

**More Than Just a Pronoun: Ethics of Sex/Gender Assessment in Pediatric
Rheumatology
Transcript**

Jacob Spitznagle, MD (Guest): I think it's really important that providers are having these conversations because they can have direct implications on patient care.

Nayimisha Balmuri, MD (Guest): It's important to normalize these questions.

Karen Onel, MD (Guest): It's our job whether you're pediatricians, whether you're adult providers, to really get to the issues that are important to our patients.

Meghna Rao (Host): Welcome to Rheum Advisor on Air, the official podcast of *Rheumatology Advisor*, one of Haymarket Media's leading publications that focuses on the latest news and research in rheumatology to inform clinical practices. I'm your host, Meghna Rao, the editor of *Rheumatology Advisor*. In this podcast series, we will be looking at emerging topics in the field of rheumatology from various experts. These perspectives may be related to the diagnosis and treatment of rheumatic diseases, current guidelines, practice management, patient care, and much, much more. So let's dive in.

Meghna: An article published in *The Rheumatologist* last year described the case of a 17-year-old girl with class 4 lupus nephritis who presented to the pediatric rheumatology clinic for a follow-up visit. Here, as part of a routine assessment and in the absence of her mother in the exam room, she was asked about her sexual orientation and the gender that she identified with.

Now, what ensued after this visit raised ethical questions about standard patient care in pediatrics.

Today, we're talking with the authors of this article – Dr Karen Onel, the chief of the pediatric rheumatology department at the Hospital for Special Surgery [(HSS)], New York, and Dr Nayimisha Balmuri and Dr Jacob Spitznagle, both of whom are pediatric rheumatology fellows also at the Hospital for Special Surgery.

Thank you all for joining me today.

Dr Balmuri: Thanks for having us.

Dr Spitznagle: We're happy to be here.

Meghna: Can one of you take me through what happened after the patient was evaluated and had left the clinic that day?

Dr Spitznagle: Sure, I'm happy to speak a little bit about that. So, we had heard from our office staff shortly after this particular visit that the patient's mother had called and was expressing anger about the questions her daughter was asked with her out of the room. So, we naturally called the mom back to clarify some of these questions that she had. She

specifically felt it was inappropriate for a rheumatology provider to be asking her daughter questions regarding her sexuality and gender identity in a visit pertaining to her lupus. She said that the questions were unprofessional and irrelevant to her rheumatology care and that she was just very uncomfortable that we had raised these [questions], especially with her outside the room.

Meghna: In retrospect, would you or your staff have done anything differently in terms of evaluation of the patient? Now, there's probably no right or wrong answer, but I guess what I'm trying to ask here is whether providers need to adhere to certain protocols or if there is an ethical standard, so to speak, for these aspects of an appointment.

Dr Spitznagle: That's a great question; and looking back and thinking about this case in particular, no, I don't think we did anything inappropriate or that we should have done anything differently in this specific scenario. We see a lot of adolescent patients in our clinics in general. A lot of rheumatologic diseases present during adolescence, and naturally the focus of each visit and the type of conversations that we have with our patients vary quite a bit from patient-to-patient. But we try our best to keep a standardized approach when we're seeing our adolescent patients.

For our teens specifically, and in our clinic that's patients 12 and [older], we routinely ask parents to leave the room for a brief portion during the encounter, so that we can have a one-on-one encounter with the patient themselves. This allows us to conduct a conversation about sensitive topics that our patients may feel uncomfortable engaging in with a parent in the room. We acknowledge that their answers may change over time. We let them know that we're asking each of our patients the same questions so they feel less put-on-the-spot when we're asking these sensitive questions.

Here at HSS, we typically use a framework called the HEADSS assessment; it stands for Home, Education/Employment, Activities, Drugs, Sexuality, and Suicide/Depression. This exact framework, I don't think, is as important as the questions that it gets at it. I think it's really important that providers are having these conversations because they can have direct implications on patient care. I think it's actually our ethical responsibility to be having these conversations with patients.

Meghna: Staying on that thought, could you tell us about the need and the importance of assessment of psychosocial factors, for example, contraception, preferences for hormone therapy, drug use, sexual activity, gender identity, etc, in adolescents, specifically those with rheumatic disease?

Dr Balmuri: Sure. I think it's really important that we sort of keep in mind that we often, at times, see our patients really frequently.

So, one of the things to kind of keep in mind is that asking all of our patients these questions are incredibly relevant; one, because they're teenagers and we know that teens often struggle with a host of different psychosocial stressors involving mental health, substance use, sexuality, per baseline [*sic*]. Then, as Dr Spitznagle mentioned, it's important to normalize these questions.

Certainly, when we get into the specifics of children, adolescents, and young adults, primary rheumatological disease as well, it starts to become more relevant for specific reasons, right?

Regarding hormone therapy, for example, as you mentioned. You know for anyone to gain hormonal therapy there are side effects. There are side effects with any medication and certainly, doses need to be monitored really carefully. There have been several reports, especially over the last 5 to 6 years, of patients, especially [of] young adults and adolescents who maybe didn't have the support of having a primary care physician [(PCP)] or specialized physicians that are helping patients transition if they're sort of in the process of transitioning from a gender identity perspective, or maybe families that weren't necessarily supportive from that standpoint. So, what ends up happening is sometimes patients actually get some of these hormones from the street.

We know that, for example, for lupus, let's say, like the example that was in *The [Rheumatologist]* article, that estrogens can, in fact, impact disease severity, activity, and, in this particular patient, she had multiple antiphospholipid antibodies being positive and that's a huge risk factor for clotting. Certain other hormones that are often used like growth hormone, we know impacts disease severity for diseases like [juvenile dermatomyositis] JDM, for example.

I think we know that LGBTQ+ spectrum patients have decreased access to care, right? There [are] many reports that show that patients often report feeling a bias from medical providers. So, when we are given the opportunity to be seeing these patients so often and creating these really trustful, long-term relationships, we often are the people that patients feel comfortable talking about these topics.

It's important for us to keep that in mind because these patients are at an increased risk [for] HIV and depression. They are 2 to 3 times more likely to have suicidal ideation and to actually have attempts of suicide. There's an increased risk [for] homelessness, substance use, victim violence, and other forms of abuse.

I think the other topic that you had mentioned was talking about sexual activity. If a patient is having active disease and either has an accidental or planned pregnancy that has a very complex interplay in terms of disease activity and flare. Many of the medications that we use in all of our diseases are to some extent, some more than others, teratogenic. So, it's important to talk about those things and to keep reminding patients about this.

And, of course our patients, just like any adolescents, are also at risk [for] sexually transmitted infections as well.

Meghna: Thank you for that clarification. Great segue to my next question, because over time, and as pointed out in your article, physicians, not just in rheumatology, who provide care to pediatric populations, including teenagers, are uniquely positioned to discuss factors such as sexuality and gender. But it's also true that not all physicians have been conditioned to or are comfortable with these situations or even have prior experiences to go by.

Dr Onel, I wanted to ask you here, would you be able to provide some guidance on how providers can facilitate having open conversations with their patients and possibly even parents of patients and address this health disparity overall?

Dr Onel: It's a really great question. First, I want to say that, of course, the way that we approach our patients had changed over time. So, many of the issues that you discussed were not, for instance, stressed in my training, which was not that long ago, but are clearly a lack in the kind of dialogue that I had with my patients as compared [with] what these guys learn now. The HEADSS construct, for instance, didn't exist as a construct when I was in training. So, there can be a level of discomfort if you haven't had training, and the truth of the matter is that this is still training that needs to be done. I learned from these guys, from Dr Spitznagle and Dr Balmuri; I learned from the patients; I learned from my children.

We had done a study. We had derived a questionnaire and the first question, for adolescents, [w]as are you male or female. My then 17-year-old daughter looked at it and said, "You're talking about young people. Where's the other gender nonconforming [category], etc?" And I was like, right.

So, we have to listen to our patients because they're thinking these things and it's our job whether you're pediatricians, whether you're adult providers, to really get to the issues that are important to our patients, some of which could be disease related, but others not. And so, we have to be continuous learners and find ways to ask questions in a sensitive manner.

The other thing that comes up, though, interestingly enough from my adult colleagues [is] talking about what we're allowed to ask and what we're allowed not to tell families. Every state is different, so it's really important to know the laws of the state that you're in. We happen to be in New York State, which has very strong regulations in terms of what information you're allowed to disclose without the child's permission, which makes it easy because it's very clear that you don't have to disclose pretty much anything. Although, we do really encourage our patients to open that dialogue with their parents.

Meghna: Yeah, that's great advice. I was talking with my colleague on this topic earlier and she brought up a specific point about whether patients and their patients can potentially be exposed to these gender-affirming practices starting at the waiting room itself. So, there's possibly less apprehension and discomfort in the examination room. You know, sort of a way to make known that clinical practices are supportive of all kinds of patients.

Dr Onel: Absolutely. And that actually has been a very large topic of conversation about where to ask people, for instance, their pronouns; what's the right location? Who is the right person? Does this vary by age? Etc.

We had a really wonderful talk by an adolescent care provider from another institution in the city who was talking about [a] qualitative survey that they had done that looked at the ways in which people were really frankly humiliated or embarrassed by being asked inappropriate questions in a very public way. So, the way in which, culturally sensitive [way in which] we ask people questions is really, really critical in exactly that – having these people that we take care of know that we are there to serve them, to be part of this experience with them.

Meghna: Yeah, absolutely. On that note, just [g]oing back to our previous question, Dr Balmuri and Dr Spitznagle, as fairly new doctors who are breaking into a subspecialty, I was curious whether your current recent training in the field included how to tackle these sensitive conversations with younger patients who are probably on the cusp of discovering their bodies and identity, as well as their rheumatic condition?

Dr Spitznagle: Yeah, I think that that's a good point that you make. Like Dr Balmuri mentioned, the 2 of us recently completed our general pediatrics training within the last 5 years, and I think, in the last decade or so, there's been a real shift in focus and a real emphasis on training providers to have these sensitive conversations with patients across the age spectrum.

Like Dr Onel mentioned, I think [a] lot of providers, especially in other generations, may still feel intimidated or uncomfortable with these sensitive conversations, especially thinking about our younger teens, our preteens who may be just experiencing these topics for the first time.

But I would say that repetition and consistency is really the key to all of this, as well as normalizing the questions like I previously mentioned, patient-to-patient. I think by doing that provider comfort just grows with time, just with experience, and making sure that they're integrating this into their clinic visits.

Meghna: On behalf of *Rheumatology Advisor*, I had a chance to attend the [American College of Rheumatology] (ACR) Convergence 2020, where there were a few compelling sessions at the meeting on improving the health care experience and outcomes of the LGBTQ[+] population.

Now as part of the pediatric rheum symposium, I came across an abstract and study led by you Dr Balmuri, discussing the incorporation of sexual orientation and gender identity screening within the HEADSS framework in a pediatric rheumatology clinic. Would you be able to discuss your findings from this analyses and their clinical implications?

Dr Balmuri: Absolutely. We've actually had the opportunity to play a pretty active role in developing this curriculum that Dr Spitznagle was talking about in training our departments, our physicians, fellows, and nurses, alongside with Dr Julian Rose and Melissa Flores who actually helped to create the LGBTQAI talk during the ACR.

In this specific study what we basically did was a multipart quality improvement [(QI)] study. So the first part really was focused on training. So, what we did, Dr Spitznagle and I, [p]ut together a kind of quick training model that we presented to our department, where we basically went over, one, why is this important; secondly, how can we do that; and thirdly, [p]roving that we can do this in a way that will not take a lot of time to do and to then illustrate the importance of doing it.

The second part of the study was to then monitor patient charts to see if this is actually happening, is this coming to fruition, have we been able to notice a change in, one, asking the questions, and secondly, getting the answers and then providing resources and supports to patients who might need it after answering questions during our HEADSS screening.

So, what we did find was [a]fter informational sessions, [which] were pretty quick to be honest, that actually our faculty and fellows felt pretty comfortable asking these questions. In fact, we have noticed over = the implementation of this QI project that we more than quadrupled the amount of screening that we did and answers that we were getting, and, in fact, doing feedback with adolescent patients, on the other end of getting screened, no one felt uncomfortable. People are actually really happy that we were talking about these things.

Meghna: That's a very positive outlook, and you know, I'm just glad we're having this dialogue. Hopefully one that leads to addressing these gender gaps in practice and ultimately an improvement in outcomes.

Now, this kind of brings me to my final question – the importance of screening for mental health, one of the other psychosocial stressors in this population, and also determining risk factors to conduct a more comprehensive patient evaluation. How routinely are mental health screenings performed and how does this tie back to the “ethics” of pediatric care management?

Dr Onel: As regards to screening for mental health issues, not nearly enough, because it should be every visit, every time. We know that the incidence of mood disorders, anxiety disorders, [and] suicidality are all increased for all children with chronic illnesses. The American Academic of Pediatrics already recommends that all adolescents get screened once a year, and for our patients, even more so. In reality, in many people's institutions, they just aren't the facilities to be able to do that in terms of room space or practitioners.

The other thing we have to be frank about is that 50% or so of children in the United States with rheumatic diseases are taken care of by adult rheumatologists who may be really uncomfortable having these conversations with 12- and 13-year olds. It's a very, very different story when you're talking to a 30-year-old.

But, as regards your last question with the ethics of providing care, [I'm] the head of the ACR's Committee on Ethics and Conflict of Interest, and I think about the Belmont Report, which came in 1978, really after the information about the horrific Tuskegee experiment came to the forefront. One of the 3 pillars of that report: justice, beneficence, but the third one is the one that we're really talking about here, which is respect for persons. Although that's a research report, the truth of the matter is that as doctors, as care providers, as physicians, and people who really I think play a very intimate role in the lives of the people we take care of, it's that “respect for persons” that is really critical. Ask any of us who has ever been a patient, immediately, you lose that sense of “respect for persons.” Instead of being Dr Onel, you're “sweetie or “doll” or any number of different things, and how awful that feels.

Well, is our responsibility to these children that we take care of and young people that we treat them with all of the respect for personhood that they deserve? And that really means asking how they want to be addressed. So, I'm very thankful to [Dr] Jake [Spitznagle] and [Dr] Misha [Balmuri], to be perfectly honest, for really running with this project because it's not something necessarily that I was initially trained for, but it's something that really is a medical ethics issue, and it's a medical emergency issue.

Dr Balmuri: I was just going to also echo that we know that there's a significant prevalence of mental health disorders among pediatric patients with rheumatic disease, as Dr Onel said. But what we often say, Dr Spitznagle and I, say to our patients really is, "Everything that you say to me in this room will stay between us unless there's harm to yourself or to others. Besides that, we're here to support you and to provide whatever supports that we can have through our multidisciplinary team approach with our social workers, psychologists, adolescent care providers, and to provide community supports to kind of help you in whichever sort of avenue we possibly can."

And so, I think there's an opportunity for huge impact here.

Meghna: That is such a wonderful thought, and this has been such an insightful conversation, even for me. Thank you all for your time today. You know, if providers can just be intentional about being inclusive, educating themselves, improving existing documentation, and maybe fostering a healthy relationship with their patients, then more than half of what you're advocating for will be done. So, thank you for that.

Dr Spitznagle: Thank you.

Dr Onel: Thank you so much for letting us join you today for a topic that obviously we feel really passionate about.

Meghna: Please stay tuned for more episodes in this series. For more information on *Rheumatology Advisor* and this podcast, you can reach out to us at editor@RheumatologyAdvisor.com. We, at Rheumatology Advisor, look forward to delivering timely, evidence-based news to you. You can also sign up for our free eNewsletters on the site.