Cutaneous symptoms of dermatomyositis significantly impact patients' quality of life

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Background: Dermatomyositis affects visible skin and causes disease symptoms that can affect patients' quality of life (QOL).

Methods: In all, 71 patients with dermatomyositis or dermatomyositis sine myositis completed two QOL measures (the Skindex-16 and the Dermatology Life Quality Index) and a visual analog scale for pruritus. Disease severity was assessed by Physician's Global Assessment.

Results: The mean Dermatology Life Quality Index score was 10.7 and the mean Skindex-16 score was 51.1. Itching contributed to impact on both the Dermatology Life Quality Index and Skindex-16. Females reported worse QOL.

Limitations: The effect of treatment on quality of life was not assessed in these analyses.

Conclusion: QOL impairment in dermatomyositis is greater than in other skin conditions including psoriasis and atopic dermatitis. Pruritus is an important treatable factor that significantly impacts QOL for patients with dermatomyositis. (J Am Acad Dermatol 2006;54:217-20)

Skin disease can have considerable affects on quality of life (QOL) as a result of physical discomfort and impairment along with emotional distress.[1,2] Frustration regarding the cost, side effects, or ineffectiveness of treatments may also arise. Dermatomyositis is an inflammatory myopathy with characteristic cutaneous lesions and muscular weakness.[3] Common cutaneous symptoms include pruritus and photosensitivity.[3] Other systemic manifestations include pulmonary disease (usually diffuse interstitial fibrosis),[4] cardiac involvement,[5] nonerosive arthritis (more common with juvenile-onset dermatomyositis),[6] and increased risk of internal malignancy.[7]

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Supported by National Institutes of Arthritis, Musculoskeletal and Skin Diseases grant number AR0348990-02.
Conflicts of interest: None identified.
Accepted for publication December 7, 2004.
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Published online December 5, 2005.
0190-9622/$32.00

doi:10.1016/j.jaad.2004.12.015

Abbreviations used:

DLQI: Dermatology Life Quality Index
PGA: Physician's Global Assessment
QOL: quality of life

Dermatomyositis reduces QOL in affected individuals. Drouet et al[8] retrospectively studied 28 patients with dermatomyositis and polymyositis with regard to survival, joint function, respiratory function, and QOL. The group found increased mortality in the patients compared with the general population in that region of France. Half of the patients demonstrated easy fatigability, decreased exercise tolerance, and abnormal respiratory function parameters. One third of the patients reported difficulty performing physical activities. The QOL impact of the cutaneous manifestations of dermatomyositis has not been well defined and is the focus of this study.

METHODS

This investigator-initiated clinical study received human subjects' approval from the institutional review board. In all, 71 patients with a biopsy-proven diagnosis of dermatomyositis (meeting criteria of Bohan and Peter[9,10]) or dermatomyositis sine myositis were recruited locally and from the surrounding 5-state referral area (North Carolina, South Carolina, Virginia, West Virginia, and Tennessee)

Table I. Patient demographics

	No.	Percent
Sex		
Male	13	18
Female	58	82
Race		
White	65	93
Black	4	6
Other	1	1
Marital status*		
Unmarried	9	13
Married	54	76
Divorced	7	10
Education*		
<High school	6	8
High school/GED	28	39
Some college	14	20
College graduate	13	18
Postgraduate	9	13
Disability†		
Present	10	14
Absent	57	80
Myositis*		
Present	53	75
Absent	17	24
Age, y	Mean ± SD (95% CI)	Range
	48.5 ± 16.7 (44.5-52.4)	3-84

CI, Confidence interval; *GED*, general education development.
Frequency missing = 1* or 4.†

(Table I). Patients were seen at least once in clinic, at which time demographic information was collected, including a yes/no response question on being disabled (defined as "not being able to work").

The Skindex-16 and the Dermatology Life Quality Index (DLQI) were used to measure QOL. Patients completed both questionnaires during the study visit.[11,12] Skindex-16 is a single-page accurate and sensitive 16-item measure of skin disease impact reported on 3 scales: symptoms, emotions, and functioning. Each item is scored on a scale of 1 (never bothered) to 7 (always bothered). Skindex-16 exhibits good internal consistency for each of the scales assessed (Cronbach's α = 0.86, 0.93, and 0.92 for the symptoms, emotions, and functioning scales, respectively). The Skindex-16 is reliable (r = 0.88-0.90) and has content and construct validity. The DLQI consists of 10 questions related to symptoms and feelings, daily activities, leisure, work or school, personal relationships, and treatment. Responses range from 0 (not at all) to 3 (very much) for a range of 0 to 30 with higher scores corresponding to greater impairment in QOL. The DLQI exhibits good test-retest reliability and has been used extensively in clinical research worldwide.[13]

Table II. Dermatology Life Quality Index, Skindex-16, and pruritus scores for patients with dermatomyositis

	Mean ± SD	95% CI	Range
DLQI	10.7 ± 8.4	8.8-12.7	0.0-27.0
Skindex-16 (total)	51.1 ± 21.8	45.9-56.3	12.0-84.0
Symptoms	16.5 ± 7.7	14.6-18.3	4.0-28.0
Emotions	32.8 ± 13.3	29.6-36.0	7.0-49.0
Functioning	18.4 ± 9.8	16.0-20.7	5.0-35.0
Pruritus	44.2 ± 30.8	36.9-51.4	0.0-100

CI, Confidence interval; *DLQI*, Dermatology Life Quality Index.

Pruritus was assessed by a visual analog scale with one end representing no itching and the other end representing severe itching. Patients were also evaluated by two dermatologists who each completed a Physician's Global Assessment (PGA). The PGA consists of a 0-to-4 scale, with 0 representing no active skin disease and 4 representing the most severe possible disease.

Statistical analyses

All analyses were performed using software (SAS, Version 8, Cary, NC). Descriptive statistics were generated with mean, SD, and the 95% confidence interval for continuous measures and frequency distribution for categorical variables. Normality of the DLQI and Skindex-16 scores were examined and the Spearman correlation coefficient was used to assess bivariate association as the results. Difference in PGA between males and females was tested using the Fisher's exact test. Test for significant difference in the DLQI and Skindex-16 scores between males and females, patients with and without disability, PGA categories from slight disease to the severest possible disease, and patients with and without muscle disease were performed using either the Wilcoxon's test or the Kruskal-Wallis test. Bivariate association was used to evaluate relationships among sex, PGA, and itching to QOL. Two separate analysis of variance models, one with the DLQI as its outcome and the other with the Skindex-16 as its outcome, were fit using the SAS procedure PROC GLM to evaluate the significance of the effects of sex, PGA, and itching on the outcome adjusting for the other factors in the model. We were unable to analyze data based on racial differences because of small sample size of non-white patients.

RESULTS

A broad range of QOL impact was seen in DLQI, Skindex-16, and pruritus (Table II). Mean DLQI