- 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

Jeanette Andersen. *Lupus Europe, Denmark*

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

Ada Ferenkeh-Koroma. *University College London Hospitals NHS Foundation Trust, London, UK*

10.1136/lupus-2023-la.23

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.

The pathway to becoming a Rheumatology/Lupus Nurse Specialist, requires a Registered Nurse undergoing additional specialised education and training, that allows them to provide autonomous advanced care and tasks to meet the patient's clinical needs (i.e., facilitating screening, initiating, monitoring and reviewing treatment and providing specialty education and timely accessible health advice to patients) in order to ensure effective disease management.[4]

As early the 1980s, Rheumatology nursing (roles include Rheumatology Clinical Nurse Specialist, Rheumatology Nurse Practitioner), was recognised as a distinct nursing speciality in the UK and USA.[5]

The Rheumatology Nurse has since remained a significant member of the multi-disciplinary team, in the management of patients with systemic lupus erythematosus.

REFERENCES

1. Felten R, Lipsker D, Sibilia J, *et al.* The history of lupus throughout the ages. *J Am Acad Dermatol* 2022;**87**:1361–9. doi:10.1016/j.jaad.2020.04.150.
2. Hinojosa-Azaola A, Sanchez-Guerrero J : Overview and Clinical Presentation : Dubois' Lupus Erythematosus and Related Syndromes (Ninth Edition) 2019, Ch 32, Pages 389–394 (Available online 7 November 2018, Version of Record 7 November 2018).
3. Zen M, Iaccarino L, Gatto M, *et al.* Prolonged remission in Caucasian patients with SLE: prevalence and outcomes. *Ann Rheum Dis* 2015;**74**:2117–22. doi:10.1136/annrheumdis-2015-207347.
4. Mounce, K., Ryan, S (2001). The historical development of extended clinical roles in rheumatology. In: Carr, A. (Ed.), Defining the Extended Clinical Role for Allied Health Professionals in rheumatology. Arthritis Research Campaign, Chesterfield, pp. 9–10.
5. American Nurses Association, 1983. Outcome Standards for Rheumatology Nursing Practice. American Nurses Association Publications.

Learning Objectives

- Explain the role of the Rheumatology Nurse
- Describe the pathway to becoming a Rheumatology Nurse
- Describe the benefits of a Rheumatology Nurse to the rheumatology/lupus patient

24 ERN-RECONNET: A MODEL FOR PATIENT-HEALTHCARE PROVIDER COLLABORATION

Marta Mosca. *University of Pisa, Italy*

10.1136/lupus-2023-la.24

The European Reference Networks (ERNs) were launched by the European Commission in 2017 with the mission to improve quality, safety and access to highly specialised and sustainable healthcare to European patients with rare, low-prevalence and complex diseases.[1]

ERN ReCONNET is the European Reference Network on Connective Tissue and Musculoskeletal Diseases and covers 10 musculoskeletal and connective tissue diseases (rCTDs): anti-phospholipid syndrome (APS), Ehlers-Danlos syndromes (EDS), idiopathic inflammatory myopathies (IIM), IgG4-related diseases (IgG4), mixed connective tissue diseases (MCTD), relapsing polychondritis (RP), Sjögren's syndrome (SS), systemic lupus erythematosus (SLE), systemic sclerosis (SSc), and undifferentiated connective tissue diseases (UCTD). ERN ReCONNET currently has 55 Full Members and 9 Affiliated Partners (APs) from over 23 European countries.

ERN ReCONNET can be viewed as an infrastructure where all the stakeholders (health care professionals, patients, families, health care systems, hospital managers, private sectors, etc.) meet and work together to achieve common goals.

One major objective of ReCONNET is to promote a partnership with patients (patients' advocates – ePAGs). Since 2017 this objective has been pursued by starting to ensure and promote patients' representation and their active involvement in all the ERN activities. In fact, the ePAG advocates have been involved in different levels of the network's governance: the Steering Committee, the respective Disease Groups where they collaborate to plan and implement activities, and more recently in the Working Groups (WG) where they act as co-chairs in three WGs. ePAG representatives provide patients' opinions and input in the different ERN activities, collaborate in the evaluation of the ERN actions, contribute to research, participate to dissemination activities, and ensure that patient's rights and choices are considered in decision-making.

Thanks to this collaboration, the opinions, needs and priorities of the ePAG advocates and of their communities have been integrated into the activities of ERN ReCONNET. ePAG advocates and patients' representatives have participated to research activities, co-authored many ReCONNET publications, participated actively as speakers to ERN meetings and in the first ERN ReCONNET congress held in Brussels in 2023, and have disseminated ERN ReCONNET activities at international meetings including EULAR.

All these activities are promoting the culture of an effective and solid patient-clinician partnership and are triggering a cultural change in the healthcare ecosystem at international level.

REFERENCE

1. European Reference Network on Rare and Complex Connective Tissue and Musculoskeletal Diseases Website. https://reconnet.ern-net.eu . Accessed July 2023.

Learning Objectives

- Explain the value of ERN ReCONNET's infrastructure in supporting patients, their families and healthcare professionals in working together to achieve common goals
- Discuss the value of patient representation and their active involvement in all the ERN activities to ensure patients' rights and choices are considered in clinical decision making.

Part II: treatment optimization and disease modification in SLE

25 DISEASE MODIFICATION IN SLE: AN INTRODUCTION

Ronald van Vollenhoven. *Amsterdam University Medical Centers, and Amsterdam Rheumatology and Immunology Center, The Netherlands*

10.1136/lupus-2023-la.25

The concept of disease modification is well-established in diverse diseases such as rheumatoid arthritis (RA), Alzheimer's disease, and asthma. In RA, the concept was initially introduced to distinguish the effects of acetylsalicylic acid and non-steroidal anti-inflammatory drugs, which had been shown to ameliorate joint pain but not to prevent erosive damage to the joint structures, from those of a heterogeneous group of medications that were able to accomplish both goals and were henceforth designated 'disease-modifying antirheumatic drugs (DMARDs)'. While gold compounds were initially the main