

Improving the Understanding, Diagnosis, and Management of Generalized Pustular Psoriasis (GPP)



Podcast Series: Episode 5

- Adrian:** Hello, and welcome to “Improving the Understanding, Diagnosis, and Management of Generalized Pustular Psoriasis,” a podcast series brought to you by the American Academy of Physician Associates and The France Foundation. This activity is supported by an independent educational grant from Boehringer Ingelheim.
- This is episode five of a five-part series focused on generalized pustular psoriasis or GPP. In this episode, we will discuss the implications of GPP on our patients’ quality of life. This episode will review the burden of the disease, its impact on the quality of life of patients, and strategies to provide supportive care to patients for long-term management.
- We will specifically focus on describing the burden of disease or morbidity of GPP from a holistic standpoint by discussing how to incorporate clinical and psychosocial elements, including motivational interviewing, to impact behavior change.
- My name’s Adrian Banning. I’m a PA and an associate professor in the PA program at Delaware Valley University in Doylestown, Pennsylvania. I’m joined today by the fabulous, fantastic, wonderful, so smart, colleagues, dermatology PA Terri Nagy and dermatology NP Leigh Ann Pansch as we discuss generalized pustular psoriasis. Terri and Leigh Ann, thank you once again for being here. For those who haven’t been able to catch the other episodes in this series yet, will you each tell us a little bit more about yourselves?
- Terri:** Well, Adrian, that was quite the introduction. It is great again to be here with you and to be with Leigh Ann on our final podcast on generalized pustular psoriasis. I am Terri Nagy and I am a dermatology PA. I have been a PA for 25 years, working in dermatology for the last 20. I am currently located in Colorado, but spent most of my time practicing in Akron and Cleveland, Ohio. It’s great again to be here with both of you to educate our audience on this disease state.
- Leigh Ann:** Thank you so much for having me. I am Leigh Ann Pansch. I am a nurse practitioner practicing in private practice dermatology in the Cincinnati, Ohio, area. As I’ve said in every one of these, I absolutely love treating patients with inflammatory skin disease.
- Adrian:** I’m so glad that we’re all here together. I think that this episode is really so important. All of the other four are as well, but today we’re really talking about the implication to someone’s life, and I’d love to hear both of your perspectives, Terri and Leigh Ann. If you can talk to us about what you see with your patients and how GPP affects their quality of life and really talk us through the burden of it to their lives. Terri, if we could start with you, can you talk to us about the influence of this disease with your patients?

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- Terri:** Of course. Of course. Prior to me going to PA school back in the Stone Age, I was actually a social worker. So, therefore, quality of life is something that I am passionate about, especially when it comes to my patients. I think if we go back to Leigh Ann's description of the clinical presentation, we know that GPP is extremely pruritic. It can even be painful in some patients. Some of these patients have horrible joint pain and swelling. So thinking about doing activities of daily living, that seems like an almost impossible chore.
- Even things like sleeping is difficult simply due to the pain that they're in. Any time an individual has a skin disease or disorder, it impacts their life perspective and their perspective on their job and their social life, everything. Skin diseases are known to be linked to feelings of isolation, embarrassment, even depression and anxiety.
- I can't tell you how many patients tell me stories of total strangers approaching them and asking if they have a disease or if they're contagious. Many patients even tell me stories of how they don't even want to go out on a date or even be close to their family because they're concerned about the disease state that they have.
- Adrian:** That's heartbreaking. Thank you so much, Terri, for sharing those stories with us. Leigh Ann, in your voice as well, can you talk to us a little bit about how you've seen GPP affect your patients' lives?
- Leigh Ann:** I have several patients with generalized pustular psoriasis, and I'll tell you, if you were to line them all up, they would all tell you that their course came on them like a freight train. It happens so rapidly, they almost mourn their lives before. The quality of life effects are significant given that most of these patients have rash on more than 50% of their bodies, and it occurs so rapidly.
- In addition, a lot of these patients have comorbid arthritis, which can be debilitating. One of the first patients I ever met with generalized pustular psoriasis came in in house slippers because that was the only thing he could get on his feet, and he couldn't open the door to get out of the room because his hands were so full of pustules that were so painful.
- I think when you understand that this pustular rash on the hands and feet, maybe even involving their fingers and toes, affects things like walking and putting on clothing and buttoning and snapping things, not to mention the other activities of daily living that are affected, this is a definitive dermatologic 911 emergency. We really want to control the inflammation as quickly as possible.
- Adrian:** So sad. I'm not trying to express pity, but really just the understanding of this is going to influence every aspect of your life, and it can come on so suddenly. When you said, Leigh Ann, that patients often mourn their previous lives, that life is so different now. I want to ask you both, how often do you interact with our colleagues in behavioral medicine? Are you referring patients to counseling or psychosocial support? Can you talk to me a little bit about that just briefly?

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- Terri:** Yeah, I mean, I'm constantly referring out and referring back to PCP and writing letters to the primary care provider about concerns or suggestions that I have. So this is something that is part of our daily regimen of taking care of these patients is making sure that this disease state is addressed with a multi-specialty approach.
- Adrian:** Thank you. Yeah, it just sounds like GPP takes over their lives and it sounds like it affects almost every aspect of life I imagine. It's just such important aspect of their mental health. So, now we're going to talk about strategies to support patients for long-term management of GPP. What have you both brought into your communication in talking with patients that has made the most difference to patients with generalized pustular psoriasis living their best lives? Terri.
- Terri:** I think the most important thing to do with any patient diagnosed with any chronic disease is to ask them how this is impacting their lives. Then listen. Patients need and want to be heard. They need and want to be seen. They also want to get better. I have heard heartbreaking stories of how skin disease impacts employment, social life, romantic relationships. Leigh Ann just told the story of her one patient who couldn't even open the door.
- I will sit and chat with my patients about their skin disease. We discuss the pathophysiology because I think that's important. Sometimes these patients believe that they're contagious or they did something wrong, and that is what caused their skin disease. Then we talk through therapeutics. We talk through the FDA guidelines on blood work. We talk about potential side effects.
- I tell my patients we're on a team together, and we both need to work together to come up with the best treatment option. I think that makes a difference for patients. They feel like someone is listening and is going to help fight this fight for them. They are also encouraged if they ever need me, give me a call or email me if they have concerns or questions. I'm there to be in their corner when they need me.
- Leigh Ann:** I love that visual picture of walking alongside our patients. I think so often they come and even our stance is standing above them, and I think often just sort of getting them at eye level and really taking pause to listen can really change the course, and the patient begins to be hopeful that their disease can clear. I absolutely love this.
- I think this is an area that we can constantly improve upon in our professional careers. I think it's really important that we establish that we're walking alongside of our patients. If a patient is demonstrating or exhibiting any signs of personal distress, if they're crying, I often slow my words and I focus on listening rather than talking. I like to put myself at their level so my stance changes. If a patient is sitting, I'm going to hand them a tissue, and I'm going to align myself as a professional who's going to help.

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Leigh Ann: I choose my words carefully and I ensure that I address and repeat a patient's goals. I absolutely love shared decision-making. So, I often begin by giving a patient treatment options. For every single one of these options, I am discussing risks, benefits, and expectations. Remember, even not treating is a valid option. I begin with the option to not treat, and then I discuss why that may or may not be a reasonable option and how it may or may not line up with their ultimate goals.

Next, I lay out treatment options beginning usually with the least risky to the greatest risk. If a patient really desires quick improvement in their skin condition, I stress this point because I'm trying to meet their goals. Other patients may be very risk averse, so it's important to hear their concerns, but also speak to the potential harmful effects of inadequate treatment, including poor life quality where it's appropriate, and even radiographic joint damage.

Sometimes patients come in with a lengthy list of what they're striving for, and they search for things like these really strict diets or stringent exercise. I think that there are evidence-based information available on diets, exercise, and even supplements in patients with inflammatory skin disease. I love to share this data with patients who are focused on these treatments while I parallel their goals and their expectations and how do we meet up and what does the evidence tell us? I use phrases like, "I hear you saying..." and, "This is what the evidence suggests should be based upon our expectations with this therapy."

Adrian: I love that phrase, Leigh Ann. Not just in medicine, but in everyday conversation. It goes so far to reflect and validate whoever you're communicating with. "I hear you saying..." and then paraphrasing what you think you just understood. I love it. What a great tip. Thank you both so much for sharing how you approach this really personal conversation. It sounds like you both help patients to feel validated, and they have a real partnership with you both.

I would like to talk about motivational interviewing now as something that we teach in PA school when we're trying to help someone change, especially changing their behavior. It's a great way to improve the therapeutic relationship and help people identify and achieve their goals, particularly those that involve making life changes.

Right now we're going to dig into motivational interviewing a little bit. I'll start with a 2016 article by Lusilla-Palacios, et al. And here the author summarized research that shows dermatology treatment compliance hovers just around 55 to 66%, and it's even lower for topical treatments and chronic conditions, falling as low to about 30% for things like psoriasis.

How can we help to foster patients' adherence to treatment plans? Ideally, we're going to start with motivational interviewing. Like Terri and Leigh Ann have summarized, shared decision-making and empathetic care to get a treatment plan together that is going to help the patient.

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Adrian: Just a quick definition of those communication strategies. Motivational interviewing is a collaborative and goal-oriented style of communication of patient care that helps to, you guessed, to motivate people to make changes for their health by kind of exploring and addressing the patient's own ambivalence. Not ambivalence like not caring about something, but kind of being torn in two directions by talking through the factors that might motivate them and what might be getting in their way. But it's all done with a thread of compassion and acceptance.

Then it's possible to go through motivational interviewing in order of some steps or to move between some steps of motivational interviewing that I'm going to summarize before we hear from Terri and Leigh Ann a little bit more. Essentially, step one involves building a trusting relationship. And then step two is discussing the reasons that the patient is there, the goals, so you can move on to discussing any changes that need to be made. But you've got to know the goals first. Then, step three is exploring why someone might want to make a change, even if it is a challenge for them. So then, finally, step four, joint decision-making when the patient is ready. Terri, how do you use motivational interviewing?

Terri: That's a great question, Adrian. Motivational interviewing is a great skill, in my opinion, for anyone to have in any setting, not just healthcare. It promotes this sense of partnership and compassion and allows for goals to be set which work within the construct of a patient's life.

I think it is really important to ask open-ended questions to gain insight on the patient's experience and expectations. If I think therapy X is the best for my patient, and I don't ask or listen to whether this is a realistic option for them, even if it's the best treatment available, it won't be effective simply because my patient won't be successful at following through.

At the end of all my visits, I always summarize the plan we put in place. I revisit the prescriptions which are going to be sent to the pharmacy, any labs which are needed, and the expected timeframe for the arrival of medication. This is especially important when we're talking about these biologics. We discuss when I hope to see improvement of the skin findings so I can set realistic expectations for my patients and the timeframe for a follow-up. I always end my appointments with, "How does that sound," which then allows my patients to have the final word on their treatment plan.

Leigh Ann: Evidence suggests that seven to 15 minutes of motivational interviewing by a dermatology provider can increase patient adherence to treatment. In this case, I think it's important to think about ambivalence not as an attitude or of not caring either way about a choice as we sometimes use the word in everyday conversation, but rather as having two opposing views on something or having two contradicting views on the topic at the same time. It's a state of mixed feelings.

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- Leigh Ann:** In motivational interviewing, we first want to assess where the person is and what they think about the topic at hand and what their views are. It's important to consider their stage of change. If they acknowledge there's a need for change and how ready they are to make or sustain the necessary change. Then address why they might have mixed feelings. If you want to review on stages of change, look up Prochaska and DiClemente "Stages of Change" for review. If you want to know more, Miller and Rollnick are leaders in motivational interviewing scholarship, and MI can be broken down into a few steps and communication styles.
- Adrian:** Thank you so much, Leigh Ann. I'll summarize some of the steps and styles here very briefly for our listeners. MI is about partnering with the patient, helping them see their own priorities and abilities to explore why they might want to change, and then for us to be accepting of what the person says and prioritizing compassion.
- In order to have an effective conversation about change, it's helpful to use open-ended questions to encourage the person's efforts and past successes and let them talk so that we can reflect back to what the person has said, summarizing what we think that we've heard. It's a conversation, so it's important to keep in mind that you're both experts in the situation. The person's an expert in their life, and you're a medical expert, and you both have valuable things to say. This chat is really about both of you going back and forth.
- This chat, Leigh Ann and Terri, with both of you, was so helpful as an overview of some of the excellent patient communication skills. What would you both say are the key takeaways from what we've discussed today? Terri?
- Terri:** Taking care of patients is something I call a team sport, and everyone on the team has an important role. However, the patient, their experience, their needs, their expectations, that should drive each and every play.
- Adrian:** Leigh Ann.
- Leigh Ann:** I wholeheartedly agree. In addition, research shows shared decision-making improves patient satisfaction. So giving patients treatment options helps us as clinicians align with our patients' goals as well as their expectations partnered with our clinical expertise. Shared decision-making is always ideal.
- Adrian:** Leigh Ann, Terri, that brings us to the end of our series on generalized pustular psoriasis. Today, we specifically focused on the burden of GPP to the quality of life of patients, and we talked about communication and collaboration strategies.

Please tune into our other podcast episodes in this series where we talk through the pathophysiology, diagnostic challenges, steps to treatment, and current and emerging treatments related to GPP. We hope that you've learned more about how GPP affects patients' lives and our role in reducing that burden. You can find the full list of podcast episodes in AAPA's Learning Central Catalog at cme.aapa.org.