

Holistic Assessment is Vital: Key Considerations in the Treatment of the Psychosocial Elements of Psoriasis



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Interviewees: Diamant Thaçi,¹ Stefano Piaserico²

1. Comprehensive Centre for Inflammation Medicine, University of Lübeck, Lübeck, Germany
2. Department of Medicine, Dermatology Unit, University of Padova, Padova, Italy

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Interview Summary

“Psoriasis isn’t just a skin disease”: depression, anxiety, and alexithymia are common in people living with the condition, as are low self-esteem and sexual impairment. The psychosocial elements of living with psoriasis, which are not always directly correlated with the extent or severity of skin lesions, can negatively impact the very foundations of a person’s life, for example, their job, the way they interact with their friends and family, what they wear, where they go, and the way they think about themselves.

In this article, EMJ conducted interviews with two key opinion leaders, each with a wealth of knowledge and experience in managing the psychosocial elements of psoriasis.

Prof Diamant Thaçi, from Germany, and Prof Stefano Piaserico, from Italy, explain some of the common psychosocial issues faced by people with psoriasis and discuss how these problems are often missed in the clinic. They believe that with a greater awareness of the issues and available solutions, clinicians can perform global assessments and suggest effective interventions based on each patient’s individual needs; for instance, newer biologic drugs can provide significant quality-of-life improvements by quickly and effectively clearing the skin and providing long-term results.

THE PSYCHOSOCIAL IMPACT OF PSORIASIS

Psoriasis can impact every facet of life, from occupation and career to family and relationships,

including everything in between. This chronic, inflammatory skin disorder typically causes plaques of dry, red, scale-covered skin. These scales may shed, and the skin can crack and bleed. Many people with psoriasis complain of

itching and/or pain but the physical symptoms are only one part of the disease.¹

Psoriasis has been linked to various comorbidities, including metabolic syndrome, liver disease, respiratory disease, cardiovascular disease, and psychosocial disorders. Studies have found that, depending on the screening method used, between 9% and 55% of people with psoriasis experience depression.² “The psychological impact of psoriasis and its overall effect on quality of life domains is really something that most people who do not have the condition couldn’t even imagine,” said Prof Piaserico. “When you are living with this and other people are reluctant to shake your hand, or people get out of the swimming pool when you are getting in for example, over time these things are crucial to the development of a deep sense of hopelessness and stigmatisation.”

Prof Thaçi and Prof Piaserico highlighted how people with psoriasis are often shy and have low self-esteem. The condition can lead them to actively avoid interacting with others or carrying out everyday activities. They often live in fear of others judging them for their skin condition and fear of the symptoms. Moving vigorously, or even sitting down in some cases, can cause the skin to painfully crack. Others may shed large quantities of scales as they move around, causing them to fear walking in public places. Psoriasis follows a relapsing-remitting path, and people in remission can also live in fear of the condition flaring.

The symptoms impact on the most intimate of relationships and can lead to sexual impairment. Both clinicians said that they have had patients who tried to hide their skin from their partners because they thought it made them less sexually attractive. Prof Thaçi described a woman who always hid her skin from her husband, even though he said he accepted her as she was. The patient feared that if her husband saw her skin, he would not love her in the same way. Prof Thaçi explained: “It is different for everyone, but young people with psoriasis especially can have more mental disorders, more anxiety, and more depression. They can be afraid of coming into contact with people. We often talk about low self-confidence, but it is more than that. They have a fear of showing their skin and feel like all the time they are being observed. They are afraid of how people may perceive them. Living like this in

the long term can have a cumulative impact on quality of life. There are patients who don’t even want to have children because they don’t want them to suffer in the way they are suffering.”

Prof Piaserico agreed, saying that many people internalised the stigma associated with the condition, which only sought to compound the psychological impact of disease. The prevalence of alexithymia, or difficulty in recognising and describing emotions, ranges from 15.6% to 33.0% among people with psoriasis.² This is much higher than the 10.0% found in the general population.³ “The more people hide themselves away, the more they hide their feelings. Because they are unable to express their emotions, they become unable to feel anything. They can just get used to feeling this way and do not seek help,” Prof Piaserico said.

“There are so many examples of the destructive power of psoriasis. I have patients who start crying after a couple of minutes; a young woman who felt she couldn’t wear a skirt due to psoriasis on her legs. There are people who are upset because of the way they have been treated in society or at work because of their skin condition. I had another patient who was moved from the job she loved, working behind a bar chatting to people, to the kitchen due to psoriasis on her face. They tell you what is going on in their lives and your heart just melts because you understand this is not just a skin disease, this is something much more.”

PSORIASIS, SLEEPING, AND ITCHING

Two areas where the physical and psychological aspects of living with psoriasis interact are sleep and itch. A report published by the UK’s Psoriasis Association and LEO Pharma⁴ last year found that these two issues had a significant impact on quality of life yet were routinely under-recognised by healthcare professionals.

This report included an online survey of 100 people living with psoriasis that found that 43% reported difficulty sleeping in the previous month. Of those, 100% said their sleep loss was caused by itching. More than one-third of those who experienced sleep loss also said they felt “despondent” about their skin.⁴ Long-term sleep deprivation is associated with an increased risk of Type 2 diabetes mellitus, hypertension, high cholesterol, obesity, and metabolic syndrome.

The literature also shows a strong link between sleep disruption and depression. Approximately 75% of people who have been diagnosed with depression report insomnia, which is itself a risk factor for the development of depression.⁵

Speaking about the connection between sleep, itch, and psoriasis, Prof Thaçi said: “If you look in old books, it is written that psoriasis does not itch. But when you ask the patients, it’s a very different story. The itch is different to what people experience in other diseases: it has a different intensity.” Current thinking, he explained, is that itch is the first sign of the Koebner phenomenon, or the appearance of new lesions on previously unaffected skin, secondary to trauma.⁶

“We find that the patient scratches, and then gets psoriasis in the place that they have scratched. This means that the itch is not only a subjective symptom but is also a psoriasis trigger. Even when the patient says they have no itch, they are scratching, trying to remove the scales. This can lead to bleeding in some areas. We have patients who wake up wondering what happened to them and why they are bleeding,” he added.

Sleep disturbance, rather than sleep loss, can contribute to psychosocial symptoms in this group of patients, according to Prof Thaçi. “We have looked at this and found that you can compensate for the amount of sleep you lose because you can sleep anywhere at any time. What you cannot compensate for is sleep disturbance. This is a big problem for our patients because if they cannot get a deep sleep, they feel tired all the time and cannot become motivated. It can have a big impact on their daily activities.”

BURDEN OF DISEASE

The severity or extent of the disease is not necessarily linked to the severity or extent of psychosocial impact, both clinicians highlighted. “The baseline Psoriasis Area and Severity Index (PASI) score is not always related to the baseline Dermatology Life Quality Index (DLQI),” explained Prof Piaserico. “You need to take into account the sex of the patient, their age, and many, many other factors. These are the things that influence how the condition affects their quality of life.”

Prof Thaçi agreed that it is just as useful to look at the burden of disease as it is to assess the severity

of disease. This can give clinicians a better idea of how the condition is impacting quality of life and, by extension, psychosocial domains, than the PASI score alone. Psychosocial impact depends on the burden of disease. That is determined by the patient’s age, sex, position in the community, level of activity and what they enjoy doing, as well as disease severity. “People who have had the condition for a long time can find the disease burden may not be as high as someone who has recently received a diagnosis. So, we have this disconnection of correlation between disease severity and psychosocial impact. I have patients who have mild disease and feel miserable and I have patients who have had psoriasis for 20 years and are indolent and you cannot move them to get treatment,” he said.

Prof Thaçi continued by describing how he saw patients who are afraid to shake hands or show their skin or nails. This, combined with the pain they often experience, means they are afraid to socialise and start to avoid contact with others. “Social contact is crucial for development in children and young adults, so from this context you can see how psoriasis can totally change the direction of a young person’s life,” he said.

Another key factor that influences burden of disease is the body area affected. Psoriasis plaques on the genitals can negatively impact on a person’s sex life, for example, and both doctors spoke of patients whose careers had been impacted by people’s perceptions of apparently mild disease on the face or hands. “Psoriasis can also be painful,” reported Prof Piaserico. “It can be like a sunburn that lasts for several months. People with psoriasis of the soles cannot even walk. This is another connection between the physical aspects of the disease and the psychological.”

NEED FOR GLOBAL ASSESSMENT

Prof Piaserico and Prof Thaçi both emphasised the importance of the global assessment of psoriasis patients. Understanding the full impact of disease on each individual patient, they believe, is the key to offering relevant, effective interventions. As most dermatologists are not specialists in psoriasis, however, they can sometimes underestimate the significance of holistic assessment. Prof Piaserico said: “Some dermatologists consider the psychological aspect of the disease to

be secondary or not relevant to the physical symptoms. They say it is their job to take care of the skin. But some therapeutic decisions are influenced by the psychological aspect.” He used the example of a person living with psoriasis that only affected the nails, a localisation that does not tend to respond to topical treatments. While such a patient would have a relatively low PASI score, the burden of disease may be high if their job required them to show their hands to others. He reported how one of his patients had felt forced to stop working as a jeweller for just that reason. “In this context,” added Prof Piaserico, “it is very important to consider the psychological impact of psoriasis.”

Identifying alexithymia in clinical practice is extremely important because the syndrome can increase the burden of disease and cause significant quality-of-life impairment. Psoriasis patients who experience the disorder experience higher levels of depression and anxiety, a higher risk of alcohol dependency, and more negative impacts on their work life than those who do not.² However, Prof Thaçi warned that the DLQI was not always sensitive to the issues that influenced the psychosocial elements of living with psoriasis. The score asks patients to rate, among other things, how their condition has impacted on activities including shopping or gardening and their ability to attend social events in the last week.⁷ When the burden of disease has led to the patient isolating themselves, such questions held little relevance. “When you do the DLQI, patients will say the condition doesn’t bother them so the score is low, but that’s because the questions are not applicable, sometimes they don’t have any friends, or they don’t go shopping or do sports, but that doesn’t mean the condition is not having a huge impact on them,” he said.

One of the questions on the DLQI, which is carried out routinely in many European countries, covers sexual activity. However, many patients will decline to answer it. The reasons for this are complex, but they may be embarrassed to talk about how their condition is affecting their sex life. If a patient is experiencing alexithymia, they may find it difficult to understand or express how sexual impairment makes them feel.

While clinicians may be experienced in identifying psychological symptoms such as depression, anxiety, and suicidal ideation, the impact of

psoriasis-related fear is harder to spot. This, Prof Thaçi said, was extremely difficult to measure. The interplay between the physical and psychological symptoms of psoriasis is another reason the two must be considered together as part of a holistic, patient-centred consultation. As Prof Thaçi explained, psoriasis can be exacerbated by stress, and a psoriasis flare is in itself a stressful situation.

“The connection goes deeper than this, however, and again relates to the fear element of living with the condition. If the patient is often in pain, they will have a perception that everything is painful. The pain may come from the skin or from a joint and it will have an impact on their perception of the disease. They may constantly be worried about sitting down for fear that their skin will crack and they will shed loads of scales that will be left when they stand up. Scaling on the skin can make them fearful of showing their skin and this can influence what they wear, where they go, and who they visit,” he said.

Rather than rely on PASI and DLQI scores, the clinicians said, dermatologists should get to know each patient and what matters to them. They recognised that the alexithymia some patients develop after years of avoiding social contact can make conversations difficult to start; however, they believe this approach is the only way to ensure patient needs are met.

“Patients are often depressed and reluctant to believe that anyone understands what they are going through,” said Prof Piaserico. “We need to change that mindset by being emotional and empathetic with our patients. I always start by telling them that I really do feel what they feel as I have a lot of experience in this area. Symptoms like pain and fear are very personal, so it helps to try to connect with them. I always say that I understand your suffering beyond the skin and what you are showing me.” Some dermatologists may be reluctant to start conversations about the psychological impact of psoriasis because they believe they cannot offer solutions to such problems. This is untrue, said Prof Piaserico and Prof Thaçi: if clinicians can get the physical symptoms under control, an easing in the psychosocial symptoms will soon follow.

TREATING THE CAUSE

Every person living with psoriasis will experience and react to the condition differently, yet there is some general consensus in terms of what they want from treatment. According to Prof Thaçi: “We have looked at this and what we have found is when you have a strong positive response to treatment, this is usually associated with a significant improvement in quality of life. If you ask patients what they want from treatment they say: ‘First, I want my skin to improve fast. Secondly, I want all my skin lesions to disappear, and finally I want this to last for the long term.’ We have found that once the skin has improved, their perception that their quality of life has also improved follows a few weeks or months later.”

Newer biologic drugs can provide rapid onset of action, high skin clearance, and sustained response. “Once you treat them and the skin is clean,” says Prof Thaçi, “you show them heaven and they do not want to go back to hell; they have a relapse in their understanding of the burden of the disease. Showing them how the skin can improve dramatically in a short period of time is crucial for their self-confidence and for giving them the belief that they can improve their psoriasis.”

Prof Piaserico has also recorded success with the new class of treatments. “The newer drugs are definitely more effective in improving quality of life, as measured with DLQI or other indexes. That is probably related to their higher efficacy in terms of skin activity.” He also added: “Some therapeutic decisions that I take might be influenced by the psychological aspect. In the case of the jeweller (above), if I was only looking at the picture from the symptoms, I would not have taken the decision to prescribe him a systemic treatment, and eventually a biological drug, but because of his profession and the impact on his quality of life, I did this.”

There could, he believes, be another factor influencing the high quality-of-life efficacy of the biologic products: immunopsychiatry, or the study of the relationship between mental diseases and the immune system. “There is some evidence to show that depression is an inflammatory disease.¹ If you lower inflammation with specific and powerful drugs, you might eventually improve the mood of some patients. I am quite convinced

about this because I have patients who have been using the biologic drugs and within 2 or 3 weeks are so happy and energetic that it must be something other than the efficacy on the skin.”

VALUE OF TREATMENT

Treating the skin treats the psychosocial issues surrounding psoriasis, both clinicians agreed, resulting in value not only for individual patients, but for society at large. “Ultimately,” stressed Prof Thaçi, “what makes a treatment successful isn’t any number or score, it’s the improvement in quality of life. When you treat [a patient] effectively, you bring them into a totally different condition. They feel much better, they are more productive in their lives, their work productivity improves dramatically. Once you give them their lives back, they are so happy to be able to contribute to society again.”

These wider benefits need to be taken into account as part of the therapeutic decision-making process, added Prof Piaserico. “In Europe, there are a lot of doctors who are not using these biologic drugs for psoriasis because they are expensive. It means that many do not ask about the psychological elements of living with the condition because they do not have a way of treating them. We need to give clear value to the treatment by giving value to the holistic assessment.”

As psoriasis is a long-term condition, people are resigned to living that way forever, but offering treatment provides them with something that cannot be measured, said Prof Thaçi. “When you help to improve the signs and symptoms of the disease and show them how important it is to control the disease, they are more engaged, they are more involved in their care. They are having a life. You can give them hope that the psoriasis is manageable. By improving quality of life, you tell them that they are not alone, that you will help and support them, and that this is not a disease they will take with them to the grave. If we tell them that this is a chronic disease that cannot be controlled, that there is nothing they can do because everything is too expensive, then we are taking away that hope. As a physician, there is one thing I appreciate more than anything else: someone opening my door with a smile on their face.”

WHEN YOU CAN'T TREAT, ACT

Of course, not every patient will be suitable for treatment with systemic biological drugs, but that does not mean psychological symptoms should be ignored. "If you cannot treat the psoriasis in the most optimal way, or you feel your patients need a more holistic therapeutic approach, for example, there are additional ways you can provide help. For instance, there are a couple of nice trials on the role of psychological interventions,"^{8,9} explained Prof Piaserico, who has published work looking at biofeedback and cognitive behavioural theory (CBT) in people with psoriasis and believes there is also a role for combining psychological and pharmacological interventions.

Prof Piaserico's 2016 paper¹⁰ describes a trial of 40 people. Candidates were randomly allocated to either an 8-week programme of CBT and narrow-band ultraviolet-B (UVB) phototherapy (treatment group), or an 8-week course of UVB phototherapy only (control group). A total of 65% of those in the treatment group achieved a 75% reduction in their PASI score, compared to 15% in the control group ($p=0.007$). The study demonstrated that CBT combined with biofeedback increased the beneficial effect

of UVB therapy in the overall management of the condition, reduced the clinical severity of psoriasis, improved quality of life, and decreased the number of minor psychiatric disorders.

"I was very sceptical," said Prof Piaserico, "but the study showed that patients treated with both UVB phototherapy and CBT heal more rapidly. I think this is something we should consider in our patients with psoriasis."

CONCLUSION

Psoriasis is more than a skin disease. Patients often live in fear of coming into contact with others, fear of symptom recurrence, fear of pain, and fear of embarrassment. People living with the condition commonly report depression, anxiety, and alexithymia, all of which can impact their ability to seek help. Despite such issues having a huge impact on quality of life, they are not always easy to identify with traditional scores such as PASI and DLQI. A greater awareness of the psychosocial elements of psoriasis among clinicians would allow for patient-centred global assessment and the provision of effective interventions. Systemic treatments that can quickly and effectively clear the skin and provide long-term results can also deliver significant quality-of-life improvements.

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