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Psoriatic Arthritis & Better Measuring Patient Response to Therapy

Announcer:

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Here's your host, Dr. Matt Birnholz.

Dr. Matt Birnholz:

As treatments for psoriatic arthritis evolve, traditional physician-centered outcomes measures, such as assessing disease activity for inflammatory joint disease, skin manifestations, and extra-articular features remain important, and are starting to be examined in light of newer patient-centered measures so as to better guide clinical management. But one of those measures, the subject of patient satisfaction or dissatisfaction with symptom control is still often missed, which can strongly impact future care decisions, willingness to accept recommended treatment changes, and patient quality of life.

Coming to you from the ReachMD studios in Fort Washington, Pennsylvania, this is CME on ReachMD, and I'm Dr. Matt Birnholz. Joining me today to focus on the value of patient experience in managing psoriatic arthritis is Dr. Jeffrey Curtis, the Harbert Ball Professor of Medicine in the Division of Clinical Immunology and Rheumatology at the University of Alabama at Birmingham. Dr. Curtis, welcome to the program.

Dr. Curtis:

Thank you. It's a pleasure to be with you today.

Dr. Birnholz:

So, why don't we get a baseline on the outcomes measures to start. Can you share how clinicians measure patient response to psoriatic arthritis treatments in the clinical setting?

Dr. Curtis:

Certainly. And it's not that much different, at least in a qualitative way, than what we might value in clinical trials. We're typically going to assess tender joints, swollen joints. We're probably at least aware of imaging features, some of the extraarticular features such as dactylitis and enthesitis, and of course for people who have psoriasis themselves and obviously have skin involvement, then assessing its extent and activity and severity is exceedingly helpful, and that can either be done in a formal way using body surface area or even a PASI, which somewhat complicated and rather cumbersome, or in a bit more of just consistent with what one would do as part of a physical exam.

There are a number of validated tools that can be used to measure psoriatic arthritis disease activity in clinical practice, but much like in RA, those tools are infrequently used as part of routine standard of care. Some of the clinical measurement tools that one could apply include the Composite Psoriatic Arthritis Disease Activity Index, the Psoriatic Arthritis Disease Activity Score, and the Disease Activity Index for Psoriatic Arthritis. In 2011, the International Group for Research in Psoriasis and Psoriatic Arthritis (GRAPPA) and the Outcome Measures in Rheumatology Clinical Trials (OMERACT) developed a Disease Activity and Responder Index for Psoriatic

Arthritis. But because they are complicated and do take time, many clinicians will feel that they are rather impractical for routine clinical use,

Dr. Birnholz:

That's a great background. That gives us a better sense of the issues, the barriers that physicians are encountering when it comes to looking at the validity and actually applying these outcomes measures. You mentioned rheumatoid arthritis as a comparator, and we know that the approach in rheumatoid arthritis is similar, and yet research shows that these patients are often not satisfied with the level of symptom control they achieved with psoriatic arthritis. Is this the situation that you're encountering?

Dr. Curtis:

It is still very much the case. And much like in RA, where it seems like in rheumatology, many of the therapies and many of the approaches and the paradigms that started first in RA for the treatment of inflammatory arthritis, eventually often trickle down to other forms of rheumatoid arthritis such as psoriatic arthritis. That has obviously changed in more recent years as it has become clear that certain therapies, certain mechanisms of action, and frankly some disease considerations are not the same in psoriatic arthritis as they are in rheumatoid arthritis.

Occasionally it can be a don't ask-don't tell – do you even know if your patient is satisfied? Have you asked him or her, and I think in moments of honesty, many rheumatologists, including myself, would say probably not. The impact on people's lives based upon those symptoms, may have very different influences on how disease activity is perceived by patients. The idea that patient self-assessment and the clinician's self assessment of what he or she thinks of how the patient is doing, may in fact not be aligned very well.

For some people, they are much more bothered by their joint disease. Their joint disease is limiting and may depend a lot on what they do or what they wish they could do, but for others, the skin involvement may be very disabling and may be perceived by patients even to be disfiguring, and so the relative importance of skin disease versus joint disease is likely to differ in a very substantial way from patient to patient in terms of the impact on day-to-day living.

The other aspect that I think are important to recognize is that sometimes we get very focused on our own specialty, is that the impact of this disease on the patients is not just how active their skin and their joints are, but touch is the key, and emotional coping, and interactions with family and friends, and how people sleep, and social isolation, and what they can do. Clearly, if you have very active skin disease, you may not want to wear short-sleeved shirts or shorts or be comfortable in a swimming pool environment, at a party with friends – those sorts of things. So, all of the psychosocial factors that frankly sometimes rheumatologists would prefer not to want to have to deal with. Much like in RA, depression and anxiety are very, very common in people with psoriatic arthritis. In some qualitative studies that have been done, patients often complain of a lack of psychological support from their clinicians. Conversely, many rheumatology providers may feel somewhat ill-equipped to manage depression or other health domains, and feel like that's more of primary care sort of thing. But people with psoriatic arthritis, often because of their age distribution, they're younger people that this may be their main or only main medical problem and may see rheumatology far more often, and they don't need to see their primary care physician, so we as a specialist may have much more contact with them to assess and screen for depression and some of the psychosocial issues that are very common in people with a chronic illness like psoriatic arthritis.

Dr. Birnholz:

And I would like to dig a little deeper into that discordant environment. This don't ask-don't tell situation and the cascade effect there. What would you say are the downstream consequences when clinicians and patients don't align in terms of how they each perceive treatment success, as you've been talking about?

Dr. Curtis:

Certainly, and there are multiple potential implications. But when patients aren't satisfied or there are trust issues, not surprisingly that is correlated with low patient adherence to treatments; thereby, to worse treatment outcomes. Even downstream, health-related quality-of-life, not surprisingly, worsens. It's just part of a vicious cycle that feeds upon itself. Co-therapies like methotrexate for example that may be effective in psoriatic arthritis is still somewhat controversial, but likely is going to be helpful for most people's skin disease. Symptoms that may be bothersome but not rise to the level of what we might think of as a true adverse event. Those things are very important to patients and yet, if we made a strong case that, 'You really need to be on this,' and the patient doesn't feel like they can really say no because the medicine makes them feel crummy; not life-threatening illness, not liver function tests off the chart, but they just feel sick the next day; if they don't take it, but they don't want to be forthcoming because they don't want to be labeled as the "bad patient," not surprisingly outcomes are worse. If you think your biologic drug is failing when given with background methotrexate, only the patient isn't actually taking the background methotrexate, but feels uncomfortable telling you because of the way that the conversation has evolved, then you're going to give up on a treatment combination that the patient is not actually taking, and clearly you could probably do better to try to remediate that and even try to improve some of the tolerability issues by lowering the dose, etc.

It was also sobering to me to realize that people with psoriatic arthritis have probably never, ever met any other patients who also have psoriatic arthritis. That is not a shocking revelation when you merely consider the epidemiology, but most rheumatologists, including myself, I see people with psoriatic arthritis, rheumatoid arthritis, etc. All day long, so the isolation that people may feel having no one else to talk to about their health condition, frankly having no sense of what is normal, 'what should I be feeling,' and to set expectations and even goals about their own healthcare is very problematic. When they're interacting with friends and family, the pervasive 'you don't look sick' for people in their 30s, 40s, or 50s with psoriatic arthritis I think is very damaging and frankly damning to people's psyche, where they're expected to fulfill all the roles and functions of a mother, father, employee, or whatever their social context is, and yet they don't feel like they can if they have poorly-controlled disease. So the lack of social support, and social isolation and some of the downstream consequences.

When patients aren't satisfied, not surprisingly, they are less likely to be on more advanced therapies, and they're more likely to have active disease. In a number of studies looking at work productivity, there is more work impairment, there is more negative impact on daily activity in higher disease burden when there is not good treatment alignment with the rheumatologist and the patient.

Dr. Birnholz:

For those just tuning in, you're listening to CME on ReachMD. I'm Dr. Matt Birnholz, and I'm talking with Dr. Jeffrey Curtis on some important obstacles to patient satisfaction with symptom control in psoriatic arthritis treatments. So Dr. Curtis, looking forward, what do you think are the tools that we should be using now or in the near future to better measure patient response to therapy?

Dr. Curtis:

We need to measure the things that matter to patients. Patients don't really care about how many swollen joints they have. They don't really care about their nail pitting or enthesitis or dactylitis, per se; they care about the impact of those symptoms and those signs on their pain, their function, their ability to engage socially, to fulfill their roles, etc. Regrettably, we have really not had in randomized controlled trials, much in the way of patient-reported outcome data or patient-generated data to give back to patients with the exception of a few legacy things like the short form 36. I still have yet to meet any rheumatologist at practice that actually measures that. It's 36 questions, it's very long, it's cumbersome.

We're not even quite certain which health domains matter most to patients, and not just on average, but to patients – the one in front of you, like what are her or his treatment goals, what matters most to them, in what way does the disease impact the most. I try to ask a fairly general question, 'What are the ways in which your health condition negatively impacts you, your life, your work, your family?' just to get a sense about what are the health domains that we seem to have the most negative detriment on, because sometimes I'm surprised about what I get. You need to explicitly ask them, and you get a very different sense about impacts on work productivity, fatigue, other psychological, anxiety, depression, marital and sexual relationships, etc. Those are hugely important, not surprisingly. Patient input has been incorporated into some of the measures like the Psoriatic Arthritis Quality of Life Index, or the [Psoriasis] Symptom Inventory, Worst Itch-Numeric Rating Scale. We sometimes don't think that much about itch for people with psoriasis, but that can be a big deal, as can the impact of any of those things in what partners might report in some of those conditions.

The National Institute of Health, the NIH, has developed over the last decade or so a new set of patient-reported outcome instruments, or surveys if you will. They are very short, they are very feasible, they're generic, you can deploy them no matter what chronic health condition people have. They have excellent face validity, they're benchmarked against the U.S. adult population. You can do these in less than 60 seconds. They all have the same score, so it's not like you have six different domains that you have to all learn. They're all on a scale of 1-100, where the mean is 50 for the U.S. adult population; standard deviation is 10. They are all like that. So they are pretty easy to understand. We're starting to see the rise of digital tools, registries, standalone apps, things you can get on your smartphone or on a tablet, iPad, or other sorts of technology that can be used in an office setting.

Dr. Birnholz:

And I like this combination of digital tools that are becoming more efficient with a renewed focus on more intuitive simple questions to really gauge how the patient feels he or she is doing. Where do you anticipate that focus on the patient experience in care affecting future management decisions for psoriatic arthritis?

Dr. Curtis:

So in terms of patient satisfaction and, I think goal setting is really important. I try to do that for patients at the very beginning, so 'the goal of me treating you is remission.' I think too long we have essentially been satisfied with the 'it's good enough' approach to disease management. The relevant point though is to really ground patients in where they should be satisfied, both by asking them, but again by giving them some hope and expectation, and remission hopefully is part of that discussion.

Whether it's defined in treat-to-target trials like TICOPA where you set a goal and keep changing until that goal has been met – whether you do that in a highly formalized way or not, the idea that you set a goal, ideally you and the patient set a goal, and you keep changing

things until that goal is met, I think that concept is quite resonant, and certainly the concept of remission, however defined formally or informally using metrics like the minimal disease activity that has been looked at in psoriatic arthritis and seems to perform well. That idea I think patients can understand that, even if they don't care about the numbers or what you might quantify. Multidisciplinary, multispecialty team assessment is likely to be very helpful. One might say, 'I have 15-minute office visits, I can't do this my own self,' and we're starting to see advanced practice providers, perhaps pharmacists, as we use at UAB in my clinic, that really can extend the reach of what clinicians are trying to achieve, both in education, as well as in goal settings, and patients are certainly turning to online patient communities like Creaky Joints, and the research registry arthritispower, not only to connect with other patients, but to be able to track their health and domains that matters most to them.

Dr. Birnholz:

Dr. Curtis, before we wrap up, let me just open the floor to you for anything else on this subject that you would either like to reiterate as a key concept, or that you want audiences to take away with something we didn't cover today regarding psoriatic arthritis.

Dr. Curtis:

Certainly. So, while there are a lot of topics we did cover, and we've touched on just a few of them like treat-to-target, I think the idea of goal-setting between patients and clinicians, and then continuing to change therapies and some of the health-tracking tools that may be available and out there that are likely to relate both to forthcoming clinical trial data, as well as new guidelines from the American College of Rheumatology to really achieve those goals are very important. I also think that the workforce shortage we're going to see not just looming on the horizon, but really we're already dealing with to some extent, there just aren't enough rheumatologists. We're going to need to be very thoughtful about how we deploy care and right-size it, that we don't say, 'follow up every three or four months' just because that's the lab monitoring schedule that's required, but that we really need to accelerate for is that we have capacity in our schedules to do that. I think we are going to need to better right-size what we do and how we do it that may require some remote monitoring tools with digital biomarkers or lab based or imaging biomarkers to help make us effective as clinicians to get people the care they need and then do careful monitoring. I think of it as kind of a care traffic controller that doesn't always have to be the rheumatology clinician providing this, but in a team environment to really have multidisciplinary care to be efficient so we can make sure those patients that we really need to help the most and probably aren't as accelerating as often as we should, are seeing us often enough so that's happening, and that we don't just accept that it's a good enough goal.

Dr. Birnholz:

Well based on everything you've shared, clearly there is some work yet to be done to bridge some of these gaps leading towards the role of care traffic controller, which is a term I hope you coin immediately, it's fantastic. But we're definitely moving in the right direction to put that patient experience at the forefront of care decisions. Dr. Curtis, I want to thank you so much for your time. It has been great having you with us.

Dr. Curtis:

Thank you. It has been wonderful, and I very much appreciate the discussion.

Announcer:

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