Abstracts

Pre-meeting

Friday 1st September 2023

Reducing illness burden, modifying disease and improving treatment outcomes: a patient-physician collaboration

01 SLE BURDEN OF DISEASE: THE PATIENT'S PERSPECTIVE

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Systemic lupus erythematosus (SLE) imposes a great burden on the lives of patients. Patients' and physicians' concerns about the disease diverge considerably. Physicians focus on controlling disease activity to prevent damage accrual, while patients focus on symptoms that impact on health-related quality of life (HRQoL). The existing clinician reported outcomes (ClinRO), such as disease activity indices, remission, low disease activity (LLDAS), response (SRI and BICLA) do not include the patient perspective.

Several investigations show that patients judged in remission by the treating physician, still report the presence of relevant clinical symptoms.[1 2]

- Patients and physicians assess the disease differently (discordance up to 58% of cases)
- Patients tend to score disease activity higher than physicians
- Patients consider subjective manifestations as more relevant than physicians
- Physicians consider laboratory abnormalities as more relevant

It seems there is a discordance between patients and physicians when it comes to prioritising outcomes.

The best way to identify the patients' priorities is through Patient Reported Outcomes (PROs). PROs allow us to capture aspects of the disease which have an impact on patients and constitute their burden of the disease. Ideally, the dialogue between doctor and patient should address the most bothersome symptoms for the individual patient. What is most bothersome for one might not be the same as for someone else and it most likely won´t be the same priority as the doctor has. At the same time, some of the most bothersome symptoms are difficult (if not impossible) to manage with traditional SLE treatments. In these cases, the communication becomes even more important, and a communication gap can be detrimental to the HRQoL and overall care.[3]

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Learning Objectives

- Describe the burden of the disease from the patient´s perspective
- Explain the importance of patient-physician communication
- Distinguish between patient and physician priorities

02 CHALLENGES IN THE DEVELOPMENT OF A UNIVERSAL SLE PATIENT CHARTER

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Despite advances in understanding and managing systemic lupus erythematosus (SLE), patients continue to face significant challenges in receiving optimal care and support. The concept of a universal SLE patient charter, outlining the rights, needs and expectations of SLE patients, has emerged as a potential solution to address these challenges. However, the development and implementation of such a charter present several significant hurdles.

Firstly, there is a need for consensus among healthcare professionals, patient advocacy groups, researchers, and policymakers, regarding the content and scope of the charter. Standardizing care and efforts to ensure that the charter reflects evidence practices are crucial components in the development and implementation of a universal SLE patient charter. This requires robust communication and collaboration to guarantee that the charter encompasses the diverse needs and perspectives of the global SLE community.

Secondly, the inherent heterogeneity of SLE poses a challenge in creating a charter that can accommodate the unique experiences and requirements of individual patients. SLE manifests differently in each patient, making it crucial to strike a balance between specificity and inclusivity within the charter.[1]

Thirdly, the charter must address the barriers to access and equity in SLE care. Issues such as disparities in healthcare access, limited availability of specialized healthcare professionals, and high treatment costs need to be considered and addressed within the charter.[2–6]

In addition, the charter should emphasize the importance of patient education and empowerment to facilitate informed decision-making and self-management. Furthermore, the implementation and enforcement of the charter pose practical challenges. Adequate resources and infrastructure, along with legal and regulatory frameworks, are required to support the implementation of charter principles across different healthcare systems and jurisdictions. Additionally, the charter should encourage the integration of research and data collection efforts to advance our understanding of SLE. Despite these challenges, a universal SLE patient charter holds great potential in improving the quality of care and outcomes for SLE patients globally. It can serve as a guiding document to promote patient-centered care, raise awareness, and advocate for the rights of SLE patients.

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Learning Objectives

- Recognize the potential of a universal SLE patient charter to address lupus care
- Identify significant barriers in developing and implementing the charter, including stakeholder consensus and defining key elements
- Appreciate the need to accommodate the heterogeneity of SLE and address barriers to access and equity in care
- Understand the importance of patient education and empowerment and the practical challenges of implementing and enforcing the charter across healthcare systems and jurisdictions

03 DISEASE MODIFICATION AND PREVENTION OF DAMAGE

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Although there is currently a need to adopt a treat to target approach in systemic lupus erythematosus (SLE), there are no clear descriptions of disease modifications to guide this approach. Recently van Vollenhoven *et al* reported a conceptual framework for defining disease modification in SLE in three epochs, year 1, years 2–5, and ≥5 years.[1] They suggested criteria to define disease modification for each epoch including minimizing disease activity and slowing or preventing organ damage progression.[1] Failure to achieve these disease modifications results in damage accrual either due to the disease or its treatment. Furthermore, damage accrual predicts increasing damage and mortality.[2 3] Very few of the therapeutic agents currently available to treat SLE have been successful in disease modification in all three epochs either because their therapeutic effect is short lived, or they have not yet been used for ≥5 years or toxicity has precluded long term use.

Four medications merit mention at this time: corticosteroids, antimalarials, belimumab and anifrolumab. Corticosteroids are very effective anti-inflammatory/anti-immunologic agents, but should not be used long term because of their significant toxicities. One should use a dose required to achieve suppression of the acute inflammatory clinical disease BUT strive to wean to a dose of ≤5 mg prednisone by 3 months. Time to achieve the clinical response desired may vary depending on disease manifestations, but rapid weaning should remain the desired target. With complete remission weaning the last 5 mg prednisone is possible, using a slow taper schedule.[4] Antimalarials used early and consistently have been shown to protect against damage accrual and mortality.[2 3] Belimumab, the first biologic developed for the treatment of SLE, was first approved in 2011 and has now been shown to be disease modifying in each of the three epochs with minimal toxicity. Belimumab's long term use has demonstrated a reduction in organ damage progression, a slowed rate of organ damage progression and reduction in the magnitude of year-to-year organ damage.[5] Anifrolumab was approved by the FDA in 2021 but has data for 3 years of follow-up in an extension study that show the initial therapeutic responses persist. There is a lower cumulative corticosteroid dose in patients and there was no safety issue signal.[6]

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Learning Objectives

- Describe a definition of disease modification in SLE
- Describe that failure of disease modification results in significant damage
- Explain how managing corticosteroids, antimalarials and two newer biologics may aid damage prevention

04 BIOLOGIC DISEASE MODIFYING DRUGS IN SLE

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Although the concept of disease modification is well-established in several immune-mediated diseases, there is no widely accepted definition of disease modification in systemic lupus erythematosus (SLE). A group of international lupus experts recently proposed a framework for the definition of disease modification in SLE that includes minimizing disease activity with the fewest treatment associated toxicities and slowing/preventing organ damage progression.[1] Achieving this goal in SLE will require a multifaceted approach including the use of therapies that target key immunologic pathways important to disease pathogenesis and shared decision making between patients and physicians to encourage therapeutic adherence.

The successful development and approval of two targeted biologic agents, belimumab and anifrolumab, will hopefully accelerate our ability to achieve disease modification in SLE. Both agents target key mechanisms that contribute to ongoing SLE disease activity and damage. Belimumab is a fully human IgG1l antibody against soluble B cell activating factor (BAFF) and anifrolumab is a fully human IgG1k against subunit 1 of the Type I Interferon receptor. In large scale international phase III trials of participants with SLE, both agents reduced disease activity across multiple organ domains and enabled tapering of glucocorticoids.[2–5] The agents differ in kinetics of response, with anifrolumab demonstrating a faster time to response, particularly in people with cutaneous lupus manifestations. The availability of belimumab over the past decade has enabled studies demonstrating reduction in damage