VALIDATION AND RELIABILITY OF A DISEASE-SPECIFIC QUALITY OF LIFE MEASURE IN PATIENTS WITH CUTANEOUS LUPUS ERYTHEMATOSUS

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Background Cutaneous lupus erythematosus (CLE) is a potentially disfiguring, chronic autoimmune disease with variable skin manifestations, negatively affecting the quality of life (QoL) of patients. Patient-reported outcome (PRO) measures used in assessing QoL in CLE patients have been either generic or developed without input from patients with CLE. The objective of this study was to demonstrate the reliability and validity of a disease-specific QoL measure for CLE the cutaneous lupus erythematosus quality of life (CLEQoL).

Methods A total of 101 patients with a diagnosis of CLE were recruited at outpatient dermatology clinics at the University of Texas Southwestern Medical Center and Parkland Health and Hospital System in Dallas, TX. Each patient was asked to complete the CLEQoL and Short Form 36 (SF-36). The CLEQoL contains 29 questions from the SKINDEX, a generic skin disease QoL measure, three questions relating to photosensitivity and alopecia (adapted from the SKINDEX-29 +3), and four questions from the vitiligo-specific quality of life (VitiQoL) (figure 1). These questions were validated via focus groups of patients with CLE. Internal consistency was used as a measure of reliability. Validity was measured in two ways structural validity via exploratory factor analysis and convergent validity via Spearman correlations between CLEQoL and SF-36. Patient demographic and disease characteristics were collected. Data was analyzed using SPSS and significance was set to p<0.05.

Results The average age of our CLE patients was 48±13 with discoid lupus (n=72, 71.3%) being the most predominant CLE subtype. Patients were mostly female (n=88, 87.1%) and African-American/Black (n=59, 58.4%). Internal consistency ranged from 0.67 to 0.95. A total of five domains, functioning, emotions, symptoms, body image/cosmetic effects and photosensitivity, were extracted with a total explained variance of 71.06%. CLEQoL-related domains correlated with SF-36 domains (r ranging from 0.39 to 0.65). The Cutaneous Lupus Activity and Severity Index (CLASI) activity scores correlated positively with the CLEQoL functioning (r=0.24, p<0.05), emotions (r=0.26, p<0.05), and symptoms (r=0.32, p<0.05) domains. CLASI damage scores correlated positively with the CLEQoL body image/cosmetic effects (r=0.41, p<0.001) and photosensitivity (r=0.25, p<0.05).

Conclusions The CLEQoL was found to be a valid and reliable PRO measure for assessing QoL in patients with CLE. Demonstrating that the CLEQoL has strong psychometric properties is an important step towards the development of a disease-specific PRO measure for future CLE clinical trials.

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IDENTIFICATION OF DAMAGE CLUSTERS IN SYSTEMIC LUPUS ERYTHEMATOSUS

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Abstract 253 Figure 1 The CLE-specific quality of life measure CLEQoL

Abstract 253 Figure 1

These questions concern your feelings over the past 4 weeks about the skin condition that has bothered you the most. Check the answer that comes closest to the way you have been feeling.

NEVER RARELY SOMETIMES OFTEN ALL THE TIME

1. My skin hurts
2. My skin condition affects how well I sleep
3. I worry that my skin condition may be serious
4. My skin condition makes it hard to work or do hobbies
5. My skin condition affects my social life
6. My skin condition makes me feel depressed
7. My skin condition burns or stings
8. I tend to stay at home because of my skin condition
9. I worry about getting scars from my skin condition
10. My skin itches
11. My skin condition affects how close I can be with those I love
12. I am ashamed of my skin condition
13. I worry that my skin condition may get worse
14. I tend to do things by myself because of my skin condition
15. I am angry about my skin condition
16. Water bothers my skin condition (bathing, washing hands)
17. My skin condition makes showing affection difficult
18. I worry about side-effects from skin medications / treatments
19. My skin is irritated
20. My skin condition affects my interactions with others
21. I am embarrassed by my skin condition
22. My skin condition is a problem for the people I love
23. I am frustrated by my skin condition
24. My skin is sensitive
25. My skin condition affects my desire to be with people
26. I am humiliated by my skin condition
27. My skin condition bleeds
28. I am annoyed by my skin condition
29. My skin condition interferes with my sex life
30. My skin condition makes me tired
31. I worry about going outside because the sun might flare my disease
32. I am worried about my hair loss
33. My skin disease prevents me from doing outdoor activities
34. When talking to someone, I worry about what they may be thinking of me
35. My skin condition influences the clothes I wear
36. My skin condition affects my grooming practices (e.g., haircut, use of cosmetics)
37. My skin condition affects my sun protection habits during recreation (e.g., limiting exposure time during sun peak hours, seeking shade, wearing a hat, long sleeves or pants)

Background Damage in SLE is an irreversible change of organ system results from SLE involvement or adverse effects of medications. Recently, the awareness and evidence of subphenotypes in SLE has been increased. In this study, thus we are to identify damage clusters and compare organ damage involvement, demographic and clinical manifestations, mortality and weighted genetic risk score (GRS) between clusters.

Methods The study was conducted from Hanyang Bae lupus Cohort. Patients whose disease duration is less than 5 years were excluded to minimize potential confounding effects of disease duration. Patients were grouped into 3 clusters based on SLICC Damage Index (SDI) at last follow-up visit using K-mean cluster analysis. Comparison of characteristics between clusters were performed using ANOVA and Chi-square test.

Results A total number of 1130 patients were analyzed. Both the last follow-up visit, musculoskeletal damage was the most frequent damage domain followed by ocular, renal and...