

PO.6.121 **EPISTEMIC INJUSTICE AND EDUCATIONAL NEEDS FOR SELF-MANAGEMENT IN SYSTEMIC LUPUS ERYTHEMATOSUS**

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Purpose Information and education are epistemic goods; if an individual lacks them, their full development as a person may be affected. This research aims to describe issues related to epistemic injustice (lack of information and/or education) in systemic lupus erythematosus and to interpret them regarding their educational needs for self-management.

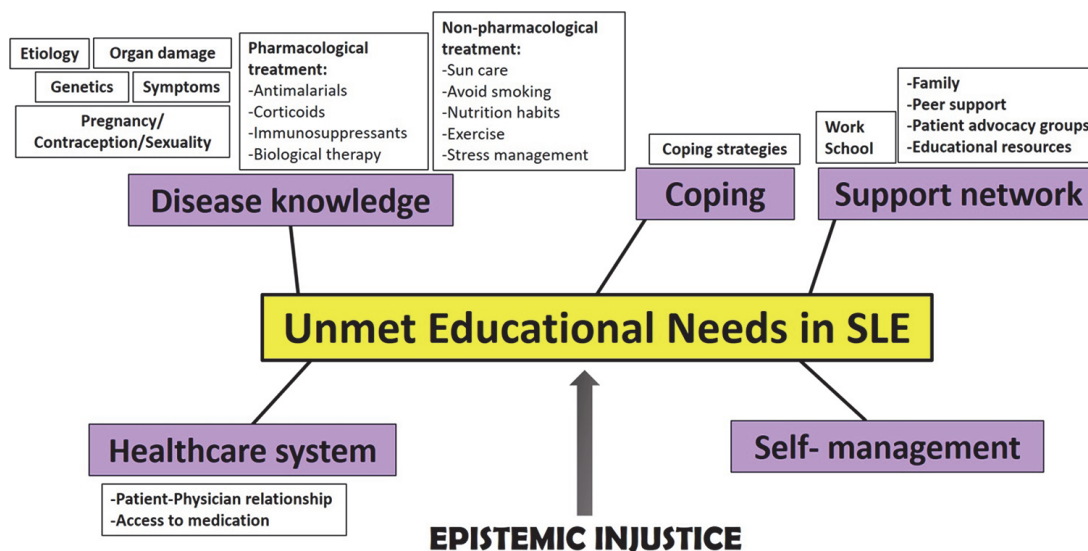
Methods We conducted a qualitative assessment of comments organically posted by people with lupus, physicians, and relatives on the Facebook page Hablemos de Lupus (Let's Talk about Lupus), which is part of a comprehensive online program in Spanish to educate Latin-Americans about lupus. In this page, live video chats (LVC) are launched monthly, they include a short overview of the topic by the expert, followed by the audience-expert chat. LVC were led by healthcare professionals, patients or family leaders with expertise or experience in lupus. We intentionally selected 7 LVC: 1. Patient-physician relationship, 2. Why is it necessary to group patients together?, 3. Lupus: the patient and his/her social environment, 4. Self-management in lupus, 5. Lupus and quality of life, 6. Remission in lupus from the patient's perspective, and 7. Patient organizations: opportunities and challenges. LVC and comments triggered (or posted in reaction to) were

transcribed verbatim and analyzed using an hermeneutic approach. Comments containing only greetings or emoticons were excluded. This research was approved by the Ethics Committee of Emory University (Atlanta, USA) with registration number IRB00111590.

Results The 7 LVC lasted overall 443 minutes and 16 seconds, and generated 1.749 comments of which 758 were excluded due to lack of content. Among 991 comments analyzed, nearly 70% indicated epistemic injustice (e.g., 'no one understands our disease'; 'We need more awareness because we are seen as dramatic [people] and doctors see it [lupus] as [something] common, and we need [them] to be more sensitive'. The most frequent type of epistemic injustice was hermeneutic (e.g., 'Being a patient with this invisible disease, it's very difficult to be understood'; 'It is very very difficult first when we don't know what is wrong with us and then the diagnosis

Abstract PO.6.121 Table 1 Critical appraisal of studies by study design

Study design	Robust	Intermediate	Weak	Total
Quasi-experimental	25	57	2	84
SLE	8	30	1	39
SSc	17	27	1	45
RCT	3	33	61	83
SLE	0	16	47	49
SSc	3	17	14	34
Analytical cross sectional	7	4	0	11
SLE	6	4	0	10
SSc	1	0	0	1
Case series	0	8	1	9
SLE	0	2	1	3
SSc	0	6	0	6
Meta-analysis, with or without systematic review	6	0	0	6
SLE	5	0	0	5
SSc	1	0	0	1
Cohort	3	1	1	5
SLE	3	0	1	4
SSc	0	1	0	1
Qualitative	3	0	2	4
SLE	2	0	1	3
SSc	1	0	1	2
Case control	1	2	0	3
SLE	0	1	0	1
SSc	1	1	0	2



Abstract PO.6.121 Figure 1 Core categories related to epistemic injustice and unmet educational needs in lupus

and the process of acceptance, and then all that is required in daily life'). The core themes that emerged from the LVC and comments encompassed: disease knowledge, support network, coping strategies, healthcare system, and self-management (Figure 1).

Conclusions Understanding these aspects is necessary to address the educational needs of people with lupus. A health-promoting curriculum aiming to support lupus patients' self-management should consider the critical role that the knowledge plays to move forward into effective personal and collective actions. Epistemic justice is also a primary principle to conduct health policies that seek the full integration of these patients into the society.

PO.6.123 A RAPID DECALAGE OF IMMUNOSUPPRESSIVE THERAPY IN A YOUNG WOMAN WITH SYSTEMIC LUPUS ERYTHEMATOSUS

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Purpose Autoimmune myopathies are an heterogeneous group of diseases, among which polymyositis and dermatomyositis are probably the best known. Autoimmune myositis can overlap with other autoimmune rheumatic diseases, particularly it is a rare but recognized complication of systemic lupus erythematosus (SLE).

Here we report a case of SLE-related myositis, successfully treated with combined immunosuppressive therapy with rituximab and immunoglobulin infusion and then relapsed due to rapid decalage of immunosuppressive therapy with mycophenolate mofetil.

Methods A 28-year-old woman was affected from 2016 by SLE with haematological, articular and renal involvement treated with immunosuppressive therapy with good clinical response.

After five years of disease remission, patient presented to the emergency department for a rapid onset of a clinical scenario with fever, alopecia, articular and muscular pain. The pharmacologic treatment was mycophenolate mofetil 500 mg/day (at this dose for about a year, after decalage by 2 gr/day), hydroxychloroquine 200 mg/day, belimumab 200 mg/week, prednisone 5 mg/day. On physical examination, she presented severe asthenia, pain on muscle palpation and loss of muscle tone with slight edema in the lower limbs. No signs of arthritis or active ulcers. Laboratory examinations revealed proteinuria > 2g/24h, severe increase of transaminases, phosphocreatine kinase, ANA positivity (titre 1/2560) with high titres of anti-dsDNA and complementary consumption (both C3 and C4).

Clinical and laboratoristic examinations raised the suspicion of SLE reactivation complicated by myositis. We performed a kidney biopsy with histological examination suggestive for class IV lupus nephritis and an electromyography with a pattern of myositis.

So we decided, according to disease involvement, to begin treatment with Rituximab (four administrations, 375 mg/m²) and gradual reintroduction of full-dose mycophenolate mofetil therapy (2 g/day).

Results Disease activity was high so immunosuppressive therapy with high-dose corticosteroids, Rituximab and mycophenolate mofetil was started with subsequent good clinical response.

One month after the infusion of Rituximab, muscle enzymes were yet elevated thus we added therapy with endovenous immunoglobulin with discrete clinical and laboratory improvement.

Conclusions Pharmacological treatment with rituximab and endovenous immunoglobulin can be considered as a good and safe therapeutic option for clinical management of SLE-related myositis. This clinical case underlines the importance of maintaining immunosuppressive treatment for a long period, and to decrease dose very slightly, when disease is in long remission.

PO.6.124 EFFECT AND SAFETY PROFILE OF BELIMUMAB AND TACROLIMUS COMBINATION THERAPY IN THIRTY-THREE PATIENTS WITH SYSTEMIC LUPUS ERYTHEMATOSUS

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Introduction/Objectives Belimumab combined with mycophenolate mofetil has been proven to be effective for treating systemic lupus erythematosus (SLE) in several randomized controlled trials. Calcineurin inhibitors are also useful in controlling the activity of SLE. However, the safety and effectiveness of belimumab-calcineurin inhibitor combination therapy have not been addressed. Therefore, the current single-center retrospective study aimed to analyze the safety/efficacy profile of belimumab-tacrolimus (B-T) combination therapy in patients with SLE.

Method Patients with SLE administered tacrolimus and belimumab during treatment were included in the study. Samples were analyzed for the drug retention rate, SLE flare rate, infection incidence rate, and glucocorticoid-sparing effect of the B-T combination therapy.

Results Thirty-three patients with SLE were treated with B-T combination therapy at our institution. Four patients discontinued treatment due to insufficient response or adverse events. The drug retention rate was over 90% at week 52 and approximately 80% at day 1000. Only one patient developed serious infection. The lupus low disease activity state (LLDAS) achievement ratio was 9.1% on the day of initiation and improved to 64.0% at 52 weeks after initiation. SLE flares were observed in three patients (9.1%) in the first 52 weeks after initiation, and in five patients (15.2%) throughout the study period. A glucocorticoid-reducing effect was also observed in patients treated with B-T combination therapy.

Conclusions In most patients with SLE, B-T combination therapy is well tolerated with a good efficacy profile and glucocorticoid-reducing effect. Thus, B-T combination therapy represents a feasible option for patients with refractory lupus.