Episode 252: Ignoring Women's Pain

Lizzy: Hi, I'm Lizzy Ghedi-Ehrlich

Lisa: And I'm Lisa Hernandez.

Lizzy: And we're your hosts for Scholars Strategy Network's No Jargon. Each month, we'll discuss an American policy problem with one of the nation's top researchers without jargon. And this month, we're talking about the dismissal of women's pain in the healthcare system by healthcare practitioners.

Lisa: Well, you know, us both identifying as women, I'm sure we're familiar with the plethora of stories and personal experiences of this issue, but I am interested in learning about patterns that maybe we don't know about and how it plays out in different aspects of healthcare as well.

Lizzy: Yeah, absolutely. And you know, there's an angle I hadn't considered here, which is why I'm so excited to introduce this episode. This is a legal issue. This isn't just... you know, affecting individual people's lives and their experiences at the doctor's office, but when we're talking about laws that govern who gets certain services, like disability coverage, if you're experiencing certain types of pain and cannot work, um, and now in our, you know, patchwork reproductive healthcare laws, there's just a ton of like patients reporting how they feel that goes into medical and legal decision making.

So that's just a whole nother layer added on to that. And that's why I'm so excited for this week's episode, where I spoke to Dara Purvis, an Associate Dean for Research and Partnerships and Professor of Law at Penn State. She's a scholar of family law, feminist legal theory, masculinity, sexuality, gender identity and the law, and her work examines gendered impacts of the law, including how gender stereotypes cause and reinforce inequality and what neutralizing reforms could do about it.

Here's our conversation.

Lizzy: Hello, Dr. Purvis.

Dara: Hello! It's a pleasure to be here.

Lizzy: Thank you so much for coming on No Jargon. I'm super excited to talk to you. and I'm really interested in your dual perspective. You're a scholar, who, you know, speaks about and researches reproductive rights in many ways, and you are a professor of the law. And together, you kind of combine that duality sometimes to look at an issue, which is women's pain, how it is ignored, how it affects healthcare.

What are the impacts of whatever's going on there? And we really thought this was an example of someone's got to have a story. You know, what got you interested in this? When did this become an area of inquiry for you?

Dara: Well, I have to go back quite a while to get to the start of my interest. I had just graduated law school. I was clerking in the Ninth Circuit. And you think of the Ninth Circuit as having immigration cases maybe, big constitutional law impact cases. But I kept seeing all these appeals from denials of social security benefits.

And most of the time, the person being denied was a woman who said, I can't work because I have fibromyalgia, and I am in so much pain that it's keeping me from being able to live my life. And it was just a genuine question for me. I, I was very surprised at how many of these cases with really similar facts were coming up as appeals.

And so after I finished the clerkship and as I entered academia, I started just trying to answer that question. And a big part of it was Fibromyalgia really turns on people subjectively describing their levels of pain, and it's not something that's easily shown in an x ray or another kind of medical problem.

And I was already very interested in gender and feminism, and then this just led me down what turned out to be a very deep path of skepticism about what women say about their bodies.

Lizzy: And let's talk a little bit about like what exactly that looks like. I think fibromyalgia might actually be a good arena of discussion to maybe give some examples from. Like, what does it look like when we have a female patient experiencing pain, when that is ignored or downplayed by a medical professional?

How have you seen those narratives played out from your perspective as a legal scholar?

Dara: So it happens in a lot of different contexts. So, disability determinations, uh, women saying that they're not able to work because of fibromyalgia is a great one because everything about sort of the diagnosis, everything about what are your, your limitations in your daily life kind of turn on someone reporting how much pain they're in.

But it plays out in lots of other contexts as well. So most recently, we've seen litigation over abortion bans following the decision in Dobbs versus Jackson Women's Health that overturned Roe v. Wade, where women who are experiencing miscarriages seeking care are being turned away from hospitals, essentially because they, aren't clearly in enough danger from something going wrong with a pregnancy that the hospital, that the doctors, feel like they can treat the women with abortion care.

And one of the things that goes into that is whether the doctor believes a woman when she shows up at the hospital and says, I am experiencing severe pain. Something is going drastically wrong here. So we see it play out in all sorts of contexts, this distrust of what women are telling people about themselves.

Lizzy: And how common is this? Is it something that can be quantitatively measured? You know, I'm hearing you describe something that is so qualitative, this idea that you have a patient doctor relationship, and some of what a doctor is able to discover is very empirical. You're taking, you know, an x ray of someone, they have a broken bone.

And then some of it so relies on a patient's description of self. Like, that's actually a huge part of medicine. Do you, do we know of quantitative measures for this dismissal effect? Like, how do we see that playing out, you know, on a, on like a public health scale?

Dara: Well, there's not an easy measure of it. In, in other words, because there's not a quantitative scale of pain, it, it's always going to be subjective. There's not an easy way to say, like, here's how much the doctors are recognizing pain, and here's how much the pain actually exists. But I think you see it play out in a lot of different contexts, and one that I would point to has an, intersectional aspect.

So we're not just talking about women, we're talking specifically about Black women and the care that Black women get when they are pregnant. It is much worse care. The health outcomes for pregnant women, pregnant Black women, are much worse than for pregnant white women. The number of... Black women who die while they are pregnant or while they are giving birth is three to four times higher than it is for white women.

And one of the, the reasons behind that I think is that there's even greater distrust of Black women for, for a variety of reasons. But one quantitative thing that we can point to is that there is still this misperception, a stereotype that significant numbers of doctors report in surveys where they believe that Black people and Black women feel less pain than white people do.

Totally racist stereotype. Absolutely no basis in fact, but it's something that has persisted even in the medical profession and I think it helps to explain these drastically different outcomes for Black women trying to get the same level of care as white women do.

Lizzy: You know, I just think about what histories of dehumanization mean when they're sort of laundered through these systems in that way, you know, because we know that we have this intense history of dehumanizing Black people and an intense history of dehumanizing women and then when those meet, you know, in the body of a Black woman, you absolutely see how that's something that that could play out.

And I and so now I'm wondering about, you know, are there similar effects that could be seen in research on how medical professionals are treating immigrants or people with low English proficiencies, how we're treating people with larger bodies, like all of these things that we know have these histories of dehumanization, And it's quite terrifying, and I suppose that's more of a comment than a question.

Dara: Well, I, I will absolutely agree with that comment. When we rely on how much medical professionals believe someone, and we do it a lot in the law, we defer to medical professionals judgment as though it's objective, as though it's clear, as though it's neutral. When we do that, we risk just magnifying problems that we already know are there.

Lizzy: I want to back up for a second. We have been talking about fibromyalgia as if that is a term that everyone is

familiar with. And that may not be true. Not everybody has a boomer mother who was diagnosed in the nineties like mine was.

So let's pause for a minute because again, and I kind of gave you like a leading intro there because not because I think it is, you know, the sole focus of your research, but because I do think it's a really. Interesting sort of case study space, uh, from which to discuss some of the bigger issues you're talking about.

So, can you tell us a little bit more about fibromyalgia and like what that, how you kind of discovered what was going on there as a, at first a, an actual jurist and then as a researcher?

Dara: Sure. So fibromyalgia is an interesting label. It is not a health condition that there's a single test for. Like you, you don't take a test that comes out positive for fibromyalgia the way that you could with lots of other illnesses and lots of other conditions. It's defined as a syndrome. It's defined as chronic pain that lasts for a particular period of time that you report a certain number of times.

It often becomes what is sometimes called a diagnosis of exclusion, that someone comes to their doctor saying I'm having all this pain, and the doctor kind of tests for lots of things that it might be, and it's not any of the things that we have tests for, and then there's a test about do you have a certain number of tender points that you report pain at a certain number of these tender points.

So it's a kind of broad idea. There's not a sort of binary, uh, you know, we'll take a bit of your blood and tell you if you have fibromyalgia or not. So it's similar. There, there are lots of other conditions like this. The one that I think will be very interesting to see developments in is long COVID. The kind of, someone is having symptoms, they're reporting them, we believe that

these symptoms are occurring, but we're not sure why, and so now we've created this label for it.

Lizzy: As soon as you said that, I was just like, Oh, wow, yes. I have been thinking about the sort of miasma of long COVID, you know, that this is going to be difficult to diagnose. This is going to be difficult to treat. What are the different mechanisms we're going to have to set up from a policy angle?

Because, you know, that's my job. That's kind of how I think of all these things. What is this going to mean for, you know, Medicaid reimbursement procedures? Kind of how do we label it now? You've got me thinking, you know, even it's even more complex because how are these biases going to be playing out in how that's diagnosed, you know, when you have something that is so non specific in that way?

What is that going to mean for Black people with long COVID? What is that going to mean for low English proficiency speakers with long COVID? What is that going to mean for industries that rely on certain demographics of people largely to do certain kinds of work? Like, wow, there is going to be, there's a real, what a research opportunity, I guess, is uh,

Dara: Yeah, I'm, I'm torn because is it a research opportunity? Yes. Is it also really terrible? Absolutely.

Lizzy: They often do go hand in hand. Sadly, but I'm, I'm glad for you to bring it up because I do think, um, helping people think about it in these ways and make those kinds of biases and their effects plain is so important because otherwise it's either part of your life and then it's about you, you know, or your family and your perspective, or it's not.

And then you may not see it at all, you know, we're not thinking about how these things lead to increased costs overall, we're not thinking about how they affect labor, we're not thinking about, you know, how they affect just family's ability to, to get by and kind of, you know, how racism plays out still, in a health care field and how, you know, gender stereotypes do too.

So I do think that is important. Taking it back to reproductive health, because, you know, we see these incredible disparities by race and we know that reproductive health largely is a space where we're talking about a certain type of body, you know, bodies that are categorized as female. So again, there's lots of kind of different interesting things that that area of research can kind of bring up because we do treat people with that type of body differently, than others.

And I think that has such interesting implications for the entire field of reproductive health. and obstetric medicine. So let's talk a little bit more about some of the changes that we're seeing in the law that you alluded to earlier in our conversation. Like, what does, what do abortion bans

versus states that don't have those kinds of laws in place mean when it comes to pain diagnoses?

How does that all work together? What are we seeing in data so far that's telling you why this stuff matters?

Dara: So, states that have abortion bans have an exception for abortions that are necessary to save the life of a pregnant person or protect a pregnant person from serious injury. And abortions take place in a variety of ways. So we're not talking just about elective abortions.

Someone is pregnant and doesn't want to be. And so seeks out an abortion. Abortions are part of reproductive health care. It might be that someone has an ectopic pregnancy. It might be that someone is about to miscarry or has started to miscarry and the miscarriage has not finished and you need an abortion to make sure that the, miscarriage is completely finished and their body is clear.

Someone may have a pregnancy that threatens their life, a pregnancy that's not viable. There, there are lots of places where abortion becomes part of regular reproductive health care. And so there are these exceptions even in states that have these bans, but the question is, well, is this person's life in danger?

Is this person's health in serious danger? That doctors face potentially criminal liability. They might go to jail or lose their medical license if they give someone this kind of care and later prosecutors or judges or a medical board says, well, that wasn't really necessary. Versus in states where abortion is not banned, where abortion is legal as it was, prior to the Dobbs decision.

It's just part of the spectrum of care that doctors can provide, and so they're not thinking, am I going to go to jail if I give this person this kind of care?

Lizzy: And so this is, of course, all pretty infuriating, you know, um, hearing about this. It's, you know, it really is, I, I, what I, I'm interested in the law because I think it is really interesting to think of how, you know, we have sets of rules, we're trying to kind of write down all of these rules and regulations, and then the practice of the law and, and like research about like legal theory is really about like what happens when those rules meet reality, you know, and every case that's ever been brought is sort of about that adjudication.

Like you said that XYZ had to happen or was the way it was, but am I special a little bit? You know, and we keep testing these things and testing these things and seeing how it really works. When you divorce it from actual human lives, you know, in people's pain and people suffering and in injustices, that's -

it immediately becomes such an interesting academic exercise. Like, we're always doing that. We always have to refine it. What was a rule that we thought was standard, but actually has this unintended consequence that is not what we want, and then how do we change it? And when you think about plaintiffs who are women, you know, plaintiffs who are Black women, any of these people who were saying have these histories of being ignored, um, of having their concerns dismissed, of not being able to receive care in the way that we assume they can or should.

And then, you know, what happens when it runs into these spaces where we get to try to untangle that and figure it out and improve it and how it doesn't sometimes, you know, like that is kind of exactly what the courts are for is to say, Hey, you know, this is this thing that you did that this abortion ban, you know, or whatever policy.

Did you think about these effects? Did you think about how that actually affects a body like mine? Did you think about how that affects a pregnancy like mine? And you know, for me, I'd hope for the law to be working. It's not that you would never have those circumstances. It's that as soon as you would, there's your opportunity to change something and say, oh, that was not our intent.

That is not fair. Something has to happen here.

Um, but so this is where we pause to wonder. About hopeful things, like, let's talk about potential solutions to some of the issues that you've illuminated here. What can be done? What are people doing? Are there policy changes that could be implemented that would minimize the problem around the ignoring women's pain?

Are there judicial solutions? Have you seen is this an individual thing? Is this an advocacy thing? Is it about doctor's associations? Tell us what you're seeing, you know, to confront some of this stuff.

Dara: So, I will sound like a very pessimistic and cynical lawyer by saying right now, the courts are not going to help with this. And as much as I wish that the law took facts into account all of the time, that's not the way that we structure this analysis as lawyers. And in some ways, I think that this is a criticism of the law and legal education really broadly because in law school we talk about neutral principles that should apply across the board and in a lot of ways try to downplay individual people's lived experiences and how those experiences are different.

And it's something that I don't think current legal analysis really captures the way it should. And this is particularly true. Of the Supreme Court and of a lot of federal judges. So even though I am a law professor, even though I want to believe in the promise of crusading lawyers in courts, it's really difficult.

Where there is a ton of action right now is in the political sphere. So state after state, when people are actually asked, do we want to make abortion legal? Do we want to keep abortion legal? You get a chance to bring people out who have needed abortion care. You get a chance to hear stories from actual individuals and talk to people and explain.

This is how this could affect you. This is how this affects your neighbors. And over and over in the last few years, as states, even relatively politically conservative states like Kansas, was one of the earliest and best examples of this. When people hear and think this could happen to me, this could happen to someone I know and love, maybe it has happened to someone I know and love, public opinion is to make abortion care available.

And in the states that are able to get it on the ballot in front of general voters rather than a state legislature over and over voters say this is important to us. So there is a lot of action in direct elections and there's a lot of action in elections for representatives where it's going to be determinative, where we know that this fight is going to be playing out.

So when Wisconsin was having their election for a seat on the state supreme court, everyone knew that abortion was on the line. Pennsylvania, where I live, is similarly having state elections where it's very clear that It's going to be in our courts and in our legislatures. And I think we're seeing that support.

And I think it matters, even if, if someone is not a political activist and is not, knocking door to door, making sure that people know how to vote or something like that, just sharing stories and sharing individual experiences matters. Because I think one of the things that makes talking about pain and particularly talking about pain in the course of reproductive care -one of the things that makes it difficult is that we consider it private. We consider it almost shameful in a lot of circumstances. And so, so many people who have had bad experiences or needed abortion care or experienced pain at the gynecologist don't talk about it except maybe with close family and close friends.

And I think the more that people acknowledge it, the more that we talk about this as an issue that affects tons and tons of people in society, that does work. That makes people realize that this is something that they should be paying attention to.

Lizzy: Thank you so much, Dara.

Dara: Oh, my pleasure. My pleasure.

This was fun.

Lizzy: And thank you everyone for listening. For more on Professor Purvis's work, check out our show notes at scholars.org/nojargon.

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