Validating a Quality-of-Life Instrument for Allergic Contact Dermatitis

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Background: **Contact dermatitis is a prevalent condition that has a significant impact on quality of life (QoL). Although many generic dermatological QoL instruments exist, none were developed by and for patients with allergic contact dermatitis (ACD).**

Objective: **The aim of the study was to create and validate a reliable QoL instrument specific for the ACD population.**

Methods: **We identified QoL items specific to ACD through a series of qualitative interviews with ACD patients and experts. We created a 17-question survey that queries the patient across the following 3 major domains: symptoms, functioning, and emotions. We used statistical methods to evaluate the reliability and validity of this tool.**

Results: **Ninety patients with relevant positive results on patch testing completed the novel ACD instrument and the Skindex-29. This instrument exhibited reliability and validity in individuals with ACD and was more sensitive than the generic tool Skindex-29.**

Conclusions: **This novel instrument is the first tool developed specifically to assess the unique impacts of ACD on QoL. Providers can reliably use this index to assess the specific aspects of the disease most problematic for the ACD patient and use this information to more properly inform counseling and management.**

Allergic contact dermatitis (ACD) is a chronic pruritic dermatosis resulting from repeated exposure to sensitizing personal products or occupational substances. The prevalence of ACD varies by population and geography, but recent literature estimates a 15% to 20% prevalence of ACD in the general population.[1,2] Because the detection, diagnosis, and management of this condition can be difficult, ACD can cause significant patient distress and disability. Allergic contact dermatitis and its more common counterpart irritant contact dermatitis comprise 90% of occupational skin disorders and contribute to lengthy leaves of absence; this impacts both the socioeconomic state of the individual and the society at large.[2]

Despite the significant number of patients affected by ACD, specific and unique impacts of this disease on quality of life (QoL) remain poorly understood. Little consensus exists as to which standardized instruments are most useful in assessing the burden of disease for patients with ACD. Among the most frequently used QoL instruments in dermatology, the Dermatology Life Quality Index (DLQI), Skindex, and the Dermatology-Specific QoL (DSQL) instrument, only the DSQL has been validated in ACD patients.[3–8] Existing ACD-specific QoL instruments are limited by either their clinical applicability or psychometric properties.[3,9–11] As such, available QoL instruments may not adequately capture the unique impact of ACD on both clinical and psychosocial aspects of patients' lives.

A comprehensive, validated, and disease-specific QoL instrument would enable clinicians to better characterize the effects of different therapies and diagnostic strategies on patients' lives. For example, limited data suggest that patch testing leads to improved QoL in patients with ACD,[9,12–14] but no studies to date have used ACD-specific QoL tools to prospectively assess the effect of allergen identification and education on QoL.

The objective of this study was to create a validated and reliable ACD-specific QoL instrument for use in patients with ACD.

METHODS

Participants in this study were recruited from the University of California, San Francisco (UCSF) Patch Test Clinic. All patients gave consent for participation. This study was approved by the UCSF Institutional Review Board administration.

Item Development

Using qualitative research techniques, we conducted interviews with patch test–positive patients diagnosed with ACD and 2 ACD experts

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TABLE 1. Mean Scores of Skindex-29 and Novel ACD Instrument by Item at 0 Hour and 48 Hours

	0 h	48 h	
	Mean (SD)	Mean (SD)	Domain
Skindex-29 items*			
I am frustrated by my skin condition	3.70 (1.21)	3.48 (1.06)	Emotions
I worry about side effects from skin medications/treatments	2.98 (1.18)	3.12 (1.15)	Emotions
I am humiliated by my skin condition	2.04 (1.29)	2.04 (1.13)	Emotions
I am annoyed by my skin condition	3.86 (1.06)	3.47 (1.19)	Emotions
I am embarrassed by my condition	2.78 (1.25)	2.42 (1.17)	Emotions
I worry that my skin condition may be serious	3.04 (1.25)	2.78 (1.07)	Emotions
My skin condition makes me feel depressed	2.62 (1.21)	2.42 (1.28)	Emotions
I am angry about my skin condition	2.49 (1.37)	2.42 (1.24)	Emotions
I worry about getting scars from my skin condition	2.47 (1.26)	2.25 (1.22)	Emotions
I am ashamed of my skin condition	2.42 (1.24)	2.30 (1.14)	Emotions
I worry that my skin condition may get worse	3.47 (1.00)	3.24 (1.02)	Emotions
My skin condition burns or stings	3.01 (2.81)	2.81 (1.05)	Symptoms
My skin hurts	2.85 (1.17)	2.89 (1.04)	Symptoms
My skin condition bleeds	2.23 (1.08)	2.30 (1.07)	Symptoms
My skin is sensitive	3.92 (1.02)	3.88 (1.03)	Symptoms
My skin is irritated	3.69 (0.93)	3.68 (0.89)	Symptoms
My skin itches	3.90 (1.01)	3.79 (1.04)	Symptoms
Water bothers my skin condition (bathing, washing hands)	2.18 (1.27)	2.30 (1.24)	Symptoms
I tend to stay at home because of my skin condition	2.14 (1.19)	2.03 (1.10)	Functioning
My skin condition affects my social life	2.90 (2.01)	2.51 (1.07)	Functioning
My skin condition makes showing affection difficult	1.94 (1.14)	2.02 (1.09)	Functioning
I tend to do things by myself because of my skin condition	1.84 (0.99)	1.86 (0.97)	Functioning
My skin condition affects how close I can be with those I love	2.29 (1.24)	2.14 (1.13)	Functioning
My skin condition affects my desire to be with people	2.14 (1.15)	2.10 (1.10)	Functioning
My skin condition affects how well I sleep	2.96 (1.18)	2.93 (1.19)	Functioning
My skin condition is a problem for the people I love	1.82 (1.13)	1.79 (0.97)	Functioning
My skin condition makes it hard to work or do hobbies	2.77 (1.18)	2.70 (1.14)	Functioning
My skin condition affects my interactions with others	2.34 (1.03)	2.15 (1.02)	Functioning
Novel ACD instrument items*			
I am bothered by the cost of “sensitive skin” care products	2.53 (1.39)	2.55 (1.26)	Cost
My skin condition makes me feel “high maintenance”	3.10 (1.39)	3.00 (1.22)	Emotions
I am worried about infecting other people	1.29 (0.67)	1.33 (0.78)	Emotions
My skin condition makes me feel hopeless	2.01 (1.22)	2.10 (1.18)	Emotions
My skin condition makes me feel desperate	1.99 (1.25)	2.19 (1.22)	Emotions
I am bothered that my skin condition never goes away	3.38 (1.13)	3.32 (0.99)	Emotions
I am worried because my skin condition is unpredictable	2.97 (1.23)	3.01 (1.16)	Emotions
My skin condition makes me feel out of control	2.45 (1.34)	2.36 (1.25)	Emotions
I worry about being exposed to things that make my condition worse (eg, triggers like temperature, sweat, activities, stress, fabric, and scents)	3.26 (1.38)	3.20 (1.21)	Emotions
My skin condition makes me feel dirty	1.80 (1.35)	1.85 (1.12)	Emotions
My skin condition makes me feel crazy or neurotic	2.01 (1.35)	1.97 (1.24)	Emotions
I am bothered by cracking in my skin	2.80 (1.36)	2.66 (1.36)	Symptoms
I am bothered by sloughing and flaking from my skin condition	2.83 (1.32)	2.69 (1.23)	Symptoms
I am bothered by peeling from my skin condition	2.66 (1.37)	2.58 (1.30)	Symptoms
I am bothered by the appearance of my skin condition	3.21 (1.23)	3.03 (1.16)	Symptoms
I think about my skin condition all the time	3.02 (1.32)	3.04 (1.21)	Functioning
My skin condition makes it hard to use my hands	2.05 (1.33)	2.01 (1.29)	Functioning
My skin condition makes it hard to concentrate or focus	2.59 (1.13)	2.65 (1.14)	Functioning

**Scored on a Likert scale (1 = never, 2 = rarely, 3 = sometimes, 4 = often, 5 = all the time).*

to understand the impact of ACD on QoL. We asked patients and experts questions until we could no longer elicit new information. Based on these interviews, we developed the following 4 major domains that describe the effect of ACD on patients' QoL, which were encompassed by the 3 main categories or subscales: emotions, functioning, symptoms, and the additional factor of cost. This framework is consistent with Skindex-29, a commonly used skin-related QoL tool, which also contains the following 3 factors: emotions, symptoms, and functioning. We then created 18 ACD-specific questions, based on our qualitative interviews that were not covered by the generic parent instrument, designed to capture the impact of ACD on QoL (Table 1). Items were appended to the Skindex-29 questionnaire to develop a comprehensive assessment using both our experimental items along with a generic validated QoL tool. Similar to Skindex-29, our ACD-specific questions asked about experiences for the past 4 weeks. The tool used a 5-element Likert scale from 0 "never" to 5 "all the time," where a higher score indicated poorer QoL.

Sample Population, Measures, and Data Collection

Patients were selected from those referred to the UCSF patch test clinic. Individuals were included if they had eczematous dermatitis, were 18 years or older, were English speaking, and had possible, probable, or definite relevant positive patch test results. Patients with other primary dermatological diagnoses (eg, bullous pemphigoid, scabies) were excluded, although those with other secondary dermatologic disease(s) (eg, rosacea, acne, atopic dermatitis) were included. We administered the novel 18-item ACD instrument along with Skindex-29 to all patients. Patients answered all questions on a paper questionnaire at the initial visit and then again 48 hours later to assess the reliability and validity of the questions.

Psychometric Evaluation

The instrument was tested for reliability and validity. We assessed internal consistency and reliability using Cronbach α to examine how closely patients' pretest (0 hours) ratings were to their posttest (48 hours) ratings for individual questions and groups of questions (factors). For test-retest reliability, we compared scores of patients with ACD at 2 time points, 0 and 48 hours later using analysis of variance (ANOVA).

We examined the validity of our instrument by evaluating the face, content, construct, and discriminant validity. Face validity and content validity were established in focused interviews of patients with ACD and analyzed using qualitative research techniques. We evaluated construct validity by analyzing whether variation in patients' responses to our instrument was explained by our hypothesized factors—emotion, symptom, function, and cost. This was evaluated by calculating the intraclass correlation coefficient, a descriptive statistic giving a measure of agreement between the presurvey and postsurvey overall, to quantify how strongly the 2 administrations of the survey agreed.

Principal components analysis was used, followed by an orthogonal rotation to identify the factors. The number of factors was established by retaining those with eigenvalues greater than 1.0 and also examining the scree plot. Questions were included in a factor if the factor loading for that variable was greater than 0.6. Factor scores were saved for each patient. Results at 0 hours and 48 hours were compared using ANOVA to ensure that they were similar. After the creation of factors, we constructed scores for each patient by summing their responses to the questions within each factor. This allowed us to identify which factors had the greatest impact on QoL both in individuals and the group as a whole. Individual test scores were also correlated with the factor scores to assess reliability (Table 2).

TABLE 2. Psychometric Results

		Factor		
		Emotions	Functioning	Symptoms
Cronbach α*		0.866	0.812	0.877
Intraclass correlation coefficient†		0.858	0.911	0.898
Correlation between individual factor scores and patient summary scores	Factor 1	0.841	0.502	0.652
	Factor 2	0.768	0.607	0.639
	Factor 3	0.658	0.415	0.763

Cronbach α, measuring internal consistency, varies between 0 and 1 where values greater than 0.80 show high reliability.

†The intraclass correlation coefficient measures how closely 2 sets of measurement agree ranging from −1 to 1.

To measure discriminant validity, we compared our tool to Skindex-29. We first assessed for correlation of patient scores on the 2 tests and among the individual factors. We then evaluated the sensitivity of the questionnaire as a measure of QoL in ACD. Using all participant responses to each answer choice, we judged a specific question to be insensitive to QoL in ACD if more than 60% of patients chose one particular answer. We hypothesized that our novel, ACD, disease-specific instrument would be a more sensitive measure of QoL of patients with ACD than the generic Skindex-29.

All statistical analyses were performed using STATA 15.1 (Stata Statistical Software: Release 15, 2017; StataCorp LLC, College Station, TX).

RESULTS

We contacted 181 patients to participate in this study. Forty-one patients were not included because they were found to be patch test negative, had nonrelevant patch test reactions, did not have eczematous dermatitis, or did not have a primary diagnosis of ACD. Thirty-six (19.8%) of these patients declined to participate because of lack of interest or because they were not proficient English speakers. Fourteen participants did not return the 48-hour survey. Thus, a total of 90 patients met the qualifications, consented to participate in the study, and completed both the baseline (time 0) and the 48-hour survey. Subscale (emotion, symptom, and function) scores and individual item scores are presented in Table 1 for both Skindex-29 along with our novel 18-item ACD instrument. The emotion subscale was the most impacted, indicating that the QoL of patients with ACD is most affected by its emotional effects.

Item Analysis

Quality of life due to ACD was most affected by the item, "I worry about being exposed to things that make my condition worse," and the items relating to the emotional impact regarding the persistent nature of ACD, for example, "I am bothered that my skin condition never goes away." Quality of life was least affected by the item, "I am worried about infecting others," with the greatest number of patients answering "never" on the Likert scale.

Items with relatively low sensitivity, measured by more than 60% of participants selecting "never," included "My skin makes me feel dirty" (66%) and "I am worried about infecting other people" (84%). Because most of the responses to the cost item were "sometimes" (but neither positive nor negative), this item was determined not to be a sensitive measure of the effect of ACD on QoL. This factor was thus removed, reducing the 18-item tool to 17 items.

Reliability

Our hypothesized ACD subscales of functioning, emotions, and symptoms exhibited strong reproducibility between the 2 administrations of the survey. Individual Cronbach α coefficients for these factors were as follows: 0.87 for emotions, 0.88 for symptoms, and 0.81 for functioning (Table 2). An overall Cronbach α coefficient of 0.83 was calculated using all questions on the ACD instrument, indicating high internal consistency of the tool overall.

Construct Validity

The 3 hypothesized factors we analyzed were labeled by their predominant role in the assessment of new ACD: symptoms, emotions, and functioning. The intraclass correlation coefficients looking at associations in respondents' answers to questions within these categories at 0 and 48 hours were 0.90 for symptoms, 0.91 for functioning, and 0.86 for emotions, indicating that the answers at baseline and 48 hours were highly correlated (Table 2). Because it was found to be an insensitive measure of QoL, the cost factor was not included in the validation comparing the novel ACD instrument to Skindex-29.

Principal components factor analysis of the novel ACD instrument validated the presence of the 3 factors at both initial testing and 48 hours later, which explained 75% and 72% of the common variance, respectively, similar to the principal components analysis of Skindex-29 (68% and 62%, respectively). These factors identified—symptoms, functioning, and emotions—are the same as those seen with Skindex-29. In addition, ANOVA, a comparison of responses by individual questions and by subscale, was performed to determine test-retest reliability and showed no significant difference between the initial testing and 48 hours later. Tables 1 and 3 show the initial and 48-hour mean values for individual questions and by subscale.

TABLE 3. Mean 0- and 48-Hour (Pre and Post) Scores for Skindex-29 and ACD Novel Index by Domain

	0 h	48 h
Question Factors	Mean (SD)	Mean (SD)
Skindex Symptoms Factor	21.8 (5.4)	21.65 (5.4)
Skindex Emotions Factor	27.73 (8.5)	26.64 (8.5)
Skindex Functioning Factor	25.43 (9.7)	24.34 (9.4)
	11.49 (4.6)	10.97 (4.41)
ACD Emotions Factor	28.59 (10.9)	28.68 (10.19)
ACD Functioning Factor	7.65 (4.21)	7.71 (1.14)
ACD Cost Factor	2.53 (1.39)	2.55 (1.26)

Discriminant Validity

The total score on the novel ACD instrument was highly correlated with the total Skindex score (0.78, $P < 0.001$) as were the emotion, symptom, and function subscales of both tests (0.81, 0.75, and 0.73, respectively; all $P < 0.001$). This indicates that participants with the poorest QoL had similarly high scores on both tools; likewise, those with better QoL were recognized as such by both Skindex-29 and the novel ACD tool, evidenced by low severity scores on both indexes. Although highly significantly correlated with Skindex-29, overall and by subscale, the disease-specific ACD tool was more sensitive, as hypothesized. In only 2 (11%) of the ACD disease-specific questions versus 6 (21%) of the Skindex-29 questions did at least 60% of the participants answer "never."

DISCUSSION

Although our disease-specific questionnaire correlated highly with the generic tool Skindex-29, it was more sensitive than the generic tool to measure specific QoL effects in ACD patients. This was evidenced by the greater proportion of questions in our instrument that categorized patients based on their nuanced experiences. This is to be expected in a disease-specific tool developed with an intimate focus on ACD-specific experiences in mind.

Analyzing the specific responses to individual items on both the ACD index and Skindex-29 portrays a more granular picture of how the novel ACD tool is more sensitive to the impact on ACD patients' QoL. For example, on Skindex-29, our patients were most affected by the "itch" and "sensitive skin" items (both in the symptoms domain) and were most bothered by feelings of "annoyance" and "frustration" (in the emotions domain). The novel ACD index uncovered a further distinction regarding patients' frustration and worry with regard to their disease, which was concern about the persistent nature of their disease ("never goes away") and worry about exposures to possible triggers. This nuanced measure of QoL, generated by interviews with ACD patients and validated in this study, helps capture and quantify issues unique to ACD that provide more sensitive targets for improvement in individual ACD patients and inform which interventions and management (patch testing, counseling, and allergen avoidance) may be most effective in an individual patient's recovery.

In general, it is challenging to compare our ACD QoL results with other QoL studies of the disease for a few reasons. First, the existing ACD-specific QoL instruments are limited either by their clinical applicability or by psychometric properties. For example,

the fragrance QoL instrument (FQL index) is a 13-item tool developed to measure QoL in ACD patients but is applicable only to those with fragrance allergy.[9,11] Another contact dermatitis–specific tool, the Contact Dermatitis–Specific Questionnaire, does not provide validation methodology.[10] In addition, other tools validated for use in contact dermatitis, such as the DSQL, broadly include both irritant contact dermatitis and ACD and were not generated by and for ACD patients specifically.[3,9] Finally, available QoL data in ACD involve different instruments with different items and scoring systems that make it difficult to directly compare results.

A valuable attribute of a QoL tool is to provide insights into which aspects of a disease are most troubling to the patient. This ACD-specific tool provides understanding of how ACD impacts different domains of QoL, as has been reported for other dermatological conditions. Our patients with ACD reported a negative impact on QoL in all domains measured—symptoms, functioning, and emotion—on both the novel ACD instrument and Skindex-29 (Table 3). Specifically, our patients with ACD were most negatively affected by the emotion subscale, connoting the worst QoL. This is in contrast with the Skindex-29 measurements in patients with eczematous dermatitis,[8] which has shown patients with a general diagnosis of eczematous dermatitis to be most affected by the symptoms subscale (Table 4). The same was true when comparing our ACD patients with those with psoriasis.[8] This finding is of interest to clinicians treating patients with ACD, because addressing emotional impairment in this patient population may improve the care and support of ACD patients.

The emphasis of our results on the emotional impact of ACD compared with symptoms and functioning suggests that the perception of ACD and its long-term implications causes more distress than the impact of ACD on day-to-day activities (such as with functional impairment and symptoms). The higher scores on emotion-based questions, which depict the disease as "unpredictable," "never going away," or making patients feel "out of control," indicate that feelings of insecurity and fear of prolonged suffering are more troubling than short-term difficulties. Bother about the peeling or flaking of skin, or the inconvenience of performing certain tasks with hands affected by ACD, may be perceived as more of an annoyance than a major roadblock.

TABLE 4. Mean (SD) Skindex-29 Scores of Patients With ACD Compared With Patients With Other Skin Conditions

	Symptoms	Emotions	Function
Diagnosis (No. Patients)	Mean (SD) Score	Mean (SD) Score	Mean (SD) Score
ACD (90) (results of our patients on Skindex-29)	22 (5)	28 (9)	25 (10)
Psoriasis (44)*	42 (21)	39 (27)	23 (27)
Acne vulgaris (63)*	30 (19)	41 (25)	16 (16)
Eczematous dermatitis (102)*	48 (23)	41 (25)	16 (16)
No skin disease (107)*	14 (2)	9 (13)	4 (8)

*These results are adapted from Chren.[8]

Kadyk et al[15] found patients with active ACD (patch tested within 6 months of being surveyed) to have worse QoL than both those with chronic ACD (patch tested for 6–12 months prior) and those with a general diagnosis of eczematous dermatitis, as seen by Chren et al,[16] possibly suggesting that acute ACD is at least as disruptive as other eczematous dermatitides.[15,16] Alternatively, our Skindex-29 results showed better QoL in patients with ACD compared with the findings of Chren et al[8] in those with eczematous dermatitis, which may further suggest that patients with ACD are less impacted than those with other eczematous conditions. However, there are a number of other reasons that may explain this difference in QoL scores. First, ACD is chronic and episodic in nature; patients who come to our tertiary referral center for patch testing have typically had their dermatitis managed by another dermatologist before coming to our clinic. In addition, ACD patients undergoing patch testing must be clear enough to patch test; thus often, the acute phase of their dermatitis is well managed by the time they come for patch testing.

The DSQL was developed from clinical expertise with contact dermatitis experts and from focus groups with acne patients.[12] Although not an ACD-specific tool, the DSQL was validated broadly for contact dermatitis patients, including those with both irritant contact dermatitis and ACD. It has been used in contact dermatitis patients and validated for this patient population. It found that the symptoms domain was most negatively impacted for contact dermatitis patients, which differs from our findings; we found the symptoms domain to be least impacted for ACD patients, as measured by the novel index.

In comparison with the tool we developed, the DLQI has 6 subscales, which do not completely capture some of the emotion subscale items that were important for our patients. For example, condition persistence, annoyance, and frustration were the most important items for our ACD patients but are not assessed, as such, by the DLQI.[3]

Using the DLQI, Woo et al[14] found that ACD patients were impacted similarly to psoriasis patients with regard to QoL. Interestingly, our ACD patients demonstrated better QoL compared with the results of psoriasis patients (Table 4).[8] Our data also parted with the literature with respect to the effect of sleep on QoL. Using the DLQI, Holness and Nethercott[17] found sleep to be one of the most significantly affected QoL factors in occupational ACD patients. With a mean score of 2.93 to 2.96 on the Likert scale for the question addressing impact on sleep, our patients seem to be only moderately impacted by sleep impairment (Table 1), which again may be due to varying degrees of disease control by referring dermatologists in anticipation of patch testing.

The novel instrument described in this study was developed specifically for ACD—as opposed to irritant contact dermatitis, contact dermatitis as a whole, or ACD to any particular subclass of allergens. To this end, the creation of this specific tool originated with intensive and in-depth interviews of patients with ACD to distill the most common and most significant aspects of the ACD experience.

This tool individually addresses the effects of ACD on patient function, symptoms, and emotional well-being in a nuanced way

that is specific to ACD and its specific impact on QoL. This novel tool allows providers to assess and understand QoL in ACD patients by whichever aspect of the disease the patient considers to be most troublesome. For example, some patients with ACD may present with facial or hand dermatitis. However, some may be troubled by functional elements of disease (eg, difficulty using the hands), whereas others more so by emotional elements (eg, worried about exposures to triggers). Understanding how the condition impacts the individual patient better informs the patient-provider relationship and allows for improved and targeted patient counseling. In addition, a disease-specific QoL tool can demonstrate to managed care organizations and insurance companies the impact of ACD on QoL, as well as the utility of medical intervention and therapy for ACD, making insurance coverage more likely for these interventions.

In addition to being statistically validated against a well-established generic dermatological instrument, this tool has the advantage of efficiency; it consists of 17 items and takes less than 5 minutes to complete. A shorter tool that provides a more sensitive measure of QoL may not only be of advantage to providers in a busy clinic setting but also be more amenable to the patient.

There are several limitations to this study. First, this study was performed at a single location, in a tertiary referral center in San Francisco, CA. Non-English speakers were excluded from the study, to ensure adequate understanding when developing and testing the tool. Second, only adults 18 years or older were included in this study, and thus, the instrument has not been validated in children. Third, our population was heterogeneous, and our referral patients often have more than 1 dermatologic diagnosis other than ACD and may have confused these in their responses.

CONCLUSIONS

Through patient and dermatitis expert interviews, we created a valid ACD disease-specific QoL instrument and used it to assess QoL in our tertiary referral patch test clinic. We found that our patients were most affected by the emotion subscale of our novel ACD instrument. In particular, our patients were most negatively affected by worry about exposures to potential triggers and worry about the persistent nature of their condition. We believe that our novel, validated tool is best paired with a generic instrument such as Skindex-29, for comprehensive disease assessment, and can be used to measure the nuanced aspects of QoL in patients with ACD and also compare QoL effects with those of other conditions. Finally, we believe that this tool will be useful in research aimed at better understanding QoL in patients affected by ACD and the management approaches for this disease in the future.

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