



An online survey of the Spanish Lupus Patient Association (FELUPUS): patient perceptions and experiences

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Abstract

Objectives A survey conducted by the Spanish Lupus Federation (FELUPUS) shows the results on perceptions and experiences of the people who live with lupus in Spain. The information was gathered anonymously from May 21st to June 30th, 2020. The aim of the study was to monitor the impact of the disease on quality of life, as well as to measure the impact of organ damage in lupus patients.

Methods A national survey was conducted among people with lupus living in Spain who belong to the Spanish Lupus Patient Association (FELUPUS). Online interviews of approximately 25 min were completed. The information was gathered anonymously from May 21st to June 30th, 2020.

Results One thousand two hundred sixty-three interviews were completed. 92% had a diagnosis of Systemic Lupus Erythematosus (SLE) and 8% of Cutaneous Lupus Erythematosus (CLE); 95% of the patients surveyed were female. Most of the patients claimed they stay up late, exercising and work/study were the most limited actions due to the disease. 73% of patients considered that there was little knowledge of the disease by society and at the time of diagnosis, the patient's level of knowledge about lupus was low in 92% of them. Regarding organ damage, many patients did not understand the concept of chronicity and irreversibility of the term, relating it erroneously to acute symptoms like fatigue (38%), joint pain (47%) and even to the presence of cutaneous symptoms such as the presence of oral ulcers (17%).

Conclusions The survey highlighted the need for disease awareness campaigns, greater involvement of healthcare professionals and the need to provide more information to lupus patients from the time of diagnosis. Nationally and to our knowledge, this is the survey with the largest number of participants ($N = 1263$) conducted in patients with lupus.

Key Points

- A national survey was conducted among people with lupus living in Spain and belonging to patient associations in Spain (FELUPUS).
- Nationally and to our knowledge, this is the survey with the largest number of participants ($N = 1263$) conducted in patients with lupus.
- Most of the patients claimed they stay up late, exercising and work/study were the most limited actions due to the disease.
- 73% of patients considered that there is little knowledge of the disease by society and at the time of diagnosis, the patient's level of knowledge about lupus was low in 92% of them.

Keywords FELUPUS (Spanish Lupus Federation) · Lupus Patient Association · Organ damage · Systemic lupus erythematosus

Introduction

Lupus is a chronic, autoimmune disease of variable course. Within the pathology, we can clearly differentiate CLE (cutaneous lupus erythematosus) and SLE (systemic lupus

erythematosus). SLE is the most prevalent, with a universal distribution of 1.8 to 7.6 cases per 100,000 habitants/year in different areas of the USA (United States of America) and 3.3 to 4.8 cases per 100,000 habitants/year in different countries of Northern Europe [1, 2]. Recent data collected from the Spanish EPISER2016 study show a prevalence in Spain of 210 cases per 100,000 inhabitants [3].

SLE is a very heterogeneous disease that affects several organs and systems (skin, joints, kidneys, heart, lungs and brain) causing multiple clinical manifestations, from mild

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symptoms to really severe manifestations such as end-stage kidney disease or central nervous system (CNS) compromise [4, 5]. To assess chronic organ damage in SLE, the SLICC/ACR (Systemic Lupus International Collaborating Clinics/American College of Rheumatology) damage index (SDI) has been used since 1996 [6]. As shown in the work of Urowitz MB et al., even though the inflammatory activity of the disease decreases after the first 5 years of diagnosis, irreversible damage accrual (SDI) can reach 40% of patients in the first year and up to 50% in the first 5 years [7]. Mortality from SLE has decreased substantially in the last few years, with 10-year survival currently exceeding 90% [8]. This is due to several reasons: improvements in healthcare systems, the appearance of biological therapies, greater access to medical information, the great role played by patient associations and the new attitude of the patient towards the disease (the concept of the “expert” patient, the “empowered” patient appears). All this leads to an increase in the importance of establishing solid patient-physician relationships for better disease control, and the need to measure PROs (Patient Reported Outcomes) and train expert patients is becoming more evident.

The scientific community does not know accurately the perception of our patients regarding the knowledge of the disease, just as the relationship between patients and the disease. Adherence to therapy, the impact on quality of life and work productivity, the relationship with and knowledge of the disease, and the interaction with healthcare providers and treatments are identified as major challenges in this area [9–17]. For this reason, it was decided to carry out a survey in 2020 conducted by the Spanish Lupus Federation (FELUPUS), about the perceptions and experiences of patients with SLE, in order to give voice to the patient and understand their future needs. Nationally and to our knowledge, this is the survey with the largest number of participants ($N=1263$) conducted in patients with lupus.

Objective

The aim of the survey was to describe the profile of patients with lupus in Spain, to evaluate their relationship with the disease and healthcare providers, as well as to reflect their knowledge of it. In addition, other aspects such as the impact on quality of life and organ damage were assessed.

Methods

A national survey was conducted among people with lupus living in Spain who belong to the Spanish Lupus Patient Association (FELUPUS, <https://www.felupus.org/>). The

survey was developed by patients from the 21 Regional Patient Associations that belong to FELUPUS. Subsequently, it was corrected and validated by the members of the FELUPUS scientific committee. Online interviews of approximately 25 min were completed. The information was gathered anonymously from May 21st to June 30th, 2020. Patients were contacted via email through FELUPUS distribution list to all regional patient associations. They had support from an external provider to design and create the survey (Ipsos, <https://www.ipsos.com/es-es>). Adherence to relevant recommendations on online surveys was performed [9] and all patients were asked for informed consent via the web at the beginning of the survey and participated voluntarily. There were no specific patient selection criteria, but rather every patient with lupus was a candidate to answer the survey. The patients did not receive any compensation for answering. No validated questionnaire was used for SLE, but questions that could be of interest to understand the perspective of the patient with lupus about her disease were included. FELUPUS developed the questionnaire taking advice from trusted experts who are part of its scientific committee. The survey was divided into 6 well-defined sections: [1] SLE patient profile, [2] impact on quality of life and work productivity, [3] relationship with healthcare providers, [4] relationship with treatments, [5] knowledge of the disease and, finally, [6] relationship with the disease, with a total of 41 themes to be dealt with in all the sections. The main results of the survey are presented below.

Results

SLE patient profile

One thousand two hundred sixty-three interviews were completed. The survey population sample was representative of the lupus patient population in Spain [associated sampling error: 2.76%]. The vast majority of patients were from Andalucía (276), Catalonia (184), Madrid (168). Regarding age, most were in the range 46–65 years ($n=484$) or 36–45 years ($n=423$). Regarding the lupus patient profile, 92% had a diagnosis of SLE and 8% of CLE; 95% of patients surveyed were female, most of them with medium–high education and only 32% of them, full-time salaried. 64% of patients had no recognized degree of disability and about half of the patients had been diagnosed with SLE for more than 10 years. The majority (73%) did not have private health insurance, 45% of patients had smoked or were smoking at the time of the survey and up to 25% of them stated that they did not practice any type of sport activity.

On the other hand, 46% of the respondents belonged to a patient association which they had entered mostly of their own free will.

Impact on quality of life and work productivity

In relation to quality of life and work productivity, most of the patients claimed they stay up late, exercising and work/study were the most limited actions due to the disease (Fig. 1), 23% presented a high impact in their work productivity, 35% in their daily activities and 60% of patients were unable to work more than 32 h per week. 64% of patients had no recognized degree of disability. Of the remaining 36% that they do have recognized, only 6% had a minor disability.

Relationship with healthcare providers and treatments

Regarding the physician–patient relationship, it was observed that 77% of the respondents prepared the consult in advance; however, 40% of the respondents considered that the physician–patient dialogue was scarce. It was noted (75%) that the language used by the physicians was adequate and without excessive technicalities.

The majority of patients (69%) stated that, despite a high demand, they did not receive any type of informative material at the physician office visit. Some of the materials that the patient would have liked to receive were the following: the drug package leaflet and verbal explanations; schematic and graphic materials to facilitate interpretation of the information; and written materials that were as exhaustive

Fig. 1 Everyday actions limited by the fact of suffering from lupus. [Indicate to what extent the fact of suffering from Lupus limits your ability to perform the following everyday actions]

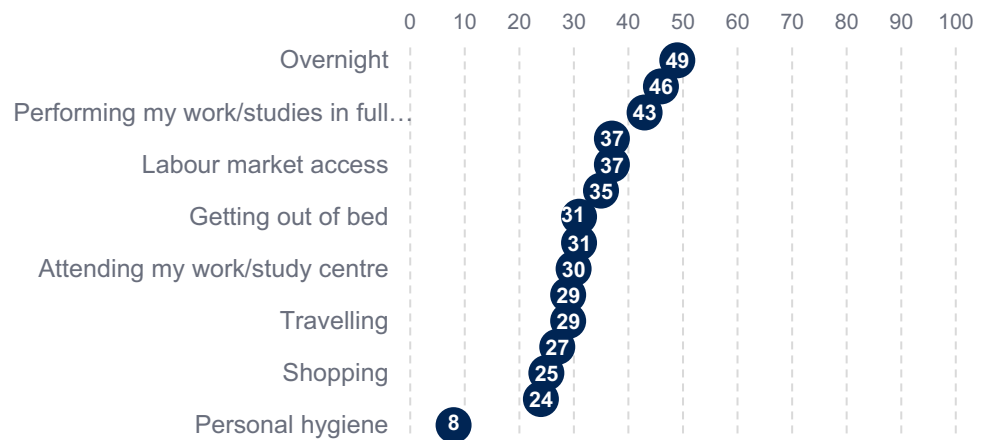
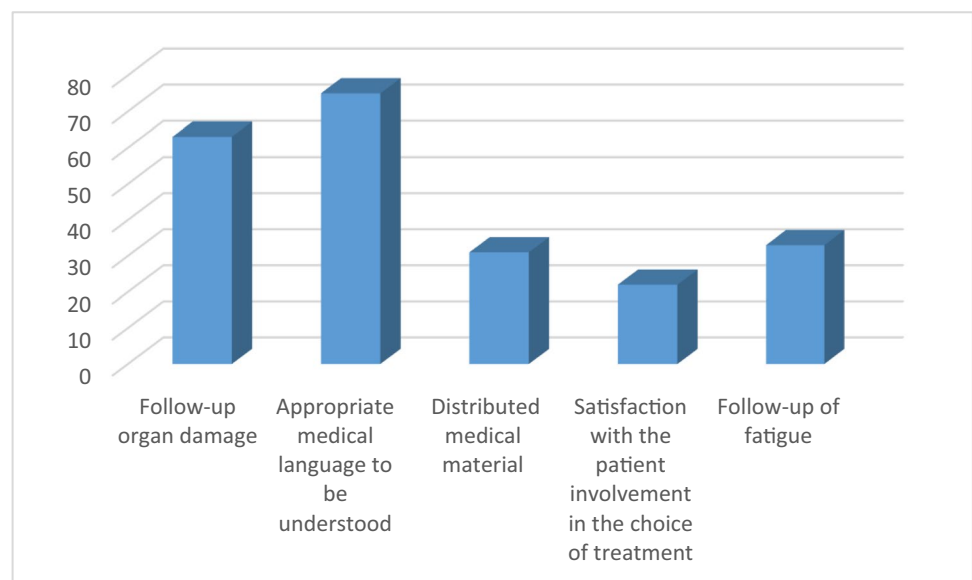


Fig. 2 Healthcare professional–patient relationship. The frequency of satisfaction represents the percentage of patients who scored 4 or 5 points (out of 5) of satisfaction for each item. 1. Organ damage follow-up, 2. Medical language adequate to be understood, 3. Medical material distributed, 4. Satisfaction with the degree of patient participation in the choice of treatment, 5. Follow-up Fatigue



as possible. Satisfaction with the information received was, therefore, moderate, with slightly higher satisfaction related to treatment access. (Fig. 2).

Regarding the search for information about lupus on the web, 75% of patients visited websites about their pathology and only 14% had received information about reference websites from their physician.

With regard to the follow-up of the disease by the physician, the respondents highlighted that only 63% and 30% were concerned about following up on organ damage and fatigue, respectively. In addition, they highlighted the low satisfaction with the degree of patient participation in the choice of treatment. In this respect, only 56% were satisfied with the treatment, this satisfaction being higher in those treated with biologics. Among those treated with biologics, 2/3 had been treated for more than a year.

Knowledge of the disease

The questions regarding the knowledge of the disease showed that 73% of patients considered that there is little knowledge of the disease by society; and as for the patient's knowledge about lupus, it was noticed that it increased as the disease progressed, therefore, at the time of diagnosis, the patient's level of knowledge about lupus was low in 92% of patients, while at the time of the survey, 68% of patients claimed to have a high knowledge of the disease.

Relationship with the disease

Questions about the patient's relationship with the disease revealed that up to 97% of patients were mostly aware of symptoms related to renal, cardiac involvement, fatigue and skin involvement. On the other hand, 3 out of 4 patients had disease-related symptoms such as muscle and joint pain

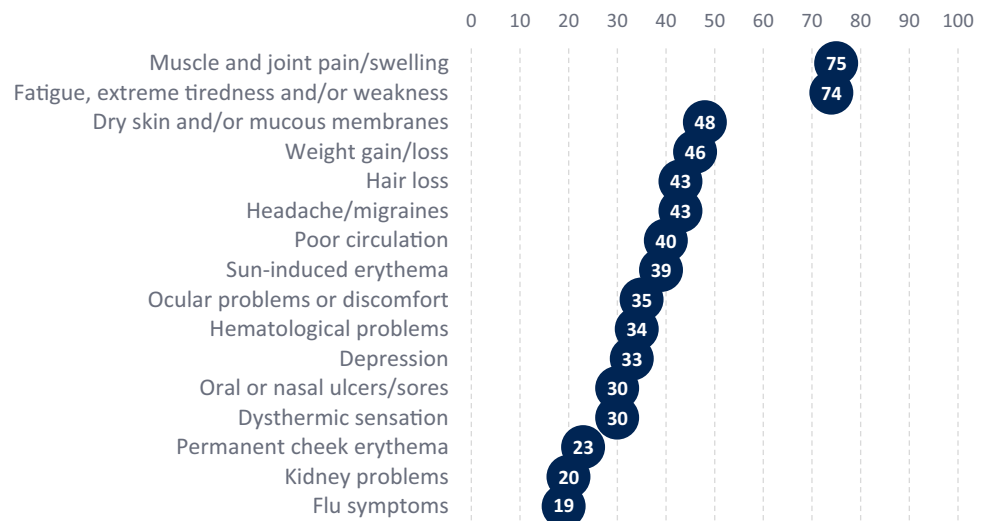
(75%), fatigue (74%), being these which generated the most discomfort to the SLE patients surveyed (Fig. 3). In terms of statements related to suffering from lupus, there was considerable agreement with not being able to sunbathe (78%), lack of energy (61%) and weakness of the whole body (60%). Flares (86%), followed by fatigue (78%) and pain (77%) were palpable causes of great concern for patients. At the time of the survey, 71% of patients reported joint involvement, 42% skin involvement, 27% renal involvement, and up to 17% CNS involvement. In relation to organ damage, it was found that many patients with systemic involvement (SLE) did not understand the concept, mistakenly relating it to fatigue (38%), joint pain (47%) and even with the presence of cutaneous symptoms such as the presence of oral ulcers (17%).

Discussion

The survey showed the need to strengthen physician–patient relationships in a disease as complex as SLE. The survey was conducted during the start of the COVID-19 pandemic, and it was distributed almost at the same time (2 months later) with the start of the pandemic in Spain. The interaction of the patient with the doctor and the healthcare team is based on trust, communication and the willingness to achieve common goals such as health preservation and recovery, rehabilitation and family, social and work reintegration and above all, the aim is to seek the well-being of the patient.

In this regard, we find in the literature some studies and surveys conducted in cohorts of lupus patients outside the Spanish territory that assess the “burden” of the disease on the different patient outcomes. Some examples are the SLE-UPDATE survey that mainly assesses

Fig. 3 Presence of SLE symptoms. [Indicate the degree of discomfort you experience with each of the following SLE symptoms]



patient satisfaction with treatments [10], assessment of quality of life using the LupusQol (Lupus Quality of life) questionnaire in Venezuela [11] and Turkey [12], the 2014 LUPUS UK Members survey [13], some international multicenter studies [14, 15], a French survey [16], different questionnaires that assess how the disease affects work productivity [15, 17] and fatigue [17, 18]. Nationally and to our knowledge, this is the survey with the largest number of participants ($N = 1263$) conducted in patients with lupus.

The survey indicated that SLE affects mainly young women of working age at the professional level, affecting their quality of life and work productivity. 64% of patients had no recognized degree of disability and among those with a known degree of disability, only 6% had a minor disability. The majority of respondents were moderately disabled, and some were severely disabled, thus highlighting the above mentioned, it seems that only moderate-severe patients are recognized to have some degree of disability. In this regard, 23% of respondents presented a high impact on their work productivity, 35% on their daily activities and 60% of patients were unable to work more than 32 h per week, which is in line with previous studies [15, 17], where up to 52% of the patients had to stop working altogether. Therefore, the surveys reflected the current problems faced by these patients, since it is difficult to be granted a degree of disability and, in turn, the disease substantially affects their work productivity. One of the reasons for this impact of the disease on work life, physical activity and even daily social activities is fatigue. In the survey, up to 74% of patients stated that fatigue was one of the symptoms that generated the most general discomfort, which is consistent with previous surveys [17, 18].

The physician–patient relationship is the generally unwritten contract, established by autonomous persons free to initiate, continue or terminate this relationship where both share the same goal, to restore the health of one of them. The language used by physicians to communicate with their SLE patients seemed adequate in 75% of cases; however, respondents highlighted that only 63% and 30% were concerned about following up on organ damage and fatigue, respectively, a data not previously published in the literature. 40% of patients reported that there was little dialogue with their specialist, and the majority of patients (69%) reported that, despite high demand, they did not receive any information material at the physician office visit and also reported low satisfaction with the degree of patient participation in the choice of treatment and moderate satisfaction with the information received, thus reflecting the need for greater involvement of healthcare providers and the need for more information for SLE patients from the time of diagnosis. There is evidence that all of these strategies are associated with better disease control, greater adherence to treatment,

greater treatment satisfaction with fewer side effects and more positive beliefs about disease control [19, 20]. A relevant finding is the lack of agreement on disease control between physicians and SLE patients [21–25]. In general, once the treatment has been established, different studies show that patient satisfaction with the treatment is high in most patients [10, 16, 26].

At the time of diagnosis up to $\frac{3}{4}$ of SLE patients had little knowledge of the disease, which is in line with the previously published French survey [16]. Among the findings of the survey, it is highlighted 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. On the other hand, half of the patients were diagnosed after 10 years of symptoms and 92% of the patients had organ involvement at diagnosis. This means that we are late in diagnosing many patients, which makes it necessary to promote close collaboration between primary care and hospitals to refer patients with suspected SLE.

Finally, it is noticeable that many patients did not understand the concept of irreversible organ damage, mistakenly relating it to fatigue (38%), joint pain (47%) and even to the presence of cutaneous symptoms such as the presence of oral ulcers (17%). In the work of Mok et al. [26], up to 48% of patients had irreversible organ damage at baseline, so it is essential that patients understand the concept of damage and differentiate it from acute activity.

In summary, the survey highlighted the need for disease awareness campaigns, where patient associations alongside health authorities have a crucial role to play; in turn, there is a need for greater involvement of healthcare providers and the need for more information for SLE patients from the time of diagnosis.

Conflict of interest

The authors have no conflicts of interest to declare. All co-authors have seen and agree with the contents of the manuscript and there is no financial interest to report.

Supplementary Information The online version contains supplementary material available at <https://doi.org/10.1007/s10067-023-06500-3>.

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References

1. D’Cruz DP, Kamastha MA, Huges GRV (2007) Systemic lupus erythematosus. *Lancet* 369:587–596

2. Weiss JE (2012) Pediatric systemic lupus erythematosus: more than a positive antinuclear antibody. *Pediatr Rev* 33:62–73
3. Cortés Verdú R, Pego-Reigosa JM, Seoane-Mato D, Morcillo Valle M, Palma Sánchez D, Moreno Martínez MJ, Mayor González M, Atxotegi Sáenz de Buruaga J, Urionaguena Onaindia I, Blanco Cáceres BA, Silva-Fernández L, Sivera F, Blanco FJ, Sánchez-Piedra C, Díaz-González F, Bustabad S; Working Group Proyecto EPISER2016 (2020) Prevalence of systemic lupus erythematosus in Spain: higher than previously reported in other countries? *Rheumatology (Oxford)*. Sep 1;59(9):2556–2562. <https://doi.org/10.1093/rheumatology/kez668>. PMID: 31998955; PMCID: PMC7449807.4.Tsokos GC. Systemic lupus erythematosus. *N Engl J Med*. 2011;365:2110–21
4. Carrión-Barberà I, Salman-Monte TC, Vélchez-Oya F, Monfort J (2021) Neuropsychiatric involvement in systemic lupus erythematosus: a review. *Autoimmun Rev* 20(4):102780
5. Ghazali WSW, Daud SMM, Mohammad N et al (2018) SLICC damage index score in systemic lupus erythematosus patients and its associated factors. *Med (Baltimore)* 97:12787
6. Urowitz MB, Gladman DD, Ibañez D, Fortin PR, Bae SC, Gordon C, Clarke A, Bernatsky S, Hanly JG, Isenberg D, Rahman A, Sanchez-Guerrero J, Wallace DJ, Ginzler E, Alarcón GS, Merrill JT, Bruce IN, Sturfelt G, Nived O, Steinsson K, Khamashta M, Petri M, Manzi S, Ramsey-Goldman R, Dooley MA, van Vollenhoven RF, Ramos M, Stoll T, Zoma A, Kalunian K, Aranow C (2012) Evolution of disease burden over five years in a multicenter inception systemic lupus erythematosus cohort. *Arthritis Care Res (Hoboken)* 64(1):132–7. <https://doi.org/10.1002/acr.20648>
7. Ståhl-Hallengren C, Jönsen A, Nived O, Sturfelt G (2000) Incidence studies of systemic lupus erythematosus in Southern Sweden: increasing age, decreasing frequency of renal manifestations and good prognosis. *J Rheumatol* 27(3):685–691
8. Gaur PS, Zimba O, Agarwal V, Gupta L (2020) Reporting survey based studies - a primer for authors. *J Korean Med Sci* 23(35):e398. <https://doi.org/10.3346/jkms.2020.35.e398>
9. Birt JA, Hadi MA, Sargalo N, Brookes E, Swinburn P, Hanrahan L, Tse K, Bello N, Griffing K, Silk ME, Delbecque LA, Kamen D, Askanase AD (2021) Patient experiences, satisfaction, and expectations with current systemic lupus erythematosus treatment: results of the SLE-UPDATE survey. *Rheumatol Ther* 8(3):1189–1205. <https://doi.org/10.1007/s40744-021-00328-6>
10. Carrión-Nessi FS, Marcano-Rojas MV, Freitas-DeNobrega DC, Romero Arocha SR, Antuarez-Magallanes AW, Fuentes-Silva YJ (2022) Validation of the LupusQoL in Venezuela: a specific measurement of quality of life in patients with systemic lupus erythematosus. *Reumatol Clin (Engl Ed)* 18(6):355–360. <https://doi.org/10.1016/j.reuma.2021.02.007>
11. Yilmaz-Oner S, Oner C, Dogukan FM, Moses TF, Demir K, Tekayev N, Atagunduz P, Tuglular S, Direskeneli H (2016) Health-related quality of life assessed by LupusQoL questionnaire and SF-36 in Turkish patients with systemic lupus erythematosus. *Clin Rheumatol* 35(3):617–622. <https://doi.org/10.1007/s10067-015-2930-1>
12. Morgan C, Bland AR, Maker C, Dunnage J, Bruce IN (2018) Individuals living with lupus: findings from the LUPUS UK Members Survey 2014. *Lupus*. 27(4):681–687. <https://doi.org/10.1177/0961203317749746>
13. Ngamjanyaporn P, McCarthy EM, Sergeant JC, Reynolds J, Skeoch S, Parker B, Bruce IN (2017) Clinicians approaches to management of background treatment in patients with SLE in clinical remission: results of an international observational survey. *Lupus Sci Med* 4(1):e000173. <https://doi.org/10.1136/lupus-2016-000173>
14. Gordon C, Isenberg D, Lerstrøm K, Norton Y, Nikai E, Pushparajah DS, Schneider M (2013) The substantial burden of systemic lupus erythematosus on the productivity and careers of patients: a European patient-driven online survey. *Rheumatol (Oxford)* 52(12):2292–301. <https://doi.org/10.1093/rheumatology/ket300>
15. Meunier B, Jourde-Chiche N, Mancini J, Chekroun M, Retornaz F, Chiche L (2016) Characteristics and information searched for by French patients with systemic lupus erythematosus: a web-community data-driven online survey. *Lupus* 25(4):370–375. <https://doi.org/10.1177/0961203315610644>
16. Kent T, Davidson A, Newman D, Buck G, D'Cruz D (2017) Burden of illness in systemic lupus erythematosus: results from a UK patient and carer online survey. *Lupus* 26(10):1095–1100. <https://doi.org/10.1177/0961203317698594>
17. Booth S, Price E, Walker E (2018) Fluctuation, invisibility, fatigue - the barriers to maintaining employment with systemic lupus erythematosus: results of an online survey. *Lupus* 27(14):2284–2291. <https://doi.org/10.1177/0961203318808593>
18. Georgopoulou S, Prothero L, D'Cruz DP (2018) Physician-patient communication in rheumatology: a systematic review. *Rheumatol Int*. 38(5):763–775. <https://doi.org/10.1007/s00296-018-4016-2>
19. Costedoat-Chalumeau N, Pouchot J, Guettrot-Imbert G, Le Guern V, Leroux G, Marra D, Morel N, Piette JC (2013) Adherence to treatment in systemic lupus erythematosus patients. *Best Pract Res Clin Rheumatol* 27(3):329–340. <https://doi.org/10.1016/j.berh.2013.07.001>
20. Golder V, Ooi JY, Antony AS, Ko T, Morton S, Kandane-Rathnayake R, Morand EF, Hoi AY (2018) Discordance of patient and physician health status concerns in systemic lupus erythematosus. *Lupus* 27(3):501–506. <https://doi.org/10.1177/0961203317722412>
21. Mozaffarian N, Lobosco S, Lu P, Roughley A, Alperovich G (2016) Satisfaction with control of systemic lupus erythematosus and lupus nephritis: physician and patient perspectives. *Patient Prefer Adherence* 4(10):2051–2061. <https://doi.org/10.2147/PPA.S111725>
22. Chang CM, Wu WH, Kuo BI, Lee TY, Liu CY, Chang HH (2014) Using a questionnaire among patient, resident doctor and senior supervisor: are their answers the same? *Complement Ther Med*. 22(2):296–303. <https://doi.org/10.1016/j.ctim.2014.02.006>
23. Hardy C, Gladman DD, Su J, Rozenbojm N, Urowitz MB (2021) Barriers to medication adherence and degree of nonadherence in a systemic lupus erythematosus (SLE) outpatient population. *Rheumatol Int* 41:1457–1464. <https://doi.org/10.1007/s00296-021-04898-0>
24. Ferreira JCOA, Trindade VC, Espada G, Morel Z, Bonfá E, Magalhães CS, Silva CA (2018) Epidemiology and management practices for childhood-onset systemic lupus erythematosus patients: a survey in Latin America. *Clin Rheumatol* 37:3299–3307. <https://doi.org/10.1007/s10067-018-4254-4>
25. Strand V, Galateanu C, Pushparajah DS, Nikai E, Sayers J, Wood R, van Vollenhoven RF (2013) Limitations of current treatments for systemic lupus erythematosus: a patient and physician survey. *Lupus* 22(8):819–826. <https://doi.org/10.1177/0961203313492577>
26. Mok CC, Ho LY, Cheung MY, Yu KL, To CH (2009) Effect of disease activity and damage on quality of life in patients with systemic lupus erythematosus: a 2-year prospective study. *Scand J Rheumatol*. 38(2):121–7. <https://doi.org/10.1080/03009740802415527>

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