Body painter captures anguish of those who suffer from psoriasis

Patient Perspectives

If you’ve ever assumed that psoriasis is little more than a cosmetic issue, you would not be the first. According to the IFPA, the chronic inflammatory disorder affects roughly 125 million people worldwide, but it's still largely misunderstood. Because skin lesions are often the most obvious symptom of the disease, many write off psoriasis as only skin deep, ignoring its physical, mental and emotional toll.

A recent 49-page World Health Organization (WHO) global report debunked this myth, bringing the public health impact of psoriasis into focus with the message that much of the suffering caused by this common and complex disease can be avoided.

I just want to feel comfortable with myself and live normally, without the shame of showing myself.

Anonymous psoriasis patient

Inspired by the WHO report, we partnered with 25 patient organizations around the world to survey 8,300 patients from 31 countries, the largest global psoriasis survey to date.

But data tells only part of the story. To make the results more tangible, we commissioned an artist – body painter Natalie Fletcher, who also has psoriasis – to interpret survey participants’ experiences, using skin as her canvas.

Fletcher took inspiration from survey participants’ answers. Here are their words and the pictures they inspired:
“No matter how many times I tell my daughter that psoriasis is not contagious, she will not allow me to hug her.”

33% of those surveyed report feeling inadequate as a partner. That feeling can extend to all kinds of relationships, even between a parent and child. This photo brings to light the sensation of fear of contagiousness, which often lies at the heart of the issue.
43% of patients surveyed say that psoriasis has affected their relationships.
“At my worst, the cracks in my feet were so bad I could only hobble around. It is extremely painful even to just walk. Let me walk a step without pain.”

In addition to emotional issues, many survey respondents say they experience physical symptoms less commonly associated with skin disease, such as difficulty walking or even performing simple actions such as opening a jar.
54% of the employed patients surveyed feel their condition has affected their professional life.
Many survey respondents say they have dealt with feelings of aloneness and brokenness, as well as fear. For this photo, the artist used a broken mirror to represent a broken heart.

“I feel like this will last forever... I’m scared I will die alone.”
84% of the total sample report having experienced discrimination or humiliation because of their psoriasis.
“I dream of being able to go to the beach in a bikini and look beautiful.

Instead, I get disgusted looks from everyone.”
55% of patients surveyed do not feel that clear skin is an achievable goal.
“I hope people get a little bit of awareness about what psoriasis is and what people who have it deal with,” says Natalie Fletcher, who created these paintings using real patient quotes as inspiration. “I think it’s nice to put that message out there of ‘it’s not contagious, it’s not your fault’ to just bring some kindness.”

Tags:
Access to Healthcare [1]
Chronic Illness [2]
Living With Disease [3]
Patient Education [4]


Links
[1] https://www.novartis.com/tags/access-healthcare