

## A Narrow Window of Opportunity: Diagnosis and Management of Rheumatoid Arthritis in Underserved Populations

Podcast 4 | Run Time: 29.02 minutes

D Kaminski: [00:00:00]

Hello, everybody, Welcome to our session. Let me introduce myself. I'm Donna Kaminski, I'm a family medicine physician. I'm faculty at Robert Wood Johnson University Hospital Somerset with their Residency program. I certainly consider myself a primary care provider... Very interested in building my skill set around rheumatoid arthritis, and I'm really fortunate to be here with Dr. Prabhakaran, who is a rheumatologist. I'm going to let Dr. Prabhakaran introduce herself.

S Prabhakaran: [00:00:35]

Hi everyone. This is Sajina Prabhakaran. I'm a rheumatologist at Capital Health Rheumatology Specialists and I work out of Hopewell, New Jersey, and I'm thrilled to be here with Dr. Kaminski to talk about rheumatoid arthritis.

D Kaminski: [00:00:48]

Wonderful. Welcome Dr. Prabhakaran and thank you so much. These sessions have been really, really helpful. Thank you for going through diagnosis and treatment with us which I really feel has been really, really critical, and helping us to sort of, as I said, build our skillset around managing rheumatoid arthritis in our patients. One of the things that I'm finding so many of the patients that that we... that I serve, not only in training but now as an attending, you know, struggle with compliance with many of their medications. And so, with rheumatoid arthritis, I know that this is also an issue. Can you talk a little bit about what you've seen in terms of being helpful, to help increase and improve compliance with medication, especially in a chronic disease, such as rheumatoid arthritis?

S Prabhakaran: [00:01:46]

Absolutely. Yeah. Compliance is one of those great challenges that I think all physicians... all specialties deal with, with our patients. We can do everything right and we can say everything right in the 20-minute visit, but the patient, once they leave, we don't quite know if you're following through with what's been told. So, it depends a lot on what the reason is behind a non-compliance... it could be one... it could be just a lack of understanding of what they should be doing or why they should be doing it or how they should be doing... polypharmacy, as we know, can lead to poor compliance... financial burden. Sometimes the medications are just too expensive for a patient. They have a very high copay, or they may not have a high copay, but they have 20 medications to purchase, and they cannot afford all 20 so they're picking and choosing what they're going to take that particular week or month. It could be side effects that they're not voicing to the physician but decide that they're not going to take the medicine because it's just the easier thing to do. It could be cultural... could be social. There are several reasons for non-compliance. So, one of the jobs as a physician...when a patient walks in, I think we all do this, is we ask open-ended questions as to what do you take? What was the medication that you take every day? And asking them...how do you take it? Well, how many do you take? So, that will give us an idea of the truly taking the medication at the state they are, or if they're not. And also, always maintain an open dialogue with the patient so that they feel comfortable telling us if they are not taking a medication and as to why they're not taking it so that we can address the issue. One of the important things about improving compliance is that the patient understands what's going on with them and why they need to take the medication. If one doesn't understand it's highly unlikely that they are going to follow through with instructions. So, one of the things that we want to invest our time in during every visit is at least

going through a brief overview of what it is that they have, and what's the importance or the necessity of taking a medication, and what it is that we're looking for. Sometimes patients are taking meds and they don't know why they're taking it. They will tell us, "Well, I don't know how I'm supposed to feel, but I'm taking it." Well, then you enumerate...this is why we're giving it to you. It's sometimes... we assume that the patient understands or knows these facts, but not everybody is at the same level of, you know, education or expertise or viewpoints. So, explaining that to the patient...educating the patient will definitely make them feel more empowered and helps to increase their sense of responsibility to follow through on these instructions. As we all know, now we have, we have Dr. Google also, which can really be very helpful or sometimes can be one of our biggest problems is that the patient can... Sometimes you can talk to them about the drug, tell them everything they need to know, and then they go and Google the drug's name and they see something on a website and they come back and say, "Nope I'm not taking it. Someone said this about this medication." So, making sure that the patient understands... educating them as to where you want to go look for information.... what do you want to avoid? So, giving them that direction so that they are aware that there is information out there, but not, every piece of information is reliable. So as a physician, keeping that open dialogue with the patient is extremely important so that the patient feels that they're being heard, that they're being listened to, and that their viewpoints are taken into consideration when we as physicians are educating them and informing them what they should do. I don't want to use the word telling them... I'd rather say informing them, on how they should be doing and what they should be doing to help themselves. And when it comes to cause there are ways to get around that, I'm not sure if you going to come and talk about that a little bit later.

D Kaminski: [00:05:42]

Okay, well, we'll talk about it a little bit later. You know, if I can like just to step back to Dr. Google... who is, I think, the most commonly seen doctor in the United States... because you bring out a really important point that I just want to home in on a little bit more and which is about misconceptions, and I think Dr. Google can help create misconceptions. And it's really, really important that we really hear our patients where they're at, and really get a feel for what their conceptions are so that we can sort of walk with them, right, and build from there. What are the most common patient misconceptions that you've found so that we can be aware, and again, we can engage in dialogue with our patients around this and sort of work through those misconceptions?

S Prabhakaran: [00:06:26]

So, frequently it's the patient who is most concerned about side effects with medications that I see will resort to Dr. Google because you're trying to, or looking online essentially, to find side effects of medicines or adverse reactions that they are...you know, afraid they're going to have, right. So, directing a patient... in the very beginning, when we talk to the patient about the disease process, providing them with sources of information. So, we have plenty of sources online. As a physician, we can print things out from, for example, Up to Date, if you use Up to Date in your office. There's patient information in Up to Date, which is a great tool to print out. It's just three pages... and tell the patient, "Hey, listen, this is for you, you can go back and review this...You have any questions you ask me" and that's important. They're going to read three pages and they won't follow everything on it and to be aware that they have... they can ask questions to you, that would be one good place. And another website I like to use is WebMD. I like to refer patients to Mayo Clinic... arthritis.org, which is... and of course Rheumatology.org...they are both very, very good websites for patients to go to, to collect information. And the reason why I give these particular websites is because there are things out there where patients have reported their experiences with medications or their experience with a disease. So, there are Facebook pages or there are patient forums that are out there and... that... while it can be very heartening for a patient to read other people like themselves going through a disease process, it can also give you a very skewed view of

the disease or of medication. As long as the patient understands that what one person goes through is not what everyone is going to go through, and keeping that awareness, so the patient has that awareness, it's good. But I try to discourage patients from going on those kinds of blogs or forums and sticking to medical websites so they can get more of a neutral... as well as wholesome, and more accurate information of the disease and the drug so that they understand what's going on with them.

D Kaminski: [00:08:38]

Yeah, got it, I got it. Yeah, that makes sense being able to offer them accurate sources of information. And especially... we were talking a lot segment about newly diagnosed patients, especially in a newly diagnosed patient, which... it can really be hard for them...they just received this really big news, sort of like a very big diagnosis that they're going to be caring for a long time and a lot of times they're overwhelmed with emotions and it's very hard for them to remember everything that you've talked with them about...and so, I'm just wondering if there are tools that you...you've seen really helpful with patients, such as maybe bringing the family member so that family member you know, can capture or maybe you have them... I've heard about this teach-back approach where the patient sort of teaches back, you know, to you what you shared with them. So, that again, that's another tool that can ensure that, you know, they're, they're capturing all this information and, you know, in addition to, of course, having great written materials, which is what you're describing.

S Prabhakaran: [00:09:41]

Absolutely. So, besides giving out handouts in the in the office, a couple of things I do when I call them in for the next appointment, one of the things I do is I ask the patient a little bit about their disease itself. I use keywords like, "So, how long is your stiffness" or "Have you had swelling..." in their joint so they know what they're looking for when I ask them these questions...so they know what they need to complain to me about the next time, they see, they see me. A couple of other things that I do ask patients to understand better about the disease process also is to ask them about their ADL... about their, you know, things that seem... seem... very, very... tangent. Like, "How's your job going on?" or... what did you do for your hobby? Are you still doing this sport? This kind of tells us that... gives us an idea as to where the patient is with disease activity. As a physician, which is important for us, because we want to improve their quality of life. If I have a patient who I feel, like you said, is very overwhelmed... and you can get a sense of this in the first one or two visits...you would know right away if this patient is... will they will tell you, "I don't know how to manage this." That's what they would use... "I don't know how to manage this," "I'm very confused," "I am overwhelmed," "I don't like this," "I wish this would just go away." You know, these are all the different...phrases that patients who used to describe.... And sometimes I will ask them to bring a family member in or I might just call somebody on the phone with the patient in the room and can I talk to both of them and say, "Listen, this is what we're doing," "This is what's going on..." This is what we do, and this is what we need to do, to get to where we want to get to. And this is how we can get there. And also involving the family member to identify what the obstacles are...what are the barriers that this patient is facing at home, or at the workplace, or maybe they have a very unsupportive partner or like I said, they have financial issues or there is, you know...children... so there could be so many different reasons why somebody is non-compliant. So, try to tease that out and it may take more than a visit to... for us to identify that...which is okay, but at least trying to pursue it, that does help a lot in trying to identify what the issue is primarily that we can address it. And if you have social workers available in your office, they can be a great tool so that we are not spending as much time during a clinic visit doing this. They can help navigate a lot of these other issues that we may not be able to do, or they can do it better than us and provide the patient with the necessary tools and resources to do better with their medications and their disease. In terms of... especially in my patients where I feel they may not necessarily have the level of education or understanding, then I really like to use the Talk-

Back method. I use it a lot in my patients who don't speak the same language as I do. So, if I'm using an interpreter for some reason, I always have the patient tell me back what I told them because it's... it will be very interesting, then I would know exactly... did I, did they get the point across? So, with the medication directions, what are the side effects that they're looking for? What other specialists do I want them to see? I want them to follow up with the ophthalmologist because they're on hydroxychloroquine. I'm like, well, this is what you're going to do in six months, and I expect the patient to tell me that. So that that helps to reinforce the idea and also lets me know that I was able to communicate properly and that the patient understood... I needed for them to understand, which also in turn helps improve compliance and again, when we do that then I think the patient also feels that they have been listened to. They've been taken seriously... and that we truly care for their well-being, which really goes a long way in improving their compliance with medications.

D Kaminski: [00:13:32]

Excellent. And I think that's very important...Among the barriers, you know, I think you touched upon some of the barriers, but I'm wondering if you... if there any strategies that have you been... you found helpful when financial resources are the limiting factor, they are the barrier. So, you know, medications not being affordable.....So, a good number of patients I've served in the past have been uninsured or underinsured and so, you know, the medications and treatments can be quite costly. I mean, some of the things we talked about earlier, our custom-built devices for reading and writing in patients with severe, severe rheumatoid arthritis, and physical therapy, may not be affordable if it's not covered within somebody's insurance plan. Have you found any strategies to be helpful when financial resources are the barrier for patients?

S Prabhakaran: [00:14:30]

Absolutely. So, physical therapy, I think, is one of the easier ones. So, a lot of times patients have insurance coverage, but they have a very high co-pay and they can't afford \$50 a visit to the therapist... physical therapist and you have to go twice a week for six weeks, that amounts to a good amount of money. So, a lot of times I have handouts for patients, and I go through the exercises with the patient in the room. Kind of quickly...take about five minutes to go through them and say, hey, this is what I want you to do, and I give them directions, to do it twice a week for 15 minutes and I tell them to after all that to take a hot shower, because that's when your muscles are the most supple. It's easiest to do... or after you do some cardio...that will be the best time to do the exercises. So, giving them very clear directions, making sure that you're as precise as possible, and writing it on the handout... saying, 15 reps, twice a day for the next six weeks or for the next 12 weeks. When we do that for the patient, that seems to be very helpful for them to follow. When it comes to medication coverage, it is such a challenge for us because of... granted, a lot of the medicines we use in RA, for example, the immunotherapy, they are very expensive and some insurance is easy to get coverage, some insurances are not. So, we do have to go through either a two-year program, where you have to try three medications before we get to the fourth one...we have to do peer to peer sometimes... patients who are charity care, believe it or not, is actually easier because if I want infusions, I get them. It's a lot easier because they come on charity care and my own hospital does have it, but a lot of the companies have patient assistance programs in effect. So, we do use them a lot in our patients, especially patients...who are in the lower socioeconomic groups, where we use the company copay cards or the company sponsors the medications. I have patients who I give samples to.... we just work with the medical reps and we provide samples to patients to cover them...so that we can use... provide them with treatment. We use Good RX for the oral DMARDS, we've used Good RX a lot of times in patients... with patients so that we can get them the drugs that they need so that they can be covered. So, there are some options. If they're in New Jersey, we have PAAD, PAAD New Jersey can also be helpful, which is again...for subsidized rates for patients

with low socioeconomic status, we can use that to get patients drugs... standalone infusion centers can be helpful. So, there are some methods to go about it...it is not, it is not easy.....in my opinion you need someone dedicated who's going to do just this in your office. It's not in a physician's clinic time. It's very difficult to find the time to sit down and do these things. So, fortunately, in our office, we do have someone who does it, but these are avenues which are out there available to provide help to those patients who need much needed medications to live their life...you know, and to carry on and to work and provide earnings for the family, you know, who are frequently depending on them for their day-to-day life. So, there are some avenues out there, but they're challenging.... but they are there.

D Kaminski: [00:17:42]

They certainly can be a barrier to care for sure.... but thank you. These are very helpful, very, very helpful. Okay, next question, which I think is a really important one... for me, it's about disparities of care...disparities...among our patient groups. So, are you noticing any disparities in, for example, let's just start with the diagnosis? Are you noticing certain groups are just getting diagnosed... not early enough... quite late...which then impacts their whole disease course. You know, I think it's important for us as primary care physicians to be aware of what those are so that we really, really can put RA on our radar and diagnose earlier. Can you... can you talk a little bit about what you're seeing?

S Prabhakaran: [00:18:30]

Absolutely, this is one of the very reasons for a poor outcome. We look at patient outcomes with chronic diseases...Yes...if you look at patient populations, we do see that patients of African-American descent and of Hispanic descent...they do tend to have delayed diagnosis compared to patients of Caucasian descent. So, I think it is a bias that we, unfortunately, have as providers. It's an unconscious bias, and that we tend to misdiagnose these patients as having, you know, osteoarthritis, or just chronic pain syndrome a lot of times... and not all the time are we doing a complete workup or hearing the patient when they're describing their symptoms to us. And sometimes it's also because of the barrier... like we talked about, was the barrier... could be a language barrier. You know it's if it's somebody who doesn't speak the language that we speak and they're trying to explain symptoms they may not necessarily say pain, they may call it weakness. They may not call it burning... they may not call it discomfort.... they may call it a burning sensation in my joints. They may just... they may have... they may not describe stiffness...they may say that their hands feel tight. So, there are different adjectives that patients use, and when you have a language barrier on top of that, as a provider you could really miss... a lot of times you can miss these diagnoses if it's not on your radar. So, studies have shown that African American patients... patients of Hispanic descent...they are frequently getting diagnosed later than they should be compared to Caucasian patients when it comes to rheumatoid arthritis... and then when you translate that to the next step we talking about treatment... so now you've already lost that time where you could have intervened in a lot sooner and now you making the diagnosis a lot later and now you're trying to institute therapy, so you've already lost that time, so now we're going to have a bigger...a more steep hill to climb now to get these patients to where you want to get to. So, when it comes to diagnosis, when it comes to treatment as well, it's been shown that patients of Hispanic descent, for example, or, I'm sorry, African-American descent, I should say, they're less likely to be given a biologic or an immunotherapy compared to somebody of Caucasian descent.

D Kaminski: [00:20:47]

Interesting...interesting.

S Prabhakaran: [00:20:48]

Studies have shown that that's again... and it's interesting that... Hispanic patients are more likely to be started with a biologic. There was one paper, if I'm not mistaken, that came out from New York a few years ago that thought... that said Hispanic patients got biologics, for whatever reason, offered to them before it was offered to an African-American patient. So, even...even treatment-wise, we tend to have this unconscious bias in terms of when we are treating patients. And then if you look at insurance, that also leads to an issue too. Because if, as a provider you're taking care of a patient, you have somebody who's got a poor insurance plan, you're already in your mind, you're thinking, well, I'm not going to get this drug approved. So you're less likely to use something that you know would be the first line of therapy because you know it may not get approved and you're using something which is probably going to be less effective...but this patient, even though you know something better is out there that because you know you're going to go through all these barriers as a provider... you may choose not to...so, unfortunately, doing a disservice to the patient. So that also has been shown that this is another disparity that we have in our practice, in our day-to-day practice, which unfortunately will affect our patients negatively.

D Kaminski: [00:22:06]

So, you are seeing disparities in diagnosis... You're seeing disparities in treatment. How about remission? Because that's where we want to get our patients. We want to get our patients, we want all of them to be in remission, and we want them, you know, as close to symptom-free as possible. Are you seeing any differences there?

S Prabhakaran: [00:22:23]

Yeah, absolutely. I think there was, there was a paper that looked at patients all the way from 2014 to, I want to say, 2017. And they looked at... they divided the population groups into Caucasians, African-Americans, and Hispanics, and over the years they looked at patients going into remission. Every year our remission rates were increasing in all three population groups, right, because we have better treatment modalities, better diagnostic tests. So, patients are...were doing better. But in looking at each population, comparatively, it seemed like fewer patients in the African-American population and fewer patients in the Hispanic population were achieving remission and low disease activity compared to patients of Caucasian descent. So, even though there was success in that group, in those groups, we didn't see the success that we saw in our Caucasian group of patients. So, even at remission rates, even though they're all available and again, this could come to all the other things we talked about, we talked about insurance, we talked about language, it could be the fact that they can't afford or have a rheumatologist available to the patients. It could be education... when you're not educated enough to know how to treat the disease, so education can also play a role. We do know patients of lower socioeconomic status generally tend to do worse with these chronic diseases, compared to others. So, all of those factors probably play a role... but yes, to answer your question remission rates are different in these different populations.

D Kaminski: [00:23:52]

Yeah. So, you're... you're seeing a difference in the burden of the disease. That's what you're saying.

S Prabhakaran: [00:24:00]

Yeah, in looking from a financial standpoint as well, we do know a lot more of our African-American patients are the ones who are in eventually requiring to go into disability...or looking... applying for Medicaid... or using opiates for chronic pain control compared to our Caucasian patients...which all

translates to disease burden as well. So, from a financial standpoint, as well, these patients tend to carry a greater burden than our Caucasian counterparts.

D Kaminski: [00:24:35]

That's really important for us as providers to really be aware so that... we have, you know, because we have a potential to be able to intervene at any of these levels, really....I have... well, please forgive me for this question but I'm going to indulge myself to ask this because my patients ask things like this all the time... with COVID. The topic that will never go away or doesn't seem to ever go away. Are you noticing with COVID... and I'm thinking both in terms of active COVID infection... are there any things for me to keep in mind for my patients with rheumatoid arthritis who get COVID infection and for me to consider? And then my second part is going to be also patients with long COVID.... People have gotten through the COVID infection but still have lingering symptoms... anything you're noticing in those patients who also have RA.

S Prabhakaran: [00:25:36]

Absolutely. I mean I'm hoping...looking at things, the way it is now, fortunately, we're not in the thick of it like we were a year or two ago, but yes, so with COVID, it definitely did...it did impact Rheumatology, just like it impacted every other specialty, I should say, but in Rheumatology patients one of the biggest concerns were that our patients are all on immunosuppressants. All of our medications, pretty much almost all of them, the target is the immune system, and therefore, the consequence is immunosuppression. So, with patients who have COVID, one of the important things that we were trying to do as rheumatologists when we were in the thick of the pandemic was to educate the patients in terms of symptoms to watch for. Make them understand that this is something... this is a real threat for you, and we want to make sure you're protected. So, to understand what the disease is... COVID is... what symptoms to watch for, and then protecting themselves. So, we were really encouraging vaccination in all our patients with RA who are on treatment just to provide them with some protection against COVID, or at least reducing the disease activity to a minimum...to a relatively mild disease activity compared to the others. So that's one very, very important thing. Masking...we were encouraging patients to mask and so forth. The other important thing is, and this goes to patients with autoimmune diseases who are on immunosuppressants, the understanding that if they have an infection...if they have a fever... if they have to go on an antibiotic...if they have to have a surgical procedure of some sort done, just hold their immunosuppressants. That's very, very important because you want the immune system to be as potent or as strong as possible to fight off infections, except when it comes to hydroxychloroquine, which can be continued because it's not an immunosuppressant. Talking about long COVID, however, that's a different ballgame. So, with long COVID, it's really sad when one of our patients gets long COVID symptoms because one it becomes a challenge to differentiate between that and the underlying rheumatic disease, and also to deal with another disease process altogether, in addition to their autoimmune disease condition. So that's been an ongoing battle and unfortunately, we don't have great treatment for long COVID. But again, a lot of it has to do with education... but in a lot of patients it seems like they've gotten better...their long COVID symptoms seem to eventually go away, especially if they've been vaccinated, as opposed to patients who are not vaccinated. So, there is some light at the end of the tunnel in those patients as well.

D Kaminski: [00:28:14]

Wonderful. Wonderful. Dr. Prabhakaran and this has been amazing. Thank you so much. You've really been so generous really with your knowledge, as well as your time. So, I'm really, really grateful. I think

that it gives us a tremendous amount to be able to think about... to be able to integrate, as primary care providers so that we can address not only the disparities that we talked about during this session but also be able to better diagnose and treat and manage rheumatoid arthritis in our patients. So, thank you. Thank you for your... great knowledge that you've shared with us and thank you to our listeners. Thank you very much.

S Prabhakaran: [00:28:53]

Thank you, thank you for having me. Yes. And if you can get some help out there absolutely. Thank you so much.