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Systemic Lupus Erythematosus and Skin Damage: Patient's Experience

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Abstract

Systemic lupus erythematosus (SLE) is a non-organ-specific autoimmune disease that affects young patients and women in particular. We describe a Cross-sectional study conducted in the internal medicine department of Farhat Hached University Hospital in Sousse, Tunisia. We interviewed 12 patients with SLE about what they know about SLE, their skin symptoms and the measures they take on a daily basis to protect themselves. The DLQI questionnaire was used to evaluate their dermatological quality of life using.

Keywords: systemic lupus erythematosus, skin manifestation, quality of life

1. Introduction

Systemic lupus erythematosus (SLE) is a non-organ-specific autoimmune disease that affects young patients and women in particular. SLE is one of the most common autoimmune diseases, but remains rare and can be a mystery to patients and their relatives. Dermatological manifestations may be the first signs of the disease and remain a major concern for patients because of their appearance and the way they impact on their daily lives (McCauliffe DP, 2001).

2. Methods

Cross-sectional study conducted in the internal medicine department of Farhat Hached University Hospital in Sousse, Tunisia. We interviewed patients with SLE about what they know about SLE, their skin symptoms and the measures they take on a daily basis to protect themselves. The DLQI questionnaire was used to evaluate their dermatological quality of life using (Finlay AY & Khan GK, 1994).

3. Results

There were 12 women, aged between 23 and 57 years old with a mean age of 41 years. Age at diagnosis ranged from 20 to 52 with a mean of 34.5 years.

All our patients had been hospitalized at some stage for a relapse and had received at least one long-term treatment: hydroxychloroquine (for all patients), glucocorticoids for 9 patients and local corticosteroids for a long time for 5 patients.

Among our patients, 10 had dermatological symptoms such as photosensitivity, malar erythema and oral ulcerations. These manifestations were present at the time of diagnosis or even preceded the diagnosis in 9 cases.

Six patients had consulted a dermatologist at least once. The reasons for consulting a dermatologist were alopecia and hair loss for 2 patients and facial erythema for the rest.

All our patients used at least one means of photoprotection. Sunscreen was used by 9 patients, 5 of whom used it occasionally. Physical means were used by 8 patients, 2 of whom used scarves, 2 straw hats and 4 caps. Exposure to the sun was present in 6 patients, 4 of whom were farmers with high exposure to the sun.

Three of our patients planned to go to the beach in summer, two of whom sunbathed. None of our patients had undergone laser depilation, peeling, Botox or filler, and none were planning to do so. Table 1 highlights the dermatological habits of our patients.

Table 1. Different behaviors related to skin in lupus patients

Patient's Behavior	**Number of patients (n =)**
sunscreen	9
caps	4
straw hats	2
scarves	2
direct exposure to sunlight	6
sunbathing	2

The products used by our patients were mainly sunscreen and moisturizers.

When choosing their products, they relied on the pharmacist's advice in the majority of cases (6/10), a doctor's prescription for two patients and only one patient was influenced by advertising spots when buying her products.

When they were asked about the nature of the disease, 10 knew the name of their disease. The pathophysiological mechanism of the disease was not well known by patients, with 3 patients considered that SLE is a genetic disease and 4 patients stating that it is a non-transmissible disease.

All our patients expressed a desire to learn about their disease and think that this could improve their symptoms. Table 2 summarizes the knowledge of our patients about the disease course.

Table 2. Evaluation of patients' knowledge about SLE

Information	**Number of patients (n=)**
Patients who know the name of the disease	10
Patients who know the major symptoms	5
Patients who know basic dietary rules	5
Patients who consider that sun protection is crucial	4
Patients who think that SLE is contagious	3
Patients who consider that SLE has a genetic mechanism	3

To assess the impact of skin manifestations on the daily life of our patients we used the DLQI questionnaire.

The questionnaire used was designed to study the influence of dermatological symptoms on daily life over the last seven days. It studied various areas, namely the embarrassment caused by scratching or itching, which was present in 4 patients, one of whom was extremely embarrassed. The feeling of discomfort or of complex due to the lesions was present in 4 patients. Difficulty with shopping or household chores was noted in two patients. Skin involvement influenced the choice of clothes worn by all our patients. It affected social and leisure activities in one patient. Two patients found it difficult to work or study. Skin involvement makes family relationships and relationships between friends difficult for 5 patients and causes sexual difficulties for the patients for 3 patients. Table 3 shows the results of the DLQI questionnaire in our patients.

Table 3. DLQI quetionnaire results

Area of life	**Number of patients (n=)**
Itching or burning sensation	4

Discomfort or complex due to the lesions	4
Difficulty with shopping or household chores	2
The influence of SLE on the choice of clothes	10
The influence of SLE on social and leisure activities	1
Work or study difficulty	2
Personal relationship (family/friends) difficulty	5
Sexual difficulties	3

4. Discussion

The most prevalent clinical symptom of SLE is skin damage, which is disfiguring, challenging to treat, and little understood. Clinicians often focus on other manifestations of lupus such as renal or neurological involvement because these are life threatening injuries and forget that skin lesions also impact the life of the patient on a daily basis making living with lupus more challenging, as challenging as it already is.

Physicians should explain to patients the nature of these skin lesions and the measures they need to take to prevent them or at least reduce the scars occasioned by skin lesions.

Patients with SLE must use photoprotection, which includes broad-spectrum sunscreen, a wide-brimmed hat, and long-sleeved clothing (Lehmann P., Holzle E., Kind P., Goerz G. & Plewig G, 1993).

Topical medication and prevention actions might be enough to manage minor cases of skin lesions in SLE. Topical corticosteroids are quite good at reducing the erythema and scales that come with the condition (Sigges J., Bizar C., Landmann A., Ruland V., Patsinakidis N. & Amler S, 2013).

Other authors studied the impact of skin lesions on the quality of life of lupus patients using the DLQI which showed results similar to our study: Patients with SLE and who had cutaneous manifestations had severe QoL impairment, which negatively impacted their sense of wellbeing (Sendrasoa FA, Razafimaharo TI, Ramily L, Rakotoarisaona MF, Andrianarison M, Raharolahy O, Ratovonjanahary VT, Razanakoto NH, Ranaivo IM, Ramarozatovo LS & Rabenja FR, 2021).

Lupus is a very visible disease, with skin manifestations that can be restrictive for patients and impair their quality of life.

The management of patients with SLE goes beyond pharmacological measures, and requires ongoing education tailored to the patient’s needs in terms of skin involvement and means of protection.

Therapeutic education should be systematically combined with pharmacological measures, which could improve adherence to treatment and the quality of life of lupus patients.

References

Finlay AY and Khan GK, (1994). Dermatology Life Quality Index (DLQI): a simple practical measure for routine clinical use. *Clin Exp Dermatol, 19*, 210-216.

Lehmann P., Holzle E., Kind P., Goerz G., Plewig G, (1993). Phototesting in lupus erythematosus. *J Invest Dermatol, 100*, 53S-57S.

McCauliffe DP, (2001). Cutaneous lupus erythematosus. *Semin Cutan Med Surg, 20*, 14-26.

Sendrasoa FA, Razafimaharo TI, Ramily L, Rakotoarisaona MF, Andrianarison M, Raharolahy O, Ratovonjanahary VT, Razanakoto NH, Ranaivo IM, Ramarozatovo LS, Rabenja FR, (2021). Quality of life in lupus erythematosus female patients with cutaneous lesions in Antananarivo, Madagascar. *Int J Womens Dermatol, 7*(5Part B), 743-746. doi: 10.1016/j.ijwd.2021.07.013. PMID: 35028375; PMCID: PMC8714573.

Sigges J., Bizar C., Landmann A., Ruland V., Patsinakidis N., Amler S, (2013). Therapeutic strategies evaluated by the European Society of Cutaneous Lupus Erythematosus (EUSCLE) Core Set Questionnaire in more than 1000 patients with cutaneous lupus erythematosus. *Autoimmun Rev., 12*(7), 694-702.

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