UNDERSTANDING THE PSORIASIS PATIENT: A Practical Approach to Patient Care

EXPERT DISCUSSION CHAIRED BY
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Psoriasis is a chronic immune-mediated skin disease affecting 7.4 million US adults\(^1\) and an estimated 125 million people worldwide.\(^2\) Its effects on the skin, however, are only part of its impact; psoriasis is linked to arthritis and other comorbidities, physical and emotional, and it frequently disrupts interpersonal relationships and work productivity.\(^3-5\) Psoriasis has also been linked to elevated cardiovascular morbidity, particularly for patients with more severe skin disease.\(^3\) Furthermore, according to patient reports, the disability associated with psoriasis is comparable with that associated with cardiovascular disease, diabetes, arthritis, depression, cancer, and other major medical diseases.\(^6\)

Psoriasis management is generally driven by disease severity. Patients with moderate disease (3%–10% of body surface area [BSA] affected) or severe disease (>10% BSA affected) are candidates for systemic therapy.\(^7,8\) In addition, nontopical therapeutic approaches may be needed when particular body regions are involved.\(^8\) The individual patient's assessment and perceptions of his or her disability are also considered when disease severity and therapeutic choices are being determined.

There are now more options for providing effective systemic treatment for patients with moderate or severe psoriasis. Development of newer systemic biologic therapies has been based on improved understanding of the pathogenesis and immunologic mediators of psoriasis.\(^9\)

Optimization of psoriasis outcomes depends on improved dermatologist-patient communication about the best way to manage the lesions and any social and emotional issues the patient may have. Evidence suggests there is too often a gap between patients and dermatologists in their understanding of a wide range of topics, including the disease in general, all available treatment options and their benefits and risks, and the presence and extent of emotional distress and associated disability.\(^10-13\) Many patients with psoriasis, particularly those with moderate or severe disease, are dissatisfied with how their condition is being managed, do not adhere to treatment, do not receive optimal treatment, or receive suboptimal treatment.\(^14,15\)
Psoriasis Undertreatment and Patient Dissatisfaction

In a 2013 report, the National Psoriasis Foundation (NPF) highlighted undertreatment and treatment dissatisfaction rates among patients with psoriasis in the United States. The reported study, which was based on NPF surveys conducted biannually from 2003 to 2011, analyzed data from 5604 patients with psoriatic disease who were randomly sampled from the NPF database and who completed the survey. Of these 5604 patients, 1286 had mild disease (self-defined as <3 palms of psoriasis), 2031 had moderate disease (3-10 palms), and 1894 had severe disease (>10 palms). (These criteria correspond to the BSA criteria described earlier.)

Psoriasis Undertreatment

Figure 1 shows that 49.2% of patients with mild psoriasis, 23.6% with moderate psoriasis, and 9.4% with severe psoriasis were not treated for the disease. In addition, although a higher percentage of patients with moderate or severe psoriasis received topical treatment in 2011 than in 2003–2005, 29.5% of moderate-disease patients and 21.5% of severe-disease patients in the 2011 survey received topical treatment alone. The NPF guidelines recommend the use of phototherapy, a systemic agent, or phototherapy plus a systemic agent as treatment for moderate and severe psoriasis. Panel member Dr. Andrew Blauvelt noted that these data indicate significant undertreatment of psoriasis in the United States: “The numbers may be even worse than they appear, considering that they are based on responses from members of the NPF registry, who likely represent more highly motivated and informed patients compared with those generally encountered in clinical practice.”

Less clear from the data are the reasons for undertreatment. The panel examined a few potential reasons. First, the term undertreatment seems to imply that the physician is providing less than appropriate treatment. In many cases, however, the physician fully informs the patient of all suitable options, including potential benefits and risks, but the patient, for any of a variety of reasons, decides to forgo treatment. Some patients are concerned about side effects, some deny the disease or its significance (they do not want to be “sick,” and being treated equals being sick), some do not want to be inconvenienced by regular administration of therapy, and some are accustomed to one therapy and do not want to switch to another, even if the alternative may improve outcomes (these risk-averse patients, who are better than they were before starting treatment, now ask, “Why risk loss of disease control?”). The panel concluded that the most the dermatologist can do in these situations is to fully educate patients about options and potential benefits, listen to their concerns and address them as best as possible, and, when treatment refusal is not in a patient’s best interest, strongly advocate for a different suitable therapy. With respect to potential drug-related side effects, the dermatologist must ensure that patients have a
clear understanding of the risks and benefits of the treatment being offered.

Another set of potential reasons for undertreatment involves physician knowledge and training, and the number of moderate and severe psoriasis cases in a physician’s practice. “Currently, of the roughly 10,000 dermatologists in the United States, only around 3000 will write biologic prescriptions, and only about half of those do so on a regular basis,” Dr. Blauvelt said. “Rheumatologists are better trained in use of the full range of systemic agents available for moderate to severe psoriasis, but dermatologists often see these patients first—and they should be more knowledgeable about all options, so they can be prepared to prescribe them when appropriate.” In a recent study in which 500 NPF members and 500 American Academy of Dermatology members were surveyed, up to 38% of the respondents who were treating psoriasis reported they “didn’t know” the effectiveness associated with various oral systemic and biologic therapies, and up to 49% “didn’t know” the likelihood of side effects associated with these agents.17

Although some dermatologists have not been sufficiently trained in biologic therapies and other systemic therapies, others have simply decided not to use them. Even a busy dermatologist may see only a handful of patients with moderate or severe psoriasis each month. As Dr. Blauvelt indicated, it would not be surprising to learn that, among infrequent users of biologic therapies, there is a general discomfort prescribing them.

Patient Dissatisfaction With Treatment

Besides reporting undertreatment issues, the 2013 NPF report based on surveys from 2003 to 2011 highlights high rates of treatment dissatisfaction among patients with psoriasis in the United States (Figure 2).14 When asked “How satisfied have you been with the treatment you have received for your psoriasis?”, 52.3% of patients with psoriasis said they have been dissatisfied. As for disease severity, 52% of patients with moderate psoriasis, 42.5% with severe psoriasis, and 39.3% with mild psoriasis reported treatment dissatisfaction (Figure 3).

It may be that, among dissatisfied patients with moderate or severe disease, the condition has been undertreated (treated only with a topical agent) and therefore poorly controlled. In addition, and as the panel members generally agreed, having to regularly apply a topical agent over a substantial portion of the body is unappealing. In a recent cross-sectional study on satisfaction among 1182 patients with moderate or severe plaque psoriasis, those who received biologic monotherapies, biologic-methotrexate combinations, or phototherapy had the highest overall satisfaction scores, and those who received topical therapy only, or acitretin, had the lowest scores.18 These findings may provide some reasons for the treatment dissatisfaction that the NPF report identified among patients with moderate or severe psoriasis.

Improving Dermatologist-Patient Communication

Good communication between dermatologists and patients is an important factor in uncovering and addressing patient dissatisfaction. “You want to be their cheer leader and their advocate, as well as their sounding board,” Dr Neal Bhatia said. The panel agreed that, ideally, dermatologists must allot enough time to educate patients about psoriasis and treatment options, and must try to learn of any potential social or emotional issues their patients may have. With respect to education, dermatologists typically define psoriasis, discuss its potential comorbidities (psoriasis is “more than a skin disease”), and lay out the full range of the patient’s disease-management options.

Social and Emotional Impact of Psoriasis

Optimal management of psoriasis involves addressing comorbidities. We now more clearly understand that psoriasis is a complex chronic inflammatory condition with multiple physical, social, and emotional issues that may have a significant impact on patients’ personal and professional lives.19 Although psoriasis treatment is appropriately focused on reducing skin
lesions while minimizing side effects, patients with psoriasis should also be assessed for any of the social and emotional effects of the disease and be offered any needed treatment. Emotional issues commonly associated with psoriasis include anxiety, depression, employment problems, low self-esteem, negative body image, sexual dysfunction, social difficulties or inhibition, stigmatization, and suicidal ideation. As these issues may contribute to a patient’s psoriasis-related disability, it is important to assess for them and, if needed, to discuss what can be done.

Identifying Social and Emotional Issues in Patients

The panel agreed that the first step in improving the management of social or emotional issues surrounding a patient’s psoriasis is to identify these issues. Out of embarrassment or another concern, however, patients are often reluctant to initiate discussion of these issues. Many times, when a dermatologist begins an examination by asking how the patient is doing, the quick and uninformative reply is “fine.” To identify or otherwise draw out this information, the dermatologist may need to turn to other strategies or tools.

Dr. Bruce Strober shared that, in his experience, asking a question such as “Are you happy with what we’re doing?” or “How happy are you with the outcomes of what we’re doing?” usually elicits a fuller, potentially more productive response. In addition, the panel experts recommended building enough time into patient visits, particularly the initial visit, to address both the physical and the emotional components of the disease. The initial visit may take longer than subsequent visits, which may not require any extra time. Should scheduling of longer visits prove difficult, the dermatologist can collect information about emotional issues in other ways.

One approach is to ask patients 2 simple general questions in sequence—the first involving the physical component, and the second the emotional component.

### Two Simple Questions That Can Make a Difference

1. **Thinking about how severe your psoriasis physical symptoms (such as itching, flaking, burning, pain) have been over the past week, how severe have they been on a scale of 0 to 10, 10 being the worst and 0 being no symptoms?**

2. **Thinking about how severe your psoriasis emotional symptoms (such as embarrassment, frustration, and depression) have been over the past week, how severe have they been on a scale of 0 to 10, 10 being the worst and 0 being no symptoms?**

The physical issues are addressed first, because patients generally perceive them as less threatening. The dermatologist asks patients to use a 10-point scale (10 = the worst, 0 = no symptoms) to describe the extent to which physical symptoms are bothering them. Subsequent questions address itching, flaking, bleeding, and pain from the disease as well as the extent and location of lesions. Then the dermatologist explores the emotional impact of the disease by asking the patients to use the same 10-point scale to describe how much embarrassment, frustration, social isolation, anxiety, worry, and other feelings are bothering them.

The panel emphasized that nonverbal signs can be useful in detecting social or emotional issues. Fidgeting, wearing
season-inappropriate clothing, and not looking the dermatologist in the eye are some of these signs. Lesions on the face or scalp may be disrupting patients’ lives more than lesions on other body areas are. Because many nonverbal signs differ from person to person, the same sign does not necessarily mean the same thing, but signs do offer suggestions or opportunities for further probing. Although not technically nonverbal, some indirect signs may be informative as well. For example, a new patient who had seen 2 or more dermatologists before coming to you may have been dissatisfied with the care received earlier.

Nonverbal signs may be helpful in identifying social or emotional issues that are affecting the patient with psoriasis. However, a sign may mean one thing for patient A but something different for patient B.

Some dermatologists are reluctant to probe a patient with psoriasis for emotional issues because they perceive it as opening Pandora’s box, panel members said. Once an issue is out, it must be addressed. Other dermatologists are uncomfortable talking with patients about social stigmatization, depression, or sexual intimacy issues: “Is the dermatologist’s office really the best place for this discussion?” Perhaps most important for many dermatologists, starting a discussion may give a patient an opening to bring up many other issues, and there is not enough time in the schedule to take them all on and have the practice function properly and remain profitable. Although we can talk about the ideal from a patient perspective, the reality is that many dermatologists do not have the time to fully examine and discuss patients’ emotional issues.

Given such time constraints, yet knowing the benefits of identifying and managing social or emotional issues in patients with psoriasis—care optimization and increased patient satisfaction—dermatologists should consider other creative ways to identify and address patients’ concerns. The panel suggested 2 possible approaches: enlistment of other dermatology clinicians and use of patient-reported outcomes and objective measurement tools.

DERMATOLOGY CLINICIANS
Physician assistants (PAs) and nurse practitioners (NPs) can play an important role in assessing the full impact of psoriasis on patients’ lives. For many dermatologists and other physicians whose time with patients is necessarily limited, PAs and NPs offer valuable assistance in patient care. For example, in the days before a dermatologist-patient consultation, a PA or an NP can speak with the patient and try to identify any social or emotional issues the patient has been having. If an emotional issue is identified, the clinician can discuss it with the patient and then give the dermatologist a summary report that can be reviewed before the consultation. The PA or NP can also facilitate discussion after the consultation and try to answer any of the patient’s additional questions about treatment options and other topics.

Tele dermatology consultations may be another avenue for patient-expert discussions about social and emotional issues surrounding psoriasis. One panel expert said that at least one group, in a study funded by the National Institutes of Health, is exploring this technological solution. Tele dermatology consultations presumably would also benefit patients who live in rural or other remote areas with limited access to psoriasis experts.

PATIENT-REPORTED OUTCOMES AND OBJECTIVE MEASUREMENT TOOLS
Objective measurement tools may be useful in reducing the time burden that comes with efforts to assess and manage the emotional and physical effects of moderate and severe psoriasis. Patient-reported outcomes (PRO) questionnaires, for example, could be used to screen for emotional issues. PRO questionnaires have already been developed for the exploration of patient satisfaction with treatment outcomes and for various other uses in psoriasis management, and questionnaires for other uses are in development. PAs and NPs can easily administer such a questionnaire to a patient, and report the results to the dermatologist just before the consultation.

PRO data are arguably more useful than physical examination findings, and in many cases may supplant them, Dr. Strober suggested. The problem with physical examination findings and other commonly used measures of psoriasis severity, such as BSA and the Psoriasis Area and Severity Index, is that there is often a discrepancy with patient satisfaction—the ultimate aim of care. Some patients have very little disease but are dissatisfied with their treatment outcome; others have more involved disease but are satisfied. In other words, the impact of psoriasis is patient-dependent. PRO data provide a more direct measure of patient satisfaction as well as clues to emotional issues negatively affecting the patient. Although PRO questionnaires must receive further validation before they can be routinely used in dermatologic practice, they hold the promise of serving as surrogate markers that can make the most of time-limited patient visits.

Psychosocial visual analog scales and other quality-of-life instruments, such as the Dermatology Life Quality Index, may also have a place in assessing the emotional impact of psoriasis. The panel suggested that these tests can be administered by office staff, and the results given to the dermatologist before...
he or she enters the consultation room. With these results in hand, the dermatologist gets an impression of the impact of psoriasis on the patient and can proceed accordingly.

**Clinical Pearls for Selecting Therapeutic Options**

Persistence on just one psoriasis treatment is fairly low. For this reason, dermatologists provide patients with education and guidance regarding alternative approaches to disease management. Patients typically look to dermatologists for such guidance.

Much panel discussion centered on the criteria for switching or adding therapies. Panel members agreed that prescribing alternative treatment options is an art involving many factors. Changes in effectiveness and safety are important, but so is the patient's satisfaction with the therapy he or she has now. The patient may or may not think that a relatively small decrease in effectiveness is reason enough to alter therapy. The dermatologist may consider a change when (1) an alternative therapy might be more effective for a long-standing patient whose disease control is suboptimal, (2) a therapy is insufficiently effective or is producing troublesome side effects, or the patient for some other reason is no longer satisfied with it, or (3) a therapy has lost its effectiveness or is now linked to safety or tolerability issues. According to Dr. Blauvelt, a simple way to quickly assess treatment satisfaction is to ask the patient if he or she is “clear and without side effects.” If the answer is yes, treatment continues; if the answer is no, treatment is reassessed.

**Consider treatment change when:**

- An alternative therapy might be more effective.
- A recently initiated therapy is insufficiently effective or is intolerable.
- A therapy has lost its effectiveness or has become intolerable or unsafe.

Panel members also agreed that, in their practices, movement to an alternative therapy tends to be a gradual process—occurring over 2 or more consultations with the patient, following trends in treatment effectiveness, and taking into account safety issues. Patient dissatisfaction with a therapy tends to be given more weight than a specific trigger (eg, a significant change in affected BSA) when alternative treatment options are being considered.

With respect to timing, panel members agreed that 3 to 6 months is generally a good point at which to evaluate and consider changing a therapy that is ineffective. Therapy change may also be considered when there has been a reduction in disease control. (Note that some patients are more concerned about losing the control they have than about improving it.) Further, which area is affected by the reduction in control—scalp, palms, legs, genitals, or other visible or sensitive area—may also alter patient perceptions. The evaluation can be highly patient-dependent.

Patients with psoriasis generally are more receptive to considering different therapies, or even eager to consider them, once they have perceived a reduction in control. Their willingness is driven less by the prospect of improving control. As Dr. Arthur Kavanaugh said, “Psychologically, people are more willing to do something to prevent getting worse than they are to get better. So if you say, ‘If you don’t do this, you’re going to get worse,’ you could probably get more people to consider alternative treatment options than if you say, ‘Well, you’re doing okay, but you could do better.’”

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Patients become anxious when it appears they might be losing whatever psoriasis control they have, especially when a significant amount of time and effort went into getting to that point. When presented with the prospect of improved control, they are more likely to consider how satisfied they are now, and to weigh whether possible improvement is worth the treatment change and whatever might occur with it.

Relationships with past and present dermatologists can also influence a patient’s receptiveness to alternative treatment options. For instance, a patient who has a positive psychological bond with one dermatologist may resist seeking another, or making any other move to change therapy, even therapy that has been suboptimal. The patient may also feel guilty about leaving the doctor’s practice, even if not completely satisfied with the care received—he or she improved to some degree there, after all.

Similar issues can arise when a patient’s longtime prescriber recommends changing treatment options. It is therefore important that the dermatologist lay out treatment expectations.
for the patient at their first and subsequent meetings. The dermatologist should make it clear that psoriasis treatment is not simple and that finding the best therapy may take some time. Patient and dermatologist need to collaborate to try to achieve the treatment goals that are set. In this collaboration, the patient needs to give the dermatologist an honest sense of his or her satisfaction with treatment. “It is important for the dermatologist to create a relationship where the patient feels comfortable saying that the treatment does not work,” Dr. Blauvelt suggested. “It is critical to establish a feeling of trust and openness at the initial visit in particular. This will pay large dividends in the future.”

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**Summary and Conclusions**

Psoriasis is a chronic inflammatory skin disease that is often accompanied by physical, social, and emotional issues. Recent data from the NPF report and other studies suggest that many patients with psoriasis are both undertreated and dissatisfied with how their condition is being managed.

In this article, psoriasis experts have reviewed these findings and presented their recommendations to help improve dermatologist-patient communication. In particular, they have drawn on their clinical experience to suggest better ways to identify psychological, emotional, and social issues that may negatively impact their patients with psoriasis. The panel members also discussed how improved communication can help in recognizing the need for alternative approaches to management. By following these recommendations, dermatologists will be better able to identify psoriasis patients’ sources of dissatisfaction and provide more effective treatment.

**REFERENCES**


