

Helene Hedian on Building Patient-Centered Trans Healthcare

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Welcome to the Hopkins Press Podcast. My name is Rahne Alexander and I'm the Senior Publicist for the Hopkins Press Journals Division.

Earlier this year, the Journal of Health Care for the Poor and Underserved published the findings of a 2016 survey of transgender patients in the United States, designed to find out more about how respondents perceived healthcare organizations that provide services to trans patients, and to learn more about how organizations might adapt to better serve those needs —how trans healthcare providers can build a patient-centered program, because, as the article notes, patient experience and reputation in the community influence where patients seek care.

Today, we're talking with Dr. Helene Hedian, one of the authors of this new article called "What Patients Want in a Transgender Center: Building a Patient-Centered Program." Dr. Hedian is an assistant professor of medicine at the Johns Hopkins University School of Medicine. She's the Assistant Vice Chair for LGBTQ+ Equity and Education in the Department of Medicine and the Director of Clinical Education at the Johns Hopkins Center for Transgender and Gender Expansive Health. We have made this article free to read through the month of June, so see the show notes for links and more details. And with no further ado, let's talk with Dr. Hedian.

Welcome to the Hopkins Press Podcast. Would you like to introduce yourself and your relationship to the study?

Dr. Helene Hedian

Sure, I'm Helene Hedian, and my pronouns are she/her. I am a primary care provider here at Johns Hopkins, I offer a lot of gender affirming care, so I care for a number of trans and gender diverse patients in my patient panel, including hormone prescribing for my patients. I do a lot of teaching around that. I'm the Director of Clinical Education at the Center for Transgender and Gender Expansive Health.

Rahne Alexander

Fantastic. How long have you been in that role?

Dr. Helene Hedian

I've been a primary care provider for several years now, and I've been doing a lot of work with the Center for Transgender Health. Basically, since I came to join Hopkins, and I've been in the role of Director of Clinical Education for a couple of years now.

Rahne Alexander

What brought you to trans health care, specifically?

Dr. Helene Hedian

I came to trans health care as, I think, many providers do. I didn't get a lot of training in it in my own studies, but pretty early on, as I was establishing my practice, I had a patient come to me, who came out to me as trans and said, "You know, I'm thinking about starting hormones, but I have a few health conditions and I'm looking to establish a relationship with a provider who I can trust to help me manage those health conditions while I embark on this transition-related part of my journey." And I said, "It's lovely to meet you. I support you in that journey, but I don't really have expertise or training that I need to be able to advise you. I think I need to do some homework." So I did, and one trans patient became two trans patients, and just sort of snowballed from there.

Rahne Alexander

That's fantastic. By way of disclosure, I am trans myself and for years relied on medical providers that were functioning similarly — "Oh, I guess I will figure this out with you." It's nice to see a program that doesn't necessarily have to be trained.

Dr. Helene Hedian

Yeah, I think your experience is a pretty common one in the community. We know from a lot of research that's out there that many trans patients are put in the position of having to train their healthcare providers to be able to get the type of care that they need. So your situation was not unique; my situation was not unique. But that's maybe a good segue to talk about the article that was published and why we felt it was necessary. The Center for Transgender Health opened several years ago, and before it was established, there was an interest in exploring what the trans community needs and looks for in a center of excellence. So what types of services they might need, [what] they might expect to see in that type of health care center? Does it need to be multidisciplinary? How far are people willing to travel? And how much does a historical institutional reputation play a role in whether patients be willing to go to any single center? So we took the opportunity to survey the community in a few different settings and use their feedback and responses to really shape the beginnings of the Center for Transgender and Gender Expansive health at Johns Hopkins.

Rahne Alexander

One of the sentences that stood out to me from the middle of the article is, "Patient-centered gender-affirming care is considered standard in contemporary medicine. Yet transgender individuals struggle to find institution achieving those goals and consistently report limited access to care and concerns about health care quality." Can you talk a little bit about what that means? What does it mean to have patient-centered care? And what are some of the struggles institutions face in meeting that standard?

Dr. Helene Hedian

So, patient-centered care really means that the clinicians who are helping their patients achieve their goal gender embodiment are not trying to treat every single patient exactly the same. Each person has their own experience with gender, and their own gender embodiment goals. And historically, in medicine, the approach was to say there is essentially one way to be transgender, there's one narrative or experience that every trans person has, which, of course, we know is incorrect. But that sort of justification meant that trans people who had experiences that were outside of what medicine dictated that their experience should have been weren't able to get the type of care that they needed. So as we have learned more and grown more as a field, we have moved in the direction of individualizing care. And recognizing that not only is each person's experience with gender individualized, each person's goals are individualized, and that the way in which they approach treatments and the order in which they approach medical treatments, if that's part of their journey, is going to be kind of unique to them, right? It used to be that we would make people go through all of these different steps in a certain order. And it was like, "Yes, now you're trans, or you're trans enough for this treatment." And that is no longer considered standard of care, according to the international guidelines.

Rahne Alexander

Yeah. That's fantastic. It's great to watch that evolution over the years. Are there other studies like the one you were engaged in, that have informed this transformation? Or is this like kind of a groundbreaking study in terms of drawing out new data on trans populations?

Dr. Helene Hedian

I think we're always looking to collect more data and do more research on what trans people need and what they're seeking and care settings. As much of a fan as I am of this study, I hesitate to call it groundbreaking. And maybe that's just my approach, but I do think it was important. I am proud of the work that we did, but I don't think it answers every question and every situation.

Rahne Alexander

Were there results from the study that you found, especially revelatory?

Dr. Helene Hedian

Yeah, I was not surprised, I guess, but I was interested to see how frequent it was that trans folks had experienced mistreatment in medical settings, and how often they had reported knowing of a friend or loved one who'd had a similar mistreatment experience. Another theme that came up for me was the importance of soliciting community feedback, and really involving trans people from the ground up in building a center and continually sort of coming to the community asking for feedback about how are we doing as a center? Is it easy for you to access the care that you need? I think that there are a lot of insights that trans people can bring to the table to help make our center a better place. And that is why we, at the beginning, collected this data — but that even in collecting the data, trans folks were like, "Yes, thank you for this." And also, "You may not just do one survey and answer all of the questions, you should continue to involve trans folks throughout the leadership and solicit community input."

Rahne Alexander

This data all comes from 2016, so I imagine a lot has changed, a lot of the landscape has changed. What do you think the future holds? What are what are some of those opportunities for research that you're seeing within your clinical practice and then in the community writ large?

Dr. Helene Hedian

Yeah, the landscape definitely is different now than it was in 2016. When we collected this data, one of the statistics that I remember looking at is the percentage of trans patients who would travel 200 miles or more to access care from a provider that they knew was skilled in transgender medicine, or who they knew to be affirming and that I remember that percentage was a lot higher than I thought it would have been. But now in 2024, there are many states in which gender-affirming care is illegal. Best practice care is unable to be accessed where many people are in this country, and we on the ground are seeing patients seeking care and moving from states where they can no longer access the medical care that they need or have, in many cases, been receiving for many years. The landscape is different.

And I think that — I don't think that the overall message is different. I think that trans people need high quality medical care. The areas where they can get it is now unfortunately limited, and what we're seeing here is patients traveling long distances for care. But those are patients who have the resources and the wherewithal to be able to leave those situations, those unsafe situations, and get care here. And that, unfortunately, is not representative of the entire population. One of the things that I think that we have been working on at the Center to try to address this increased demand for services is really refining and working on our provider education.

My own experience, which we talked about in the beginning of being sort of generally supportive of my patients, but not having the medical skills and tools to really help them. I had to go on my own and do that research and training. But wouldn't it be great if our providers could get that training in a more formalized and consistent way? And so yeah, we've designed a number of programs at our center to try and address those knowledge gaps at different levels throughout the institution.

So following up on provider training, and the importance of training, I want to highlight a couple of quotes from participants in our study that I think really sort of highlight the need. One participant said, "Doctors who know how to handle trans bodies." They needed somebody with the clinical skills to be able to treat trans people. Another person said, "Don't make any assumptions, everyone is different." And another one said, on the theme of just having a caring provider, or one who is sort of accepting of a diversity of experiences, says, "Caring team who listens to you. Helpful in answering questions. Respects yourself and family, and explains in detail as much as possible." Someone else said, "Treat me with my gender identity with no hesitation and treat me like a person."

People want and deserve respectful and skillful care. I think the general population doesn't necessarily appreciate or understand all of the anxiety that a trans person might have going into that first doctor's appointment with a provider that they haven't yet met, and I think this study hopefully shines a light on what that experience is like and what providers and centers can do to help make it better.

Rahne Alexander

Well, thank you for your time today. I'm grateful for your continued work. I hope that I hope you get all the resources that you need, and I hope you just continue to do great work.

Dr. Helene Hedian

Thank you Rahne, this was a lot of fun. I appreciate it.

Rahne Alexander

Thank you for listening to the Hopkins press podcast. The music featured in today's episode is by Jean Toba, which you can find on the Free Music Archive and it's also linked in the show notes for this podcast. Thank you for listening and we hope to see you next time on the Hopkins Press Podcast.