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Catching HS Before Scarring Sets In

Announcer:

You're listening to *On the Frontlines of Hidradenitis Suppurativa* on ReachMD. And now, here's your host, Dr. Alexandria May.

Dr. May:

This is *On the Frontlines of Hidradenitis Suppurativa* on ReachMD, and I'm Dr. Alexandria May. Today we'll be exploring how we can recognize hidradenitis suppurativa early on to help prevent scarring. Joining me for this conversation is Dr. Iltefat Hamzavi. He's a dermatologist at Hamzavi Dermatology in Michigan, and he also serves as senior staff physician at Henry Ford Health Systems Department of Dermatology. Dr. Hamzavi, welcome to the program.

Dr. Hamzavi:

Thank you for having me, Dr. May.

Dr. May:

To set the stage for us, Dr. Hamzavi, why is it so important to recognize HS before scarring develops?

Dr. Hamzavi:

So there's a couple of reasons. The first element is, once you have scarring in HS—and let's break down what scarring means. So there's post-inflammatory hyperpigmentation, which can last months to probably years, and then there's structural damage, which is the sinus tunnels and atrophic scars. Atrophic scars and post-inflammatory hyperpigmentations are psychosocially disfiguring, especially in intimate areas, and especially in younger people who are trying to develop their own personality and their sense of self prior to major intimacy events.

The second component is functional. Once you have scarring—in this situation, we're talking about sinus tunnels—and when the sinus tunnels are draining, they have a change in the immunophenotype. As you might know, HS starts off as a disease mostly of T cells, and the T cells seem to be driving and being activated by the innate immune system, and then the adaptive immune system starts to kick in. But once you have a sinus tunnel—and if you've seen that clinically, there's a lot of pain that's associated with that sinus tunnel—it becomes a co-organelle with B cells, plasma cells, and a polyimmunophenotype. So now, you've added another source of inflammation, and if you look at all the studies so far, once you have sinus tunnels, it's very hard to get the disease back under control again.

And oftentimes, you will use medications to help reduce the drainage of the sinus tunnel, but ultimately, you need to do surgery to really remove that. So there's a disfigurement that's psychosocial in pigmentation as well as atrophic scarring, and there's a functional pain and progression of disease component that occurs once you have a sinus tunnel. And those are the two reasons why we want to prevent that scarring, which involves those three components.

Dr. May:

With that in mind, let's go back to the very beginning of a patient's journey. What does early HS look like, and how do patients tend to describe their symptoms before getting diagnosed?

Dr. Hamzavi:

HS can often be picked up just on a physical. As you might know, the definition of HS is two recurrent boils within six months, most often in flexural surface areas. So they'll describe these incredibly painful nodules, like the worst acne, pimple, or worst cyst they can imagine in flexural areas: the underarms, below the breast, inguinal creases, buttock. And oftentimes, they'll have this initial phase of sudden onset of swelling and then the pain, and then, depending on the subtype of HS, they'll have a drainage event that will occur when the

lesion breaks down.

And all of those steps can occur, one of them can occur, but they tend to have this burning, itching sensation, then subsequent pain. The pain builds up until the lesion opens up, and if it doesn't open up, it does resolve in some instances. And then the cycle starts back up again in a different location. Depending on the type of HS, some people do not scar for years. Some people get these individual lesions again and again without scarring.

Dr. May:

We know that HS is often missed or misdiagnosed. From your perspective, where does the diagnostic pathway typically break down?

Dr. Hamzavi:

So it breaks down often, at multiple locations. Oftentimes, people aren't screening for HS in a dermatology clinic. You're tending to engage with people in the early phases of their relationship with their bodies, and HS often develops in the 20s—late teens, early 20s—but can occur at any time in life. But if the majority of the population is occurring there, they walk in the dermatology clinic and they have acne, but the dermatologist may not ask them to elicit any history of lesions in the underarms or the gluteal folds of the buttock. So one of the things we ask dermatologists to do is, when people come in for an acne visit, just ask them to lift their arms up. And Dr. Steven Daveluy loosely describes this as a quick screening tool to see if there's any involvement of the axilla.

In the dermatology visit, people may have comorbidities associated with HS, such as severe acne or inflammatory bowel disease. But the vast majority of the population is being seen outside of the healthcare system even, often in GYN, in pediatric, in internal medicine visits, and it's not brought up, because, at this time we don't really do general examinations as frequently as we used to, and also there's an embarrassment of bringing this up.

So we need broader awareness in the public to ask, and clinicians evaluating these common locations. In the dermatology community HS is much more common we thought in the past. A quick question helps: when people have comorbidities, ask them if they have involvement in those locations.

Dr. May:

And as a follow-up to that, what are the most effective ways to navigate those challenges and ensure accurate diagnosis? What I'm looking to see is, are there any specific exam findings or history questions that reliably raise your index of suspicion?

Dr. Hamzavi:

Well, I think it's when you have recurrent boils that are symmetric, because as you know, furuncles and MRSA are relatively common infectious events. But when you have symmetric disease, when you have recurrent disease, when you have flexural disease, those should all raise your concern that you may have HS.

When you have atypical lesions that just do not heal properly, those are all elements that should raise your suspicion. When you have comorbidities such as tremendous increases in weight, metabolic issues with high hemoglobin A1Cs, in a family with a history of inflammatory bowel disease or individual spondyloarthritis, ask the patient, "Do you have involvement in these flexural folds? Do you get recurrent painful lesions in those areas?" And you'll often find that many patients do.

Dr. May:

For those just tuning in, you're listening to *On the Frontlines of Hidradenitis Suppurativa* on ReachMD. I'm Dr. Alexandria May, and I'm speaking with Dr. Iltefat Hamzavi about early recognition and management of HS.

So, Dr. Hamzavi, once HS is suspected, who else typically needs to be involved in a patient's care team, and how early should those referrals happen?

Dr. Hamzavi:

Jenny Hsiao has a very nice handout that is derived from one of her papers that lists the key primary care physicians and allied specialties, and I use that. And so, on that list, first off is caregivers and intimate partners. So it's helpful to encourage parents and partners to be aware of what the diagnosis is, especially the component that there'll be fluctuations. They may need some assistance, but also, this is not an infectious condition. This is not going to be transmitted. So that's one part of the care team, and probably the most actively involved part of the care team.

And then there's a list of allied specialties. So the primary care team should definitely be alerted because of the metabolic relationship to HS, as well as comorbidities such as spondyloarthritis and inflammatory bowel disease. And then, within that subgroup, you also want to have your surgeons. And the surgeons that you want to have are colorectal, reconstructive urology, and really, essentially, plastic surgery to assist you with the procedures beyond what the dermatologist can do.

And then you want to have your subsequent related fields such as psychiatry. Mental health is really impacted by HS. Unfortunately, this disease has the highest rate of completed suicide in dermatology, so having that team available is important. Now the vast majority of patients don't have it, but it's just that it's a significant comorbidity. Rates of depression are generally higher in that population.

In addition, you also want to add in rheumatology if they have spondyloarthritis, and the GI physicians if they have symptoms of inflammatory bowel disease. And then having a wound care specialist, a wound care nursing team, or a nurse that has experience with wound care can really help you manage the overall care. There are other allied professionals such as endocrinology and, other groups that you may want to add. But again, a lot of that will be dictated by your quick visit with them. But the primary care team, the GYN team, and the pediatric team really is your first line of defense.

Dr. May:

Let's shift gears now and talk about treatment. What does timely intervention actually look like in practice, and how much of a difference can it make in preventing scarring and tunnel formation?

Dr. Hamzavi:

So in the early years of work in HS—say, 10 years ago—we didn't know what the natural course of the disease is. We didn't know how many people would end up with boils that do not progress to scarring and how many people would. But then, we also were missing the fact that the lesions themselves can be very painful and disabling. So we have a better understanding of who's going to progress to scarring. We're not totally clear on that, but we have some information on that. And then we're also recognizing the comorbidities of significant pain, drainage, and itch that occurs with the nodules.

So essentially, the question is, who's considered to be moderate to severe, and then who's going to progress to significant disfigurement, scarring, and sinus tunnel formation? So, in general, when you have more than three nodules at any one time, you're moving into moderate-to-severe category. When you have two regions or more, that seems to be moderate to severe and more likely to progress. And when you have even one sinus tunnel, you are moving into the high-risk, severe category.

Dr. May:

Finally, Dr. Hamzavi, if there's one takeaway you want our audience to walk away with on early recognition of HS, what would it be?

Dr. Hamzavi:

It's much more common than you think it is, and a simple question can really develop a relationship with your patients. If you ask these questions, it takes you less than five to 10 seconds, and then you'll find these patients. And once you get them onto the right track, they tend to be really loyal patients who value your support. But you're also supporting your community, because it's a hidden plague that is occurring in our population that we're missing consistently. So I don't think it'll take a lot of time, and it'll really build up a great rapport with your patients.

Dr. May:

That's a great note for us to end on. A big thanks to my guest, Dr. Iltefat Hamzavi, for joining me to discuss early detection of HS to reduce the risk of scarring. Dr. Hamzavi, it was great having you on the program.

Dr. Hamzavi:

Thank you for having me.

Announcer:

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