In Conversation with stef shuster
Transcript

Sandro Galea:

Thank you for joining us. Welcome to our latest Public Health Conversation Starter. This is a series of discussions we're having with thinkers who provide a critical perspective on the work of public health. Today I have a real privilege of being joined by stef shuster. Dr. shuster is an associate professor in Lyman Briggs College and Department of Sociology at Michigan State University. The research and teaching engages with how evidence is a social construct is constituted through social, cultural, and historical context. Dr. shuster serves in the editorial boards for the Journal of Health and Social Behavior and Gender in Society. Dr. shuster is the author of Trans Medicine, the Emergence and Practice of Treating Gender, which is a terrific book. It was published in 2021 by New York University Press. I really enjoyed it, and I am delighted to be speaking with Dr. shuster today. Dr. shuster, stef, welcome.

stef shuster:

Yeah, thank you so much for having me.

Sandro Galea:

Let's just start with a easy, obvious question. Can you talk a little bit about your background? Can you talk a little bit about how you came to be doing the work that you're doing?

stef shuster:

Sure. Actually, it was a little haphazard coming into the work. I moved to Iowa City, Iowa in 2007 to start a PhD program. I am a trans and non-binary person, so I asked a question that a lot of people ask, which is, "Where are the doctors who can work with people like me?" There were not great answers, so for a couple of years I started doing health advocacy work, meeting with doctors, scaling up their knowledge. Just thinking a lot about the kinds of questions they had, the concerns, the challenges that they experienced in trans medicine. All that health advocacy work really kicked off my own sociological interests in all the uncertainty that they experienced or the challenges that they faced. Was that reflected more nationally? It was not necessarily intentional to devote a career to studying trans medicine and providers who work in this area, but it certainly has been rewarding.

Sandro Galea:

Let's talk a little bit about that. I have a few questions here which sort of remind myself what I meant to ask you. You just said it right now and you also said this in your book about how far the practice of providing healthcare in the context of gender remains an emerging field. Can you just talk a little bit about what you see as the challenges and opportunities? What have you heard from providers who are actually working in the space of gender-affirming care? What emerges from those who have been successful that actually works that we can generalize to others?

stef shuster:

I think that there's a lot of providers who go through medical school, go into practice and have very few opportunities to work with trans people that they know of. A lot of the uncertainties and challenges that they describe experiencing, it's more about the interpersonal relationships with their patients. They get a little nervous about am I going to say something offensive or insulting? I think that what happens cognitively is that providers are so concerned about messing it up that they forget that the person in front of them is a human who has all kinds of healthcare needs. But then there's also... In trans medicine, it's a field that has... It's been around for a long time, but it really took off in the 1950s. But even though that was over 75 years ago, there's just these persistent concerns that providers have. Not only interpersonally, but there's clinical guidelines that are supposed to help them figure out how to make decisions when they're working with trans patients.

They don't always feel like those guidelines help them. Instead, they have to do a lot of interpretive work because they're fairly rigid. First, the patient should do this. Then they should do that. Then they should do this. But one of the challenges is trying to standardize patient care for a population of people who in some ways is unstandardizable. There's 100 different ways that people understand themselves as trans or non-binary. There might be 100 different reasons why they might seek out something like hormone therapy or surgery, and so doctors are put in this situation where they're looking for guidance. They find these guidelines, they try to apply them and find that they just don't work for a lot of their patients.

Sandro Galea:

It's a perfect segue to the next question which I want to ask which is about uncertainty and made a note for myself. Uncertainty is a theme in your book. It comes across well, and care providers have to grapple with a landscape of uncertainty. Now, this ties in... I'm going to make perhaps an unexpected connection to COVID because I felt like one of the biggest shortcomings in how we dealt with COVID as a health profession broadly [inaudible 00:04:56] is we really had a hard time handling uncertainty. I feel like we lean into extremes. We're either overly dispositive and say, "There's no uncertainty. Here's the answer." Which of course then loses us all sorts of faith when it turns out to be wrong, or else we're too afraid because of uncertainty to take any action to say anything. I'm just wondering your reflections on that? Obviously I'm asking the context of trans medicine, but I'm asking more broadly actually as somebody who engages with issues of health and medicine?

stef shuster:

Yeah. I also have been thinking a lot about COVID and how there still remain a lot of uncertainties about long COVID and long-term effects. I think that in trans medicine... In my work, I'm always thinking about what does the case teach us about trans medicine and lasting inequalities in trans medicine? But also, how can we study trans medicine as a case that reflects back on broader concerns in health and medicine? Most doctors experience medical uncertainty. Sometimes they don't know quite the right course of action. Sometimes there's a lack of information. But I think that there is something a little particular about trans medicine

and it is anchored in some of the historical context that trans medicine came about. In the 1950s, providers were incredibly concerned about and felt uncertainty around how do I verify that the person before me is trans? There's not a biomarker for being trans, so you can't run a blood test. I think that that question of ensuring that trans people are really "trans," and I'm using air quotes here, but that is a question that has just persisted in trans medicine.

Because I think that there are some providers who are worried that patients will begin medical interventions and then decide that it's not right for them, which has been maybe mispackaged as regret. There's all these lasting concerns in trans medicine about how do you actually figure out if the person is trans and that this is the right decision for them? A lot of that uncertainty that providers feel, it gets shuffled back on the trans people to ensure doctors that they are certain about beginning transition. In a case like COVID, I think that what we see is that even though there was a lot of uncertainty, especially as it was unfolding, that doctors still had to mobilize all of the tools and all of the training and knowledge that they had to work within this pandemic. It really strikes me how much knowledge has accumulated in just the last couple of years around COVID. Then if we think about something like trans medicine, there's still so much uncertainty, but it's like 75 years of medical providers working in this area.

Sandro Galea:

That was a terrific answer. The only problem with the answer was there are three different ways I could go with my follow-up question, but let me take way one. This builds a little bit on the lack of evidence, which is what you just said right now. I'll read you a sentence from your book where you say, "There is little existing evidence in medicine that meets the gold standards for evidence-based medicine." That's from your book, which echoes what you just said right now. Can you just talk a little bit about the barriers to creating the body of evidence that would support best practices for gender-affirming care as you see them?

stef shuster:

Sure. This was one of the aspects of the book that I was maybe the most nervous about being out in the world. I think that it's difficult to think about trans medicine right now without also thinking about some of the current political conversations that are underway. The idea that there's a lack of evidence in trans medicine is being used by certain people... For them, the logical conclusion is therefore we should shut it all down. But what I'm talking about in the book as far as a lack of evidence is really that we don't have long-term studies about the potential risks and benefits of people being on hormones. There's certain basic pieces of information that are just not clearly defined still. If you, for example, have a trans woman who's on estrogen. You want to take a blood lab to see how her organs are doing. Are you supposed to be using the baseline for cisgender men or cisgender women?

In the medical community, those kinds of questions just have not been answered in a way that I think a lot of providers find unsatisfying. But what I'll also say is that in spite of the lack of evidence around longitudinal trials, we can't create randomized controlled experiments and have 100 cisgender men and 100 trans men take testosterone and see what the effects are.

That would be an unethical practice. But at the same time, we do have a lot of evidence from the therapeutic community that one of the most harmful things that can happen is blocking someone from accessing hormones. My answer I think is it's a yes, and... Because yes, we don't have a lot of great evidence in certain aspects of trans medicine, but we do know from the therapeutic community that there are a lot of psychological benefits and social benefits of not impeding people's access to gender-affirming care.

Sandro Galea:

Thank you. Let me now pick on a different theme, which actually you also echoed here right now. You used a word which I really liked earlier, "mispackaged." I thought it was a really nice word. Now you also made reference to the fact that people have used the fact that there's limited evidence to say, "Well, we should therefore do nothing." I just wonder if we can comment a little bit about disentangling good faith concerns about evidence gaps from bad faith attacks that are motivated by bigotry and political cynicism? I took it as a subtext when you said you were cautious about this in your book, that you were afraid of it being going one way versus another. I'm just wondering your thoughts about that, the good faith, bad faith approaches and how we can have a conversation that obviously elevates one and removes the other?

stef shuster:

I think that part of my answer comes from that I'm a sociologist, so I think about the world in very particular ways. I think about what data we need to help support our ideas. I'll offer an example of a doctor that might be having trouble with the lack of evidence. I was interviewing this one provider who I think had been working in the field for about 10 years. She kept using the language of... One of her concerns was when trans people have co-occurring conditions. I was like, "Well, tell me a little bit more? I don't need to know patient-protected health information, but tell me a little bit more about what you mean when you say co-occurring?"

She was like, "Well, I have this elder trans woman who's starting to show some cardiovascular stress. I really think that before I renew her estrogen prescription that we need to get the cardio stuff under control." I'm like, "But I'm still trying to... What is the co in the co-occurring?" She was like, "Well, the person's trans and they have a cardio problem? I'm like, "But does that mean that you're thinking of trans people as having a..." I wasn't attacking her. I was just trying to understand her logic. I think that what she was suggesting without even thinking about it is that there's a lot of providers who carry some of these implicit biases and assumptions into their work with trans people.

That is a provider who I think is acting in good faith, feels like she wants more evidence to help her make decisions about her patients, and leaned on some of her medical knowledge about the risks of cardiovascular disease without fully grappling with all of the evidence that was before her. That this was a trans woman who was 62 years old and was making an informed decision that she was willing to take the risks of being on estrogen despite the fact that it might also increase her cardiovascular risk as well. I think it's like those are moments where it's a lot

more complex than there is or there is not evidence or there's good or bad doctors. There's doctors who I think are really trying to do the best they can and sometimes make mildly misinformed assumptions about how they should be working with trans people.

Sandro Galea:

Thank you, that's a really nice example. Let's perhaps get to the hardest question and conversation. You've talked about the importance of helping individuals get the care they say they need based on their own experience of gender identity. Placing the perspective of trans and non-binary folks at the heart of shaping healthcare access. I think that's a theme throughout your book. In recent years, there's been all this controversy about how best to do so in the context of children. I think it ties in very well to the bad faith, good faith conversation we're having. How do we make sure that transgender kids are listened to and supported while also making sure that there is rigorous scientifically sound process in place as they consider potentially irreversible medical decisions?

stef shuster:

I think that there is so much controversy right now about what to do with trans kids, it tells us something about some of our own social anxieties around gender itself. What is gender? What does that mean for each individual? How do we know when we are a particular gender? I think that what's happening is that's getting mapped onto additional concerns about at what age can someone make informed decisions that might impact them for the rest of their lives? I don't work a lot with trans youth, but what I will say, just engaged in conversations with other folks whether it's providers or other parents who have trans youth, is that the one thing that everyone seems to point to as far as how to best support trans youth is to take them seriously. To listen to how they're making sense of their gender and their bodies and their identities.

I know for some people it can seem a little alarming when a seven-year-old is like, "I do not identify as a girl. I'm a boy." But in some ways, there are a lot of steps that are in place in trans medicine when it comes to working with youth that really slows the process down. I think that if you were to turn on the news and listen to a story about trans youth, I think one of the pieces of misinformation is that a kid wakes up and is like, "I don't identify as a girl," or, "I don't identify as a boy." Then the next day, they're on hormones. Most doctors don't prescribe hormones to youth. They might do puberty pausers to give kids a little more time before they get to puberty. But I think at the end, what I've come to understand is that the best way to support trans youth is to take them seriously. To not patronize them, and that somehow adults know their gender better than they do.

Sandro Galea:

That's a really helpful answer. I actually particularly appreciate how you said there's a lot of heat about this particular question. But actually, it perhaps reflects our larger confusion about how to actually deal with youth and how we deal with our own conceptions of gender. That's really interesting. Thank you. Shifting topic for a second. Actually, you mentioned COVID

earlier, and I just want to come back to it actually. I want to read another line from your book where you said the pandemic quote, "brought new anxieties to our collective social life while amplifying persistent social inequalities in healthcare." I'm just wondering about now that we're let's say a year out from acute COVID what your reflections are about what we should be taking from COVID, and what we should be learning from it in terms of making for better healthcare at this moment in time?

stef shuster:

I think a lot about health infrastructure. I think that COVID showed us that our health infrastructures are not set up well to deal with crisis and to respond quickly to emerging problems or illnesses. I also think that COVID showed us that the health infrastructure when it comes to medical providers, whether it's nurses, PAs, surgeons, whomever, that we have a bit of a problem in overworking and overtaxing and asking too much of medical providers. I think that we're seeing the spillover effects of burnout. But as far as COVID as it affects LGBTQ+ populations, in a completely separate study with a colleague, we interviewed LGBTQ+ people of color about their experiences going through COVID.

We find I think what we would expect. It's unfortunate, but what we would expect to find is that the health access and the delay of care and mistrust in providers and mistrust in science really is exacerbated because of historical traumas that both people of color and people of color who are queer or trans have experienced. That tells us we need to... I'm a little disappointed that coming out of acute COVID, we haven't really hit the pause button to talk about and think through how COVID showed us all of those health inequalities just rolling out. Instead of using that moment as a learning opportunity, I feel like we're just continuing on forward without really grappling with what is it and why is it that historically marginalized groups continue to experience such health inequities in the US?

Sandro Galea:

Thank you. Two more questions, if you don't mind. Let me ask about language. Can you just talk a little bit about the importance of language in the context of gender and healthcare? How thoughtful people can best use language to help support trans and non-binary populations?

stef shuster:

Yeah, absolutely. This comes up a lot speaking with trans and non-binary people, but also providers. It's not only about using the names that trans and non-binary people use for themselves. It's not only about the pronouns, but it's also about body parts. There are some body parts that the language that we use is so gendered that it can be difficult for trans and non-binary people to really feel like they can just be present in health encounters. If you have a trans man who shows up to a family physician and the physician keeps referring to their chest as breasts, that might immediately shut that person down because it's gendered language that's being used to describe a part of their body that they might not identify with.

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I think there's this interesting slow movement happening right now in... At least I work with a lot of pre-med students, I think there's this really interesting movement where they're becoming more aware of how gendered our language is. Even basic things like body parts. But even some of my work is starting to move into reproductive health, and we see it there too. We constantly hear about pregnant women. Women who are pregnant. The risks that women have when they become pregnant. It's so subtle, but if we shift that just a little bit to pregnant people, it includes a whole lot more people who might possibly get pregnant. I think that that matters because it fundamentally shapes how we understand people and bodies and health and illness.

Sandro Galea:

One last question. What gives you hope?

stef shuster:

A lot, actually. A lot of my work focuses on all these just terrible compounding inequalities. I ended the interviews with medical providers asking them what they found joyful about working in trans medicine, and I think that their answers to those questions, it helps feed my own sense of hope about the possibilities for the future. Medical providers talked about how yes, working with trans people can be challenging. It challenges their sense of themselves as experts. It challenges their sense of how they should doctor.

But they also talked about how working with trans patients made them better doctors. It asked them to slow down. It asked them to learn more about the lives of their patients, to stop making assumptions about their patients. That's a reframe. For them, it was like a professional reframe of how to be in the clinic and one that they started using with all of their patients. I think it is those small moments where I get hope. Also, working with pre-meds. I think that we're going to see a generational shift in what providers look like and the values and norms that providers bring into their work with this up and coming generation of students.

Sandro Galea:

For sure. Thank you. That was a really interesting conversation. Thank you for writing an excellent book and for taking the time to talk and for everything you do. I really enjoyed talking and I learned from you.

stef shuster:

Yeah, thank you. Thank you. This has been great.