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QoL and disease severity in a CLE pilot study

Elizabeth Gaines, B.A.¹, Zuleika Bonilla-Martinez, M.D.¹, Joerg Albrecht, M.D.¹, Lynne Taylor, Ph.D.², Joyce Okawa, RN¹, Andrea B. Troxel, Ph.D.², and Victoria Werth, M.D.^{1,3}

Elizabeth Gaines: eg489@med.nyu.edu; Zuleika Bonilla-Martinez: zuleikaliz@yahoo.com; Joerg Albrecht: Joerg.Albrecht@gmail.com; Lynne Taylor: ltaylor@pobox.cceb.upenn.edu; Joyce Okawa: Joyce.Okawa@uphs.upenn.edu; Andrea B. Troxel: atroxel@mail.med.upenn.edu; Victoria Werth: werth@mail.med.upenn.edu

¹Univ. of Pennsylvania, Department of Dermatology, Philadelphia, PA

²University of Pennsylvania, Center for Clinical Epidemiology and Biostatistics, Philadelphia, PA

³Philadelphia V.A., Philadelphia, PA

As part of a study to evaluate the clinical responsiveness of the Cutaneous Lupus Area and Severity Index (CLASI) (1) we assessed the relationship between the change in cutaneous lupus erythematosus (CLE) disease severity and quality of life. CLE activity and severity was measured as assessment of the global skin health by the patient and physician on a 0-10 analogue scale and with the CLASI; quality-of-life was measured by the Skindex-29 (2). We prospectively followed 8 Patients with biopsy-proven CLE (6 DLE, 2 SCLE) over 56 days after they started new treatment regimens. At each visit patients completed the CLE-modified Skindex-29, which included three questions beyond the previously validated Skindex-29. Of the additional questions, two questions related to concerns about photosensitivity and one related to concerns about hair loss. The PI evaluated disease severity with the CLASI, and the patient and PI evaluated the patient's skin health.

The results of our study were surprising in that quality of life did not easily correlate with improvement or deterioration of the disease. We found a moderate correlation (Spearman $r=0.55$) between the change in CLASI activity scores and the change in Skindex scores. In patients 4 and 6, with SCLE, the complete resolution of the active disease without significant scarring was associated with only minimal improvement in their Skindex scores (see table 1 for detailed results). In patient 3 there was moderate improvement of the Skindex even though the skin condition as measured by the CLASI did not significantly improve. Although there was improvement of activity in patient 2, there was increased damage, with worsening of the Skindex. The improved activity in patient 7 and 8 correlated with an improved Skindex score, despite a worsening of the damage score. Only patients 1, 5, and 6 had both the CLASI and Skindex correlate as expected with parallel improvement of both scores.

This small monocentric study cannot validate or devalue the Skindex as a measure for quality of life in CLE. The correlation between what physicians and indeed patients perceive as objective improvement or deterioration of a skin condition may not correlate with the patient's quality of life. Our observations may imply that our treatment goals should extend beyond the obvious control of the disease, which is reliably measured by the CLASI. The Quality of Life (QoL) does not uniformly improve as the activity of the disease wanes. This may mean that

Corresponding Author: Dr. Victoria Werth, 2 Rhodes Pavilion, 3400 Spruce Street, Philadelphia, PA 19104, Ph: (215) 823- 4439, Fax: (215) 823-5994, werth@mail.med.upenn.edu.

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attention to cosmetic outcomes may need to become a routine part of our treatment plans for CLE patients. For future trials this has implications for power calculations based on QoL outcomes. In addition, analysis of our additional Lupus-oriented questions indicates that patients with SCLE have a persistent concern about photosensitivity after disease activity and damage improves. It is likely that the risk of subsequent flares of their disease in response to outdoor activity does indeed reduce their QoL, even though disease activity has improved.

Clearly QoL is tremendously impaired in patients with cutaneous LE, and measurements of disease improvement will not always correlate with measures directed at quality of life.

References

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Abbreviations

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| CLE | Cutaneous Lupus Erythematosus |
| QoL | Quality-of-Life |
| CLASI | Cutaneous LE Disease Area and Severity Index |
| DLE | Discoid Lupus Erythematosus |
| SCLE | Sub-acute Cutaneous Lupus Erythematosus |
| SLE | Systemic Lupus Erythematosus |
| HRQL | Health-Related Quality-of-Life |