Decades of clinical research have yielded only one useful subset in systemic lupus erythematosus (SLE), which consists of those patients where lupus nephritis is the principal manifestation. Genetic studies have revealed numerous lupus-associated polymorphisms, but none of any practical use. In contrast to these disappointments, multiple molecular and cellular studies in recent years have unexpectedly begun to converge on the pivotal finding that SLE consists of a small number of distinct immunopathological entities, and that these can be identified by standard methods alone or in combination. Moreover, the same subsets can be identified in patient groups with different clinical diagnoses, such as Sjogren’s syndrome, systemic sclerosis, or even rheumatoid arthritis. The results of these studies are not yet fully consistent with one another but gain in importance as multiple targeted therapies for lupus emerge. Thus, I will argue that we are standing on the threshold of a new taxonomy for the systemic autoimmune diseases, based on molecular and cellular analyses, and that such a taxonomy will facilitate more personalised therapeutic approaches.

Learning Objectives

• Explain the limitations of classifications based on clinical criteria
• Discuss recent research demonstrating the clustering of SLE and other systemic autoimmune diseases into distinct subgroups based on molecular and cellular markers
• Describe how a new taxonomy of the systemic autoimmune diseases will facilitate personalised therapeutic approaches

Health related quality of life (HRQOL) improvement in patients with SLE is defined as one of the treatment goals in the Treat to Target (T2T) recommendations and the 2019 EULAR recommendations for the management of SLE. However, the definitions of remission and low disease activity (LLDAS) do not address the health-related quality of life or disease burden. In fact, the physicians’ view on lupus dominated the development of remission criteria and it was postulated that a control of disease activity would improve QOL in patients with SLE.

The relationship between activity, organ damage, and HRQOL, however, remains complex and controversial, and the value of activity and damage indices as predictors of patient quality of life continues to be debated. The attainment of remission in SLE represents the main treatment target, but QOL and fatigue are still insufficiently controlled in the state of remission and, despite improvement of disease activity, QOL can remain unchanged over several years.

A patient’s perspective is still not accepted as equivalent to the physician’s perspective in treatment decisions. HRQOL is neither directly nor indirectly captured by disease activity instruments. Therefore, a better understanding of the patients’ experiences with the disease is crucial.

Looking at the evidence of patient reported outcomes (PROs) as treatment targets for SLE, it is important to consider that, in clinical trials, the target response is mostly defined by changes in disease activity instruments and physician global assessments, while PROs were never used as the primary endpoint.

Studies to integrate the patient’s perspective with the physician’s definition of remission and low disease activity are needed.

References


Learning Objectives

• Discuss quality of life in SLE, its determinants, discordance between physician’s outcomes measures and PROs and the significance of PROs in clinical trials

Interactive case study workshops

12 MANAGEMENT OF LUPUS SKIN MANIFESTATIONS

Marta Mosca. University of Pisa, Italy

10.1136/lupus-2022-la.11

Health related quality of life (HRQOL) improvement in patients with SLE is defined as one of the treatment goals in the Treat to Target (T2T) recommendations and the 2019 EULAR recommendations for the management of SLE. However, the definitions of remission and low disease activity (LLDAS) do not address the health-related quality of life or disease burden. In fact, the physicians’ view on lupus dominated the development of remission criteria and it was postulated that a control of disease activity would improve QOL in patients with SLE.

The relationship between activity, organ damage, and HRQOL, however, remains complex and controversial, and the value of activity and damage indices as predictors of patient quality of life continues to be debated. The attainment of remission in SLE represents the main treatment target, but QOL and fatigue are still insufficiently controlled in the state of remission and, despite improvement of disease activity, QOL can remain unchanged over several years.

A patient’s perspective is still not accepted as equivalent to the physician’s perspective in treatment decisions. HRQOL is neither directly nor indirectly captured by disease activity instruments. Therefore, a better understanding of the patients’ experiences with the disease is crucial.

Looking at the evidence of patient reported outcomes (PROs) as treatment targets for SLE, it is important to consider that, in clinical trials, the target response is mostly defined by changes in disease activity instruments and physician global assessments, while PROs were never used as the primary endpoint.

Studies to integrate the patient’s perspective with the physician’s definition of remission and low disease activity are needed.

References


Learning Objectives

• Discuss quality of life in SLE, its determinants, discordance between physician’s outcomes measures and PROs and the significance of PROs in clinical trials

Interactive case study workshops

12 MANAGEMENT OF LUPUS SKIN MANIFESTATIONS

Marta Mosca. University of Pisa, Italy

10.1136/lupus-2022-la.11

Case 1: A 19-year-old patient with bullous systemic lupus erythematosus

A 19-year-old patient presented with single, disseminated, erythematous papules and sharply demarcated, partly urticarial plaques on his face. Over the past few weeks, the skin manifestations had spread to the décolleté and blisters had developed on his forearms after sun exposure. A skin biopsy of one of the blisters showed a subepidermal vesicle containing neutrophils and scattered eosinophils. A perivascular and interstitial infiltrate of lymphocytes and neutrophils was seen in the upper and mid dermis, as well as formation of neutrophil microabscesses. In the direct immunofluorescence test (lupus band test), linear immunofluorescence was shown along the basement membrane zone with anti-IgA and anti-IgG antibodies. In addition, the patient showed a moderately diffuse alopecia, Raynaud’s phenomenon, polyarthritides, synovitis, tendovaginitides, splenomegaly, lymphadenopathy, fatigue, and night sweats. Laboratory analysis demonstrated anemia, leukopenia, hypocomplementemia, and autoantibodies (ANA and anti-dsDNA antibodies).

Bullous systemic lupus erythematosus (BSLE) is a rare disease associated with subepidermal blistering and, in most cases, severe systemic manifestations. The vesiculobullous skin changes can occur after sun exposure and can be associated with activation of SLE. Dapsone is the mainstay of systemic corticosteroids and antimalarials have shown minimal improvement.

Discussion Points: Different forms of skin lesions and treatment options in patients with cutaneous lupus erythematosus.