Undertreatment, Treatment Trends, and Treatment Dissatisfaction Among Patients With Psoriasis and Psoriatic Arthritis in the United States
Findings From the National Psoriasis Foundation Surveys, 2003-2011

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IMPORTANCE Psoriasis and psoriatic arthritis inflict significant morbidity. Data on undertreatment, treatment use, and treatment satisfaction are paramount to identify priority areas for advocacy, education, and research to improve patient outcomes.

OBJECTIVES To determine the extent of nontreatment and undertreatment of psoriatic diseases, trends in treatment use, treatment satisfaction, and reasons for medication discontinuation among patients with psoriasis and psoriatic arthritis.

DESIGN, SETTING, AND PARTICIPANTS We used the national survey data collected by the National Psoriasis Foundation via biannual surveys conducted from January 1, 2003, through December 31, 2011, in the United States. Survey data were collected from randomly sampled patients with psoriasis and psoriatic arthritis in the US population from a database of more than 76,000 patients with psoriatic diseases.

MAIN OUTCOMES AND MEASURES Nontreatment, undertreatment, and treatment trends determined by the use of prescription medication (topical, phototherapeutic, oral systemic, and biologic), as well as treatment satisfaction and reasons for medication discontinuation.

RESULTS A total of 5604 patients with psoriasis or psoriatic arthritis completed the survey. From 2003 through 2011, patients who were untreated ranged from 36.6% to 49.2% of patients with mild psoriasis, 23.6% to 35.5% of patients with moderate psoriasis, and 9.4% to 29.7% of patients with severe psoriasis. Among those receiving treatment, 29.5% of patients with moderate psoriasis and 21.5% of patients with severe psoriasis were treated with topical agents alone. The most frequently used phototherapy modality is UV-B, whereas methotrexate is the most commonly used oral agent. Although adverse effects and a lack of effectiveness were primary reasons for discontinuing biological agents, the inability to obtain adequate insurance coverage was among the top reasons for discontinuation. Overall, 52.3% of patients with psoriasis and 45.5% of patients with psoriatic arthritis were dissatisfied with their treatment.

CONCLUSIONS AND RELEVANCE Nontreatment and undertreatment of patients with psoriasis and psoriatic arthritis remain a significant problem in the United States. While various treatment modalities are available for psoriasis and psoriatic arthritis, widespread treatment dissatisfaction exists. Efforts in advocacy and education are necessary to ensure that effective treatments are accessible to this patient population.
Psoriasis is a chronic, inflammatory skin condition that is associated with significant morbidity.1 The direct and indirect costs of psoriasis are estimated at $11 billion annually in the United States.2 Patients with severe psoriasis often experience decrements in health-related quality of life similar to those with depression, diabetes mellitus, and congestive heart failure.3 In addition to the physical and functional impairments from their joint destruction, patients with psoriatic arthritis experience significant decrements in other aspects of activities of daily living, decreased quality of life, and loss of work productivity.4

Various topical medications, phototherapy, and systemic medications are available to treat patients with psoriasis of varying disease severity. For the treatment of psoriatic arthritis, nonsteroidal anti-inflammatory agents, disease-modifying antirheumatic drugs, and biological agents have been variably effective. Despite the availability of these therapies, little is known about the extent to which patients are being treated for their psoriasis and psoriatic arthritis. Few studies have examined whether patients with psoriatic disease are undertreated because such data are not routinely captured from health care systems. A 2007 study5 using survey data from the National Psoriasis Foundation (NPF) showed that almost 40% of patients with moderate to severe psoriasis did not receive any treatment.

Patients' perspectives are rarely explored in the literature, and few data are available about their satisfaction with psoriasis and psoriatic arthritis treatment, reasons for being dissatisfied, and rationale for discontinuing particular treatments. These data are valuable because they provide patient-centered views on the effect of treatment in real-world settings.

The NPF conducts surveys that identify undertreatment, treatment satisfaction, and reasons for discontinuation from patients with psoriasis and psoriatic arthritis. Such nationally representative data on real-world medication use as reported by patients are unavailable through other databases in the United States. In these surveys, the patients are asked to report their body surface area involvement of psoriasis (BSA), which allows for direct assessment of psoriasis severity at the time of survey administration. The objectives of this study were (1) to determine whether patients with psoriasis are undertreated, (2) to ascertain trends in medication use, and (3) to identify overall treatment satisfaction and reasons for medication discontinuation.

Methods

Study Design and Participants
Institutional review board approval was waived for this study. The NPF conducts biannual surveys to collect data from more than 76,000 patient members with psoriasis and psoriatic arthritis. We used the survey data collected during 13 biannual waves from January 1, 2003, through December 31, 2011 (2010 data were unavailable).

The questionnaires assessed the use of prescription medication to treat psoriasis and psoriatic arthritis. The medication categories included topical, phototherapeutic, oral systemic, and biological treatments. Specifically, the prescription medications included topical corticosteroids, nonsteroidal topical medications, calcipotriene and betamethasone dipropionate, calcitriol, cortisone, UV-B phototherapy, psoralen-UV-A, excimer laser, methotrexate, acitretin, cyclosporine, etanercept, adalimumab, alefacept, infliximab, ustekinumab, efalizumab, and golimumab. For each question on medication use, the responses were dichotomized to using the medication currently or not using the medication currently. Patient incentives to use or discontinue certain treatments were also examined.

The association between psoriasis severity and medication use was assessed. Psoriasis severity was determined by self-reported BSA. The participants were asked to estimate the number of palms that represented their BSA, where one palm represented 1% BSA. Psoriasis severity was categorized as mild (<3% BSA), moderate (3%-10% BSA), or severe (>10% BSA). The survey did not query patients about the severity of their psoriatic arthritis.

Statistical Analysis
Descriptive statistics were calculated for the demographic information of the surveyed population. To assess medication use over time, the survey waves were grouped into their corresponding calendar year, and the Cochran-Armitage test for trend was performed. Each medication was first analyzed independently, and each medication category (topical, phototherapeutic, oral systemic, and biological) was then subsequently analyzed. Analysis of the association between topical treatment alone and psoriasis severity was performed, and contingency tables were calculated across all waves and grouped periods. Statistical analyses were performed using commercial software (SAS, version 9.3; SAS Institute Inc).

Results

From 2003 through 2011, a total of 5604 patients with psoriasis or psoriatic arthritis completed the survey. The demographic information for the surveyed population is summarized in the Table. We assessed the proportion of patients not receiving treatment for psoriasis or psoriatic arthritis, treatment trends, and treatment satisfaction and reasons for medication discontinuation.

Not Receiving Treatment for Psoriasis or Psoriatic Arthritis
The respondents were asked whether they received any treatment for their psoriasis and psoriatic arthritis (Figure 1). The proportions of respondents with psoriasis receiving and not receiving treatment were analyzed by disease severity. From 2003 through 2011, 36.6% to 49.2% of patients with mild psoriasis were not receiving treatment compared with 23.6% to 35.5% of patients with moderate psoriasis and 9.4% to 29.7% of patients with severe psoriasis.
Treatment Trends (Topical, Phototherapeutic, Oral Systemic, and Biological)

The trends in medication use over time were assessed. The medications were categorized as topical, phototherapeutic, oral systemic, and biological.

Topical

The survey sought to determine the association between psoriasis severity and the use of topical treatments over time (Figure 1). In patients with mild psoriasis who were receiving treatment, the percentage of respondents using topical medications alone increased by 29.9% from 2003-2005 to 2006-2009 and then decreased by 13.6% in 2011 compared with the 2006-2009 period. Similarly, compared with 2003-2005, the percentage of respondents with moderate psoriasis who were using topical medications alone increased by 30.3% in 2006-2009 and then decreased by 17.5% in 2011 compared with the 2006-2009 period. In patients with severe psoriasis, the percentage of patients using topical medications alone increased by 11.3% overall from 2003 to 2011.

In 2007, patients who reported receiving topical medications alone were asked to assess the reasons why they were using topical therapy alone (Figure 2). The top-cited reasons from patients’ perspectives for using topical therapy alone were the following: fewer adverse effects than other treatments (18.6%), disease is not serious enough for other kinds of treatments (16.7%), and physician will not prescribe any other treatments (14.7%).

Phototherapeutic

The trend for phototherapy and laser use over time is summarized in Figure 3. The proportion of patients receiving UV-B phototherapy increased from below 8.5% in 2003 to 33.2% in 2004, was sustained from 2004 to spring of 2005, and decreased to a mean of 11.2% between fall of 2005 and spring of 2011. The subgroup analyses showed that the transient increase in phototherapy use from 2003 to 2005 was consistent between both sexes, across the various age groups, and among the different severity groups.

A similar but less dramatic trend was observed for psoralen–UV-A, which was used less frequently overall compared with UV-B. The proportion of patients with psoriasis receiving psoralen–UV-A increased from 1.8% in 2003 to approximately 10.0% between 2004 and spring of 2005 and decreased to less than 3.5% during the fall of 2005 to 2011.

Table. Demographics of National Psoriasis Foundation Survey Participants*

<table>
<thead>
<tr>
<th>Variable</th>
<th>Mild Psoriasis (n=1286)</th>
<th>Moderate Psoriasis (n=2031)</th>
<th>Severe Psoriasis (n=1894)</th>
<th>P Value</th>
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<tr>
<td>Sex, No. (%)</td>
<td></td>
<td></td>
<td></td>
<td>.72</td>
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<tr>
<td>Male</td>
<td>498 (38.7)</td>
<td>814 (40.1)</td>
<td>756 (39.9)</td>
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<tr>
<td>Female</td>
<td>788 (61.3)</td>
<td>1217 (59.9)</td>
<td>1138 (60.1)</td>
<td></td>
</tr>
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<td>Age, mean (SD), y</td>
<td>51.4 (15.8)</td>
<td>49.9 (15.3)</td>
<td>49.9 (14.6)</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Race/ethnicity, No. (%)</td>
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<td></td>
<td></td>
<td>&lt;.001</td>
</tr>
<tr>
<td>White</td>
<td>1130 (87.9)</td>
<td>1792 (88.2)</td>
<td>1609 (85.0)</td>
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<td>African American</td>
<td>17 (1.3)</td>
<td>27 (1.3)</td>
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<tr>
<td>Asian American</td>
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<td>35 (1.7)</td>
<td>49 (2.6)</td>
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</tr>
<tr>
<td>Hispanic</td>
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<td>58 (2.9)</td>
<td>79 (4.2)</td>
<td></td>
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<tr>
<td>Native American</td>
<td>13 (1.0)</td>
<td>21 (1.0)</td>
<td>25 (1.3)</td>
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<tr>
<td>Unknown</td>
<td>55 (4.2)</td>
<td>98 (4.5)</td>
<td>76 (3.7)</td>
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</tr>
<tr>
<td>BMI, mean (SD)</td>
<td>28.0 (8.6)</td>
<td>28.2 (6.2)</td>
<td>29.8 (7.4)</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Psoriatic arthritis, No. (%)</td>
<td>359 (27.9)</td>
<td>637 (31.4)</td>
<td>879 (46.4)</td>
<td>&lt;.001</td>
</tr>
</tbody>
</table>

*Psoriasis severity was categorized as mild (<3% body surface area involvement of psoriasis), moderate (3%-10% BSA), or severe (>10% BSA).
A cimer laser was infrequently used, with only 1.3% of respondents with psoriasis reporting treatment in 2011.

Oral Systemic

Regarding oral systemic medications, the patients were asked if they were using methotrexate, acitretin, or cyclosporine to treat their psoriasis. In general, methotrexate was the most frequently used oral systemic medication compared with cyclosporine and acitretin (Figure 3). The percentage of patients receiving methotrexate fluctuated between 9.8% and 14.5% from 2003 through 2011. From 2003 to 2009, acitretin was used infrequently in about 0.7% to 4.2% of the patients. In 2011, 22.6% of the respondents reported using acitretin. Cyclosporine was used in only 0.5% to 2.3% of the respondents during the survey periods.

Biological Agents

The trend for biological agent use over time was assessed for etanercept, adalimumab, alefacept, infliximab, golimumab, and efalizumab. Etanercept was approved by the US Food and Drug Administration in 2002 for the treatment of psoriatic arthritis and in 2004 for the treatment of moderate to severe plaque psoriasis. Correspondingly, the proportion of patients receiving etanercept increased from approximately 8.0% in 2003 to 24.5% in 2004 (Figure 3). While its use was sustained from 2004 (24.5%) to spring of 2005 (25.2%), the proportion of patients using etanercept then varied between 11.3% and 19.8% from autumn of 2005 to 2009 and 2011. Following the approval of adalimumab for psoriatic arthritis in 2005 and then for psoriasis in 2008, a gradual increase in adalimumab use was observed from 2008 (8.7%) to 2011 (12.4%). Overall, the respondents reported infrequent use (<5%) of alefacept, infliximab, golimumab, and efalizumab. Efalizumab was withdrawn in 2009 because of safety concerns. Alefacept was removed from the market in 2011. Of note, ustekinumab was unavailable in the United States until shortly before 2011. Because of its approval time, ustekinumab was not assessed by the NPF surveys during these periods.
medication use patterns from patients’ perspectives. Furthermore, this study provides insight into the NPF surveys comprise the largest data source for determining treatment trends and undertreatment patterns among patients with these conditions within the last decade. Although claims and pharmacy data are useful to ascertain prescription patterns, the NPF survey allows for direct assessment of whether patients actually used the medication. To date, the NPF surveys comprise the largest data source for determining patient use of medications, nontreatment rates, treatment satisfaction, and reasons for medication discontinuation in the United States. These study findings help determine gaps in therapy in which patients are not treated or are undertreated for their psoriatic diseases. Furthermore, this study provides medication use patterns from patients’ perspectives.

Discussion

With an expanding array of therapeutic options for the treatment of psoriasis and psoriatic arthritis, it is imperative to determine treatment trends and undertreatment patterns among patients with these conditions within the last decade. Although claims and pharmacy data are useful to ascertain prescription patterns, the NPF survey allows for direct assessment of whether patients actually used the medication. To date, the NPF surveys comprise the largest data source for determining patient use of medications, nontreatment rates, treatment satisfaction, and reasons for medication discontinuation in the United States. These study findings help determine gaps in therapy in which patients are not treated or are undertreated for their psoriatic diseases. Furthermore, this study provides medication use patterns from patients’ perspectives.

The NPF survey allows for data collection from patients with psoriasis and psoriatic arthritis who are more representative of the general population than those recruited for clinical trials. In traditional clinical trials, data are collected from participants meeting defined inclusion criteria, while the NPF surveys collect data from patients having psoriasis and psoriatic arthritis with various demographic and socioeconomic backgrounds. The random sampling method ensures that there was less than 1% overlap in the sampled population from one survey to another, providing representative medication use rates among the larger pool of patients.

These study findings show that a large proportion of patients with psoriasis are not receiving any treatment at all. Specifically, in 2011 almost half of the patients with mild psoriasis, one-quarter of the patients with moderate psoriasis, and almost 10% of patients with severe psoriasis were not receiving any treatment. These estimates are likely more conservative than those among the general US population with psoriasis because the respondents, who are members of the NPF, are probably more engaged with their health care.

Undertreatment also represents a significant problem. Approximately 30% of patients with moderate psoriasis and about 20% of patients with severe psoriasis receive topical medication alone. With the availability of multiple immune modulatory agents, ensuring that patients are offered these therapeutic options is paramount to improving patient outcomes.

Regarding treatment trends, UV-B remains the most preferred phototherapeutic modality. Among systemic treatments, the proportion of methotrexate use is consistently greater than that for acitretin and cyclosporine. For biological agent use, although etanercept was initially the most preferred treatment, adalimumab exceeded etanercept use based on these patient-reported data. Reasons for discontinuing a biological agent were explored in selected survey waves. Although the primary reasons for discontinuation of a biological agent in 2007 and 2008 were related to efficacy and adverse effects, insurance-related access issues were also among the top reasons for discontinuation of a biological medication.
The NPF surveys showed that the patients’ treatment dissatisfaction was widespread. With more than half of the patients having psoriasis and more than 40% of the patients having psoriatic arthritis dissatisfied with their treatments, increased efforts in advocacy, education, and research are necessary to improve patient satisfaction.

The study findings need to be interpreted in the context of the study design. Some selection bias may be present among the surveyed respondents. Although this is the most comprehensive patient-oriented survey to date about medication use and treatment satisfaction, the NPF survey respondents may differ from the general population in that they might represent a population intrinsically more motivated and knowledgeable about their disease and treatment options. Therefore, this potential selection bias may result in an underestimate of the degree of nontreatment or undertreatment among patients with psoriasis. In addition, because respondents were queried about the extent of disease at the time of the survey, it is possible that the severity at that time may not be representative of their usual disease course. Therefore, future studies that query patients’ disease severity assessments at multiple time points would likely yield more representative severity evaluation.

Nontreatment and undertreatment of patients with psoriasis and psoriatic arthritis remain a significant problem in the United States. Although various treatment modalities exist for psoriasis and psoriatic arthritis, widespread treatment dissatisfaction exists. As efficacious treatments are introduced to this patient population, concurrent efforts in advocacy and education are needed to ensure that these medications are accessible to those most likely to benefit and that patients are properly informed of the benefit-risk profiles. Collaborative efforts from the various stakeholders, including patients, physicians, payers, regulatory agencies, and advocacy organizations, are necessary to improve the lives of those affected by psoriasis and psoriatic arthritis.

**REFERENCES**