Paper

Lupus
2024, Vol. 33(7) 663–674

DOI: 10.1177/09612033241242886
journals.sagepub.com/home/lup

Lack of awareness of systemic lupus erythematosus and its consequences in a cohort of moderate and severe patients in Spain: The LupusVoice study

Maria Galindo Izquierdo[1], Joaquín Borrás Blasco[2], Silvia Pérez Ortega[3], Tarek Carlos Salman-Monte[4], Paloma Vela-Casasempere[5], Esther Rodríguez Almaraz[1], Jaime Calvo-Alen[6], José María Álvaro-Gracia Álvaro[7], Mª Julia Barbado Ajo[8], Raül Rubio Renau[9], Marta Galvez-Fernandez[10], Noemí Bahamontes-Rosa[10], Joaquín Sánchez-Covisa Hernández[10] and Carlota Solà Marsiñach[9]

Abstract

Background and objectives: Systemic lupus erythematosus (SLE) is an autoimmune condition that can highly impact patients' quality of life (QoL). However, there is a lack of knowledge about SLE, affecting the general population and health care professionals (HCPs) alike. This lack of knowledge has negative implications for patients and the healthcare system, worsening prognosis, negatively impacting QoL, and increasing healthcare utilization. The aim of this paper is to draw attention, according to the perspective of the participants of this study, to the lack of awareness of SLE and its consequences in Spain, and to suggest improvements.

Patients and methods: This qualitative, descriptive, observational, multicenter, and cross-sectional study included 40 patients with moderate or severe SLE, recruited during their routine visits in six university hospitals in Spain. The study also included 11 caregivers and 9 HCPs. All participants were individually interviewed. Data from the interviews were coded and analyzed thematically by two anthropologists following a phenomenological perspective.

Results: Our study identified a lack of disease awareness among primary care physicians, emergency medicine doctors, and other specialists treating SLE symptomatology. This led to diagnostic delays, which had a clinical and emotional impact on patients. Furthermore, symptom awareness was found to be context dependent. Differences in symptom awareness between HCPs and patients led to a mismatch between the severity evaluation made by doctors and patients. Some HCPs did not consider the limitations of the current severity evaluation of SLE, and therefore attributed symptoms potentially caused by SLE to the unfavorable socioeconomic conditions patients lived in. Finally, a lack of social awareness among friends, family members, and romantic partners led to lower social support, increased isolation, and negative physical and emotional impact for patients. Gender differences in the provision of support were identified.

Conclusion: This study highlights the need to increase SLE awareness among patients, HCPs, and the broader public in order to improve patient QoL. Being aware of the clinical and emotional impact of such lack of awareness, as well as the role

[1]Rheumatology Department, Hospital Universitario 12 de Octubre, Madrid, Spain
[2]Hospital Pharmacy, Hospital de Sagunto, Sagunto, Spain
[3]President of FELUPUS (Spanish Lupus Federation), Madrid, Spain
[4]Rheumatology Department, Hospital del Mar, Barcelona, Spain
[5]Rheumatology Department, Hospital General Universitario Dr Balmis Alicante/ISABIAL/Universidad Miguel Hernandez, Alicante, Spain
[6]Rheumatology Department, Hospital Universitario Araba, Instituto de Investigación BIORABA, Universidad del País Vasco, Vitoria-Gasteiz, Spain
[7]Rheumatology Department, Hospital General Universitario Gregorio Marañón, Madrid, Spain
[8]Internal Medicine Department, Hospital Universitario Rio Hortega, Valladolid, Spain
[9]Evidence Generation Department, A Piece of Pie, Barcelona, Spain
[10]Medical Department, AstraZeneca Farmacéutica Spain S.A., Madrid, Spain

Corresponding author:
Carlota Solà Marsiñach, Evidence Generation Department, A Piece of Pie, Calle Tanger 86, Barcelona 08018, Spain.
Email: carlota@piecepie.com

played by context on the patient experience of SLE, is a crucial step towards achieving this goal.

Keywords
Awareness, systemic lupus erythematosus, patient perspective, qualitative study, quality of life

Date received: 7 December 2023; accepted: 22 March 2024

Introduction

Systemic lupus erythematosus (SLE) is an autoimmune condition that, in its moderate and severe stages, can highly impact patients' quality of life (QoL). However, there is a lack of knowledge about SLE, affecting the general population and health care professionals (HCPs) alike.[1–3] The frequently non-specific symptoms of the disease's onset make its early diagnosis difficult.[4] Furthermore, the "invisibility" of some of SLE's symptomatology contributes to the lack of understanding by the patients' social circle.[5] It has been shown that a lack of knowledge about the disease has negative implications for patients and the healthcare system, worsening prognosis, negatively impacting QoL, and increasing healthcare utilization.[1,6–8]

The aim of this paper is to draw attention, according to the perspective of the participants of this study, to the lack of awareness of SLE and its consequences in Spain, and to suggest improvements. Firstly, we focus on the lack of disease awareness by HCPs. Secondly, we evaluate differences in symptom awareness according to patients' and HCPs' perspectives, suggesting that symptom awareness is context dependent. Additionally, we show how patients' contexts are conceptualized by HCPs. Finally, we delve into the social awareness of SLE. Overall, this paper argues that increasing SLE awareness at each of these levels may benefit patients, improving their lived experience of the disease and their QoL.

Materials and methods

Study design

This paper is based on part of the results of the LupusVoice Study, a qualitative, descriptive, observational, multicenter, and cross-sectional study with 40 patients with moderate or severe SLE. Additionally, the study included 11 caregivers and 9 clinicians, reaching a total of 60 participants. Patients were recruited during their routine visits in six Spanish university hospitals. After obtaining written informed consent, doctors compiled information about patients' personal characteristics, disease, and treatment, and shared their contact information with two anthropologists, who scheduled and conducted the interviews with patients. On eleven occasions, a caregiver was also interviewed; in these cases, informed consent was given by both patient (written) and caregiver (orally) beforehand. Interview questions were open-ended and aimed to elucidate the lived experience of SLE.

HCPs were recruited by the principal investigators from the participating hospitals: eight rheumatologists and one internal medicine doctor. HCPs were interviewed after almost all patient interviews were conducted, with the aim of complementing their view. Interview questions were also open-ended but covered the themes identified in patient and caregiver interviews.

Sample and recruitment

Patients had a documented diagnosis of moderate or severe SLE, were ≥ 18 years at the time of consent, and had been diagnosed with SLE for at least one year prior to enrollment. A moderate-severe diagnosis was determined by either a SELENA-SLEDAI score ≥ 6, current treatment with a biologic or immunosuppressant, treatment with systemic corticoids at a dose ≥ 7.5 mg/day, or by a Physician Global Assessment (PGA) score > 1.5 (on a scale from 0 to 3). Participation in a clinical trial, a Sjogren's syndrome and/or primary antiphospholipid syndrome diagnosis, hospitalization at the time of inclusion, holding a managing position in a patient association, or having a cognitive dysfunction were all exclusion criteria. Caregivers were defined as people who accompanied the patient throughout their patient journey. HCPs had to be specialized in the treatment of SLE.

Data gathering and analysis

Patients, caregivers, and clinicians participated in remote semi-structured interviews—2h long for patients and caregivers and 1h long for clinicians—via videocall. Interviews were conducted in Spanish. Semi-structured interviews allowed participants to raise issues of concern while simultaneously covering the researcher's areas of interest. During the interview, patients completed two patient reported outcome measures (PROMs), the generic EQ-5D-5L and the disease specific Lupus Impact Tracker™. The information gathered with these PROMs was analyzed descriptively. Interview data were coded and analyzed thematically by two anthropologists following a phenomenological perspective, which aims to elucidate the lived experience of a disease and the conditions

shaping said experience.[9,10] The analytical process was both inductive and deductive, meaning that themes were identified by topics emerging directly from the data and applying prior knowledge.[11] A vast amount of themes emerging from the LupusVoice Study reached saturation.[12] To be able to present them in depth, this paper solely focuses on those related to the lack of SLE awareness and its impact.

Ethics

Study materials were approved by the Research Ethics Committee of Euskadi on the 8th of June, 2022. The study was given the following code: D3461R0005. All participants were asked to verbally confirm their informed consent and permission for the interview to be recorded and transcribed before the beginning of the interview. All data was pseudonymized to protect participant confidentiality. The study followed the principles outlined in the revised version of the Declaration of Helsinki, Good Clinical Practices.

Results

Patient characteristics

Our sample consisted of 40 patients. Their mean age was 41 years-old, and 93% were women. All patients spoke fluent Spanish. Their demographic and clinical characteristics are compiled in Table 1.

Disease awareness

According to all HCPs, there is a delay in the diagnosis of SLE occurring due to two factors: lack of awareness of SLE and an overwhelmed healthcare system without enough time for doctors to properly assess patients. According to patients' and HCPs' perspectives, the lack of awareness is present in primary care, in the emergency department (ED), and among specialists potentially treating SLE symptomatology. In our sample, 30% of patients were reported to be diagnosed within 3 months after the first medical consultation, 30% within 3 to 6 months, 20% within 6 to 12 months, and 20% after a year.

Although our sample had a self-reported mean diagnostic time of approximately 3 months, 33% of the patients complained about how long it took to be diagnosed, highlighting that they had to insist about not being well and had to visit several specialists and the ED without receiving the correct diagnosis. Rather than time, it was the number of visits to the doctors—including to the ED—the number of tests undertook, and the number of times they were dismissed, which constituted a delayed diagnosis as far as patients were concerned.

According to HCPs, a delayed diagnosis can worsen SLE prognosis, increasing disease activity, cumulative organ damage, and the risk of early mortality. Furthermore, a delayed diagnosis may diminish disease control and complicate finding the right medication. Sometimes, a delayed diagnosis implies a misdiagnosis, which may be treated with unnecessary treatments that can cause short- and long-term side-effects.

However, patients' narratives focused on different consequences (Table 2). The one most commonly mentioned—by 38% of patients—was distrust in the doctors—usually general practitioners (GPs), but also specialists and ED doctors—and the healthcare system. The distrust remained to this day: patients expressed not wanting to visit their GPs, consulting their rheumatologists instead. The rheumatologists interviewed confirmed this, adding that frequently patients' concerns could be solved by the GP. Additionally, 20% of patients also drew attention to their emotional wellbeing: the uncertainty of not knowing what was happening and the dismissal they felt from HCPs led them to feel angry, powerless, frustrated, sad, anxious, and even depressed. Furthermore, 20% of patients highlighted that a delayed diagnosis had led them to unnecessarily experience side-effects of medications they did not need. Finally, 10% of patients expressed anger because a delayed diagnosis had led to the "disease getting worse" and to events such as lupus nephritis, pericarditis, and stroke.

Symptom and context awareness

The study identified a mismatch between the severity evaluation made by doctors and patients. To be included in the study, patients needed either a SELENA-SLEDAI ≥ 6, to be taking biologics, immunosuppressants, or systemic corticoids at a dose $\geq$ 7.5 mg/day, or a Physician Global Assessment (PGA) > 1.5 (in a scale from 0 to 3). The distinction between moderate or severe was determined by the treating physicians. To be considered moderate, generally patients had to have a SELENA-SLEDAI ≥ 6 and ≤ 10, a BILAG B or C, treatment with methotrexate or azathioprine, and minor organic affectation such as moderate arthritis, as well as pericarditis and pleuritis without complications. The following criteria were generally used to classify patients as severe: a SELENA-SLEDAI >10, a BILAG A, organic affectation such as pericarditis with tamponade and effusion, lupus nephritis, or severe or refractory arthritis. For their part, patients perceived the severity of their disease according to its impact on QoL.

The results of the Lupus Impact Tracker™ showed that the medium impact score was higher for severe patients (20.1) than for moderate ones (13.6) (Table 3). Additionally, the impact score was higher for severe patients in all categories except for the one regarding pain. Table 3 also shows the impact of SLE between moderate and severe

Table 1. Patient characteristics (n = 40).

Disease evolution (time since diagnosis): n (%)		Time from first symptoms to diagnosis			
		<3 months (n = 12, 30%)	**3-6 months** (n = 12, 30%)	**6-12 months** (n = 8, 20%)	**>12 months** (n = 8, 20%)
<5 years:	09 (23%)	3	2	3	1
5-10 years:	11 (27%)	1	5	2	3
>10 years:	20 (50%)	8	5	3	4
Comorbidities: n (%)					
Lupus nephritis:	19 (48%)				
Cutaneous involvement:	22 (55%)				
Joint involvement:	36 (90%)				
Hematological involvement:	25 (63%)				
Cardiovascular involvement:	07 (18%)				
Current treatment: n (%)[a]					
Hydroxychloroquine:	35 (88%)				
Glucocorticoids:	23 (58%)				
Immunosuppressors:	24 (60%)				
Biological treatment:	19 (48%)				
Severity: n (%)					
Moderate:	26 (65%)				
Severe:	14 (35%)				
Current treatment line: n (%)					
1st line:	13 (33%)				
2nd line:	09 (23%)				
3rd line:	04 (10%)				
4th line:	09 (22%)				
5th line or above:	05 (12%)				
Educational level: n (%)					
Primary education:	6 (15%)				
Secondary education:	9 (23%)				
Non-university tertiary education:	5 (12%)				
University tertiary education:	17 (43%)				
Prefer not to say:	3 (7%)				
Nationality: n (%)					
Spanish:	33 (83%)				
Portuguese:	1 (2%)				
Polish:	1 (2%)				
Uruguayan:	1 (2%)				
Dominican:	2 (5%)				
Venezuelan:	1 (2%)				
Moroccan:	1 (2%)				

[a]This refers to the sequence of treatment options undergone by a patient.

patients. The EQ-5D-5L questionnaire shows similar results: severe patients were more affected than moderate ones except in the mobility domain (Table 4). Overall, the results of these questionnaires match the conceptualization that the higher the SLE severity, the higher the impact on QoL.

However, if we investigate the results of the EQ-5D-5L questionnaire further, we can observe that this does not apply to all patients. From the total amount of patients who were classified as severe by their doctors, 50% told the interviewer that they were in good health and marked a score above 75. Of the total amount of patients classified as moderate by their doctors, 16% told the interviewer that their health was poor and indicated a score of less than 50. These patients' perceptions of their health did not match the severity evaluation given by their doctors.

According to the data from the interviews and PROMs, pain and fatigue are one of the reasons for this mismatch. Even though, according to patients, pain and fatigue are very debilitating symptoms with a high impact on QoL, they

Table 2. Illustrative quotes: Lack of disease awareness leading to diagnostic delays and their consequences.

a. "I was at work and I was feeling very tired and I said, 'that's weird, but I had a rest' and I was super exhausted, and I went to do some tests, and I said 'look' to my family doctor: 'I feel very bad, I feel very tired, I'm not like that, something is wrong with me.' I felt like my arms were breaking, every morning I was throwing up. I would tell people that parts of my body hurt, and people would tell me: 'everything hurts you, you're making it up'. They would do tests, they would tell me: 'it's nothing, you're missing that, you're missing the other thing, but you're fine'. And that's how it started. They told me: 'Please, we have already done one test, we can't do any more'. They did more tests, but then they didn't want to do them because they said I was fine, the disease was hiding. Until one day [six or seven months later] my legs started to swell, and one day I woke up with blood clotting inside and I thought that since I had had laser [hair removal] it was because of that, but I called the laser and they told me to go to the hospital because that was very rare. At the hospital they gave me corticosteroids, but it didn't get better. Until one night I saw that I had these spots all over my leg and I had to go to the emergency room, because I could hardly walk. I was waiting in the waiting room, the doctor came by, saw me, and he had this look on his face… because my condition was horrible, it looked as if my leg had gangrene, both legs… I know it's a difficult disease to diagnose, but I was telling them I was feeling bad. They should have told me [the diagnosis] when it wasn't so severe." (30-year-old female patient with severe SLE)
b. "The dermatologist told me it was urticaria and didn't do a single blood test the whole time. One day I was so itchy and swollen that I couldn't walk for three days and I went to the outpatient clinic and they gave me medication… The doctor thought I had nothing better to do than go to the outpatient clinic. From then on I decided to pay for a private consultation. And just then I had the stroke. I felt tired and angry with the dermatologist. Powerless. If they had done things earlier I wouldn't have had the stroke." (61-year-old patient, moderate SLE)
c. "The gastroenterologist found nothing and told me that my problem was mental… I felt very frustrated that they did not recognize my pain… Sometimes I have felt a lack of credibility and empathy on the part of the professionals… I felt a lot of frustration that they didn't recognize my pains." (28-year-old patient with severe SLE)
d. "The family doctor is a bit lost with this issue; one day I went to them because I had something on my skin, he told me it was just a rash, but it turned out to be an outbreak. There are times when I avoid going to the family doctor, he doesn't have much information about the disease… When I go to the emergency room there are some who don't know how to treat me because they don't know my case." (30-year-old female patient with severe SLE)
e. "Today our patients go to primary care for their things, but every time they have a problem they call here, they look for us, they leave us notes… even for problems that could be solved by their family doctor, but because they already have the concept that 'the family doctor will not fix it' or 'they never give me an appointment' or 'they take too long'. Management is becoming complicated, since the pandemic this has become quite complicated…. In primary care it is a big problem right now and we are losing this connection of managing the patient simultaneously, in parallel on a daily basis". (Rheumatologist)

are not necessarily correlated with disease activity, and therefore not considered in the severity classification of SLE. In other words, symptom awareness differs for patients and HCPs.

Furthermore, for patients, symptom awareness is heightened by the characteristics of the context they live in (Table 5). Next, we present some examples regarding work. Several patients had joint pain and fatigue as main symptoms. Some of them had high socioeconomic and educational levels, and the possibility of working remotely from their homes. This allowed them to continue working, even if under some limitations. Instead, other patients with the same symptoms had very different working and economic conditions. They had low educational attainment, and an in-person physical job—having to stand up for long hours, having to carry weight, etc. For these patients, working implied a lot of suffering, but they had to continue doing so due to economic constraints. Finally, other patients with similar symptoms but a high educational level found challenging to pursue a career that implied physical effort, which required them to find a job adapted to their circumstances.

Symptom awareness is also context dependent regarding mild cognitive dysfunction. Some of our patients reported experiencing forgetfulness, difficulty maintaining conversations, and an increased tendency to make mistakes. Those with demanding jobs requiring high levels of concentration were afraid of making mistakes. Mild cognitive dysfunction not only diminished their productivity and increased their fatigue, but also caused problems with management and clients. In the worst cases, patients were worried and anxious about being reprimanded, asked to obtain sick leave, or being fired. Instead, mild cognitive dysfunction was not regarded as a problem by those who did not have a job, arguing that it had no impact on their QoL.

When not paired with disease activity, pain and fatigue are symptoms that are difficult to evaluate by doctors and inspectors granting sick leave and disability. For a patient to be granted disability due to incapacitating pain and fatigue, these symptoms would need to be objectively measured, proven to be caused by SLE, and irreversible. However, it is not possible to prove any of these conditions with the currently available tools. Some doctors considered that the current conceptualization, evaluation, and treatment of SLE have limitations, and that ideally, the suffering of these patients would be scientifically recognized and dealt with. However, other

Table 3. Differential impact of each item of the Lupus Impact Tracker between severe and moderate patients.

		Feeling very tired when waking up	Feeling pain in the body	Not being able to carry on usual activities due to pain or fatigue	Feeling limited to fulfill family responsibilities	Not being able to plan	Being worried	Feeling depressed	Difficulty concentrating	Feeling uncomfortable due to one's physical appearance	Side-effects of the medication	TOTAL
Mean*	**Severe (*n* = 14)**	**2,4**	**2,1**	**1,5**	**1,7**	**1,9**	**2,4**	**2,0**	**1,9**	**2,6**	**1,6**	**20,1**
	Moderate (*n* = 15)	**2,2**	**2,2**	**1,4**	**1,1**	**1,1**	**1,4**	**0,9**	**1,6**	**0,8**	**1,2**	**13,6**
	TOTAL	2,3	2,2	1,4	1,3	1,4	1,7	1,3	1,7	1,4	1,3	15,9
Difference between severe and moderate		*0,2*	*−0,1*	*0,1*	*0,6*	*0,8*	*1*	*1,1*	*0,3*	*1,8*	*0,4*	6.5

(*) 0= Never / 1=Hardly / 2=Sometimes / 3=Most of the time / 4=All the time.

Table 4. Results from the EQ-5D-5L questionnaire.

		SEVERE		MODERATE		TOTAL	
		n	%	n	%	n	%
MOBILITY	I have no problems in walking about	10	71%	15	60%	25	64%
	I have slight problems in walking about	2	14%	4	16%	6	15%
	I have moderate problems in walking about	1	7%	4	16%	5	13%
	I have severe problems in walking about	1	7%	2	8%	3	8%
	I am unable to walk about	0	0%	0	0%	0	0%
	TOTALS	14	100%	25	100%	39	100%
SELF-CARE	I have no problems washing or dressing myself	11	79%	20	80%	31	79%
	I have slight problems washing or dressing myself	1	7%	4	16%	5	13%
	I have moderate problems washing or dressing myself	0	0%	1	4%	1	3%
	I have severe problems washing or dressing myself	2	14%	0	0%	2	5%
	I am unable to wash or dress myself	0	0%	0	0%	0	0%
	TOTALS	14	100%	25	100%	39	100%
USUAL ACTIVITIES	I have no problems doing my usual activities	6	43%	9	36%	15	38%
	I have slight problems doing my usual activities	5	36%	10	40%	15	38%
	I have moderate problems doing my usual activities	2	14%	5	20%	7	18%
	I have severe problems doing my usual activities	0	0%	1	4%	1	3%
	I am unable to do my usual activities	1	7%	0	0%	1	3%
	TOTALS	14	100%	25	100%	39	100%
PAIN/DISCOMFORT	I have no pain or discomfort	2	14%	9	36%	11	28%
	I have slight pain or discomfort	5	36%	6	24%	11	28%
	I have moderate pain or discomfort	5	36%	9	36%	14	36%
	I have severe pain or discomfort	2	14%	1	4%	3	8%
	I have extreme pain or discomfort	0	0%	0	0%	0	0%
	TOTALS	14	100%	25	100%	39	100%
ANXIETY/DEPRESSION	I am not anxious or depressed	2	14%	12	48%	14	36%
	I am slightly anxious or depressed	6	43%	7	28%	13	33%
	I am moderately anxious or depressed	3	21%	3	12%	6	15%
	I am severely anxious or depressed	1	7%	2	8%	3	8%
	I am extremely anxious or depressed	2	14%	1	4%	3	8%
	TOTALS	14	100%	25	100%	39	100%
YOUR HEALTH TODAY	<50	4	29%	4	16%	8	21%
	50–75	3	21%	13	52%	16	41%
	>75	7	50%	8	32%	15	38%
	TOTALS	14	100%	25	100%	39	100%

Table 5. Illustrative quotes: symptom awareness as context dependent.

a. "I kept my corporate job thanks to working remotely. I had to work naked because of itching. I had to shower every 15 minutes. I bought wristbands to use the computer and just move my fingers…. If I had to go to work face-to-face I wouldn't have been able to." (54-year-old female patient with moderate SLE)
b. "With lupus I can't work, I just ache all over. I'm supposed to have surgery on my arms and I have a ruptured tendon, but I'm a waitress. So I've been working through the pain until I couldn't do it anymore. I had no other choice, otherwise how could I feed my children?" (45-year-old female patient with moderate SLE)
c. "What worries me most are the problems of lack of concentration. I have been found to have mild cognitive dysfunction. I work in a customer-facing bank… I have a hard time concentrating, sometimes I run out of words in the middle of a conversation with a client…. I count money, recently I made a huge mess…. Every day is getting worse and this affects me at work. My bosses don't understand me and tell me to take sick leave or go on disability. I'm going to have to do it in the short term, and it's going to affect me [emotionally and financially]." (48-year-old female patient with moderate SLE)
d. "I have a lot of memory loss, but I don't worry because I don't work. The worst thing that can happen to me is that I forget to go pick up my son from school (she laughs)." (54-year-old female patient with moderate SLE)
e. "I feel perfectly well, and I don't consider myself sick. I know I am sick, but I forget." (34-year-old patient with severe SLE)

doctors did not problematize the issue; instead, when pain and fatigue did not correlate with disease activity, they put the blame on patients' contexts, establishing a correlation between their unfavorable socioeconomic conditions, mental health, and symptoms (Table 6).

Social awareness

Forty-six percent of patients in our sample reported having family members and friends who were unsupportive due to not understanding SLE because of its "invisibility." This was especially true when pain and fatigue were the main symptoms. This perceived lack of social understanding took place at different levels.

Firstly, in intimate relationships, 37% of the patients reported being in a relationship and not feeling understood by their partners. Furthermore, 7% reported not being in a relationship and fearing they would not be understood by potential partners; according to them, this thought deterred them from pursuing intimate relationships. Finally, 56% reported being in a relationship and feeling supported and understood by their partners.

Sixty-three percent of HCPs perceived a gender bias in the understanding and support provided by partners. According to them, lack of social awareness of SLE made male partners take SLE less seriously, making female patients feel less supported and understood. In contrast, lack of disease awareness increased the worry of female partners, who fretted over male patients. Of the three male patients in our sample, only one had a partner; they were both interviewed, and the described dynamic applied to them. However, HCPs perceived that younger men were more involved as caregivers—they attended medical appointments with their partners more frequently and they proactively participated in them—than older men.

Friendship was the second level at which the perceived lack of social understanding was identified. Only 38% of patients declared feeling understood and supported by their friends. On the contrary, 47% reported not feeling understood and supported, and 15% feared that they would not be understood and supported. Those patients with a more "visible" disease—such as those with joint deformation—reported feeling more understood and supported because of it.

SLE prevented 59% of the patients from keeping up with their social circle. According to them, lack of SLE awareness meant family members and friends were less likely to accommodate the needs of the patient. Additionally, many patients refrained from socializing to avoid embarrassing questions and insensitive comments. According to patients, this increased their isolation, which in turn worsened their emotional and psychological wellbeing.

Discussion

According to the HCPs interviewed, diagnostic delays in SLE are due to a combination of lack of disease awareness by both patients and doctors—especially in primary care—and an overburdened healthcare system that limits the time spent with each patient.

Several authors have drawn attention to the existence of systematic delays in the early detection of SLE.[6,13–17] One study identified a delay of 47 months since symptom onset in a cohort in Germany.[6] Another study with an American cohort reported an average of 5.6 years from the time patients noticed symptoms until they received a formal diagnosis.[14] Several studies have also identified worse health outcomes caused by a diagnostic delay. One study with a German cohort found that the longer the time to diagnosis, the higher the disease activity, disease-related damage and fatigue, and the lower the health-related QoL.[6] Another study with a Danish cohort reported that a delayed diagnosis in patients with lupus nephritis increased the risk of

Table 6. Illustrative quotes: HCPs views on context.

a. "There are times when there is discordance between the lupus activity data and how the patient feels clinically. So, when I see a discordance and I see that the lupus does not have so much activity, but instead the patient feels very fatigued, very asthenic, in a lot of pain and so on, well, I try to see their context, if there is a family problem, a problem at work… If they have a little more anxiety, if they are depressed, because in the end all that does is accentuate all the symptoms. That is to say, you have a social, family or socioeconomic context that is not… the most adequate, maybe, or is not well, so that will affect you on an emotional level and that will make you perceive the symptoms in a more magnified way, right?" (Rheumatologist)
b. "For the disability, I tell them that the lupus at that moment is inactive, but that there may be other things that are being associated at that moment, such as an anxious-depressive disorder, which is causing the symptoms to be more accentuated. And in this case, what I often do is to send him to the psychologist or to the family doctor, to see if they can give him a temporary leave of absence. For the disability I put what I see. In other words, if I see that [the lupus] is inactive, I say that it is inactive. There has to be a diagnosis for the disability. Pain as such is not a diagnosis." (Rheumatologist)
c. "There are people who come with social problems, with associated fibromyalgia, chronic fatigue or generalized pain, with lower level jobs, and when they discover they have lupus they blame everything on lupus. But the disease activity is practically nil. They may have a little bit of osteoarthritis associated with it. They blame it on lupus to get a disability or get a job upgrade or whatever. But it's really not so much the lupus that limits them as the rest of the [socioeconomic, family and work] conditions. It is true that within lupus there are some symptoms such as fatigue, it has been described. But of course, what a coincidence that the majority of lupus patients who have had severe lupus, who have then been controlled, but who have a good economic and family situation, do not complain so much about fatigue, which they may have, eh? They know that they have to dose themselves, adapt, and that does not detract from their happiness. On the other hand, it is the patients with the problems described who do complain." (Rheumatologist)
d. "And then there are the patients who are apparently well controlled, serologically, etc. but complain of two things, with some frequency. Of fatigue or asthenia, which for many is very limiting. Or of joint pain without objective arthritis or anything else. Or both. And they say, 'but if I am incapable of performing my functions, and they don't give me anything, put it in the report…'. 'It says on the report that you have lupus. It is already there. I can put that you had a flare-up of arthritis, but now we can't put that you have arthritis, because you don't have it. I can refer that you have arthralgias and asthenia, but serologically you are fine.' There are things about lupus that we don't know. There are certain manifestations, well… those who start with that tiredness, can't it have an origin in lupus? Nobody is going to deny it, nobody is going to confirm it. You give them corticosteroids and it doesn't go away, you give them biologics and it doesn't go away, etc. Is it related [to lupus]? Or is it something more, let's say, psychological in the sense that the impact that a chronic disease has on you and so on? We don't know. But of course, the evaluator, at the legal level, cannot quantify that, because otherwise everybody would say that he is too tired and he would be incapacitated. It is difficult to legislate. The law has to go on more objective things." (Rheumatologist)

progression to end stage renal disease.[18] Diagnostic delays have also been found to favor an accelerated accumulation of damage, a decrease in quality of life and fatigue, and an increase in mortality in a cohort spanning North and Latin America, Europe, and Asia.[8] Furthermore, a delayed diagnosis has been linked to an increase in health care utilization and flare rates in an American cohort.[7]

The mean self-reported time to diagnosis in our sample was much shorter—3 months—than those identified in the previous studies. This may be explained by several factors. First, our study calculated time to diagnosis since first doctor visit, while the rest started at symptom onset. Second, our study included only moderate or severe patients, which may be faster to diagnose than mild ones. Third, patients may have consulted doctors about symptoms much earlier but without these symptoms ever being attributed to SLE. Regardless, 53% of the patients perceived a delay in their diagnosis due to the large number of times they had visited their doctors. This suggests that to consider the impact of a delayed diagnosis, we should not only consider a certain timeframe, but also the frequency of consultations within that timeframe. A study with a British cohort found that patients with SLE attributable clinical features who were ultimately diagnosed with SLE consulted more frequently during the five years prior to their diagnosis compared to a control group.[4] Many of our patients also reported having consulted their doctors many times before diagnosis. And while it seems to be clear that a diagnosis delayed in time can have worse health outcomes for patients, this data suggests that a high number of visits before reaching a diagnosis also has negative consequences, impacting the emotional wellbeing of patients, fostering distrust towards the healthcare system, and increasing the economic burden of SLE.

Therefore, increasing awareness of SLE among HCPs may be a step towards reducing diagnostic delays and their consequences.[19] To this end, more qualitative studies understanding the SLE education needs of HCPs are needed.[3]

Several studies have drawn attention to the discrepancies between patient and physician assessment of SLE severity.[20–23] In a cross-sectional study with a Peruvian cohort, patients were found to assess disease activity higher than their HCPs due to patients scoring according to how they perceived SLE affected them rather than according to disease activity.[20] Another study reported that patients' predominant concerns focused on fatigue and function, while physicians' concerns centered on SLE-related organ complications. This study highlighted that the three highest

ranked patient concerns (fatigue, pain, and feeling worn out) were ranked significantly lower by physicians.[22] Our study also showed discrepancies between patient and physician assessment of disease severity, agreeing with the literature and providing new information for Spain.

Additionally, our study underlines the importance of pain and fatigue as symptoms prompting a discrepancy between patient and physician assessment, and argues that awareness of these and other symptoms, such as those resulting from cognitive dysfunction, is context dependent. In this way, our study has identified that cognitive dysfunction has a major impact on the QoL of those patients conducting mentally demanding jobs. In contrast, in a recent quantitative study with a Dutch cohort, cognitive dysfunction was found to be highly prevalent, but with a low impact on QoL.[24] We hypothesize that the discrepancy may be due to the importance of symptom awareness being context dependent. Further quantitative studies are needed to gauge whether the impact of cognitive dysfunction on patients is related to their contexts. If so, contexts should be taken into consideration and analyzed as a risk factor when evaluating cognitive dysfunction in patients with SLE.

The mismatch in the severity evaluation of SLE has real implications for the QoL of those patients who suffer from pain and fatigue but who do not show signs of disease activity. We have seen that the impact of these symptoms on QoL is context dependent, which is not to say that context causes these symptoms by worsening mental health, but rather, makes more salient the impact on their QoL. Nevertheless, our study shows that some HCPs do conceptualize unfavorable contexts as causing unexplained pain and fatigue due to worsening the mental health of patients. Such conceptualization can place a higher burden on patients, who are left not only without a solution to their problems, but also without validation from their HCPs. In a recent study, patients were found to desire to feel validated in their experiences by their HCPs, a desire that, if fulfilled, was perceived by patients to be positively associated with improvements in their condition.[25] In this sense, attributing SLE symptoms such as pain and fatigue to mental health problems caused by unfavorable contexts may contribute to the stigmatization of disadvantaged populations and may preclude the possibility of improving their QoL.

Consistent with the current literature, our study stresses that a lack of social awareness of SLE has a negative impact on patients' QoL, intensifying their sense of isolation, and worsening their emotional wellbeing.[26,27] Several studies have demonstrated that patients' QoL was compromised when lacking validation and support by their social network.[28–30] Trivialization and lack of understanding of SLE, as well as patient stigmatization by family, friends, and physicians, intensified patients' sense of isolation.[31] Few studies have analyzed the consequences of the lack of social awareness of SLE on intimate relationships. One study with a South African Black cohort drew attention to the concerns of women with SLE, who worried their partners would commit infidelity as a result of the esthetical and physical impact SLE had had on their bodies.[32] Another study focused on the impact of SLE on intimate relationships at the time of diagnosis, revealing patients' worry about the possibility of not finding a partner.[33] Our study showed that for several patients, these perceptions and worries continued to be present a long time after diagnosis, impacting their emotional wellbeing. Furthermore, several women in our study who had a partner complained about the lack of understanding and support received from them. This matches the work of Schattner and colleagues, who explain that many of the women they interviewed encountered skepticism on the part of their caregivers, consequently experiencing stress, shame, and disempowerment.[34]

To the best of our knowledge, there is not much literature regarding the topic of gender differences in SLE beyond the clinical impact they may have. Some studies have identified a gender bias in the diagnosis of SLE, with women frequently waiting two years longer than men to be diagnosed.[35] A study on arthritis in Latinas in the United States identified that women faced a greater burden and psychological distress than men when they were ill themselves or their spouse was ill, and that support providers tended to be other female family members, especially daughters.[36] Our study, conducted almost 30 years after the aforementioned one, seems to indicate that this gender bias in the experience of SLE is still valid for Spain today.

However, and in contrast to the literature, our study also highlights that many of the women interviewed felt understood and were happy with the support provided by their partners. Moreover, HCPs perceived that younger men were more involved as caregivers than older men. Further research is needed to explore whether a shift in male caregiver attitudes is occurring in Spain, as well as the implications it may have on SLE patients' experience and QoL.

Conclusion

According to patients and HCPs, lack of SLE awareness may delay diagnosis, considered not only in terms of a timeframe but also in terms of the frequency of medical visits. Continuing education for GPs and specialists is essential to reduce diagnostic delays. Our study has identified a mismatch between the severity evaluation of SLE by patients and HCPs. It has also argued that patients' contexts should not be perceived by HCPs as a causal factor for mental health problems magnifying symptoms. Increasing awareness of the living conditions of patients and the constraints they put on them may help overcome such perception. This would ensure that patients feel validated instead of blamed for the socioeconomic conditions they live in. Finally, our study has shown that lack of social

awareness of SLE has a negative impact on patients' QoL. To address it, it may be beneficial to create awareness campaigns and to involve family members in the treatment of SLE whenever possible. Overall, increasing awareness of SLE at these different levels may improve the lived experience of patients with SLE and their QoL.

Acknowledgments

We would like to thank all study participants for kindly sharing their experiences with us. We also extend our gratitude to the study coordinators, who ensured this study was smoothly executed.

Declaration of conflicting interests

The author(s) declared the following potential conflicts of interest with respect to the research, authorship, and/or publication of this article: RRR and CSM are employees of A Piece of Pie and have received research funding from AstraZeneca to conduct this study. JSH, MG, and NBR are employees of AstraZeneca. ERA has received honoraria from GSK. All other authors report no competing interests.

Funding

The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: This study was fully financed by AstraZeneca. As authors of the manuscript, AstraZeneca employees JSH, MG, and NBR have participated in the design of the study and the revision of the final manuscript.

ORCID iDs

Joaquín Borrás Blasco https://orcid.org/0000-0003-0248-4208
Tarek Carlos Salman-Monte https://orcid.org/0000-0002-4676-0174
Paloma Vela-Casasempere https://orcid.org/0000-0001-8566-5172
Jaime Calvo-Alen https://orcid.org/0000-0001-9378-8412
Mª Julia Barbado Ajo https://orcid.org/0000-0002-8097-5179
Raül Rubio Renau https://orcid.org/0000-0002-9881-3020
Marta Galvez-Fernandez https://orcid.org/0000-0003-1996-7425
Noemí Bahamontes-Rosa https://orcid.org/0000-0003-3035-6975
Joaquín Sánchez-Covisa Hernández https://orcid.org/0000-0002-6407-3669
Carlota Solà Marsiñach https://orcid.org/0009-0006-3833-5289

References

1. Salman-Monte TC, Fanlo Mateo P, Galindo Izquierdo M, et al. An online survey of the Spanish Lupus Patient Association (FELUPUS): patient perceptions and experiences. *Clin Rheumatol* 2023; 42: 1259–1265.
2. Lam NCV, Ghetu MV and Bieniek ML. Systemic lupus erythematosus: primary care approach to diagnosis and management. *Am Fam Physician* 2016; 94: 284–294.
3. Amsden LB, Davidson PT, Fevrier HB, et al. Improving the quality of care and patient experience of care during the diagnosis of lupus: a qualitative study of primary care. *Lupus* 2018; 27: 1088–1099.
4. Rees F, Doherty M, Lanyon P, et al. Early clinical features in systemic lupus erythematosus: can they be used to achieve earlier diagnosis? A risk prediction model: consulting behavior of SLE cases preceding diagnosis. *Arthritis Care Res* 2017; 69: 833–841.
5. Brennan KAM and Creaven AM. Living with invisible illness: social support experiences of individuals with systemic lupus erythematosus. *Qual Life Res* 2016; 25: 1227–1235.
6. Kernder A, Richter JG, Fischer-Betz R, et al. Delayed diagnosis adversely affects outcome in systemic lupus erythematosus: cross sectional analysis of the LuLa cohort. *Lupus* 2021; 30: 431–438.
7. Oglesby A, Korves C, Laliberté F, et al. Impact of early versus late systemic lupus erythematosus diagnosis on clinical and economic outcomes. *Appl Health Econ Health Pol* 2014; 12: 179–190.
8. Bruce IN, O'Keeffe AG, Farewell V, et al. Factors associated with damage accrual in patients with systemic lupus erythematosus: results from the Systemic Lupus International Collaborating Clinics (SLICC) Inception Cohort. *Ann Rheum Dis* 2015; 74: 1706–1713.
9. Carel H. Phenomenology and its application in medicine. *Theor Med Bioeth* 2011; 32: 33–46.
10. Desjarlais R and Throop JC. Phenomenological approaches in anthropology. *Annu Rev Anthropol* 2011; 40: 87–102.
11. Lipscomb M. Abductive reasoning and qualitative research: abductive reasoning. *Nurs Philos* 2012; 13: 244–256.
12. Saunders B, Sim J, Kingstone T, et al. Saturation in qualitative research: exploring its conceptualization and operationalization. *Qual Quantity* 2018; 52: 1893–1907.
13. Lateef A and Petri M. Unmet medical needs in systemic lupus erythematosus. *Arthritis Res Ther* 2012; 14: S4.
14. Al Sawah S, Daly RP, Foster S, et al. SAT0423 Understanding delay in diagnosis, access to care and satisfaction with care in lupus: findings from a cross-sectional online survey in the United States. *Ann Rheum Dis* 2015; 74: 812.3.
15. Ozbek S, Sert M, Paydas S, et al. *Delay in the diagnosis of SLE: the importance of arthritis/arthralgia as the initial symptom*. [Internet]. 2003 [cited 2023 Sep 12];Available from: DOI: 10.18926/AMO/32807.
16. Rúa-Figueroa I, López-Longo FJ, Calvo-Alén J, et al. Registro nacional de pacientes con lupus eritematoso sistémico de la Sociedad Española de Reumatología: objetivos y metodología. *Reumatol Clínica* 2014; 10: 17–24.
17. Riveros Frutos A, Casas I, Rúa-Figueroa I, et al. Systemic lupus erythematosus in Spanish males: a study of the Spanish Rheumatology Society Lupus Registry (RELESSER) cohort. *Lupus* 2017; 26: 698–706.
18. Faurschou M, Dreyer L, Kamper AL, et al. Long-term mortality and renal outcome in a cohort of 100 patients with Lupus Nephritis. *Arthritis Care Res* 2010; 62: 873–880.

19. Schlencker A, Messer L, Ardizzone M, et al. Improving patient pathways for systemic lupus erythematosus: a multistakeholder pathway optimisation study. *Lupus Sci. Med* 2022; 9: e000700.
20. Elera-Fitzcarrald C, Vega K, Gamboa-Cárdenas RV, et al. Discrepant perception of lupus disease activity: a comparison between patients' and physicians' disease activity scores. *JCR J. Clin. Rheumatol* 2020; 26: S165–S169.
21. Leong K, Chong E, Kong K, et al. Discordant assessment of lupus activity between patients and their physicians: the Singapore experience. *Lupus* 2010; 19: 100–106.
22. Golder V, Ooi JJY, Antony AS, et al. Discordance of patient and physician health status concerns in systemic lupus erythematosus. *Lupus* 2018; 27: 501–506.
23. Neville C, Clarke AE, Joseph L, et al. Learning from discordance in patient and physician global assessments of systemic lupus erythematosus disease activity. *J Rheumatol* 2000; 27: 675–679.
24. Monahan RC, Middelkoop HAM, De Voorde B-vanLJJ, et al. High prevalence but low impact of cognitive dysfunction on quality of life in patients with lupus and neuropsychiatric symptoms. *Arthritis Care Res* 2023; 75: 1017–1025.
25. Leung J, Ra J, Baker EA and Kim AHJ. Not having the real support that we need": patients' experiences with ambiguity of systemic lupus erythematosus and erosion of social support. *ACR Open Rheumatol* 2019; 1: 135–144.
26. Jordan J, Thompson NJ, Dunlop-Thomas C, et al. Relationships among organ damage, social support, and depression in African American women with systemic lupus erythematosus. *Lupus* 2019; 28: 253–260.
27. McElhone K, Abbott J, Gray J, et al. Patient perspective of systemic lupus erythematosus in relation to health-related quality of life concepts: a qualitative study. *Lupus* 2010; 19: 1640–1647.
28. Mazzoni D, Cicognani E and Prati G. Health-related quality of life in systemic lupus erythematosus: a longitudinal study on the impact of problematic support and self-efficacy. *Lupus* 2017; 26: 125–131.
29. Mazzoni D and Cicognani E. Problematic social support from patients' perspective: the case of systemic lupus erythematosus. *Soc Work Health Care* 2014; 53: 435–445.
30. Mazzoni D and Cicognani E. The problematic support scale: a validation among patients with systemic lupus erythematosus. *J Health Psychol* 2016; 21: 1711–1717.
31. Sutanto B, Singh-Grewal D, McNeil HP, et al. Experiences and perspectives of adults living with systemic lupus erythematosus: thematic synthesis of qualitative studies: living with SLE. *Arthritis Care Res* 2013; 65: 1752–1765.
32. Phuti A, Hodkinson B, Tikly M, et al. 'The feeling of not being entitled to something': fertility, pregnancy, and sexuality among women with systemic lupus erythematosus in South Africa. *Scand J Rheumatol* 2020; 49: 214–220.
33. Larsen JL, Hall EOC, Jacobsen S, et al. Being in a standstill-of-life: women's experience of being diagnosed with systemic lupus erythematosus: a hermeneutic-phenomenological study. *Scand J Caring Sci* 2018; 32: 654–662.
34. Schattner E, Shahar G and Abu-Shakra M. "I used to dream of lupus as some sort of creature": chronic illness as an internal object. *Am J Orthopsychiatry* 2008; 78: 466–472.
35. Nadel T. *Exploring the diagnostic journeys of women with systemic lupus erythematosus in New York City: a qualitative research proposal*, 2021. [cited 2023 Jul 17];Available from: https://academiccommons.columbia.edu/doi/10.7916/d8-x34j-fh04
36. Abraído-Lanza AF and Revenson TA. Coping and social support resources among latinas with arthritis. *Arthritis Care Res* 1996; 9: 501–508.