The Impact of Psoriasis on Quality of Life

Results of a 1998 National Psoriasis Foundation Patient-Membership Survey

Gerald Krueger, MD; John Koo, MD; Mark Lebwohl, MD; Alan Menter, MD; Robert S. Stern, MD; Tara Rolstad, MBA

Background: Psoriasis can have a profound impact on a patient’s quality of life.

Objectives: To assess patients’ perspectives on the impact of psoriasis on their lifestyle and emotional well-being and the social ramifications of living with the disease; to determine the range of therapies available; and to ascertain patients’ satisfaction with the management of their disease.

Design: A 4-page, self-administered questionnaire was mailed on July 13 and 14, 1998, to the entire membership of the National Psoriasis Foundation (N=40350), and followed by a telephone survey of responders with severe psoriasis.

Main Outcome Measures: Patients’ perspectives on the psychosocial impact of psoriasis and the effectiveness of the management of their disease.

Results: Of the 40350 questionnaires mailed out, a response rate of 43% was realized. The most frequent symptoms experienced by the mail-survey respondents were scaling (94%), itching (79%), and skin redness (71%); 39% reported that psoriasis covered 10% or more of their bodies. A total of 6194 patients with severe psoriasis were entered into the database for the telephone survey. Of these, 79% reported that psoriasis had a negative impact on their lives, 40% felt frustrated with the ineffectiveness of their current therapies, and 32% reported that treatment was not aggressive enough.

Conclusions: The unprecedented response to the survey provides compelling evidence that individuals with psoriasis believe that the disease has a profound emotional and social as well as physical impact on their quality of life. Many patients with psoriasis, particularly those with severe disease, are frustrated with the management of their disease and by the perceived ineffectiveness of their therapies. Physicians may need to improve communication with their patients and should reevaluate their management of psoriasis.

PSORIASIS AFFECTS more than 7 million Americans, with about 260,000 new cases occurring each year.¹ The disease has a major impact on patients’ quality of life.² ³ Several studies have documented the anguish, stress, and enormous disruption people with psoriasis experience in their daily lives, their relationships with others, and their perceptions of themselves.⁴ Sensitizing clinicians to the morbidity of the disease may help improve psoriasis management. This insight may allow the clinician to offer patients more effective therapies, especially when psoriasis is severe enough to necessitate the use of phototherapy or systemic agents.

To understand how psoriasis affects the quality of life of individuals and to learn about patients’ perceptions of current therapies, the National Psoriasis Foundation (NPF) conducted a 2-part survey of their patient membership. Because this study examines the entire NPF patient population, the largest organization of psoriasis patients in the United States, these findings are especially important. The NPF is a non-profit organization that works to educate the public about psoriasis, to support research, to build rapport between patients and physicians, and to improve the quality of life for individuals with psoriasis.

For editorial comment see page 352

The purpose of this survey of a large population of patients with psoriasis was to explore patients’ perspectives on the impact of psoriasis on their lifestyle, emotional well-being, employment, and social conditions and to gain patients’ perspec-
MATERIALS AND METHODS

A 4-page, self-administered questionnaire was mailed to the entire active 1998 NPF patient membership (N=40350) on July 13 and 14, 1998. Topics covered in the questionnaire included awareness of the NPF; demographics, incidence and severity of psoriasis; psychosocial impact of the disease, type of psoriasis, symptoms, and awareness and use of available therapies. Survey replies were accepted through October 19, 1998. Mail surveys were returned by 17488 NPF patient members, for an overall mail-survey response rate of 43%. No survey follow-up was conducted with nonresponders.

Yankelovich Partners, Norwalk, Conn, conducted a follow-up telephone survey of patients determined to have severe psoriasis. Severe psoriasis was defined as psoriasis on more than 10% of the body, erythrodermic psoriasis, generalized pustular psoriasis, or disease that caused difficulty in at least 3 of the following 4 activities: standing, use of hands, sitting for long periods of time, or sleeping. In addition, respondents were classified as having severe psoriasis if their disease was treated by any of the following medications: psoralen in combination with UV-A (PUVA), methotrexate, etretinate, acitretin, or cyclosporine. All participants in the telephone portion of the study had completed the mail survey and had signed an agreement to be contacted by telephone.

A subset of 6194 mail-survey respondents with severe psoriasis were entered into a database. These were then randomly divided into replicates (a systematically selected subsample) and randomly ordered within each replicate to build a representative list. Of the 6194 mail respondents selected, 587 were termed nonviable on the basis of duplications, nonvalid area codes, and locations outside the continental United States. Of the 5607 remaining respondents, 1369 were used to complete the 502 telephone interviews. Telephone interviews were conducted from September 1 through 16, 1998. Responses to some psychosocial and physical activity questions were analyzed by age-defined cohorts.

All surveys were conducted with a known psoriasis population and limited to a set number of participants. Although the results are important because of the large number of psoriasis patients responding to this survey, care must be taken in drawing inferences to the population of all psoriasis patients. This survey was designed to reflect patients’ experiences and perceptions. It was not designed to be a validated quality-of-life assessment or powered for statistical analysis.

RESULTS

DEMOGRAPHICS

The mail-survey respondents consisted of 56% women and 44% men. Average age of disease onset was 31 years, and respondents were predominantly white (94%). The median age of survey respondents was 54 years. The largest age groups of mail-survey respondents were aged 55 to 74 years (40%) and 35 to 54 years (38%). Smaller groups were aged 18 to 34 years (11%), 75 years or older (11%), and younger than 18 years (1%). (Because of rounding, percentages may not total 100.) Median family income of survey respondents was $64,000, and 73% had completed some level of college education.

Most mail-survey respondents (88%) reported they had psoriasis vulgaris. Other psoriasis types reported included guttate, localized pustular, inverse, generalized pustular, and erythrodermic psoriasis. Among the 17425 respondents who answered this question, the most frequent symptoms experienced were scaling (94%), itching (79%), and skin redness (71%). Other symptoms included tightness of the skin (31%), bleeding from psoriatic lesions (29%), burning sensation (21%), fatigue (19%), and other (5%). Psoriatic arthritis was reported to have been diagnosed by a physician in 31% of respondents.

One determinant of disease severity was the extent of body coverage. To gauge this percentage, respondents were instructed to equate the palm of the hand to 1% of body coverage; 39% of mail-survey respondents replied that their psoriasis covered 10% or more of their bodies. A follow-up question on classification of disease severity demonstrated that although 39% of respondents had 10% or more of their body covered with psoriasis, which therefore would be classified as severe, only 17% of respondents rated their disease as severe. Thus, many patients with severe psoriasis do not identify their disease as severe. It can be speculated that this disparity stems, in part, from patients with long-standing disease who learn how to live with their disease, and may therefore de-emphasize its impact. Also, it can be suggested that downplaying the severity of the disease may be a coping strategy for dealing with a socially unacceptable condition. Of the remaining patients surveyed, 50% rated their psoriasis as moderate, 26% as mild, and 8% in remission (ie, as having no or minimal symptoms). (Because of rounding, percentages may not total 100.) There was no observed difference in the level of severity of psoriasis reported among the different age groups.

PSYCHOSOCIAL IMPACT OF PSORIASIS

Overall, mail-survey respondents in the 18- to 34-year age range and the 35- to 54-year age range reported a greater impact of psoriasis on psychosocial aspects of their lives than respondents 55 years and older. Difficulties in the workplace, socialization with family members and friends, exclusion from public facilities, and getting a job and contemplation of suicide accounted for some of the

tives on the effectiveness of currently available therapies for psoriasis. This survey was not intended to be a validated, quality-of-life instrument. A number of studies have demonstrated the impact of psoriasis on quality of life. However, little has been published to reflect patients’ satisfaction with their treatment. This experiential survey provides this information, which may prove to be valu-

©2001 American Medical Association. All rights reserved.
problems reported by the respondents (Table 1). Younger patients more frequently reported difficulty in sexual activities (27%) in contrast to older respondents, who more frequently reported difficulties in activities of daily living such as using their hands or walking (19% and 14%, respectively), as shown in Table 2. Earlier studies also noted the decreasing impact of disease with increased age.\(^8\) An even greater percentage of those who reported a diagnosis of psoriatic arthritis reported difficulty using their hands (66%), standing for long periods of time (64%), and walking (63%).

In the telephone survey, 79% of respondents reported that severe psoriasis had an overall negative impact on their lives. This negative impact included disruption in daily activities for an average of 10% of the time in each month. In addition, employed respondents reported missing an average of 2.3 working days in a 12-month period because of their psoriasis. Among those with severe psoriasis, 6% reported discrimination at work. Among respondents not currently employed, 8% indicated that psoriasis prevented them from working outside the home. Approximately 31% of respondents reported that they had suffered some degree of financial distress resulting from their psoriasis. This was more apparent in lower income groups, with 42% of respondents earning less than $30,000 a year, citing financial distress due to their psoriasis.

Aside from the practical implications of coping with severe psoriasis, the telephone survey revealed that serious emotional issues are involved. Overall, compared with other age groups, those aged 18 to 34 years were more likely to report emotional suffering due to psoriasis. Among this group, 88% were concerned that the disease would worsen; 81% reported feeling embarrassed when people viewed their psoriasis; 90% reported feeling frustrated with ineffective treatments; 75% reported feeling unattractive; and 54% reported feeling depressed.

Socially, patients with severe psoriasis are faced with various misconceptions about their condition. Others have mistaken the condition to be contagious, as reported by 57% of the respondents; and 48% stated that their psoriasis had been mistaken by others for a different disease or condition. Among patients who have had their psoriasis mistaken for another disease, 24% have had it mistaken for poison ivy and 9% for acquired immunodeficiency syndrome. These misconceptions may contribute to exclusion of psoriasis patients from public facilities. Among those with severe psoriasis, 40% have experienced problems with receiving equal service or treatment in various service establishments, such as hair salons and barbershops (24%), public pools (19%), and health clubs (11%).

### MEDICAL TREATMENT OF PSORIASIS

In addition to gaining a greater understanding of the psychosocial and work-related issues from the perspective of psoriasis patients, an additional objective of this survey was to gauge patients’ perspectives on therapeutic options and the effectiveness of medications currently prescribed for psoriasis. A large percentage of the NPF mail-survey respondents reported awareness of various therapies (Figure 1). Many respondents reported experience with the full range of treatments, including phototherapy and topical and systemic agents.

To capture the level of satisfaction with their therapy and the degree to which it is effective, telephone-survey respondents were given a choice of responses ranging from “not at all satisfied” to “very satisfied” and “not well at all” to “very well.” Although 48% responded that they are very or fairly satisfied with psoriasis treatments, a nearly equal number of patients (49%) reported that they are only somewhat or not at all satisfied (Figure 2). Likewise, when asked to give an estimation of how well their
current treatment regimen was working, 46% of patients responded “just somewhat well” or “not well at all” (Figure 3). In addition, there was a high degree of dissatisfaction with the capacity of treatments to control many of the symptoms of psoriasis. This is discouraging, given the efficacy of most systemic therapies (including PUVA, methotrexate, and cyclosporine) and opportunities to use combination therapy.9 More than 75% improvement in virtually all patients who receive systemic therapy has been described.10

Among patients with severe psoriasis, 78% reported feelings of frustration that their treatment does not work well enough and does not make their disease more manageable. Some of the dissatisfaction with psoriasis treatments may result from insufficient communication between patient and physician. More than half (59%) of patients believe that their physicians could be more helpful in assisting them to live with psoriasis. Patients’ frustration may also be heightened by confusion about different forms of treatment available. A recent report found that when phototherapy is prescribed, there is disparity among treatment centers and physicians in the type of phototherapy chosen for psoriasis management.11

As noted above, nearly half of patients with severe psoriasis indicated that they are only somewhat or not at all satisfied with the treatment they are receiving; 32% replied that the treatment they are receiving is not aggressive enough. The finding that therapies offered are not aggressive enough is supported by data that show that topical medications are the most frequently used prescription products, with approximately 87% of patients with severe psoriasis receiving this form of medication (Figure 4). Patients with severe psoriasis note that topical therapy is a time-consuming (ie, average time spent each day applying topical agents, 26 minutes), expensive, and generally ineffective approach to providing relief. In contrast, more aggressive phototherapy and oral medications are much less commonly used (Figure 4). The survey shows that among the group with severe psoriasis, only 27% had ever tried methotrexate and only 23% had tried PUVA. Of those who have used these agents, 70% reported that methotrexate and 64% that PUVA provided a good to excellent response.

Patients report having been told of therapies that have an improved therapeutic response. Among the treatments discussed by the patients’ physicians, UV-B (65%), PUVA (65%), and methotrexate (50%) were the most frequently mentioned. The observation that these treatments are much more frequently discussed than prescribed may be due to several factors. Speculation about reasons would include reluctance by the patient or physician to deal with potential adverse effects, inadequate training in the use of these agents, or lack of access to equipment needed to provide treatment. In addition, the need for monitoring of patients receiving these therapies has an unknown impact on the decision to prescribe them.12

Many of the mail-survey respondents (43%) had tried over-the-counter (OTC) medications or alternative therapies, such as herbs, relaxation, or acupuncture, to help control their psoriasis. Of those who had tried OTC or alternative therapies, 52% reported no change in their psoriasis. However, only 1 respondent in 10 was using these types of therapies at the time of the survey. This indicates dissatisfaction with OTC medications and alternative therapies as effective management of these patients’ psoriasis.

The size of the population responding to this survey—nearly 18000 patients—and the rate of response (43%) weights the findings. The magnitude of this response provides clinicians with valuable insights into patient perceptions of the impact of psoriasis and perceived treatment efficacy. The survey was not intended to serve as a validated quality-of-life instrument, and it was not powered for statistical analysis.

The disruption that patients with psoriasis experience in their daily lives has been documented in a number of studies.2,4,5 The NPF survey, conducted within a large, well-defined population of psoriasis patients, illustrates many of the findings of previously published studies.2,5 Rather than using standardized quality-of-life scales, such as the Psoriasis Disability Index or the United King-
dom Sickness Impact Profile, which are described in other trials.°,5,13,14 the NPF survey focused on the experiences and satisfaction of patients and how they feel about their psoriasis and quality-of-life issues.

Survey questions were focused on the role psoriasis plays in multiple aspects of these patients’ daily lives, including personal and social relationships, work-related interactions, and emotional behavior. From the patients’ point of view, physicians often do not fully appreciate the seriousness and repercussions of this disease. Depression, frustration with treatment, fear of worsening disease, and embarrassment seem pervasive. Disease severity scales serve as a reference point for the physical aspects of the disease; however, what is perceived as severe by a patient may not be perceived as severe by a physician. Although patient perception of disease severity may be tempered by various factors, clinical assessment should incorporate the patient’s perspective.

This survey also demonstrates patient dissatisfaction with the management of their disease. Patient frustration is seen in the high rate of patients seeking OTC and alternative therapies and in the level of patients desiring more aggressive treatments. An understanding of each patient’s desire and tolerance for more aggressive medical intervention is an important consideration when assessing the benefit-risk ratio of available therapeutic options.

Suboptimal disease management and high relapse rates may further add to the patient’s frustration and the ongoing psychosocial disability associated with psoriasis. Better understanding and communication between psoriasis patients and their physicians may help to improve clinical outcomes in psoriasis. Information gained from this study can be used to demonstrate the importance of physician-patient communication and serve as an adjunct to future research exploring the impact of psoriasis on quality of life. In addition, this research may serve as a stimulus to explore further therapy and the use of more aggressive treatment options.

Accepted for publication June 16, 2000.

This study was supported and conducted by the National Psoriasis Foundation and funded by Novartis Pharmaceuticals Corporation, East Hanover, NJ.

Corresponding author and reprints: Gerald Krueger, MD, Department of Dermatology, University of Utah Medical School, 50 N Medical Dr, Salt Lake City, UT 84132.

REFERENCES