



Why so Blue? (Or Should I Say Red?) Recognizing the Emotional Impact of Psoriasis on Patients and Family Members: A Qualitative Study

Journal of Psoriasis and Psoriatic Arthritis
2022, Vol. 7(2) 60–66
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DOI: 10.1177/24755303211069335
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Abstract

Background: Psoriasis is a chronic skin condition with significant effects on quality of life, including impacts on emotional health. However, these experiences are not always addressed in clinic visits, despite their potential for significant effects on daily life. This study is part of a larger project on the effects of psoriasis on quality of life. The current information was analyzed separately because the amount of information on emotional impacts mentioned by participants was so significant that it warranted a separate analysis to thoroughly assess these experiences. **Objective:** To describe emotional consequences of psoriasis for patients and their family members. **Methods:** This project was conducted at an academic medical center in Utah. Experiences were discussed in interviews and focus groups with 25 patients and 11 family members. Thematic analysis was used to determine themes and subthemes. **Results:** This study sheds light on the damaging effects of psoriasis on emotional well-being, illustrating the challenges patients face from internal conflict, consequences for family members trying to cope with psoriasis in a loved one, and judgment from others who do not understand psoriasis and its challenges. **Conclusion:** Living with psoriasis leads to emotional consequences that may be left unaddressed in clinic visits, yet these experiences contribute significantly to quality of life. The stories told through this study can help clinicians understand how to identify and address emotional concerns to improve care for psoriasis patients and, as a result, improve quality of life for both patients and their families.

Keywords

psoriasis, quality of life, psychosocial impact, stress, depression, anxiety, suicidality, sleep disorders

Introduction

About 1–3% of US adults have psoriasis, a chronic inflammatory skin disease.^{1–3} Common features include characteristic skin findings and itchiness, but the effects of psoriasis on emotions and overall mental health are not as universally appreciated. While most dermatologists believe psoriasis affects their patients socially and/or emotionally, they also feel that the disease burden created by psoriasis is underestimated.⁴ A large population-based Danish study found that psoriasis was associated with most psychiatric conditions, including depression and anxiety.⁵ Diagnoses of depression and/or anxiety are more common among psoriasis patients compared to controls without psoriasis, and psoriasis patients with depression, anxiety, or both also have higher overall healthcare costs.⁶

Some psoriasis patients have trouble expressing their concerns, and clinicians may need to prompt their patients to

share the emotional impacts of psoriasis.⁷ Alexithymia, a condition where patients have difficulty identifying and expressing emotions, can affect between 20 and 30% of psoriasis patients and has been associated with worse anxiety scores, depression scores, and quality of life.⁷ Clinicians need to be

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able to understand their patients' perspectives, despite the brevity of the typical clinic visit.

To increase clinician awareness of the wide-ranging impacts of psoriasis on their patients' self-esteem, relationships, and quality of life, we conducted focus groups and interviews with patients and their family members. We explored the emotional impact of psoriasis, as expressed by patients and their family members, to bring to light concerns that would rarely come up during brief conversations in the dermatology clinic.

Methods

Study Design

We conducted a qualitative study on the emotional impacts of psoriasis on patients and their family members. This paper stemmed from a project exploring various aspects of quality of life for psoriasis patients and their family members. Emotional effects of the disease were so commonly discussed that this separate analysis was necessary to more thoroughly account for these effects. Further details on the scope of this project have been described elsewhere.⁸ In brief, this study included 10 interviews (4 patients and 6 family members) and 5 focus groups (21 patients and 5 family members). For recruitment, physicians asked patients with a diagnosis of psoriasis if they wanted to participate (clinical referral sampling) or patients were identified through the electronic medical record. Family members were recruited by asking psoriasis patients if they had a family member who would be interested in participating in the study. To obtain a diverse sample, investigators attempted to invite patients of varying age, gender, sexual orientation, and current disease status to the study. A semi-structured interview guide with questions about itchiness, pain, sleep quality, and personal relationships affected by psoriasis was used during both interviews and focus groups. Patients and family members completed a demographics questionnaire and provided written informed consent before starting the interviews and focus groups. Interviews and focus groups were conducted in-person and were audio recorded (except one interview where the audio recording did not work), and notes were taken throughout. Audio recordings were later transcribed. This project received approval from the University of Utah Institutional Review Board (#102556).

Data Analysis

To assess emotional impacts, two investigators conducted thematic analysis of the transcripts. They initially went through an interview transcript and developed a preliminary codebook on emotional impacts of psoriasis which evolved during the process of evaluating subsequent transcripts. The investigators met several times to compare and discuss their individual coding and adapt their codebook to new findings. They then assessed the data for themes and subthemes related to the emotional impacts of psoriasis found in the coding

process. The investigators assessed the transcripts using NVivo Pro version 12 (QSR International, Chadstone, Victoria, Australia) to account for results that may have been missed in the initial analysis. Data are presented in the form of quotes. A third investigator helped refine definitions for the final lists of quotes included in tables. Quotes included in this article were edited for clarity and to account for errors in transcription; editing rules are noted in [Supplementary material 1](#). Efforts were made to avoid changing the meaning of quotes.

Results

Of the 25 psoriasis patients, most (60%) identified as male, while most (64%) of the 11 family members identified as female. Most participants (92% of patients and 82% of family members) identified as white or Caucasian. Patients tended to be older than family members (median age: 46 years vs. 38 years, respectively). We determined three main themes for the emotional impact of psoriasis, including emotions for the patient, reactions of family members and friends, and reactions of society.

Theme 1: Emotions of the Patient

We found that patients were emotionally impacted by the disease itself but also by the reactions and emotions of individuals they come across, including family members, friends, strangers, and their physicians. Overall, emotions ranged broadly from irritation and despair to gratitude and sympathy ([Table 1](#)).

Subtheme 1: Emotional Impact of Psoriasis Itself

Emotions experienced by psoriasis patients were quite varied. Some were frustrated and irritated by their symptoms. Problems with itchiness, pain, discomfort, physical limitations, and trouble sleeping were described. Some felt burdened by having to spend time treating the condition or cleaning up skin flakes:

"Honestly, it's a pain in the butt. When I really break out, I itch terribly, to the point where I scratch, scratch until bleeding, and it hurts. And I have a hard time sleeping because I itch so much; and cleaning up after is a pain too, because it is flakes on top of flakes on top of flakes. It's just a pain."

Everyday things, like clothing choices, could be difficult: "She was very self-conscious, of course, about it. Will never wear a bathing suit or anything like that."

This could impact other aspects of daily life: "He does not want to show his body because of the spots; he does not use shorts or does not want to go to the beach."

One patient expressed the "mental toll" that psoriasis had taken:

Table 1. Illustrative Quotes of the Range and Complexity of Emotions Caused by Psoriasis for Patients^a.

Emotion	Quote
Acceptance/ resignation	"I never let it bother me. But I just changed. I just quit wearing dark clothes. I made sure I wore clothes that are not a single color. Usually, it's colored so that when you're shedding, I just tell people, 'I'm a snake and I shed.'" FG2 P2
Depression	"She says that when people say something, it does not bother her, but I know that bothers her just by the ways she acts afterward. [...] She just kind of shuts down a lot, like she gets very quiet and she does not interact with you. You could be interacting with her and then somebody asks and she is totally the opposite person afterward." IT8 FM "having to cover up and always being on guard to see people's reactions and have them ask you questions, it just puts you in a depressed state. So for me at that time, it just kind of put me in a depressed state; it does not make me a happy person." IT4 P
Despair	"At that time, I was like, 'What happened to me?' And I even [tried to hang] myself. My dad caught me." FG1 P2
Embarrassment/ shame	"it is embarrassing. Once, when I first got it, [...] I went swimming, and I had the big red patches. [...] I had a mother come up to me and tell me that if I didn't get out of the pool, that her kids would have to. And I tried to explain to her [...] that she couldn't get it, but she said, 'I don't care.' So that right there made me cover up more." FG1 P4
Frustration/irritation	"I just think that if people do not know, they need to educate themselves. You know, I feel that people just do not know, so they are ignorant. So, I really wish they were educated." IT1 P "You go to the doctor and he says, 'here, try this [petroleum jelly]-type stuff. And slime it all over your body [laughs] five times a day.' and you're going, 'no' [laughs]." FG2 P2 "I had to finally ask, 'Can you not draw attention to them when we're being intimate?' [...] Sometimes I don't realize how sad and frustrating this is. [...] Sometimes I just don't realize how hard this has been for me. I have plenty of other things in my life to worry about, so just add this to the list. But when you've worked on something for 13–18 years, turns out I am just going to have this? This is so unsatisfying." FG3 P2
Gratitude	"I come in to see Dr. [...] every 3 months [...] there's been twice when I've come in and had a spot on my face that I was absolutely positively sure it was psoriasis and it was not; and for that reason, I'm really grateful that I'm on the medicine and I have to come in every 3 months because otherwise, those pre-cancer spots wouldn't have been treated because I would think they're psoriasis and they're going to go away. And so, it makes me aware of other things that are going on, and she [the dermatologist] gets to look at it. And I think some people with psoriasis just feel like they have to deal with it, and then you might miss something that could be a different cancer." FG1 P5 "About 2 years ago, my daughter had a cancer scare, and she visited a dermatologist, who automatically was like, 'You have psoriasis,' and asked what I do for it; and I said, 'Nothing works,' and she told me [...] I had to see Dr. [...]. So I went and saw Dr. [...], and she fought insurance companies and got me on [ustekinumab] for over a year. And then I back slid and it came back. The insurance company wouldn't let me switch at first, but she fought it, and it worked, and now I'm on [guselkumab]. I'm starting to clear a little bit, and this is all I have left now [participant showing arms]. [...] I'm amazed. She really knows what she is doing." FG3 P5
Sadness	"And people are just like, 'What happened?'" That still hurt my feelings." FG1 P2
Sympathy	"I've seen people in the store with psoriasis just completely covering their arm, and my husband will go after them and he will be like, 'And here is the doctor in Salt Lake that you have to see.'" FG4 FM1
Worry	"I think I am getting better. I'm not totally positive. I still have some flakes at the bottom of my leg. I do panic when I see a red dot though." FG3 P4

^aStudy nomenclature: Interview type, person speaking.

Abbreviations: FG, focus group; IT, interview; FM, family member; P, participant with psoriasis.

"I've had it for so long that it has become an everyday battle for me. I remember when I first got it, I would go home crying, and I'm about to cry right now thinking about it."

Some would try to make it appear that they were not struggling, but some patients were not always able to contain their distress. One patient mentioned having suicidal thoughts and having had attempted suicide:

"I almost wanted to kill myself, when I barely had it."

Depression was also reported. Some patients felt very isolated and felt the need to stay away from others based on how they looked. Some experienced issues with self-confidence. Many patients were embarrassed and ashamed of the way they looked,

and there was mention of trying to cover up their skin so psoriasis did not show. Intimate relationships were sometimes frustrating:

"No fun, particularly in intimate relationships. Even if you have someone supportive, when you are being intimate and you feel them literally touch one of your plaques that you didn't even know was there because it's someplace you haven't seen and they can see it and they can touch it, and you're like, 'Oh bless your heart, you've just reminded me that I am leprous!'"

Some patients worried about others seeing their psoriasis-induced skin flakes and blood, and they would take precautions to make sure that no excessive flaking or blood stains were visible. The medical community's inability to help could also be frustrating:

“From a medical community that can literally sequence a genome, they just need to figure out: Where is this coming from? How can I fix it? What can I do? Even all the research isn’t great, and you start to do your own, like what can I do? I mean, a tube of cream and a pill is fine, but it doesn’t solve the entire problem. And here I am wanting to take better care of myself, and I can’t.”

Some patients became frustrated that their medications sometimes stopped working. A few patients reported not liking injections, though one patient expressed fear beyond the injection itself:

“I also hate medications and imagining being on a medication for the rest of my life was super scary.”

There was also worry about the side effects of psoriasis medications and the uncertainty of whether a medication would work.

Conversely, a couple patients mentioned being better on medication or just not letting psoriasis bother them. There were also patients who came to accept their limitations from psoriasis and resigned themselves to their current lifestyle, even if it was not the lifestyle they wanted to live.

Subtheme 2: Emotional Impact of Interactions With Family Members and Friends

Patients sometimes were irritated by family members’ and friends’ lack of understanding of the condition itself and the burden psoriasis created. Patients could feel burdened by family members’ reactions and expectations, and it was difficult for some patients to control the condition, let alone the annoyances it caused. Though family members might mean well in their suggestions, patients sometimes were very self-conscious about the condition to the point that they would become irritated by minor comments. Some patients were so ashamed of their condition that they no longer participated in outings with family and friends like they used to, whereas others experienced changes in their interactions with family and friends because of the reactions of those individuals. This could lead to shame, embarrassment, and sadness over not being able to participate in normal activities with loved ones.

Subtheme 3: Emotional Impact Created by Society

Patients felt the consequences of discrimination and stigma that exist in society against those with psoriasis. It could be difficult for patients to interact with others as there was a lot of misunderstanding. Many people did not understand what psoriasis is, and their reactions when seeing someone with psoriasis could be irritating. Strangers might believe the condition was contagious and stay away from the patient, making patients feel as though strangers were treating them like they had the “*plague*.” Patients might find that people stared or talked about the disease behind their backs. Strangers would go so far as to demand that a patient leave or tell them they could not participate, just based on

how the patient looked. Patients found it irritating and frustrating when these strangers simply judged their condition and did not listen and try to learn more about psoriasis. Lack of understanding was common. Even if strangers had some understanding of the condition, it was sometimes irritating when strangers offered unsolicited advice about how to help the patient with their psoriasis. It made socializing and being in public a challenge and created negative feelings due to the discrimination and stigma. The sadness and pain of these negative reactions from others in society could make patients feel very different and isolated from others. Patients reporting issues with these social challenges wanted these to change; they wanted to have other people learn more about psoriasis so that there is less discrimination and negative feelings toward them.

Conversely, some patients expressed gratitude for being able to talk with other psoriasis patients about the condition. The many negative interactions patients had with others who did not understand the condition made them sympathetic to others with psoriasis. It was difficult to deal with psoriasis, but patients could bond over their suffering and shared experiences.

Subtheme 4: Emotional Impact of Interactions With Physicians

Physicians did not always understand the main complaints of patients. Some patients and family members felt like physicians just brushed them off, and it could be difficult to understand what to do when the physicians did not have answers. When physicians did not seem to understand how to treat psoriasis, patients and their family lost faith in being able to receive help from physicians:

“Yes, it has been really intense. In the beginning, they told my sister, ‘That cannot be psoriasis.’ Because we were going through everything to figure out why she was getting all these sores all over her body, and that was the only thing we could come up with as, even as a possibility. And then for months, we were told, ‘No, it can’t possibly be; it can’t possibly be.’”

Patients expressed various frustrations: physicians not having clear answers, being misdiagnosed, and impractical recommendations from physicians based on patients’ their lifestyles and daily activities. However, gratitude was expressed when a physician cared about a patient and their condition, screened for other conditions beyond psoriasis, and provided adequate treatment. Patients also appreciated when physicians fought for better medication or quicker access to medication.

Subtheme 5: Emotional Impact of Interactions With Insurance and the Medical Field

Several patients were very irritated and frustrated by the high costs of their medications and delays in care waiting for needed treatment. Conversely, some were grateful when their

insurance covered their medication, especially when their medications worked.

Theme 2: Reactions of Family Members and Friends

Many family members and friends felt disgusted by the psoriasis experienced by patients (Table 2). These feelings sometimes were kept private, while others were more open about their feelings. The concerns ranged from how psoriasis looked on the skin to the shedding of skin flakes or blood, and this could lead to issues with intimacy. Some family members were irritated by the skin flakes that had to be cleaned up or losing sleep because their loved one scratched in bed during the night. Some family members were also embarrassed by the appearance of the patient. However, some also tried to be sympathetic and support their loved ones with psoriasis. There were family members who came to accept the condition and acknowledged the patients' feelings and life experiences with this chronic condition, and this led to family members having less aversion to psoriasis. Even a young child could recognize the difficulties of psoriasis and be willing to help.

Family members worried about medication side effects for patients, especially when severe side effects occurred:

"whenever he was doing the [etanercept] shots and he looked like he was ready to die, that was when it affected me. I was like, 'This isn't right.'"

For one patient, a suppressed immune system led to social isolation for her and her family because of concern that she could develop an infection. Identifying the best treatment for a patient was sometimes frustrating because patients might have to live with these side effects. Like patients, some family members also became frustrated with insurance companies not covering treatments for psoriasis or doctors not effectively treating psoriasis.

Family members might be saddened by a patient's experience with psoriasis. Some did not like seeing their loved one miss out on normal aspects of life and feel isolated from family or friends. At the same time, psoriasis could affect both the patient and their family's life decisions. Some family members worried about having children who might develop psoriasis.

Among siblings of children with psoriasis, jealousy might occur if a parent pays more attention to the child with psoriasis. One participant explained that her daughter with psoriasis had siblings who would get mad at their mother when she needed to spend time caring for her daughter's psoriasis.

Table 2. Illustrative Quotes of the Effects of Psoriasis on the Emotions of Family Members of Patients With Psoriasis³.

Emotional Reaction	Quote
Disgust	"It's definitely a self-esteem issue. [...] I've been single for 10 years now. I was married for 11 years, and when it kicked in, it really grossed out my ex-wife. I mean, she thought I was cheating on her and that it was like an STD or something, right? And there was a real trust issue there, and [...] I mean, I'm annihilated. I was married. So, yeah, I think it definitely affected my marriage. I mean, I'm divorced now [laughs]. And then, it probably dinged up my self-esteem, just by the way I look, by the way it grossed her out, and then having intimacy issues with ladies. [...] I don't want to gross people out, you know?" FG2 P3
Embarrassment/ shame	"I've noticed sometimes the girls [their daughters] would be embarrassed to be around when he was using shorts because his plaques looked so bad." FG4 FMI
Frustration	"We started with primary care doctor, and then we have seen the dermatology clinic in the university, and we have to go back through several appointments in the dermatology clinic and in the hospital before they even consider bringing in a doctor who deals with nothing but psoriasis in all its forms. And as soon as this doctor saw her, it turned to, 'This is psoriasis. I have seen it look exactly like this before. I can help you.' [...] Before it was, you know, we will go in and they want us to put ointment and a band-aid, you know, giving some kind of cream for allergies. You know. None of these is working for us. [...] This is not an allergy. It's not something that she is doing to herself. These are not just scrapes and bruises. [...] It was so many months before we got that specialist and got an answer. Before that, it just felt that we were just brushed off, and that is probably the worst feeling you can have when you are looking for help from doctors. Even if they do not have any answer: 'We do not know, but we are going to help you find it.'—that would be so much better than, 'See you. There is nothing we can help you with.'" FG4 FMI
Irritation	"It was not a big problem with her [his wife]. [...] it was just a pain [...] it flakes off, so she always got annoyed with that I suppose, knowing that I can't help it." IT4 P
Resignation	"him flaring up again reminds me how it was at the beginning, and so now, it has been pretty different. And I think there is that sort of constant awareness of his flaking around, like balance of me thinking about, 'Ok, I have to clean the house but not do it so much that he thinks I am paranoid about it.'" IT5 FM
Sadness	"Seeing him in pain—that is what bothers me the most." FG4 FMI
Sympathy	"My son knows where the [petroleum jelly] is, and he will go get it and come up behind me and start rubbing it on my back. He'll say, 'You have 'owies' on your back again,' and he just notices and knows to start rubbing them down. It's affected him that way; like, he knows more than a five-year-old should about how his mom is feeling." FG3 P6

Abbreviations: FG, focus group; IT, interview; FM, family member; P, participant with psoriasis.

³Study nomenclature: Interview type, person speaking.

They might all be playing a board game, but when her daughter with psoriasis started itching, the mom would have to stop playing to help her daughter.

Theme 3: Reactions of Society

Strangers could be disgusted by the visible effects of psoriasis. Participants indicated that many people did not know what the condition was and worried that it was contagious. This then affected how they interacted with psoriasis patients. One patient explained,

“Because you don’t have time to explain to all the customers what happened to you. [...] They can see your elbow, like, ‘What’s going on? What happened?’ But they’re not asking you, but you can tell from their look they’re like, ‘Is my food safe from here? You going to give me a disease or something like that?’ [...] She [her boss] walked straight up and told me, ‘Hey, you need to cover it up or you’ve lost your job.’”

It was somewhat easier if a patient worked with a consistent group of individuals and could explain psoriasis and its effects and lack of contagiousness to them.

Discussion

This study presents evidence of patients’ struggles with the emotional effects of psoriasis and the emotional consequences for family members. Psoriasis is not just a physical disease of the skin; its mental health consequences must be addressed. A variety of emotions were expressed by our study participants, highlighting the need to understand patients’ individual concerns and needs regarding the emotional and mental effects of psoriasis.

Given the results of our study, it may not be surprising that a significantly higher percentage of patients with psoriasis of any severity suffer with depression, anxiety, and suicidality compared to controls.⁹ Depression and low self-esteem are more commonly seen in those with severe psoriasis than those with mild psoriasis, and men struggle more with these effects than women.^{9,10} Patients in our study suffered from all of these, both as a result of personal concerns about the condition but also as consequences of others’ perceptions of psoriasis. Similar to what was expressed in our study, it has been reported that those who have heard of or known someone with psoriasis have less stigmatizing attitudes toward those with psoriasis.¹¹ A survey of US medical students found that some lacked knowledge about the range of effects that psoriasis has on health or physical pain, but medical students were less likely to endorse “myths” about psoriasis if they knew more about the disease.¹¹

Stressful situations not only impact patients mentally but also physically. Many psoriasis patients believe stress leads to psoriasis exacerbation,¹² with psoriasis exacerbation reportedly occurring within a matter of days after a stressful event.¹³ However, psoriasis patients who are more resilient may fare better in a stressful situation than those with low resiliency.¹⁴ Techniques to control

stress have been shown to be effective for some patients with psoriasis. A randomized controlled trial found that among psoriasis patients receiving narrow-band ultraviolet B (nbUVB) therapy, patients who also received cognitive-behavioral therapy (CBT) combined with biofeedback had a greater decrease in clinical severity of psoriasis than those who received nbUVB alone.¹⁵ Between the two groups, those receiving CBT also had a statistically significant improvement in their emotional state compared to controls.¹⁵ Group therapy could also help patients acquire coping skills and learn how to make their skin condition less pronounced in their everyday lives.^{16,17}

We must note, however, that while improving awareness and access to address mental health concerns in psoriasis patients would be very helpful, not all dermatologists feel comfortable or have a desire to address mental health in their patients.^{18,19} In a survey of dermatologists, 57% of participants felt comfortable making a diagnosis of depression, but 72% reported never prescribing antidepressants.¹⁸ While most felt comfortable diagnosing psychodermatologic conditions, fewer felt they were successful in treating these conditions, and dermatologists often did not refer appropriate patients for psychiatric help.¹⁸ Burnout is a real concern for those specializing in psychodermatology, and addressing mental health problems with patients can add additional burden to the already stressed physician.²⁰ Future efforts to address emotional concerns of the patient must also consider ways to alleviate burden on clinicians who wish to improve their patients’ quality of life.¹⁹

Failure to account for the overall mental health impacts of psoriasis is failure to account for a significant factor in psoriasis patients’ overall health and well-being. We found in our study that just giving patients a chance to discuss their problems, particularly with other psoriasis patients, was appreciated. Psoriasis can be an isolating disease, and patients may benefit from the chance to share their concerns and learn from others about coping strategies and complementary and alternative therapies. This study has limitations to its interpretability though.

We did not quantify our findings, but merely attempted to shine a light on common psoriasis concerns that are rarely discussed in clinic visits. Our focus was on the thematic elements of the discussions and the variety of experiences mentioned by participants. Thematic analysis brings new ideas that can inspire future research but also new approaches to interacting with patients. While our sample is biased toward a primarily white population at a single academic medical institution in Utah, many ideas have been presented to give clinicians insight into the perhaps unspoken effects of psoriasis. Further discussion of the subject may help elucidate additional specifics, but we believe our sample size was large enough to determine major themes and subthemes for the subject.

This study shows that the emotional impacts of psoriasis must not be overlooked when addressing patients’ concerns about their condition. We found that both patients and their family members struggle with the emotional toll of psoriasis and its consequences. We would advise clinicians to take a deeper look at the mental health and overall quality of life for

their psoriasis patients and consider the impacts on these factors when making treatment decisions.

Declaration of Conflicting Interest

The authors declare that there is no conflict of interest.

Funding

The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: This research project was funded by a Discovery Grant from the National Psoriasis Foundation awarded to Dr Secrest. Dr Secrest is also supported by a Public Health Career Development Award from the Dermatology Foundation.

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Supplemental Material

Supplemental material for this article is available online

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