

## Hear ye, Hear ye: The Patient Voice in Rheumatology Transcript

**Shilpa Venkatachalam, PhD, MPH (Guest):** The lived experience of those living with chronic conditions is not only valuable to research, but it is absolutely imperative.

**Betty Hsiao, MD (Guest):** And really, the ultimate goal is to provide the best individualized care for each patient.

**Meghna Rao (Host):** Welcome back to season 2 of the *Rheumatology Advisor* podcast, *Rheum Advisor on Air*. I'm Meghna Rao, the senior editor of *Rheumatology Advisor* and the host of this podcast.

In this series, we will be joined by expert clinicians and researchers to discuss emerging and compelling topics in rheumatology. These perspectives may be related to the management of rheumatic disease, guideline updates, patient care, data from conferences and scientific meetings, and much more.

In the next set of episodes, we're talking with some of the presenters of the all-virtual American College of Rheumatology (ACR) Convergence 2021.

So, let's dive in!

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**Meghna:** The importance of patient perspectives, ie, the behaviors, concerns, and experiences of patients with rheumatic conditions, and patient-reported outcomes [(PROs)], were highlighted through several studies presented at the ACR meeting in 2021.

To give us an in-depth perspective of the objective and clinical implications of some of this research, we have on the podcast today Dr Shilpa Venkatachalam, associate director of patient-centered research at the Global Healthy Living Foundation, and Dr Betty Hsiao, a rheumatologist at Yale School of Medicine.

Hi, and thank you for joining me today!

**Dr Venkatachalam:** Thank you for having us.

**Dr Hsiao:** Yes, thank you for having us.

**Meghna:** I want to congratulate both of you, Dr Venkatachalam and Dr Hsiao, for the wonderful and compelling research that was carried out by your respective teams, and that was presented at the ACR meeting.

**Dr Venkatachalam and Dr Hsiao:** Thank you.

**Meghna:** Now drawing our attention, first, to 1 study that caught my eye, and of which you were one of the coauthors, Dr Venkatachalam, and that was the impact of the COVID-19 pandemic in patients with rheumatic disease. Could you maybe provide some highlights [of] what your team of researchers learned and the possible implications of studies like these? Because I think it's an important one, with the pandemic still sort of raging on, right?

**Dr Venkatachalam:** Sure, yes, thank you; that's a very good question.

So, this year at the [ACR] annual meeting, we had the opportunity to present about 9 scientific and 4 patient-perspective abstracts, and many of these had to do with the longitudinal study that we stood up very early on when the pandemic started, called the Autoimmune COVID-19 Project.

So, what happened is when the pandemic started, we very quickly realized that there would be multiple ways in which the pandemic, and at that point this newly emerging virus, would affect our communities, especially the community that we saw with people living with chronic conditions – of which I am one myself; I live with rheumatoid arthritis [(RA)] – many of whom live with inflammatory and autoimmune diseases, specifically.

So, we wanted to track the effects and the consequences of COVID-19, of this emerging virus, both in terms of what impacts it had on physical health, as well as mental health, of the patient community that we serve, including in populations of patients living with multiple sclerosis, arthritis, [Crohn] disease, colitis, and vasculitis, to understand the very unique perspectives of people living with these conditions.

As part of this study, what we did is, we conducted several surveys to try and really understand and gauge things like were people living with these conditions having concerns and what was the impact of those concerns, right? Were they interrupting medications, for example? Many of them [were receiving] immunosuppressive therapeutics. What were the mental health consequences of this newly, back then newly, emerging virus? What was the impact on anxiety and depression? How were communities of people living with these conditions responding to their regular doctor visits?

So, we invited adults from the United States with [RA], psoriatic arthritis [(PsA)], ankylosing spondylitis [(AS)], [and] lupus, and all these are people who are part of our patient-powered research registry that's called ArthritisPower® that now has more than about 35,000 consented adults. We invited people from CreakyJoints, which is our online support community, and we compared patients with different autoimmune conditions who were [receiving] different disease-modifying antirheumatic drugs or DMARDs, as they are called. And we also looked at geographic measures: urban status, income, education, COVID-19 activity in those areas, etc.

As we progressed, more than about 1500 people had participated and we learned a lot of things. For example, we learned that in the early months of

the COVID-19 pandemic, patients with RA, PsA, AS, [and] lupus frequently avoided office visits. So, there was a disruption in their regular care and laboratory testing due to fears and concerns. DMARD interruptions, medication interruptions, commonly occurred, and what was really important that we learned was that this occurred sometimes without the advice of a physician, and were associated with socioeconomic status, office visits, disruptions in office visits, [and] telehealth availability, highlighting the need for adequate health care access, and specifically, attention to vulnerable populations during the pandemic.

[I'll] just give you 2 more examples.

**Meghna:** Sure.

**Dr Venkatachalam:** We also supported another project called the impact of the COVID-19 pandemic on the quality of life of patients with rheumatic conditions. This was a qualitative study; we worked with other researchers, and our purpose was really, again, through qualitative interviews to understand the concerns and behaviors and experiences of adults with rheumatic and autoimmune conditions to evaluate the impact of the COVID-19 pandemic on their quality of life.

We made intentional efforts to amplify the voices of patients who were Black, who were indigenous, [and] people of color. Because if there's anything that COVID-19 has taught us, it is that the underrepresented, people-of-color, [and] marginalized communities [were affected] a great deal more due to several reasons. And so, our commitment was to include their voices, as we do in every research project.

So, we learned that their experiential knowledge of rheumatic disease and [their] treatments varied. A lot of participants perceived themselves to be at higher risk for COVID-19 than the general population.

And then, just 1 last study that I'll bring up here, as an example, is we invited participants of the ArthritisPower research registry to complete PROMIS measures (PROMIS [is] Patient-Reported Outcome Measures). We asked patients to complete measures of physical health, as well as mental health. So, they completed assessments or surveys on physical function, pain, interference, fatigue, sleep, anger, anxiety, depression, and even social health, because that was greatly [affected] by the pandemic.

We got them to participate in these surveys from January 2020 to April 2021, and the findings of these were presented again at the [ACR]'s meeting in 2021, in a poster titled, Changes in Patient-Reported Outcome Scores During the COVID-19 Pandemic. We found that mental health scores varied significantly, particularly during the first US wave of the COVID-19 pandemic, whereas the scores for physical health remained relatively stable.

So, all this taught us and gave us a lot of insights, particularly within the autoimmune community.

**Meghna:** Absolutely. I think that it's so interesting. I know you've been involved in this area of study for almost, obviously, a couple of years now, and I remember speaking with you earlier about the Autoimmune COVID-19 Project as well. So, some excellent work being done there.

Focusing on some of the approaches of these studies that you were talking about, which was in the form of patient interviews, it was noted that the needs and concerns of patients were revealed with the help of the patient interviews. Could you highlight maybe the importance of including the patient voice in research to achieve better outcomes?

**Dr Venkatachalam:** The patient voice is really central to everything we do at Global Healthy Living Foundation, from research to advocacy to education. Based on our studies, and not just this study, but years of research that we've done, we've now begun to understand and we're absolutely certain that the lived experience of those living with chronic conditions is not only valuable to research, but it is absolutely imperative if we are to conduct relevant research; and the key word there is relevant.

Research has to be useful, and it must be useful for those who need it. In this case, it is those who are living with the condition. The pandemic brought significant uncertainty and fear to this community of people who are immunocompromised for several reasons, and so, we have to understand it is our responsibility as researchers to understand not only the fact that this community remains at elevated risks for infection, but how that affects this community, in terms of mental health, in terms of their social interactions, and, of course, in terms of their physical health.

That can only happen when we listen very carefully to the community that we serve and integrate their concerns, their questions, [and] their experiences into research.

We have ways to do this today. We have validated, standardized, scientific tools to do this. We cannot do research in silos anymore if it is to remain relevant.

Now, this is also particularly true in communities that have been underserved historically. In these communities, future research has to [use] tools and resources that underserved communities can [*sic*]. And by doing so, we can bridge that gap between experience of the disease and working toward better and more consistent outcomes.

This is what it really means to make advances today in research. Patients should be full stakeholders, equal partners, from the start of a research project – right from conceptualization of research to actually setting up the instruments, creating the survey tools, to deployment, what is the best way to get patients motivated to participate in research, and then, dissemination, which is really important; because the findings are of no use if you don't share them back with your community. And so this is really the importance

and the new landscape now for research, and we have to remain committed to it.

**Meghna:** I absolutely agree, and like you mentioned, this is such a critical area of thinking for research.

Dr Hsiao, I wanted to get your thoughts too. [M]oving on from COVID-19-related research, there was yet another interesting study at the conference, of which you and Dr Venkatachalam are coauthors. Would you be able to describe to us what the mental models approach to risk communication is and how that, sort of, speaks to the value of shared decision-making between patient and provider?

**Dr Hsiao:** Yes, we're very happy to present this research at the annual [ACR] meeting. Our poster was, Rheumatologists and Patients' Mental Models for Treatment of RA Explain Low Rates of Treat-to-Target.

I'd like to start by explaining a little bit of what mental models are. Mental models refer to the networks of knowledge, beliefs, and/or attitudes that develop over time in response to someone's experiences, values, and world views. So, this is an approach that's derived from decision science and it provides a framework to develop tailored communication strategies in order to address critical discrepancies between mental models held by different populations.

So originally, it was actually developed to improve risk communication of environmental hazards, such as injury risk to the lay public. But now the mental models are being applied to improve decision-making health care domains. While it hasn't been really studied in rheumatology, we know that the mental models of patients and rheumatologists – we hypothesize that they were different.

This discrepancy can explain why some patients are hesitant to escalate, even though they're eligible. In fact, fewer than 50% of patients who have RA are treated using a treat-to-target strategy. A lot of the reasons for poor adherence to treat-to-target include discordance between the physicians' and/or patients' perceived disease activity.

In order to improve the treat-to-target rates, this requires developing interventions specifically designed to improve patient decision-making and buy-in to treat-to-target.

So, we used in this study the mental models approach to understand the differences in how rheumatologists and patients approach treatment decisions in RA. In order to develop the mental models we conducted semi-structured interviews with both rheumatologists – 14 rheumatologists across the country sampled purposely for their expertise in treating RA – as well as 30 patients to elicit respondent's views regarding treatment decisions, with a focus on treat-to-target. We found several interesting differences.

The original treat-to-target model is very specific and straightforward – measure disease activity and adjust treatment to achieve or maintain a target. However, based on the other factors, there's a lot of variability in the implementation of treat-to-target. And treatment decision making RA are actually much more complex. So what we found were that there were key discrepancies between the rheumatologists and patient models that were primarily related to differences in how they value tradeoffs.

While both groups considered domains outside of disease activity measurement in the original model, they also considered target setting and risk vs benefit assessments. The importance of the patient-physician relationship and support were also included in both models, but were brought up much more frequently by the patients.

Then there were unique factors that were specific to each model. For example, the physician model stressed the importance of evaluating disease activity over time, as well as the importance of patient adherence, whereas the patients discussed more the impact of chronic disease weariness, medication-related fatigue, the importance of feeling adequately informed, and the stress associated with changing medications.

We know that patients will be less likely to add or change DMARDs if their mental models of RA and its treatment are not consistent with how physicians view treat-to-target.

So, it's really imperative for the physician to understand the patient mental models of RA treatment in order to engage in effective decision-making. The discrepancies we found also we're really able to use as targets to improve patient-physician communication and/or develop interventions to improve communication, and ultimately, uptake of treat-to-target.

**Meghna:** One additional question that I wanted to bring up, and I'd like both of you to weigh in on this, with respect to everything we've already kind of spoken about in some capacity, do you believe that [PROs] or patient perspectives in research at various levels is given enough importance currently owing to the positive outcomes and data that have come out of these types of studies that you both are talking about?

**Dr Hsiao:** You know, while there [are] still barriers in incorporating patient perspectives, there's definitely an increased emphasis in incorporating patient perspectives in research. This is reflective of a move toward more patient-centered medicine, and there's widespread agreement that patients should be involved in the development of clinical practice guidelines.

Having patient panels provide a better understanding of the patient perspective towards treatment and management decisions, and increased knowledge of patient values and preferences that play a very important role in decision-making and adherence. And really, the ultimate goal is to provide the best individualized care for each patient. So, I think that that's crucial.

A great example of how we've incorporated patient perspectives has been ACR released an updated guideline on the management of RA earlier this year. This includes new recommendations that were agreed upon by a patient panel, as well as a separate voting panel, [which] comprised both clinicians and 2 patients from the patient panel. Overall there was really agreement between both the voting panel and the patient panel; members of the voting panel agreed with the patient panel on direction and strength of everything, except for 2 recommendations where patients expressed – 2 examples – favor of initial treatment with combination DMARDs over just using monotherapy with methotrexate because patients had placed a greater value on the incremental benefits associated with combination therapy compared with the clinicians. Patients also expressed a preference for discontinuation of DMARDs over the physicians' preference of dose reduction whenever possible, because clinicians valued dose reduction to prevent flares.

So really, this really highlights the importance of using a shared decision-making approach in RA, and I think it's very important that the patient perspectives are being included in guidelines because this makes a huge impact on clinical practice.

**Dr Venkatachalam:** Dr Hsiao made some really great points and [I] have just a few things to add.

So, I'll start off by saying yes and no. This is a new paradigm of research – patient-centered research is a new paradigm of research – and so it's pivotal for us to constantly integrate the patient voice using validated measures like PROs into research.

We are lucky to be able to partner with top arthritis [researchers] like Dr Hsiao to make sure that research is patient-centered and patient-centric.

The [ACR] does this too, and Dr Hsiao referred to RA treatment guidelines of which we were a part of. So I sat on the voting committee with the ACR with 13 other rheumatologists. And again, there you see how patient-centered research, how the patient voice, is prioritized as well.

So, this is happening more and more in the landscape. IRBs, for example, Institutional Review Boards, this is all very new to them. They're still, sort of, trying to understand how to work with organizations like ours, ArthritisPower, for example, when we go to them with a patient-centered research protocol, because it does involve a very different way of doing research.

Once we begin to understand and make sure that we do this in every research project, I think this will gain more and more momentum. But I think overall we're doing a good job right now in beginning to at least change that landscape of research, where we are beginning to integrate the patient voice through tools like PROs and patient-powered registries.

**Meghna:** Absolutely. I think those are some wonderful insights, Dr

Venkatachalam and Dr Hsiao. I thank you both for joining me today. Keep on keeping on the excellent work you're both doing!

**Dr Venkatachalam:** Thank you very much.

**Dr Hsiao:** Thank you for having us.

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**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](mailto:editor@rheumatologyadvisor.com).

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