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Exploring the Patient Experience in Atopic Dermatitis: Burden and Impact of Disease

Video | Voiceover for Introduction Slide:

This medical feature, brought to you by Pfizer, is titled "Exploring the Patient Experience in Atopic Dermatitis: Burden and Impact of Disease."

Joining us today are doctors Eric Simpson and Jonathan Silverberg, two experts in the field of atopic dermatitis, and paid consultants for Pfizer.

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Podcast | Voiceover for Introduction:

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ERIC SIMPSON, MD, MCR: Hello. My name is Eric Simpson. I'm a dermatologist and professor of dermatology at Oregon Health & Science University. I'm very interested in caring for patients with chronic inflammatory skin diseases, especially atopic dermatitis. And today we'll be talking about the impact of atopic dermatitis and the psychological burden felt by patients and caregivers. And I'm very fortunate to have an expert in this field, Dr Jonathan Silverberg. And I'll let him introduce himself.

JONATHAN I. SILVERBERG, MD, PhD, MPH: Hi everyone. I'm Jonathan Silverberg. I'm also a dermatologist. I'm an associate professor of dermatology and director of clinical research and patch testing at the George Washington University School of Medicine & Health Sciences. And I love caring for patients with atopic dermatitis and all aspects of research in atopic dermatitis. And I'm looking forward to a wonderful conversation.

ERIC SIMPSON, MD, MCR: Yeah, thank you so much for being here, Jonathan. So, we know as we treat patients in clinic that itch is so important; it really impacts patients' lives. But we did do some studies in patients in the United States with moderate to severe disease to understand the burden a little bit more in depth. Would you mind sharing the results of that study with our audience?

JONATHAN I. SILVERBERG, MD, PhD, MPH: Sure. So, this study was called the Atopic Dermatitis in America Study, and it's a cross-sectional study of 602 adults with atopic dermatitis in the United States and over 2,000 nonatopic dermatitis control patients. And amongst those patients with atopic dermatitis, it was shown that really the disease has a moderate to large effect on patients' quality of life. So, in particular, 80% of patients with moderate atopic dermatitis reported, you know, that atopic dermatitis limited their lifestyle. 89% of patients with severe disease reported that atopic dermatitis limited their lifestyle. With respect to atopic dermatitis' impact on activities, 73% of patients with moderate atopic dermatitis reported such impacts and 89% of patients with severe disease reported that atopic dermatitis limited their lifestyle. And similarly, when it came to the impact of the appearance of atopic dermatitis, 64% of patients with moderate atopic dermatitis and 92% of those with severe disease reported that the atopic dermatitis led to avoidance of social interactions because of their appearance. So, we really see this sort of holistic impact in terms of not only the visual component and the aesthetic component but certainly the functional impacts on lifestyle and physical activities.

ERIC SIMPSON, MD, MCR: Yeah. Thank you so much for that insight. I think it's really helpful for us as clinicians to know it's not just the skin rash but it's really the impact on multiple aspects of their life. And if you don't mind, I'd like to share a case with you that might illustrate this impact.

JONATHAN I. SILVERBERG, MD, PhD, MPH: Absolutely.

ERIC SIMPSON, MD, MCR: Yeah, so Jonathan, I have a patient I just saw last week. It was a Caucasian male, 32 years of age and he was a chef, kind of a rising star in the local restaurant here. And he's had poorly controlled disease for several years. He's been on multiple topical therapies including medium potency topical steroids and using them a little bit more than I would like, using them twice a day, every single day, as well as using a high potency topical steroid to some of these lichenified areas on his wrists and his ankles. He also had involvement of his back, so that was just very difficult for him to reach topically. And, you know, when I saw him, he was just poorly controlled, had lots of body surface area involved, and I could tell that, you know, he's kind of scratching in the room. So, the burden of itch was quite significant for him. And what I didn't recognize until talking to him further was this impact of the itch. He works in the kitchen and it's a hot kitchen, and he gets extremely uncomfortable as you might imagine with all that eczema on the back that's untreated. So, what do we know, Jonathan, about the impact of itch and how frequent this is in these moderate to severe patients?

JONATHAN I. SILVERBERG, MD, PhD, MPH: Yeah. So, there's actually, now multiple studies that have shown that itch is by far the most common symptom that happens in atopic dermatitis, pretty much universally in all patients. But it's not just the most common, it's also the most burdensome symptom that comes up. And that's been shown in multiple studies. But it's not just about, you know, it's there and it's burdensome. It's even something that patients use as an important criterion for determining the effectiveness of their therapy. In one study, approximately 95% of patients reported that the change of itch is really what is their most important criterion for seeing how a drug works. And it's not just itch. There's also an important component of skin pain that is increasingly being recognized. In one study, 78% of patients reported concomitant skin pain, such as burning or stinging. And, you know, along with the itch of their atopic dermatitis—and it's interesting because they often go together, the itch and pain, but not always. And I think we definitely need to pay more attention to the skin pain. Skin pain is also something that is more common in those areas of the body with greater sensory nerve density like the hands, perioral region, and toes. And of course, these are some of the more sensitive skin areas to begin with. And one study found that 33% of patients with atopic dermatitis reported skin pain at least once per week. So, we see this come up. It can be severe, and it can be quite common.

ERIC SIMPSON, MD, MCR: Yeah. I know. I appreciate your paper kind of illustrating what is the pain in atopic dermatitis. And it's a symptom that I haven't thought about much in these patients. So, you know, you can imagine this patient having lots of itch, as well as pain, that it can really disrupt his sleep. And that was something else that he was complaining about. I just felt so bad for him because he had, he was, you know, important at this restaurant, his presence. And so, he would have to show up to work no matter what. And so extremely fatigued, extremely symptomatic, you know, multiple poor nights of sleep. So, what do we know, Jonathan, about how sleep is affected in these patients?

JONATHAN I. SILVERBERG, MD, PhD, MPH: Much, if not perhaps most of the sleep disturbances, are related to the underlying symptoms like itch and pain. But it turns out it's a lot more complex than that. And we know from multiple studies that patients with atopic dermatitis can have higher frequency of sleep disorders, and, of course, related to those symptoms. We see really with our patients, you know, anecdotally, but also in the studies, that itch tends to peak in its severity in the evening and nighttime, likely because they're less distracted by work or things like that. But once that intensity of the itch goes up, you know, then we have this problem manifest with sleep interruption. You know one study showed that 64% of patients reported difficulty falling asleep and also with increased awakenings at night. In a U.S. population-based study, patients with atopic dermatitis reported difficulties falling asleep, having reduced sleep overall, increased nighttime awakenings from sleep, greater feelings of unrest, so poorer sleep efficiency and overall sleepiness during the day as a sort of consequence of that. And that is important because sleep disturbances have been shown

not just in atopic dermatitis but in many other diseases to be associated with missed work, decreased work performance, and inability to concentrate during the daytime. So not only a common but very impactful symptom that we really need to pay more attention to clinically.

ERIC SIMPSON, MD, MCR: Yeah. Thank you so much for that. You know, I had a patient with their spouse in the clinic the other day and his spouse was saying, no, the disease is not controlled because I just keep feeling his elbow hitting me at night. And I think patients are scratching at night and don't even realize that they're doing that. And I can imagine how that would really reduce the quality of their sleep, and lead to these downstream impacts such as fatigue, which we're learning more about and more studies need to be performed on fatigue and atopic dermatitis. But then it can also affect the psychological aspect of patients' lives. And this patient really did have lots of psychological aspects, so, and impacts from the disease. So, it wasn't just from the symptoms, but I think also having multiple days of poor-quality sleep could potentially affect his mental health over time. And he did have somewhat of a depressed mood and just felt like he was isolated. And so, what do we know about kind of how reduced sleep, how atopic dermatitis can impact the psychological aspects of patients?

JONATHAN I. SILVERBERG, MD, PhD, MPH: Yeah. Well I think, you know, you've touched upon really most of those salient points that really matter. But, you know, there've been a number of studies that have assessed the impact of atopic dermatitis on mood, you know, symptoms of depression or symptoms of anxiety. In one study of 2,000 patients with moderate to severe atopic dermatitis and their caregivers, patients experienced an average of nine flares per year, each lasting on average about 15 days. And when you do the math, you know, it translates to approximately one-third of the year spent in a flare and more than half of those patients expressed feeling unhappy or depressed during their flares. So, the mood symptoms can fluctuate very much with that fluctuation of itch and disease severity. And the flares were also found to impact work performance and productivity. We see it's those symptoms of anxiety and depression are really some of the most important ones that come up.

ERIC SIMPSON, MD, MCR: And just one final note on my patient—I didn't recognize this before—but he came in with his girlfriend, and I didn't realize how much trouble he was having with relationships prior to this. Relationships and his girlfriends did not really understand his disease and thought he was either contagious or it was all in his head. And so, it was really nice to see him find someone who understood his condition. But it made me recognize the impact, the negative impact it can have on your social relationships as well.

So, Jonathan, let me present another case to you to illustrate an adolescent patient with atopic dermatitis. So, she was a South Asian female, had atopic dermatitis for her entire life. She was initially controlled with medium potency topical steroids but started to worsen, and when she would withdraw from steroids or try to reduce her topical steroid use, she had severe edematous and eczematous lesions. They were weeping, crusting, had multiple *Staphylococcus aureus* infections despite the use of bleach baths. So, she was using more topical steroids than I was comfortable with and the impact on her life was quite significant. It seemed like the disease was really leading to behavior problems. She had concomitant ADHD, anxiety, and we've seen previously in a population-based study in the U.S. that ADHD, anxiety, conduct disorder and even autism has been associated with atopic dermatitis and associated with atopic dermatitis severity. And we did see several of these comorbidities in this patient. She also had significant sleep disturbance, so I think because of the itch and pain. Can you tell us a little bit about what we know about sleep disturbance in adolescents with atopic dermatitis?

JONATHAN I. SILVERBERG, MD, PhD, MPH: Sure. So, certainly the atopic dermatitis can affect the sleep of the adolescent, the affected child, but it really can affect the whole family, the caregivers, the siblings, et cetera. In a survey of children with atopic dermatitis or their caregivers, approximately 60% of children experienced sleep disturbances, which can involve up to 86% of nights disturbed during a flare. And of course, these are more severe patients, but it is something that really can have a profound impact on sleep. And not surprising, sleep disturbance was associated with increased itch severity, but sleep disturbance is a major contributor to poor quality of life in children and adolescents with atopic dermatitis. And, you know, the parents of children with atopic dermatitis can also have significant sleep loss caused by time spent managing overnight itch and putting the child back to sleep after waking up from itching. And also, this idea of co-sleeping as well that comes up with children. So, a big impact.

ERIC SIMPSON, MD, MCR: Absolutely. And then, you know, this loss of sleep and this poorly controlled disease really impacted school, which is probably, you know, the biggest impact for young kids. A lot of this was from just plain activity restrictions. So, she couldn't even extend her arms because of the cracking and pain from how inflamed she was. But it was also the poor sleep, the inability to concentrate. They put a lot of pressure on her from at home. And you can imagine trying to study, trying to perform well when you have that type of disease. It was just a really difficult situation. Can you tell us a little bit about the emotional consequences this can have on caregivers?

JONATHAN I. SILVERBERG, MD, PhD, MPH: Sure. There's actually a big emotional toll on families. Studies have shown that caregivers of children with atopic dermatitis can have feelings of anxiety, depression, and helplessness, and really feelings of guilt or self-blame. And the parents sort of blame themselves that their child has atopic dermatitis. Parents of a child with atopic dermatitis can

have increased absences from work, limits on social activities, and difficulties with childcare because of the child's atopic dermatitis. So really it can be very impactful on the family.

ERIC SIMPSON, MD, MCR: Jonathan, thank you so much for reviewing these cases with us and providing such interesting data regarding the state of the literature out there. I think we've learned that atopic dermatitis not only affects patients with their symptoms of itch and of pain, but also impacts multiple parts of their life, like sleep, work, and in children, their schoolwork, as well as even the family dynamic. So, I really appreciate your insight here. Thank you so much for your attention. In our next podcast we'll be talking about the pathophysiology of atopic dermatitis, but from a clinician's perspective.

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