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Comparing dermatologic patient-reported outcome measures in cutaneous lupus erythematosus

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To cite: Sprow G, Dan J, Feng R, *et al*. Comparing dermatologic patient-reported outcome measures in cutaneous lupus erythematosus. *Lupus Science & Medicine* 2022;**9**:e000827. doi:10.1136/lupus-2022-000827

Received 22 September 2022
Accepted 6 December 2022

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Patient-reported outcome measures (PROMs) are useful tools for informing clinicians about the impact of disease on patients and are increasingly used as endpoints in clinical trials. The Skindex-29+3 is a dermatologic PROM that builds on the previously validated Skindex-29 with three additional cutaneous lupus erythematosus (CLE)-specific questions on hair loss and photosensitivity.[1] The Skindex-16 is another dermatologic PROM designed to have fewer items than the Skindex-29 while measuring bother rather than frequency of patient experiences.[2] Scoring the Skindex-29 and Skindex-16 leads to calculation of subscales in symptoms, emotions and functioning, while the additional questions in the Skindex-29+3 generate a photosensitivity subscale score. Little is known about how these measures compare in assessing the quality of life of patients with CLE. A cohort of 27 patients with CLE enrolled in a prospective database at the University of Pennsylvania Perelman School of Medicine completed both PROMs. This database, established in 2006, recruits adult subjects who have CLE using the Gilliam classifications from the Autoimmune Skin Disease Clinic at the Hospital of the University of Pennsylvania. This cohort of patients was also evaluated with the Cutaneous Lupus Erythematosus Disease Area and Severity Index, a validated disease scoring tool which creates an activity score based on erythema, scale, mucous membrane involvement and non-scarring alopecia, as well as a damage score based on dyspigmentation and scarring.[3] Overall Skindex-16 and Skindex-29+3 scores were calculated by averaging their component subscale scores.

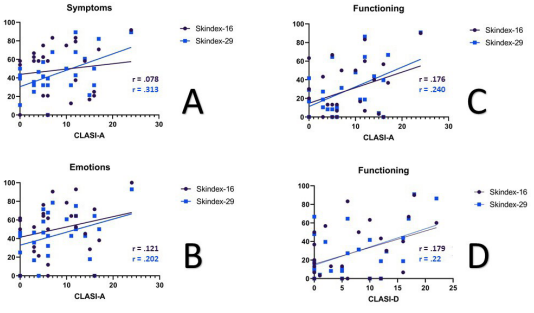

Figure 1 Scatter plots demonstrating the relationship of CLASI-A (A–C) and CLASI-D (D) to Skindex-16 and Skindex-29 subscale scores. CLASI-A, Cutaneous Lupus Erythematosus Disease Area and Severity Index–Activity; CLASI-D, Cutaneous Lupus Erythematosus Disease Area and Severity Index–Damage.

Data analysis used intraclass correlation coefficients calculated with IBM SPSS Statistics for Windows V.26.0. The symptoms subscale of Skindex-29 showed a higher degree of correlation with Cutaneous Lupus Erythematosus Disease Area and Severity Index–Activity (CLASI-A) (r=0.313) than the symptoms subscale of Skindex-16 (r=0.078) (figure 1). The emotions subscale of Skindex-29 was also found to have a higher degree of correlation with CLASI-A (r=0.202) than the emotion subscale of Skindex-16 (r=0.121) (figure 1). The functioning subscale of Skindex-16 had a lower degree of correlation with CLASI-A (r=0.176) than the same subscale of Skindex-29 (r=0.240) (figure 1). The Skindex-29+3 subscale of photosensitivity had a lower degree of correlation with CLASI-A (r=0.189) than the other Skindex-29 subscales. Skindex-29+3 overall had a higher degree of correlation with CLASI-A (r=0.305) than Skindex-16 (r=0.159). The symptoms subscale of Skindex-29 showed a higher degree of correlation with Cutaneous Lupus Erythematosus Disease Area and Severity Index–Damage (CLASI-D) (r=0.196) than the symptoms subscale of Skindex-16 (r=0.152). The emotions subscale of Skindex-29 was also found to have a higher degree of correlation with CLASI-D (r=0.172) than the emotions subscale of Skindex-16 (r=0.084). The functioning subscale of Skindex-16 had a lower degree of correlation with CLASI-D (r=0.179)

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than the same subscale of Skindex-29 (r=0.22) (figure 1). The Skindex-29+3 subscale of photosensitivity had a lower degree of correlation with CLASI-D (r=0.091) than the other Skindex-29 subscales. Skindex-29+3 overall had a higher degree of correlation with CLASI-D (r=0.220) than Skindex-16 (r=0.18).

The symptoms, emotions and functioning subscales of Skindex-29 showed a higher degree of correlation with CLASI-A and CLASI-D than the corresponding subscales of Skindex-16. Skindex-29+3 overall also showed a higher degree of correlation with CLASI-A and CLASI-D than Skindex-16. These results may indicate that the Skindex-29+3 more accurately captures information related to CLE skin activity and damage than the Skindex-16. The small sample size of our study and the use of patients exclusively at a single referral-only centre preclude definitive conclusions. However, the results presented here may provide hypotheses for larger future studies.

Contributors GS contributed to the design and implementation of the research,analysis of the results and writing of the manuscript. JD, RF and VPW contributed to the analysis of the results and the writing of the manuscript.

Funding This article received funding from the US Department of Veterans Affairs (Veterans Health Administration, Office of Research and Development and Biomedical Laboratory Research and Development) and the National Institute of Health (R01AR071653, VPW).

Competing interests None declared.

Patient consent for publication Not applicable.

Ethics approval This study involves human participants and was approved by University of Pennsylvania Institutional Review Board (protocol 805758). The participants gave informed consent to participate in the study before taking part.

Provenance and peer review Not commissioned; externally peer reviewed.

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