chronic condition," and they'll only give them pain medication or whatever they need for a little bit of time.

So, it's really difficult because pain is not easily quantifiable into these two discrete categories. So, I know that's a little bit confusing, but really, that reflects the environment of whenever they're trying to regulate medications for acute pain versus chronic, how do you define it? Because it's not easily defined.

[chill music]

CVS policies making life harder for people who use opioids

ALICE: You recently wrote a guest blog post for Rooted In Rights about the changes in the pharmacy chain CVS, their opioids, and how it would negatively affect pain patients. How will changes like this make life harder for people who are just already barely getting by getting what they need? Tell me a little bit more about that.

SARAH: So, the CVS policy is they announced a couple months ago that they were going to start limiting prescriptions for opioid medications for acute pain to seven days. And that in itself was kind of confusing 'cause again, they did not define what acute pain was. And generally, as I said before, what they consider chronic pain is cancer and end-of-life. And so, anyone who doesn't fall neatly into those categories may be subject to this policy. That means every seven days, you're gonna have to get a new scrip. And that's more than just calling up your doctor and saying, "Hey, can you send this to the pharmacy," at least in Virginia. I believe it's nationwide: You have to get a physical, written scrip, hand-written scrip from the doctor. It cannot be electronically sent to the pharmacy like many other prescriptions are.

So, that means you either have to go in and have a doctor's appointment, or you go in and pick it up from your doctor. Which, if you're having chronic pain, or if you're having pain in general, traveling may be difficult, especially for people with disabilities. Many of us don't have the same transportation options, or if we're having really bad pain, it might be really exhausting to go out and get that, especially every seven days. And then you have to drop it off at your pharmacy, of course. So, that's more errands to run.

And this is in regard to what's considered the opioid epidemic. For those who are not aware of that, there's been an increase in overdoses and deaths from opioid-related drugs. They also have, at least for the CVS policy, they're going to implement some sort of addiction counseling for people who get these scrips. I'm not sure how that's gonna happen. Is it gonna be something that just happens at the counter? For me, that's seen as they're looking at all opioid patients as potential addicts, and that's just not what the stats show. I mean, 75% of opioid abuse originates with people to whom medication is not prescribed. So, that means you're getting it from your mother's medicine cabinet or a friend or, more likely, a dealer.

Rates of addiction in the chronic pain community for opioids are around 8-12%. So, there is, of course, a risk of addiction, but it is not as high as people would think when we're talking about an epidemic. And unfortunately, putting more restrictions on opioids has been leading to quality of life difficulties for people with disabilities. They're finding that people with chronic pain conditions maybe are going to commit suicide from severe pain. There was an article in Slate, and it was talking about how people have been dealing with really severe pain and are getting their prescriptions that they've been on for years and don't have a physical addiction to, or they may not have an addition to, but a physical dependence on and may need that to be able to get through their day. And whenever they're having these prescriptions cut with essentially no time to even ween down on them, they're being left without pain management options. And so, their quality of life is degrading very greatly. Imagine being in pain day after day, with your ability to deal with it being taken away from you.

[mellow music]

Medication shaming and ableism

ALICE: And there's also this medication shaming that happens by other people in our communities or news in the media. So, what have you seen in the media about addiction and opioid usage that you see as harmful and ableist?

SARAH: Yeah. One thing I know, I have several friends who have pain issues, and including myself, we're all terrified when we go to the doctors that we're gonna be seen as drug seekers. Because in this environment, it feels like we're being treated as either addicts or potential addicts first and patients second. And they're not considering, at least for me and for many others, we don't feel any sorta high on these medications. I know the medication's working whenever my pain decreases, things like that. But there is just this very ableist assumption that people are going in, they're looking for drugs. And that has led to people being put on lists in their community that are sent out to hospitals that they're wrongly looking for drugs; don't give them drugs if you come in the ER. There's some pain management clinics that will force you to sign a contract that you will not take opioids, or you won't take prescriptions, from any other source. And I believe that includes hospitals. So, there's that.

There's also people who don't understand the nature of pain and living with chronic pain who think it's an issue of willpower. So, you'll see people say, "Oh, well, I won't take, I wouldn't take those drugs because I'm stronger than that." Or people think that you should be able to manage this without opioids, and if you do have to use pain medication, that you're just being weak and giving up, and you're giving into the pain. It doesn't work like that. I mean, if you've been in pain for days and weeks at a time, it wears you down. It doesn't matter how strong your willpower is.

And then there's also another issue within the pain management community in terms of this opioid epidemic turning people who are pain patients, kind of saying, "Well, we aren't addicts," and then essentially shaming people with addiction issues. So, one of the hashtags that has been pointed out, there's one called #PatientsNotAddicts. And there can be a lot of, "Well, we aren't these people, so don't accuse us of being these people." And it's really ignoring the fact that nobody wants to become an addict, in general. A lot of people who become addicts are people who were denied proper pain management and might turn to illegal drugs just to deal with the massive pain in their lives or have gone down a wrong path and made a mistake. That doesn't make them necessarily a bad person.

And so, there's this whole shaming of addicts, sometimes from people in the chronic pain community to say, "We aren't those people," instead of saying, "We still support people who have problems with addiction. We want to support their ability to get proper treatment and to be able to recover from that." So, there's a lot of inter-community ableism there, and I think really kind of contributes to divisiveness and an inability to really rally around this issue as a community. Of course, we need to be able to make sure that people aren't becoming addicted from prescriptions. We need to also make sure that there's adequate addiction treatment, which has been, to be honest, on the chopping block. If you cut Medicaid, 25% of addiction treatment comes from Medicaid. So, it's kind of scary because those cuts to Medicaid could definitely affect addiction treatment options, make them far more inaccessible.

ALICE: Yeah, clearly this regulation about access to prescriptions and other forms of regulations on the opioid usage, it does nothing to really assist and support the people who are currently dealing with substance abuse. And I think again, that's the missing piece that there's such othering of people who are addicted, and also a lack of community-based supports.

[low-key music]

Changing misconceptions of opioid users

ALICE: Are there any other changes that you would like to see regarding opioids or other pain issues that doesn't penalize or stigmatize people with disabilities and chronic diseases or chronic illnesses?

SARAH: Yeah. I feel like there's just a misconception. There's a lot of misconceptions right now about the opioid epidemic, about people who take these medications. It's not something we want to be doing; it's something, often, that we have to be doing. I would love to see people be less judgmental of pain patients, and that's disabled and non-disabled, and understand that this is something that we live with. And just I wish there was a better understanding among everyone, including politicians, about the real nature of the opioid epidemic. In terms of the numbers, I mean, it's astounding because in 2015, there were 20,101 overdose deaths related to prescription painkillers. Actually, that number's probably lower because they often include Fentanyl in that number. According to the Center for Disease Control, in 2015, there were 36,252 deaths by firearm. So, you have over 10,000 more deaths from guns than you do from painkillers. And I know this is obviously a politicized issue, but one's being considered an epidemic, and one is not.

So, there's just, I think, a lot of misperception about who this affects and what the numbers are and where this epidemic is coming from. It's not coming, generally, from the doctors' offices. And unfortunately, the way that the government is deciding to deal with this, potentially as one of the rare bipartisan issues we have these days that they agree on, is by instituting policies that are going to affect pain patients but not really get to the source of this actual epidemic.

ALICE: Sarah, thank you so much for talking with me today and just sharing your story and really your perspective. I really appreciate it.

SARAH: Thank you for having me. This was fun.

Wrap-up

["Dance Off" hip hop song]

ALICE: This podcast is a production of the Disability Visibility Project, an online community dedicated to creating, sharing, and amplifying disability media and culture. All episodes, including text transcripts, are available at DisabilityVisibilityProject.com/Podcast. You can also find links about Alecia and Sarah on our website.

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Thanks for listening, and see you on the Internets! Byeeeee!