A Quality-of-Life Instrument for Scalp Dermatitis

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Objective: To develop a scalp dermatitis–specific quality-of-life instrument.

Methods: Based on the results of directed focus sessions with 8 patients with scalp psoriasis or seborrheic dermatitis, we conceptualized 3 major constructs that explain the way scalp dermatoses affect patient quality of life: symptoms, functioning, and emotions. We constructed a 23-item instrument, Scalpdex, and tested its reliability, responsiveness, and validity.

Results: Fifty-two dermatology patients completed the study. We demonstrated construct validity by confirming that the factors derived by principal axes factor analyses with orthogonal rotation correlated to our hypothesized scales (r = 0.76-0.84) and that differences in symptom, functioning, and emotion scores differed among the varying levels of self-reported scalp severity more than would be expected by chance (P < .05 by analysis of variance). The instrument demonstrated reliability with internal consistency (Cronbach α, 0.62-0.80) and reproducibility (intraclass correlation coefficient, 0.90-0.97). The quality-of-life scores changed in the expected direction in our test for responsiveness (P ≤ .05, by paired t test for functioning and emotion for those who improved). We ascertained the discriminant capability of Scalpdex compared with a dermatological generic quality-of-life tool, Skindex, by demonstrating superior responsiveness (P ≤ .005 by paired t test in functioning and emotion) and improved overall sensitivity in individual items.

Conclusions: Scalpdex is, to our knowledge, the first quality-of-life instrument specifically for patients with scalp dermatitis that is reliable, valid, and responsive. Clinicians can use the instrument to determine which aspect of the disease most bothers the patient and to evaluate quality of life as one variable of responsiveness to the therapeutic intervention.

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Many people experience the adverse effects of scalp dermatitis, from its symptoms to its negative social profile. Scalp dermatitis is predominantly caused by 2 common inflammatory dermatoses: psoriasis and seborrheic dermatitis. Psoriasis affects approximately 2% of the general population, of which 50% to 90% have scalp involvement. Seborrheic dermatitis affects 1% to 3% of the general population, and up to 95% of these patients have involvement of the scalp.

Patients with scalp dermatitis routinely ask physicians for help, and pharmaceutical companies constantly develop new products to control the disease. An instrument that can measure and quantify scalp dermatitis–related quality of life would be helpful for both physicians and pharmaceutical companies, especially since studies have demonstrated that most physicians underestimate the impact of disease on quality of life and that objective clinical variables of skin disease are often poorly correlated with impact on quality of life. There are several generic cutaneous quality-of-life instruments, but a scalp dermatitis–specific survey does not exist. Although a generic instrument is valuable to compare quality of life among different diseases, a disease-specific instrument is more sensitive to quality-of-life issues relevant to the disease in question. A disease-specific tool, Scalpdex, was developed to measure scalp dermatitis–related quality of life as one variable of responsiveness to therapeutic intervention.
PATIENTS AND METHODS

All patients were recruited from the Stanford Dermatology Clinic. Consent was obtained from all patients in accordance with the Administrative Panel on Human Subjects in Nonmedical Research at Stanford University, Stanford, Calif.

ITEM DEVELOPMENT

We conducted in-depth interviews with 4 patients with scalp psoriasis and 4 patients with seborrheic dermatitis in which we asked open-ended questions to elicit all the ways that their scalp condition affected their lives. We interviewed patients to a point of saturation where no new information was elicited. Based on all patient mentions and frequency, we conceptualized 3 major constructs that explain the way scalp dermatoses affect patient quality of life: symptoms, functioning, and emotions. These are the same constructs used in Skindex. We composed 14 scalp dermatitis-specific items from the interview session information (Table 1). We also determined that 9 items from the 29-item version of Skindex were important to comprehensively assessing the constructs patients found relevant (Table 1). We called the 23-item survey “Scalpdex.” For all items, we used the same format as for the Skindex items but changed the wording “skin condition” to “scalp condition.” All items inquired about the past 4 weeks.

SAMPLE POPULATION, MEASURES, AND DATA COLLECTION

A list of patients from the Stanford Dermatology Clinic with seborrheic dermatitis or scalp psoriasis was obtained based on International Classification of Diseases, Ninth Revision, codes. Patients were randomly selected from the list. Interviewers administered the adapted Skindex-29, the 14 scalp dermatitis-specific items, 5 global questions about their general health and scalp condition, and 3 demographic questions to patients by telephone. Patients answered all questions at baseline, 72 hours (allowable range, 3-7 days), and 1 year. The demographic questions were omitted from the latter 2 interviews.

SCORING

A patient’s scale score was the average of his or her responses to items in a given scale. For example, the scale score for emotion was the average of all responses to the items in the emotion scale. Responses to item 18, “cares for my scalp condition is inconvenient for me,” were reverse scored. The responses to the items were “never,” “rarely,” “sometimes,” “often,” and “all the time.” All reported scores were converted from the 1 to 5 scale to a 0 to 100 scale.

PSYCHOMETRIC EVALUATION

We tested the instrument for reliability, responsiveness, and validity. Reliability is the extent to which a measure yields the same results on independent repeated trials under the same conditions. Specific instrument may also be more sensitive to changes over time. We developed a scalp dermatitis-specific instrument, Scalpdex, based on constructs that patients specifically mentioned in directed focus sessions and tested the measurement properties of the instrument in a sample of patients with scalp dermatitis. We based the instrument on previous work with Skindex, a measure of the effects of skin diseases of all types on patient quality of life; the measurement properties of Skindex have been studied extensively. We tested the scalp-specific instrument for validity, reliability, and responsiveness.

RESULTS

DEMOGRAPHICS AND DISEASE CHARACTERISTICS

We contacted and invited 155 patients to participate in directed focus sessions and instrument validation. Approximately 55% of the invited patients declined to participate, most because their psoriasis or seborrheic dermatitis did not involve the scalp (23%), they did not have psoriasis or seborrheic dermatitis (15%), or they were not interested (15%). The remainder were not available because the wrong telephone number was listed or they did not answer our calls. Seventy patients agreed to participate in the study. One patient dropped out at the 72-hour point, and 17 dropped out at the 1-year point. The overall patient age was 47.6 (15.2) years; for patients with psoriasis, the age was 47.2 (15.5) years, and for those with seborrheic dermatitis it was 48.0 (15.1) years.

Of the 52 patients who completed the study, 25 had psoriasis (12 women and 13 men) and 27 had seborrheic dermatitis (16 women and 11 men). Most of the patients rated their scalp condition as being poor to fair (58% [n = 31]), and of more than 10 years’ duration (65% [n = 34]).

ITEM ANALYSIS

Scalp-related quality of life was most affected by “my scalp itches,” with a score of 56.1 (28.7). Quality of life was least affected by feeling “humiliated,” with a score of 12.3 (24.5). Mean scores for all items are listed in Table 1.

Several items proved to be relatively insensitive, that is, more than 90% of the respondents answered “never” to these items, including “bittered by questions” (59% [n = 31]), “affected color of clothes” (65% [n = 34]), “bittered by cost” (58% [n = 30]), “daily life difficult” (68% [n = 35]), “makes me feel different” (59% [n = 29]), “hard to go to the barber or hairdresser” (58% [n = 30]), “depressed” (62% [n = 32]), “ashamed” (52% [n = 27]), and “humiliated” (73% [n = 38]).

RELIABILITY

Each of the 3 scales demonstrated internal consistency reliability, with Cronbach α coefficients ranging from 0.62...
same conditions, reflecting the degree to which the instrument is free from random error. We evaluated reliability with internal consistency via the Cronbach α coefficient and with reproducibility via the intraclass correlation coefficient. Responsiveness is the ability to detect a change in the quality of life of the scalp condition. We tested for responsiveness by applying the paired t test to the baseline and 1-year answers for 3 groups: those reporting improvement, no change, or worsening of their scalp condition.

Validity is evidence that the instrument is actually measuring what it is supposed to measure.9 We confirmed validity by examining face, content, construct, and discriminant validity. Face validity refers to whether an instrument seems to be measuring what it is intended to measure. Content validity is the completeness with which an instrument covers the important areas of the domain that it is attempting to represent. We ensured face and content validity of the instrument by interviewing patients with scalp dermatitis in directed focus sessions.

Construct validity is the extent to which a particular instrument relates to other measures in a manner that is consistent with theoretically derived hypotheses concerning the constructs that are being measured. We tested construct validity in 2 ways. We had hypothesized that the items would cluster into 3 factors that could be labeled as "symptoms," "functioning," and "emotions." We tested this hypothesis by using principal axes factor analyses followed by an orthogonal rotation. We retained only those factors with eigenvalues greater than 2 and by application of the scree test.10 We identified the factor onto which items loaded by selecting the largest coefficient of that item among all the retained factors. Each factor was labeled by the predominant trait of the heavily loaded items. We compared the a priori hypothesized scale assigned to each item to the factor onto which each item loaded. We also compared the regression factor scores to the unweighted hypothesized scale scores using Pearson correlation coefficients. We also tested construct validity by comparing the scale scores with the self-reported severity of the scalp condition using 1-way analysis of variance. We hypothesized that the scale scores correlate with the severity of the scalp condition.

Discriminant validity is the extent to which one instrument measures a certain health characteristic better than another instrument. Because Skindex is a generic quality-of-life instrument, we hypothesized that it was not sensitive enough to adequately measure quality-of-life issues specific to Scalpdex. We tested for discriminant validity by comparing scores from Scalpdex to Skindex in 2 ways. First, we examined the relative degree of responsiveness over time by comparing the difference in responsiveness between baseline and 1 year. Second, we qualitatively assessed the degree of sensitivity of the items to scalp quality of life. After examination of the distribution of the answers to a given item, we considered that item to be relatively insensitive to scalp dermatitis quality of life if more than 50% of the patients chose a particular answer.

ANALYSES

All statistical analyses were performed using a statistical software program (SPSS 10.0 for Windows; SPSS Inc, Chicago, Ill). All data are given as mean (SD).

RESPONSIVENESS

Patients were divided into 3 categories (better, worse, or no change) based on their responses to the question, "How has your scalp condition changed since the first interview?" Eighteen patients reported improvement, 3 reported worsening, and 31 reported no change. Using the scalp dermatitis-specific scale scores (Table 1), we found improvement in the quality-of-life scores of patients who reported improvement in their dermatitis; the difference was statistically significant (P≤.005, using paired t test) for functioning and emotion scores (Table 3). We found no significant differences in the scores of those who reported no change. We expected and found no significant difference in patients who reported worsening of scores given that there were only 3 patients.

CONSTRUCT VALIDITY

After factor analysis with orthogonal rotation, 3 factors were retained according to the criteria outlined in the "Patients and Methods" section. From the items that loaded most heavily on factor 1, the predominant trait was emotions; on factor 2, functioning; and on factor 3, symptoms. The Pearson correlation coefficient comparing the regression factor scores and the unweighted hypothesized scale scores ranged from 0.76 to 0.84. The correlation between the regression factor scores and the other 2 scales (eg, factor 1 with symptoms or emotions) were much lower, in the range of 0.07 to 0.67 (Table 2).

We compared the scale scores (symptoms, functioning, and emotions) with self-reported scalp condition severity. Severity levels were determined on a 5-point scale: poor, fair, good, very good, and excellent. We found greater differences in symptom, functioning, and emotion scores among the different levels of scalp severity than would be expected by chance (P<.05, by analysis of variance). The pairwise multiple comparison procedure revealed a significant difference in symptoms, emotions, and functioning among a variety of severity ratings (Figure).

DISCRIMINANT VALIDITY

We demonstrated the discriminant validity of Scalpdex. Scalpdex had a higher degree of responsiveness over 1 year than did Skindex for emotions and functioning (P≤.005 by paired t test). We neither expected nor found any difference in symptom responsiveness since the items for symptoms are the same in the 2 instruments. We also ascertained that Scalpdex was relatively more sensitive than Skindex during our item analysis. In 9 Scalpdex items (39%) vs 17 Skindex items (59%), at least 50% of the pa-
Patients answered “never.” Note that 3 of the items are used in both Scalpdex and Skindex.

This study presents, to our knowledge, the first quality-of-life instrument specifically for patients with scalp dermatitis. We demonstrated the reliability, responsiveness, and validity of the instrument. We demonstrated reliability with high internal consistency reliability, as shown by substantial and robust Cronbach α coefficients for all 3 scales, and reproducibility, as shown by the high intraclass correlation coefficients. We ascertained responsiveness by demonstrating that the scores improved in patients who reported improvement in their scalp condition and that the scores did not change in patients who reported no change.
Clinicians can use the instrument to help their patients in 3 ways. First, the profile of the instrument can be analyzed to determine which aspect of the disease most bothers the patient, for example, 2 patients may have identical clinical presentations but one may be bothered by symptoms and the other primarily by the appearance. Second, clinicians can evaluate changes in quality of life as one variable of responsiveness to the therapeutic intervention. Last, clinicians can use the impact on quality-of-life data to petition managed care organizations and insurance companies in the event that they deny coverage for therapies, citing the disease as a cosmetic issue.

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REFERENCES