- Describe the treatment of bullous systemic lupus erythematosus

Case 2: Hand lesions in SLE

Hand lesions are relatively common in patients with SLE. Since these lesions are not always biopsied (especially those of the digits) a correct characterization may be lacking. These lesions can appear in patients with or without SLE. The differential diagnosis includes vasculitis, vasculopathy, chilblain lupus and palmoplantar lupus. Although localized, they are usually painful with functional impairment of loss of quality of life. Among them, the most common lesions are chilblain lupus. Response to topical treatment and antimalarials is typically poor. Chilblain lupus may not respond as well to systemic therapy compared to other visceral manifestations of SLE, hence being a treatment challenge both for rheumatologists and dermatologists.

A 40-year-old woman, with an 8-year history of cutaneous lesions in the face and arms (diagnosed of cutaneous lupus erythematosus by biopsy), arthritis and ANA+, treated with hydroxychloroquine and variable doses of prednisone, was admitted in the rheumatology department due to headache and visual loss with bilateral papilledema. Magnetic resonance imaging was normal but the ophthalmological exploration showed inferior branch retinal vein thrombosis in the left eye. The autoimmunity study showed ANA 1/1280 and positivity for anti-dsDNA, anti-RNP and anti-Sm. With the possible diagnosis of SLE-related pseudotumor cerebri, prednisone dose was increased, hydroxychloroquine was maintained and acetazolamide was added, with progressive vision recovery. Two months after discharge, she started to progressively present papulosquamous lesions on the back, neckline, back of the hands and fingertips, the latter being painful.

Learning Objectives

- Describe the differential diagnosis of hand lesions in SLE
- Understand the prognostic implications of hand lesions in SLE
- Discuss how cutaneous manifestations may not respond to systemic treatments aimed at controlling active SLE
- Explain chilblain lupus and its treatment
- Describe available treatments strictly directed to the cutaneous component of lupus erythematosus

Prime time session: (hybrid)

Part I: the patient at centre stage

22 THE PATIENT´S VOICE

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10.1136/lupus-2023-la.22

Systemic lupus erythematosus (SLE) is a very complicated and heterogeneous disease, and the popular saying is that no two lupus patients are the same. This of course also means that the treatment and planning of care can be very complicated and needs to be adjusted to the individual patient.

One of the best ways to achieve this goal is through shared decision making. If the patient feels like they have a voice in the treatment plans the probability of treatment adherence increases substantially. On average the SLE patient is more aware of their own symptoms, disease progression and medication than patients with less complicated or less heterogeneous diseases. They need to become experts in their disease because they are the ones living with the symptoms and can often 'feel' a flare coming on before the laboratory results show it. Health-related-quality of life (HRQoL) when living with a chronic disease like SLE very much depends on how you self-manage; living a healthy life, keeping active, prioritising everyday tasks according to energy-level etc. The engaged and informed patient can be both a help and a burden when it comes to the physican´s disease management. It helps if the patient has the right medical information and respects that the physician has the expertise to decide what is best for them.[1] A patient needs to know that not every symptom is because of lupus and that they might not be flaring, even though they feel like they are.

This 'complicated' care of an SLE patient often takes more than one health care professional. Apart from a multidisciplinary team of physicians each specialised in their own manifestations (like kidneys, lungs, heart etc.) it is often beneficial to involve other areas such as specialised nurses, physiotherapists, psychologists, occupational therapists etc. This multidisciplinary team of course requires a good coordination, which should not be put exclusively on the patient.

REFERENCE

1. Cornet A, *et al.* Patients expectations, and what we (can) do about it. *Lupus Sci Med*.2020;**7**:doi:10.1136/lupus-2020-eurolupus.7.

Learning Objectives

- Explain the importance of involving patients in shared-decision-making
- Describe how a multidisciplinary team can be used in the SLE care
- Describe the role of the informed patient in their own care

23 THE NURSE'S PERSPECTIVE

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Lupus (Latin term for wolf) was used, since the Middle Ages to describe several types of diseases characterized by ulcerous lesions, mainly in the lower limbs. The true turning point in its history occurred at the beginning of the 19th century, with the distinction between lupus vulgaris and cutaneous lupus in its modern sense.[1]

Today, systemic lupus erythematosus (SLE/lupus) is described as a chronic systemic autoimmune disease of variable severity and course, distinguished by a tendency for flare. It is clinically and serologically, a diverse autoimmune disease that can affect any organ or system of the body and display a wide spectrum of manifestations.[2]

Evidently, due to the chronic relapsing-remitting nature of SLE,[3] a holistic approach, involving a multi-disciplinary team (Physician, Rheumatology/Lupus Nurse Specialist, Physiotherapist etc) is essential to providing high quality care to lupus patients.