Figure 1. Pearson correlation between FS and time interval until lymphoma diagnosis

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OP0292

SURVEY ON THE PERCEPTIONS AND EXPERIENCES OF SPANISH LUPUS PATIENTS. RESULTS ABOUT KNOWLEDGE OF THE DISEASE AND RELATIONSHIP TO DISEASE-FELUPUS SURVEY

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Background: Despite great advances in the diagnosis and treatment of lupus, the scientific community does not know the perception of our patients regarding the knowledge of the disease and the relationship between patients and disease. Fatigue had the greatest impact on activities of daily living, yet the majority reported receiving no support or poor support in managing it¹.

Objectives: Through this initiative, it is intended to investigate about the knowledge of the disease and impact of the disease on quality of life of Lupus patients. Another objective is to give visibility to the current needs of people living with lupus.

Methods: It was performed a national survey with 1,263 interviews with Lupus patients who reside in Spanish territory and belonging to lupus patient associations in Spain. The survey was carried out by the Spanish Lupus Federation (FELUPUS) in collaboration with GSK company. Online interview lasting approximately 25 minutes. The collection of information was anonymously carried out from May 21 to June 30, 2020.

Results: 1.263 lupus patients were interviewed, 92% diagnosed with SLE and 8% with CLE. Survey sample is representative of the Lupus patient population in Spain [associated sampling error: 2.76%]. Questions about knowledge of the disease showed that 73% of patients considered that there is very little knowledge of the disease by society. Patient awareness of lupus increases as the disease progresses, so at the time of diagnosis, level of knowledge of the patient about Lupus is low in 92% of patients and at the moment of survey, 68% of patient had high knowledge. In terms of the perception of his illness, the affectionation of the kidneys and heart (97%), fatigue and skin rashes (97%), are the statements that generate the greatest consensus. The survey about the relationship to disease demonstrated that 3 out of 4 patients have symptoms related to the disease, muscle and joint pain (75%) and fatigue (74%) are the symptoms that cause the greatest discomfort (Graph 1). Remarkable degree of agreement with the fact of not being able to sunbathe (78%), as well as the lack of energy (61%) and weakness in the body (60%). Flare-ups (86%), followed by fatigue (78%) and pain (77%) cause great concern. At diagnosis, 92% of patients have some organic involvement and regarding the diagnosis, at present, a greater number of patients present damage to the CNS (17%) and bones (21%). Many patients do not understand the concept of organ damage, wrongly relating it to fatigue (38%) or joint pain (47%).

Graph 1.

Conclusion: Among the conclusions of the survey, it stands out that society and the general population are unaware of what lupus is, while in the case of lupus patients, knowledge increases as the disease progresses. Citizen awareness campaigns about this disease are necessary, where patient associations together with health authorities have a crucial job. On the other hand, 92% of patients present organ damage at diagnosis. This means that we are arriving late to the diagnosis of many patients, which makes it necessary to promote a close collaboration between Primary Care and Hospitals, to refer patients as soon as they suspect SLE.

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What worries the most to Lupus patients?

Question P12. Please indicate your level of concern with the following aspects of Lupus. Percentage of patients who have scored a 4 or 5 for each item (% T2B).

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OP0293

OPTIMIZING A TOOL TO IDENTIFY LUPUS FLARES IN DAILY CLINICAL PRACTICE: SLE-DAS FLARE VERSUS SELENA FLARE INDEX

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Background: In the management of patients with Systemic Lupus Erythematosus (SLE), it is of utmost importance to accurately identify lupus flares. There is a conceptual consensus definition of lupus flares [1]; however, the instruments used to identify flares in clinical trials, such as the SELENA Flare Index (SFI) are too cumbersome to apply in daily clinical practice. The SLE disease activity score (SLE-DAS) is a validated continuous measure of disease activity with higher sensitivity to change and validity in predicting damage accrual when compared