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## Understanding the Psychosocial Impact of Vitiligo

### Announcer:

You're listening to *DermConsult* on ReachMD, and this episode is sponsored by Incyte. Here's your host, Dr. Charles Turck.

### Dr. Turck:

Welcome to *DermConsult* on ReachMD. I'm Dr. Charles Turck, and joining me to share counseling strategies to help patients cope with the psychosocial burden of vitiligo is Dr. Jim Del Rosso, who's the Research Director and an Investigator at JDR Dermatology Research and an Adjunct Clinical Professor of Dermatology at Touro University in Nevada in Henderson. Dr. Del Rosso, welcome to the program.

### Dr. Del Rosso:

Thank you for having me today. It's a pleasure to be here.

### Dr. Turck:

To start us off Dr. Del Rosso, what sort of psychosocial impact does vitiligo have on patients?

### Dr. Del Rosso:

Well first, we have to understand what vitiligo is, and obviously, there are changes in the color of skin because of what's happening. And it's a disease, it's not just a cosmetic issue, even though it's often perceived that way because patients develop areas where they lose the melanocytes, or the pigment cells, in their skin, and then their skin becomes discolored. And so it's going to be lighter than whatever their natural skin color is. So the darker you are in terms of your natural skin color, the more contrast you're going to have. So essentially, you're getting white spots in different areas of the skin, more than 75 percent, around the face and hands, so visible areas which obviously has an impact on that individual because they know that people are seeing it. And many patients are self-conscious about it. You might not necessarily see it when you're talking to the person or as a clinician necessarily pick up on that in conversation. But there's a lot more going on inside their head and inside their heart of how they feel than what we might understand because they're living with that every day, every time they encounter someone, and when they look at themselves in the mirror. So it really has a significant psychological effect on many people.

### Dr. Turck:

And if we take a moment to zero in on our adolescent and young adult patients, how can vitiligo impact them specifically?

### Dr. Del Rosso:

Well it could start very early in life, but often it starts later in life; it's not necessarily always early. But when it's starting earlier in life, it's obviously something that, especially nowadays, we hear about bullying, and even when I was growing up years ago, kids would pick on other kids. So they become self-conscious about it. They don't necessarily understand what's going on.

And then depending on what type of family members they have around them or parents they have around them, that support system is also going to be very important because if they're affected by it in an adverse way, that sort of gets transferred down to the child. With adolescence, I remember at 13 or 14 when I started to suddenly develop another kind of interest in other individuals, in my case in girls, you're very self-conscious about how you look, how you're being thought of, and how you're perceived. And so there's a lot of psychological effect because if somebody's looking at you, they're wondering, 'why do you have these white spots on your skin?'

And we have a lot of data to support that people get depressed about it. Their self-esteem is significantly impacted in a negative way. And other people looking at them don't know if it's contagious and they don't know what it is, what's wrong with this particular individual. So magnify that in the minds of the person that has it, if you are not experiencing this yourself, and that'll lead you to understand how it might affect someone on an everyday basis.

**Dr. Turck:**

Now with all that being said, Dr. Del Rosso, would you explain how a patient's response to treatment could also affect their quality of life?

**Dr. Del Rosso:**

The situation with vitiligo is we have to remember what's actually happening. It's an autoimmune condition. So for whatever reason, the body's developing a response that's actually causing those pigment cells to die in the areas where the condition is occurring. And so they lose the pigment cells, and any type of treatment is going to have to regenerate that factory. And sometimes that's possible, sometimes that's not. The pigment cell factory has to be regenerated. So that's going to take time.

And it can also be incomplete. So if you picture someone that has maybe 1 or 2 inches or a few areas on their face, maybe around their eyes or on the back of their hands, and it could be anywhere else on the body, when you give a treatment—and we have not had a lot of effective treatments, and the treatments, even newer ones that we're seeing much better responses with, are slow – it takes months of time to get the color to come back. Sometimes that's incomplete. So they still might have a speckled or an incomplete repigmentation of their skin. So it doesn't always come back that it looks perfectly normal or perfectly matched in color.

So even if they're going to treatment or seeing the best specialists for this, it's going to take a lot of time. And it's not always a complete improvement. So they're still dealing with the fact that it's visible or looking at themselves and seeing that difference in the skin color.

**Dr. Turck:**

For those just tuning in, you're listening to *DermConsult* on ReachMD. I'm Dr. Charles Turck, and I'm speaking with Dr. Jim Del Rosso about the psychosocial impact of vitiligo.

So Dr. Del Rosso, given the burden vitiligo can have on our patients, would you share some tactics that can help them open up about their unique challenges?

**Dr. Del Rosso:**

I think first of all, as a clinician, I've thought about this a lot. I'm seeing that individual in a snapshot in time. I'm going in, I'm seeing them, and I'm obviously going to be focusing on trying to help them with treatment. But I have to step back and think about how this might be affecting them.

And we have a lot of studies that look at quality of life parameters and different validated measures that individuals are answering. And those are pages long, and they're doing it over a long period of time to get that information of how that affects them. But that's not happening in a conversation in a doctor visit very often; we don't typically go through that much detail. There's not enough time to do it. And we're focusing on the management of it. So we don't always know exactly how it's affecting those particular individuals.

So I try to develop some way of connecting with them to let them know that I want to know how it's affecting them. They're giving me two or three ways that this really bothers them so that I could hear them say in their own words how it's affecting them. Because if you look at the literature, Charles, there's a lot of information that would surprise you on how this affects people, even in their own families. There are a lot of cultural aspects of that too that the literature points out that's different based on the background culture of the individuals, in many cases, how it really is affecting them on a day-to-day basis. So I try to make that connection early on so I could understand how it's affecting them before I get into, 'we have this treatment or that treatment. And this is the pros and cons of this treatment or that treatment,' the typical doctor talk with a patient, I try to step back and see if I could at least let them know that I want to understand how that's affecting them individually, not just assuming that is creating a problem, but understanding in their case how it's affecting them.

**Dr. Turck:**

Well once we have a better understanding of a patient's unique challenges, what counseling strategies could we use to help them cope with that burden?

**Dr. Del Rosso:**

Well what's interesting about vitiligo is that it's been described as having a low symptomatic burden or impairment and a high psychosocial burden or impairment. So it's not a condition that's creating symptoms like itching or burning; it's something that's visible. And that's why often it can be perceived as a cosmetic issue by third parties that are often paying for the different treatments.

But it's not just a cosmetic issue. It has significant psychosocial burden. People suffer from depression, fear of interaction with other people, fear of sunburning because they've lost some of the pigmentation in the skin, and fear of exposing those parts of the body, for whatever reason. So there's a lot of pressure.

So depending on what that individual is experiencing, you might need to get them help from some other professional that can help them cope with it because these people carry it for a long time; they carry it for their whole life once it manifests.

So not everybody's the same in how they can cope with it. I've seen some people who clearly tell me, 'It doesn't bother me at all. I've come to grips with it.' But many people do not. So I have some obligation as a clinician to understand how it's affecting that patient and ask them eye to eye, 'Do we need to get you some help in how to cope with this?' So you have to find out what's bothering that person and try to get them the help.

**Dr. Turck:**

Now we're almost out of time for today, Dr. Del Rosso. But before we close, do you have any final thoughts or takeaways you'd like to share with our listeners?

**Dr. Del Rosso:**

Well, I think it's important that now that we are developing much better therapies, and we can get patients often to completely repigment their skin or be significantly improved. And many of these patients will tell you that they feel a lot better. So first of all, letting people know that we have better options.

But if we can catch these individuals and get everyone to understand that if you're seeing this starting out, don't be thinking, 'well it may not get that bad, or we'll try the simpler measures that we know are not likely going to work.' Don't waste that time; that time is valuable, and the earlier you catch it, the better chance you're going to have to totally repigment someone's skin so they don't have to deal with everything that we've just been talking about. We can get around that. So earlier treatment is a very important message.

**Dr. Turck:**

Well with those key considerations in mind, I want to thank my guest, Dr. Jim Del Rosso, for joining me to discuss how we can help our patients cope with the psychosocial impacts of vitiligo. Dr. Del Rosso, it was great having you on the program.

**Dr. Del Rosso:**

Thanks a lot. It's a pleasure to be here. And I hope what I had to say will help a lot of people.

**Announcer:**

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