

Transcript Details

This is a transcript of an educational program. Details about the program and additional media formats for the program are accessible by visiting: <https://reachmd.com/programs/living-rheum/patient-centered-psoriatic-arthritis-research/70155/>

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Improving Psoriatic Arthritis Care Through Patient-Centered Research

Announcer:

Welcome to *Living Rheum* on ReachMD. On this episode, we'll learn how patient-centered research can improve outcomes in psoriatic arthritis with Dr. Alexis Ogdie. She's an Associate Professor of Medicine and Epidemiology in the Perelman School of Medicine at the University of Pennsylvania, where she also serves as the Director of the Penn Psoriatic Arthritis and Spondyloarthritis Program. Here's Dr. Ogdie now.

Dr. Ogdie:

Patient-centered research is different than traditional research in a few different ways. So traditionally, as an investigator, I see patients, so I have lots of questions that could make the care that I'm providing better. But naturally, it's from my perspective and then the perspectives that I've observed from patients. So I develop a study question, I develop a study design to answer that question, and then I run the study and publish the results. So that's not wrong by any means. That's how we've always done science.

But patient-centered research provides a little bit of a different flavor and can be more relevant to the patient sitting in front of me as opposed to me as a clinician. So what that might look like is I start with a question that seems to be coming up, and then I ask patients what they think about that. So I get some qualitative input on the particular question of interest. Let's say studying diet in psoriatic arthritis. So I might know from patients that it's a really important question, and then I will develop a study design. Then ideally, I go back to the patients again and say, "What do you think of this design?" We actually did this not long ago, and it totally changed our design because they told us all the things that were wrong with the traditional way in which I was thinking about studying diet.

Then we run the study, and we may seek input from patients along the way about what's going on. Maybe it's not recruiting fast—why isn't it recruiting, and is there something we could change with our recruitment materials or the things that we're doing in order to get patients into the study better? And finally, in summarizing the data, getting patient input about how you interpret the data can also help along the way.

We actually did a study not that long ago that was published in *Arthritis Care & Research* and found that patients' priorities are different from ours, and this makes sense. Patients want to feel better. They want to get back to their usual lives. Maybe we are overly focused sometimes on the number of tender and swollen joints, and when we do that, we change what we're looking at, and then we change what we're studying if we're focused on tender and swollen joints as opposed to getting the patient back to their previous life. So it does help to ask patients in advance about what's most important to them. In psoriatic arthritis, we've published on what's most important to them now, and then we structure a study to capture those particular outcomes along the way.

After studying patient-centered outcomes or what matters most to patients, it's changed how I ask patients questions. One of the questions I may ask now is, "What is most important to you? What is your top goal in feeling better?" As I do that, it changes how I approach the patient's care. So if I know to ask, "What's your top goal?" And the patient says, "Playing basketball again," the therapy I select matters, but physical therapy matters even more. And maybe there are some other things I'm going to help the patient think through as we're planning their next set of treatments.

So asking what the important outcomes are changes what we measure in studies and it changes how we talk to the patient in clinical practice, which changes the interventions that we may employ in order to get the patient to where they want to be.

Announcer:

That was Dr. Alexis Ogdie talking about the role of patient-centered research in improving outcomes in psoriatic arthritis. To access this and other episodes in our series, visit *Living Rheum* on ReachMD.com, where you can Be Part of the Knowledge. Thanks for listening!

