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The Full Picture of Psoriasis: Recognizing the Invisible Burden

Announcer:

You're listening to *On the Frontlines of Psoriasis* on ReachMD. Here's your host, Dr. Alexandria May.

Dr. May:

This is *On the Frontlines of Psoriasis* on ReachMD. I'm Dr. Alexandria May, and today I'm sitting down with Dr. Jennifer Cather to explore the real-world impacts of psoriasis on patients' daily lives. She's the Medical Director at Mindful Dermatology and Modern Research Associates in Dallas, Texas. Dr. Cather, thanks for being here today.

Dr. Cather:

I am so excited. Thank you so much for inviting me.

Dr. May:

So to get us started, Dr. Cather, when we think about the physical burden of psoriasis, what aspects of the disease tend to have the greatest impact on your patients, and what might clinicians underestimate during a routine visit?

Dr. Cather:

That's a really great question. So remember, psoriasis can happen at any age. We see children, adults, and older people getting it. The easy thing is to think about what has to happen for you to get ready for a day. So people talk about having trouble getting out of bed because they might have sore muscles, sore joints, or their joints might be stiff. They might feel fatigue because of the inflammation, or they might have low energy. They oftentimes have trouble sleeping. This translates into the kinds of jobs they're able to do and actually some family situations as well.

Dr. May:

Now, beyond just the physical burden, patients may encounter assumptions or misconceptions about their skin. How can those experiences add to the burden of disease, and what role can clinicians play in addressing them?

Dr. Cather:

So this is one of those things that if you look over the lifespan, there's a cumulative life experience that all of us have, right? We're all experiencing life, and we carry trauma with us, unfortunately, as we go through it. And hopefully, we get some help processing that trauma.

So if you think about children, oftentimes, mothers think children who have psoriasis are contagious and they will not let their children play with the children with psoriasis. You'll also see bullying because people look different. That translates into the misconception that this is a contagious disease. You touch it, and you get it. It is not like that at all.

The other thing is that people think they've been bad. And this happens because two-thirds of people have psoriasis on their genitals. And so one of the times we see a lot of psoriasis is when people are just starting to get into their psychosocial interactions with people, and they think they did something wrong because they had sex and they're somehow being marked for life.

So I think it's really important to tell people that a lot of genetics, environmental things, some food things, and lifestyle things are actually in the way with this disease.

Dr. May:

Building on what you were just mentioning, how can psoriasis affect the way patients navigate everyday social situations, relationships, and activities, and what can we do to better uncover those concerns?

Dr. Cather:

So the little itty-bitty kid does not realize they're different until the first other child or mother recoils from seeing their skin disease. I think it's important to break down the barriers that this is not contagious and that they're ready and able to participate in any activities that are available to them. They should not be excluded because they have psoriasis in their scalp and they have to share a helmet. This is not lice, right? You hear stories about women and men that cannot get their hair done because they go into a hairstylist and they go, "I don't want to touch that." You hear about this with women who can't get their nails done because they get psoriatic nails.

So we need to get the message out that you can't get this because it's not contagious and that we should be embracing people; we're all alike. And this is more than a rash because we do have systemic inflammation that can actually cause trauma because of what another human being does to them, and that's the thing I think we all need to be aware of: our actions have consequences, not just at the time it's done, but sometimes lifelong ramifications.

Dr. May:

Yeah, absolutely. For those just tuning in, you're listening to *On the Frontlines of Psoriasis* on ReachMD. I'm Dr. Alexandria May, and I'm speaking with Dr. Jennifer Cather about the day-to-day burden of psoriasis.

So, Dr. Cather, when it comes to the impacts on intimacy and sexual wellness, like you mentioned previously, patients can understandably be hesitant to discuss their concerns. How can psoriasis affect this part of a patient's life, and what can we do to make these conversations easier for them?

Dr. Cather:

I love that you asked this because I've written papers about this, and I've had epic failures when it came to this because I never understood that two-thirds of people have genital involvement. Nobody wants to be naked in a dermatology office. It's hard enough to get anybody to take off their shirt, let alone their pants and then their underwear. It's super vulnerable.

So I think it's really important to educate people. Two-thirds of people can get psoriasis on their genitalia. So let's think under the underwear and under the boxers. What that would mean is red, scaly skin; sometimes it's not scaly and it's macerated, meaning red and kind of glistening. They get fissures. It can affect any part of the genitals, like the labia in women and head of the penis or shaft of the penis in men. It changes if they ever want to have sex and if they can have sex, meaning that it's painful. And then again, think about the recoil. You can imagine this: a little child taking off their jacket to get in a pool covered with psoriasis, and everybody's starting to walk away going, "I don't want to touch it and I don't want to get in that water because I'm worried it's going to get on me." So again, they actually want to be intimate, but there's something called touch avoidance where if they have psoriasis, they'll do anything to cover it because they don't want to experience that social rejection.

I can remember my epic fail was not asking every single person about it. And it ends up that as a physician, people don't want to talk to me about it. They'll usually want to talk to my medical assistant about it. They will usually want to show me a picture of it. So trying to get the language out there that, "Hey, two-thirds of people can get something under their underwear. If you ever have it, it might not look like your other psoriasis, but I'm really interested in seeing it. If you do not feel comfortable showing me today, please show me a picture. I'll leave the room and you can take a picture, or when you come back, if you're comfortable and you've had a good experience with us, we'd like to treat all body areas."

The coolest thing about dermatology is you actually have an opportunity to follow somebody over their lifetime. I've got three generations of people in my clinic—all generations with psoriasis. So if a father will talk to his daughter or son like, "I've got psoriasis and, by the way, sometimes I get it under my underwear," you normalize it. So dermatology is head to toe and everything in between, and we're here for it.

Dr. May:

Now, once you understand how psoriasis is affecting an individual patient beyond just the physical burden, how do you translate that into meaningful treatment goals and conversations about management?

Dr. Cather:

Okay, so from a treatment goal perspective, our goal is to get people either completely crystal clear or less than 1% body surface area of involvement. That's actually a guideline for therapy. That guideline does not really take into account what a person's experience is. So besides getting them visibly clear, I'm very interested in the invisible impact of the disease. My invisible targets are: "are you itching? Are you in pain? Are you sleeping? Are you in an intimate relationship? Do you want to be in an intimate relationship? If you're not, why not? How can I help you with that?" I also want to make sure they're doing hobbies and being gregarious with others, right? Are they doing team sports? Are they doing Mahjong? What are they doing to actually interact with others? Because this can be a very isolating

disease.

So those are my targets, and they're very different for every person. And by the way, the best way to do this is I actually say, "If you did not have psoriasis, what would you be doing differently? Tell me three things that you'd like to be doing over our relationship, and I'm going to try to make that happen."

Dr. May:

And finally, where do you see the biggest opportunities to improve the way we care for and communicate with these patients in day-to-day practice?

Dr. Cather:

I think that normalizing the experience of having areas that are perhaps embarrassing involved with psoriasis and normalizing the experience of genital psoriasis is important. I feel like we need to validate that it does itch. By the way, I'm old. When I was training, psoriasis did not itch and dermatitis did. So validating that, "Hey, you might be fatigued because you have inflammation. Yes, you might be in pain. Yes, you might not be able to walk because it's on your palms. And by the way, you might not be able to zip up your zipper because you've got involvement of your fingertips." Validating that, "Hey, all these things are actually very important. They're important to me, and I want to try to help you with them."

And then we should communicate that we might not meet their needs. As a specialty, not every single dermatologist across the country is interested in psoriasis. I'm really interested in psoriasis. By the way, I faint at the sight of blood, so I am not your surgery girl. So there isn't one person, but if you have psoriasis and you're listening to this, you should probably consider going to the National Psoriasis Foundation. They've got a great website with nice information and a list of providers. So hopefully, you can get to somebody, and if you don't have a good experience, don't give up because I've been in this sector for 25 years, and there are medicines that can help you. We're not giving up. I don't want you to give up.

Dr. May:

That's a great comment for us to think on as we come to the end of today's program. I want to thank my guest, Dr. Jennifer Cather, for joining me to discuss how we can address the real-world impacts of psoriasis. Dr. Cather, it was great speaking with you today.

Dr. Cather:

Thank you so much.

Announcer:

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