Perspective

The Personal Viewpoints of patients on Cutaneous Lupus and its Significant Aspects

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DESCRIPTION

Lupus Erythematosus (LE) is an autoimmune disease that can affect several organ systems, resulting in cutaneous LE (CLE) and/or SLE. A CLE diagnosis can be further subdivided into three categories: chronic CLE, subacute CLE (SCLE), and acute CLE. Chronic CLE can be subdivided into more specific forms, the most prevalent of which is Discoid Lupus Erythematosus (DLE). CLE subtypes can cause itch, scaling, photosensitivity, erythema, baldness, scarring, and exhaustion.

CLE has a wide range of severity, and skin lesions can be classified as active or damage. Active lesions will be scaly and erythematous, while damage will manifest as dyspigmentation and scarring. CLE lesions can be persistent, and according to Ogunsanya et al, individuals with CLE have a quality of life that is comparable to or worse than those with chronic hypertension, congestive heart failure, or type 2 diabetes [1-3]. The available treatment methods have only moderate success rates, with hydroxychloroquine, the first-line treatment for CLE, treating around 50% of patients.

CLE that is resistant to antimalarials is frequently resistant to second-line treatment, which can result with adverse effects such as elevated liver enzymes, immunosuppression, and peripheral neuropathy [4,5].

CLE QoL has previously been assessed using quantitative instruments such as the Skindex-29, Interpersonal Processes of Care survey (IPC-29), and Dermatology Life Quality Index (DLQI), among others. The current study also used open-ended interviews. These chats, however, were held one-on-one in clinic rooms to ensure privacy and security. Individual interviews, according to many studies, are 18 times more likely to elicit sensitive information than focus groups. Furthermore, to avoid influencing patient responses, our queries were open-ended and did not allude to any specific symptoms [6,7].

During these patient interviews, six themes emerged: self-consciousness, physical signs/symptoms, fear of disease progression,

functional decline, unwanted attention, and emotional symptoms. These themes are undoubtedly intertwined, as the development of bodily signs/symptoms causes self-consciousness and anxiety of growth. Self-Consciousness and Physical Signs/Symptoms were the most frequently reported co-occurring themes.

The demographics were found to be reflective of the Autoimmune Dermatology group at the University of Pennsylvania's patient population. However, like with any qualitative interview study, where saturation is frequently attained at small sample sizes, the findings may not be generalizable to the entire CLE population. The technique of sample collecting might also have an impact on generalizability. In addition, rather than a purposeful sample, a convenience sample was used in this study. Purposive sampling is more effective than convenience sampling and may have uncovered extra themes due to the information-rich individuals in a purposive sample [8-10].

Furthermore, it stands to reason that the patients seen at the University of Pennsylvania may not have experienced or disclosed all conceivable CLE-related QoL themes, necessitating continued interview-based investigation with these patients employing a purposive sample. It would be fascinating to compare this original study to more specific patient features such as comorbidities in the future.

This study highlights CLE patients' concerns and increases awareness of how different groups of CLE patients are impacted. These themes include CLE-related psychological and physical discomfort, reduced functionality, and disrupted social connections.

The patient experiences and resulting themes described by this study should be considered in future standardized assessments of QoL in CLE patients. Young age and female sex, in particular, are two key risk factors for psychological distress in CLE, and physicians should address these issues while assessing patient disease development.

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