Development and Validation of Skindex-Teen, a Quality-of-Life Instrument for Adolescents With Skin Disease

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Objective: To develop and validate a quality-of-life index for adolescents with skin disease.

Design: Prospective, longitudinal cohort study taking place from July 15, 2005, through February 29, 2008.

Setting: Academic pediatric dermatology practice.

Patients: A total of 205 patients between the ages of 12 and 17 years with a skin condition.

Main Outcome Measures: Participants completed the Skindex-Teen questionnaire, reported sociodemographic data, and answered clinical questions at enrollment. Four weeks later, they completed Skindex-Teen and responded to clinical questions again. Forty patients also completed Skindex-Teen 48 hours after baseline.

Results: Of 205 patients, 200 (97.6%) completed all enrollment materials; 125 (62.5%) of these returned follow-up materials, of which 115 (57.5%) were complete. Twenty-three of 40 participants (57.5%) completed the 48-hour-after-initial-answers materials. The mean (SD) age of the patients was 15.3 (1.4) years (range, 12.9-18.0 years). Approximately half reported their skin condition as poor (26 [13.0%]) or fair (67 [33.5%]); most rated their general health as very good (62 [31.0%]) or excellent (80 [40.0%]). The dimensionality of the items was evaluated using factor analysis; results suggested 2 factors, termed physical symptoms (5 items) and psychosocial functioning (16 items). Both scales demonstrated excellent internal consistency. All item-scale reliabilities were greater than 0.4. Fit of items to the measurement model was supported by Rasch analysis. Test-retest reliability was supported by intraclass correlation coefficients (0.82-0.94) for total scores, physical symptoms, and psychosocial functioning scales. At 4 weeks, 16 (13.9%) reported worsening of their skin condition, 57 (19.6%) reported it had remained unchanged, and 42 (36.5%) reported improvement. Significant mean differences were present between the improved and worsened groups for the psychosocial functioning scale and total scores.

Conclusions: These data provide evidence of construct, content, and face validity for Skindex-Teen, a new quality-of-life instrument for adolescents with skin disease. Test-retest reliability was verified, and responsiveness at 4 weeks was shown for total scores and the psychosocial functioning scale scores.

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Skin disease is common in the adolescent (aged 12-17 years) population, with significant effects on quality of life at a time when many such patients are particularly vulnerable to issues of self-esteem and psychosocial development. A skin condition may cause not only physical symptoms, such as pain, pruritus, and bleeding, but also emotional disturbance and social dysfunction, such as frustration, isolation, and negative effects on self-esteem and self-image. Accurate measurement of the multidimensional effects of skin disorders on quality of life can improve the burden of disease for affected individuals by allowing the physician a better understanding of the experience of patients. Such measurement can also be used as an objective outcome for clinical research in this population. Although many quality-of-life instruments have been validated for use in adults with skin disease, fewer are available for use in children and none (to our knowledge) for adolescents. Most pediatric instruments are disease specific and involve patients affected with atopic dermatitis, including work done by some of the authors. There is no validated quality-of-life instrument designed and validated for adolescents with skin disease. This unique population requires age-specific questions addressing pertinent aspects of their lives, including participation in sports, peer activities, clothing choices, and develop-
ment of self-image. Thus, an instrument attempting to best capture quality of life in adolescents should be specifically tailored to these issues. We therefore developed and validated an instrument specific to adolescents with skin disease for use in research and clinical practice.

**METHODS**

**INSTRUMENT DEVELOPMENT**

On the basis of our clinical experience, expert opinion, and review of the literature, we hypothesized that the effects of skin conditions on quality of life in adolescents could be classified into 3 domains: physical health, emotional health, and physical and social functioning. Investigators (A.C.S. and S.L.C.) drafted items to address the hypothesized model with reference to Skindex10 and Skindex-16.17 An expert group of 11 pediatric dermatologists reviewed the drafted pilot instrument, and items were revised according to their feedback. The resulting 22-item Skindex-Teen prototype is given in Table 1. The questionnaire was administered by the patient and generally takes 5 to 10 minutes and overall content was preserved. Skindex-Teen is self-administered to the patient and generally takes 5 to 10 minutes to complete. The instrument inquires about the patients’ perceptions during the previous 4 weeks regarding their primary skin condition. Standardized response choices consist of 5-category choices relating to frequency (never, rarely, sometimes, often, and all the time). In the final version, each item is scored from 0 (never) to 4 (all the time).

**SAMPLE POPULATION AND DATA COLLECTION**

Two hundred five adolescent patients were recruited from the dermatology clinic of Children’s Memorial Hospital (Chicago, Illinois) by 1 of the investigators (A.C.S., S.P., or S.L.C.). All study participants and their parents or primary caregivers provided written informed assent and consent. Eligible criteria included the following: age between 12 and 17 years, presence of a skin condition, ability to read and understand English, and age-appropriate development (as determined by history; developmentally delayed patients were excluded). The study was approved by the institutional review board at Children’s Memorial Hospital.

Enrolled patients completed the prototype Skindex-Teen questionnaire, filled out sociodemographic forms, and responded to other clinical questions before leaving the clinic. The clinical questions relating to the patients’ general health (“In general, how do you rate your health?”) and their skin condition (“How would you rate the condition of your skin now?”) were scored using the responses poor, fair, good, very good, or excellent. In addition, the patients were asked about their overall associated bother (measured on a 10-point visual analog scale) and the effect of their skin condition on their overall quality of life (“Does this skin problem affect your happiness?” with responses of never, rarely, sometimes, often, or all the time). All patients also answered the open-ended question, “What about your skin disease bothers you the most?”

Test-retest reliability was evaluated using a subset of 23 patients (of 40 who were invited to participate; refusal rate of 42.5%). A 48-hour interval was chosen to minimize recall bias and ensure that the severity of disease would be minimally changed. All enrolled patients were sent a follow-up mailing 1 month after their visit, including the prototype Skindex-Teen and the same clinical questions previously completed. Most (125 patients; 62.5%) of the 200 respondents returned the 4-week survey, of which 115 (57.3%) answered all questions; the responsiveness to clinical change was evaluated using data from those patients. Data were entered into an SPSS data set (SPSS Inc, Chicago, Illinois); SAS statistical software (SAS Institute Inc, Cary, North Carolina) was used for all data analyses.

**STATISTICAL ANALYSES**

Dimensionality of Skindex-Teen was determined by using exploratory factor analysis with promax rotation to facilitate interpretation. Three criteria from exploratory factor analysis were used in this study: (1) K1 rule (ie, number of factors with eigenvalue >1), (2) scree plot (ie, number of factors before the break in scree plot), and (3) factors that have explained variance greater than 5%.18 Using this analysis, items with factor loading of 0.4 or higher are considered significantly loaded to that factor. Results were reviewed by the research team with reference to expert feedback to determine item inclusion or exclusion.

Rasch analysis, as implemented in the WINSTEPS computer program,19 was used to evaluate the characteristics of Skindex-Teen at the item and scale levels. Rasch analysis maps samples and items onto the same measurement continuum according to the severity levels those items measure and the degree of severity patients experience. This model was chosen over more complex item response theory models because it requires fewer cases. Fit statistics (ie, the ratio between expected and observed variance) for each item were used to evaluate whether the items fit the Rasch model. A range of 0.6 to 1.4 mean square was considered an acceptable item fit. At the scale level, Rasch analysis estimates the extent to which the set of items distinguishes distinct levels of ability within the sample being tested by reporting a separation index. A separation index less than 1 indicates that the set of items was not able to distinguish more than 1 level of domain of interest in the sample.
was determined by using the intraclass correlation coefficient, which adjusts for the difference between time points. The responsiveness of Skindex-Teen was evaluated by comparing changes of Skindex-Teen scores and changes in responses to the clinical questions about overall skin condition from baseline to 4 weeks. Patients were categorized as improved, worsened, or remained the same based on change from their baseline response to the general skin question, “How would you rate the condition of your skin now?” We used analysis of variance to examine the ability of Skindex-Teen to differentiate these 3 patient groups.

**RESULTS**

**SAMPLE CHARACTERISTICS**

Of 205 enrolled patients, 200 (97.6%) completed the prototype Skindex-Teen questionnaire and the sociodemographic items. The mean (SD) age of the patients was 15.3 (1.4) years (range, 12.9-18.0 years). Ninety-one patients (45.5%) were boys and 109 (54.5%) were girls. Of those 200, 128 (64.0%) were self-identified as white, 31 (15.5%) as Hispanic, 30 (15.0%) as African American, and 13 (6.5%) as Asian. The most common skin conditions reported by patients were acne (79; 43.2%) and atopic dermatitis (33; 18.6%). Although some patients may have documented more than 2 conditions, the primary diagnosis was used for analysis. **Table 2** demonstrates the most common conditions reported in our study population, with accompanying mean Skindex-Teen scores. A low percentage of patients reported other medical conditions, including asthma (30 [15.0%]) and hay fever (19 [9.5%]). Approximately half the patients reported the condition of their skin to be poor (26 [13.0%]) or fair (67 [33.5%]). However, most patients rated their general health as being either very good (62 [31.0%]) or excellent (80 [40.0%]). A modest correlation (Spearman \( r = 0.323 \)) between health and skin condition was found.

**CONTENT VALIDITY**

Of the 200 enrolled patients, 187 patients (93.5%) responded with 200 mentions of the ways their skin dis-ease most bothered them. The most common categories mentioned were as follows: appearance; perception by others; itching, pain or discomfort; effect on apparel choice; feelings of anger or frustration; chronicity of condition; need for medications or treatment; and effect on self-esteem or self-image. The content of the responses was compared with the retained items of Skindex-Teen, and all mentions noted by greater than 1% of patients were included.

**DIMENSIONALITY EVALUATION**

The exploratory factor analysis results showed 3 factors with an eigenvalue greater than 1.0, and only the first factor explained greater than 5% of variances. The scree plot showed 2 factors before the break. On the basis of the results of factor loadings, these 2 factors were named physical symptoms (item \( n = 5 \)) and psychosocial functioning (item \( n = 16 \)). One item, “My skin condition is a problem for the people I love,” was ultimately excluded because patients seemed to have issues endorsing response (Table 1). This exclusion resulted in a 21-item instrument. Both scales demonstrated excellent internal consistency (\( \alpha = 0.85 \) and 0.92 for physical symptoms and psychosocial functioning, respectively). All item-scale reliabilities were greater than 0.4, ranging from 0.53 to 0.75 and 0.49 to 0.79 for physical symptoms and psychosocial functioning, respectively. Rasch analysis results supported the presence of 3 factors. For the psychosocial functioning domain, all items had mean-square values between 0.6 and 1.4, except for the item “I worry about getting scars from my skin condition,” which had a borderline mean square of 1.45. The separation index was 2.51, meaning these items were able to differentiate the sample into 3 levels of psychosocial functioning (mild, moderate, and severe). For the physical symptoms domain, all items had mean-square values between 0.6 and 1.4, and the separation index was 1.46, indicating that these items separate patients into 2 levels in terms of their symptoms.

**TEST-RETEST RELIABILITY AND RESPONSIVENESS**

Test-retest reliability of the Skindex-Teen was verified by acceptable intraclass correlation coefficients: 0.94, 0.82, and 0.94 for the total score, physical symptoms scale score, and psychosocial functioning scale score, respectively. The mean (SD) changed scores between baseline and 4-week
follow-up were −0.677 (3.17; range, −16.0 to 6.0), −1.768 (9.3; range, −33.0 to 26.0), and −2.457 (11; range, −47.0 to 31.0) for physical symptoms, psychosocial functioning, and Skindex-Teen total scores, respectively. Among those who completed all items in the 4-week follow-up survey, 16 (13.9%) reported their skin condition had worsened, 57 (49.6%) reported it had remained unchanged, and 42 (36.5%) reported it had improved since baseline assessment, based on responses to the clinical question about skin condition. Analysis of variance results showed that psychosocial functioning scale and Skindex-Teen total scores significantly differentiated patients in these groups ($F_{1,110} = 4.37$, $P = .01$, and $F_{1,111} = 4.03$, $P = .02$, respectively). Follow-up post hoc tests (Tukey honestly significant difference) indicated that significant mean differences were present between improved and worsened groups on both scores, indicating responsiveness for the psychosocial functioning scale and total Skindex-Teen scores. Nonsignificant results were found for the physical symptoms scale ($F_{1,111} = 1.86$, $P = .16$).

Skindex-Teen (Table 1) is a hypothesis-based quality-of-life scale developed and refined by review of published work, feedback from expert pediatric dermatologists, and pilot and validity evaluation. This study represents the multistep process of developing and evaluating the performance and properties of Skindex-Teen, including face, construct, and content validity, test-retest reliability, and responsiveness at 4 weeks.

Items in each domain are detailed in Table 1. Skindex-Teen can be reported as a total score (range, 0-84.0) and/or by the domain scales of psychosocial functioning (range, 0-64.0) and physical symptoms (range, 0-20.0). Table 2 includes the mean Skindex-Teen scores in our sample population by diagnosis, which may be helpful in interpreting Skindex-Teen scores in clinical trials and practice.

Face validity of Skindex-Teen was ensured by a pilot study and expert review; construct validity was demonstrated by inclusion of all major concerns of enrolled patients. Construct validity was evaluated by testing whether the relationships between domains in the hypothesized conceptual framework were found in responses to the prototype Skindex-Teen instrument. Factor analysis supported combining domains, resulting in a reduced number of domains, namely, psychosocial functioning and physical symptoms. On the basis of the results of the psychometric analyses and item performance results, the hypothesized conceptual framework for the effects of skin disease on adolescents was modified. The revised framework with fewer domains simplifies the conceptualization of effect as being divided into physical and psychological components. This simplified structure does not compromise the comprehensive item content.

Test-retest reliability at 48 hours was confirmed. In addition, responsiveness evaluation demonstrated that Skindex-Teen measures change in patients whose skin condition improves or worsens for the psychosocial functioning domain and the total score but not the physical symptoms domain.

Study weaknesses include the fact that all patients were recruited from a single pediatric dermatology practice, which may introduce a referral bias because of increased disease severity in participants or increased concern about their disease; however, most patients reported good to excellent general health. Of note, a low correlation between skin condition and health status was found, which highlights the importance of including dermatology-specific scales in this setting. A generic health status scale does not suffice to measure how patients perceive their skin condition. In addition, most patients were white (128 [64.0%]), which reflects the demographics of patients seen in our specialty practice but may not be generalizable to all practice or research settings.

These analyses demonstrate evidence of construct and content validity of the refined version of Skindex-Teen as a measure of the effects of skin disease in adolescents. In addition, these analyses demonstrate strong evidence of face validity, test-retest reliability, and responsiveness at 4 weeks. We hope this instrument will prove useful for clinical and research applications in measuring and understanding the quality-of-life effects of skin disease in the adolescent population.

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Author Contributions: Drs Smidt, Lai, and Chamlin had full access to all the data in the study and take responsibility for the integrity of the data and the accuracy of the data analysis. Study concept and design: Smidt, Cella, and Chamlin. Acquisition of data: Smidt, Patel, Mancini, and Chamlin. Analysis and interpretation of data: Smidt, Lai, Cella, and Chamlin. Drafting of the manuscript: Smidt, Lai, Patel, and Chamlin. Critical revision of the manuscript for important intellectual content: Mancini and Cella. Statistical analysis: Lai and Cella. Administrative, technical, and material support: Smidt and Patel. Study supervision: Chamlin.

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REFERENCES

At the multiheaded microscope, the working dynamics of the academic dermatopathology sign-out demonstrate that much more occurs than the provision of a diagnosis. There are concurrent clinical correlation, teaching, debate, consultation, research, troubleshooting, and social interaction. With this light-hearted analysis of these dynamics, I applaud those who offer the opportunity to participate in the process.

As someone from a farming community, I have always likened the multiheaded microscope to the udder of a cow, both physically and symbolically. The heads of the microscope project like teats, while there is a jostle of parasitic younglings gathering for their scholarly feed. A clear hierarchy forms, with a dominant figure making all the noise and a new entrance runt who just cannot quite manage to get things into focus. In this medical hierarchy, a stereotypical pattern emerges.

Resident: The resident is just annoyingly enthusiastic. The rush of excitement after acceptance into the training program, coupled with a little newfound knowledge, leads to a flurry of ideas. A bewildering differential diagnosis is constructed, matched by an extensive array of special tests, some of which are available for use only on animals. The resulting immunohistochemical nuclear fallout will require years of analysis and the completion of several doctorates for adequate interpretation.

Fellow: The fellow is disturbingly quiet. This demeanor is intentional, to create an impression of vast quantities of hidden knowledge from the hours of preexamination study that is being performed. The reality is a snowballing pressure to produce a diagnosis. The initial scan is followed by a stepwise detailed analysis and the completion of several doctorates for adequate interpretation.

Chief: The chief appears as one with the microscope. The logical progression of the train of thought can be directly observed. Over time, and with increasing basic knowledge, these patterns of analysis can be learnt. The colleague departs, leaving a mild feeling of ecstasy following this successful intellectual brainstorm.

Concurrently, there is recognition of the low-power tissue-reaction pattern, with formulation of provisional differential diagnoses. The long relationship with the microscope lends to a smooth careless of the apertures between power changes and to an evolutionary advantageous focus finger callus. Of special note is the acquisition of a curious ability to detect even a subtle lag of the student’s eyelids behind the hidden corner eyepieces. For educational purposes, the ability to observe the cerebral process of reaching a diagnosis around the multiheaded microscope is unique. Primarily, there is the pattern of viewing, which at its simplest is the basic progression from low to high power. In reality, this process involves a learnt ability to scan and concentrate on the high-yield areas, which begins with an often-imperceptible but vital gross analysis of the slide.

The Dermatopathology Ward Round: A Tribute to the Multiheaded Microscope

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