Preferences for diagnostic pathways and treatment choice in systemic lupus erythematosus: a patient-based discrete choice experiment

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Abstract

Objective

Starting from the unmet need of early diagnosis and treatment in systemic lupus erythematosus (SLE), the study aims to explore patient preferences in diagnostic pathways and treatment modalities. It seeks to integrate clinical priorities with patient perspectives, providing an optimal approach to SLE treatment that remains uncertain.

Methods

A discrete choice experiment (DCE) has been conducted to investigate whether patient preferences align while maintaining consistent attributes and levels, providing a direct assessment of relative preferences and hypothetical treatment approaches in SLE.

Results

DCE results demonstrated that obtaining an early diagnosis is the most crucial attribute for patients. Additionally, a multidisciplinary care team, capable of enhancing clinical outcomes and patient satisfaction, is essential, along with a clinical centre conveniently located within 30 minutes of the patient's home. Lastly, patients prefer the opportunity to reduce glucocorticoid to a dosage ≤5 mg/day, and eventually discontinue, aligning with the new EULAR recommendations, and favour oral and subcutaneous routes of administration for new course of treatment.

Conclusion

Patient preferences contribute to enhancing the care pathway for SLE by optimising disease management, with a focus on multidisciplinarity and psychological support.

Key words

systemic lupus erythematosus, patients' preferences, discrete choice experiment

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Introduction

Systemic lupus erythematosus (SLE) is a heterogeneous, inflammatory, chronic autoimmune disease, that affects multiple organ systems, including heart, lungs, blood vessels, liver, kidneys and nervous system. It is characterised by diverse clinical and serological manifestations and follows a relapsing-remitting course, presenting various complexities in both diagnostic procedures and therapeutic interventions (1, 2).

Signs and symptoms of SLE can range from mild to severe and may evolve over time, posing challenges in diagnosis. Typical manifestations of SLE include skin rashes, such as the well-known 'butterfly rash,' alopecia, arthritis, pleurisy, serositis, and lupus nephritis. Furthermore, the SLE condition is complicated not only by the variability of symptoms but also by flares (exacerbations) of varying severity, followed by periods of remission (2). Overall, these symptoms and manifestations can significantly reduce Health-Related Quality of Life (HRQoL) (2, 3).

Despite advances in medical science, there remain substantial unmet needs in the management of SLE. The variability and complexity of the disease complicate early diagnosis and treatment, which are crucial for preventing long-term damage and improving patient outcomes. Current treatment strategies, including the use of novel targeted biologic therapies in combination with chronic steroids and immunosuppressive drugs, have improved patient care over the past 50 years, yet the optimal approach to treatment remains uncertain (4). The current strategy, called "treat-to-target", is based on disease manifestations, comorbidities, and patient-specific factors and on the evaluation of the disease activity, characterised by strong variability in SLE patients (5, 6). The treatment goal is to achieve remission or maintain low disease activity (LDA), from the early stages of the pathology, aiming to prevent flares, minimise glucocorticoid (GC) dosage, and thereby reduce the risk of organ damage and unfavourable outcomes (7, 8).

However, the heterogeneity of SLE and the immune dysregulation underlying its pathogenesis lead to significant variability in patient responses to treatment, making it challenging to predict outcomes and often resulting in frustration for both clinicians and patients (4). Early diagnosis and treatment are critical in SLE management. If SLE is diagnosed within six months of symptom onset, patients experience milder symptoms, fewer hospitalisations, and lower flare rates compared to those with a longer diagnostic delay (9). Furthermore, achieving remission or low disease activity (LDA) within 6 months from diagnosis, and maintaining them for the subsequent 12 months, is associated with a reduced risk of early damage (10, 11). Despite these benefits, many patients experience delays in diagnosis and suboptimal treatment outcomes, highlighting a significant gap in meeting the needs of the SLE patient population. To address these unmet needs and improve patient outcomes, it is essential to incorporate patient preferences into the management of SLE. The clinical variability and unpredictability of flares in systemic lupus erythematosus (SLE) can diminish patients' sense of social support. Digital health interventions (DHIs) show promise in enhancing this support and should be further explored for SLE management. A study at the Washington University Lupus Clinic found that patients frequently use the internet to understand flares and symptoms, and desire more diverse and comprehensive digital resources. Therefore, integrating DHIs into SLE management could significantly improve patient outcomes by providing better information and fostering community support (12). Patient-centred care, which involves understanding and prioritising the preferences and values of patients in clinical decision-making, has been shown to enhance treatment adherence, satisfaction, and overall health outcomes.

Hence, beginning with data from the initial discrete choice experiment (DCE) conducted to assess physicians' preferences for diagnostic pathways and therapeutic features in SLE patients (13), our goal is to investigate whether patient preferences align while maintaining consistent attributes and levels in the discrete choice experiments (DCE). Diagnostic pathways in

the management of this disease are systematic, evidence-based protocols that guide healthcare providers through the diagnostic process, ensuring early, accurate, and comprehensive diagnosis, ultimately leading to better patient outcomes. In this context, DCEs are commonly used to measure the relative importance patients assign to treatment attributes, providing valuable insights into patients' perceptions on treatment decision-making (14). It has already been applied in order to assess preferences of patients affected by various chronic conditions, including systemic autoimmune diseases (14, 15).

By investigating whether patient preferences align with the attributes and levels identified in an initial DCE conducted to assess physicians' preferences for diagnostic pathways and therapeutic features in SLE patients (13), this study aims to bridge the gap between clinical practice and patient expectations. Understanding these preferences can help tailor treatments to better meet the needs of SLE patients, thereby improving HRQoL and clinical outcomes. Compared to other methods, a DCE excels in quantifying the relative importance of various attributes, pinpointing those that should be prioritised (16). This approach provides direct assessment of relative preferences and hypothetical treatment approaches, offering a robust framework for enhancing patient-centered care in SLE (17).

Materials and methods

Study design

This study was planned, conducted, analysed, and reported following the recommendations of Bridges JFP *et al*. "Conjoint Analysis Applications in Health – a Checklist" (18). The research questions of this study were:

a. Which features of the diagnostic-therapeutic pathway are more important for SLE patients?

b. Which are the features of pharmacological therapy for SLE that mainly drive patients' preferences?

c. Is the importance of each feature dependent on the following patients' characteristics: absence/presence of nephropathy, absence/presence of psychiatric disorders?

d. Concerning pharmacological therapy, which are the trade-offs between costs (in a broad sense, including side effects and need for glucocorticoids) and benefits?

The testable null hypothesis was that the attributes (and levels within attributes) chosen to describe diagnostic-therapeutic care paths and pharmacological therapies had equal importance so that the rejection of the null hypothesis would allow us to infer that some attributes are more relevant than others and that some levels attract the preferences of clinicians. The study was placed in the Italian context, where the National Health Service provides free and equal access for all citizens to all healthcare services, including primary, hospital and emergency care, visits, diagnostic procedures, and therapies, including biologics and other innovative drugs.

Given the above research questions, conjoint analysis was chosen as a suitable method to address them since it allows us to rank the attributes by relative importance, identify levels of attributes able to capture the preferences, and quantify the trade-offs between specific gains/losses of clinical relevance.

DCE attributes identification and levels definition

The choice of attributes and levels was made by a focus group. The choice of attributes and levels was made by a focus group. A board with eleven clinicians -experts in SLE- enriched by two SLE patients, representatives of a patients' association, was constituted. Concerning the DCE design for treatments, an attempt was made to maintain the same attributes and levels of the DCE study on clinicians (Table I). After three two-hours meetings of the focus group and thanks to the opinion and the experience of the two patient representatives, it was decided that some attributes/levels could have been kept unchanged with respect to the questionnaire administered to clinicians, others should have been reworded to be better understandable by patients (in italics in Table I), others should have been reformulated (in bold in Table I).In addition, whilst clinicians were asked to choose thinking about both a severe patient and a mild-moderate patient, patients were asked to choose thinking about themselves and thus, the levels used to characterise separately severe and mild-moderate patients in the DCE for clinicians were all used in the DCE for patients.

Concerning the DCE about care pathway, an almost completely different set of attributes and levels (with respect to that established for clinicians) was defined to reflect the patients' perspective (Table II).

DCE experimental design

The tasks were built as forced-choice between two randomly-generated profiles (see an example of a choice task in Supplementary Fig. S1). The Experts and Patients Board considered that choosing between more profiles could have confused the respondents and required more time. Even the possibility of opt-out answers was not considered potentially helpful, and according to answers gathered in a testing session, there was no need to avoid choosing one of the two options. Full profiles were presented since the number of attributes was a maximum of 7, and, according to a pilot survey on 10 respondents, patients showed not much difficulty in choosing one of two 7-item profiles.

The experimental design was generated through Sawtooth Software (Lighthouse Studio 9.14), a well-known and validated software that estimates unbiased, precise preference weights for all defined attribute levels. The Expert Board chose the attributes' levels to avoid impossible, illogical, or unrealistic combinations, thus there was no need to define prohibited pairs. The generated experimental design was tested, and a simulation confirmed that it was orthogonal and balanced (Suppl. file - Experimental Design Simulation). In consideration of the cognitive burden and of the needed attention required by patients with SLE, the number of choice tasks were set at 6 (see also the considerations about sample size below). Such number of stimuli was tested by 10 patients indicated by the Experts and Patients Board, who considered the questionnaire comprehensible and

Table I. Attributes and levels selected for the discrete choice experiment about therapy.

DCE design for clinicians (each of them asked to choose between two hypothetical profiles in 12 tasks, considering both severe and mild-moderate patients)			DCE design for patients (each of them asked to choose between two hypothetical profiles in 6 tasks, considering his/her condition)	
Attributes	Levels for severe SLE	Levels for mild-moderate SLE	Attributes	Levels
Disease activity (6 months *vs*. baseline)	-80 -60 -40	-80 -60 -40	Disease activity after 6 months compared to baseline	-80 -60 -40
Glucocorticoid dose at 6 months	2.5 mg/day 5 mg/day 7.5 mg/day	0 mg/die 2.5 mg/die 5 mg/die	Cortisone dose after 6 months	0 mg/die 2.5 mg/die 5 mg/die 7.5 mg/die
Risk of serious infections at 12 months	1% 2% 5%	0.5% 1% 2.5%	**Risk of appearance of at least one side effect after 12 months of treatment (*e.g.* osteoporosis, maculopathy, infections requiring hospitalisation and/or intravenous antibiotics, cardiopulmonary worsening)**	0.5% 1% 2% 5%
Probability of organ damage progression at 12 months	5% 10% 20%	2.5% 5% 10%	**Probability of worsening after 12 months of treatment**	2.5% 5% 10% 20%
Route of administration	oral subcutaneous IV	oral subcutaneous IV	Route of administration	oral subcutaneous IV
Onset of action	12 weeks 16 weeks 24 weeks	12 weeks 16 weeks 24 weeks	Time to achieve a satisfactory clinical response to treatment	12 weeks 16 weeks 24 weeks
Patient Global Assessment	30 40 50	10 20 40	Patient Global Assessment	30 40 50

feasible. In order to elicit preferences, respondents were instructed about DCE before choice-tasks. Patients were contacted through the website and social media (Facebook, Instagram, Telegram) of the patient association named *Gruppo LES Italiano Organizzazione di Volontariato*, which published a series of posts containing a brief description of the project and a direct link to the DCE questionnaire available online in the software platform. The web-based mode of administration was chosen since it results in a feasible and even pleasant view of the questionnaire, in a great control of data gathering and in a suitable check of dataset. Besides answers to DCE tasks, patients were asked to provide information about birth year, SLE diagnosis year, sex and to answer to the following questions: 'Have you been diagnosed with nephropathy?' 'Have you experienced any neuropsychiatric disorders?' 'Do you have a platelet deficiency (less than 20 thousand)?' 'Have you been diagnosed with vasculitis?' 'Have you been diagnosed with antiphospholipid syndrome?' 'Have you been diagnosed with haemolytic anaemia?' 'Do you take or have you taken any of the following medications: cyclophosphamide, rituximab, mycophenolate, belimumab?' 'In the last month was the average dose of cortisone greater than 7.5 mg?'.

Sample size

As to sample size calculation, firstly, Orme's rule-of-thumb was applied. The minimum sample size necessary for the DCE was computed as $n \geq 500*c/ta$, where n is the number of respondents, c is the maximum number of levels per attribute (in our study, c=4), t is the number of tasks (in our study t=6), and a is the number of alternatives (in our study, a=2), resulting in n=167 patients. However, according to a simulation performed with Sawtooth Software Lighthouse Studio (9.14.2), with 200 responders the maximal standard error resulted equal to 0.064 (considering the most demanding DCE questionnaire, *i.e.* that with the highest number of attributes/levels) and, since a general guideline is to achieve standard errors of 0.05 or smaller for main effect utilities, sample size was raised up to 300 patients (maximal standard error=0.051).

The project can be considered an opinion poll and, according to Italian law, it does not require approval by an Ethical Committee or Institutional Review Board. No sensitive information was requested from the participating patients who, in any case, after having read the presentation of the survey and the instructions for completing it, gave their informed consent for the collection and analysis of data for the purposes of the study.

Statistical analysis

To measure preference weights, we used the Choice-Based-Conjoint analysis

Hierarchical Bayes procedure, recommended and provided by Sawtooth Software (CBC/HB algorithm). According to the Bayesian approach, the *a posteriori* probability combines the probability that a respondent will select a specific concept in a choice task given a specific set of utilities (likelihood) and the probability that the respondent's utilities are consistent with the pattern of utilities observed in the rest of the respondents (sample density acting as *a priori* probability). Parameter estimates from the model can be interpreted as relative preference weights (PW) indicating the average relative preference for one attribute level over other attribute levels. The mean preference weights have been used to calculate each attribute's relative importance (RI).

Table II. Attributes and levels selected for the discrete choice experiment about diagnostic-therapeutic care pathway.

	Label
Time from symptoms to diagnosis (diagnostic delay)	1 year 6 months 4 weeks
Specialisation of the referring doctor	rheumatologist immunologist team
Frequency of checks after diagnosis	First at 1 month, second at 2 months First at 45 days, second at 3 months First at 3 months, then at 6 months
Availability of other professional figures	None psychologist nurse-physiotherapist
Type of clinical centre	territorial spoke hub
Distance from home to clinical centre	1/2 hour 1 hour 2 hours
Waiting time from indication (if any) to the start of treatment with a biological drug	6 weeks 4 weeks 2 weeks

Results

The study was performed from October to November 2023 as a survey including 410 patients with Systemic Lupus erythematosus (SLE). The median age of patients was 50 years (min=18, max=80), 391 (95%) females. The results of the patient preferences were discussed in the board after a preliminary data analysis on about half of the recruited patients and two times after the planned number of respondents was reached.

To check the attention of the respondents and the reliability of their choices, one fixed DCE question was inserted among the randomly generated pairs. This choice task was constructed in a way that there would be no doubt about the choice, since one profile was consistently and strongly better than the other. Fifty patients chose the "wrong" profile and, in a sense, they could be defined "unreliable respondents". Findings are based on the whole available dataset (n=410 for DCE on treatments, n=279 for DCE on care pathway) in order to include all available patients but also, as sensitive analysis, on the subset of "reliable respondents" (excluding those who chose the "wrong" profile).

DCE about care pathway

Concerning care pathway, relative importances of each attribute are represented in Fig. 1A. "Time from symptoms to diagnosis (diagnostic delay)" is considered the most important attribute (RI=22%; 95% CI=20.9–23.6%), followed by "Availability of other professional figures" (RI=17%; 95% CI=16.3–17.8%). Patients gave less relevance to "Waiting time from indication (if any) to the start of treatment with a biological drug" (RI=10%, 95% CI=9.8–10.9%), "Frequency of checks after diagnosis" (RI=11%; 95% CI=10.4–11.6%), "Type of clinical centre" (RI=12%; 95% CI=11.5–12.8%). The importance of the other attributes was not significantly above or below the value expected in case of equal distribution (100/7=14.3%).

Looking at utilities for specific levels, the optimal care pathway (Fig. 1B) comprises mainly: a 4-week diagnostic delay, a small distance (30 min) from home to clinical centre, the availability of a psychologist and a hub clinical centre. On the other hand, SLE patients considered as major disutilities a diagnostic delay of 1 year, a time of 2 hours to reach the clinical centre and the lack of any healthcare professionals besides clinicians (Table II).

No difference emerged between subgroups defined according to presence/absence of renal and/or of neuropsychiatric involvements (Suppl. Fig. S2-S3).

DCE about therapy

As graphically represented in Fig. 2A, the first attribute in order of importance in orienting preferences for features of therapies for SLE patients was the "Probability of worsening after 12 months of treatment" (RI=21.7%; 95% CI=20.9–22.5%). At the second place, the attribute "Glucocorticoid dose after 6 months" (RI=18.9%; 95% CI=18.1–19.7%), followed by "Route of administration" (RI=15.4%; 95% CI=14.6–16.3%). The other attributes are not much relevant for patients and particularly "Time to achieve a satisfactory clinical response to treatment", which showed the least level of importance (RI=9.4; 95%CI=9.0–9.9%).

The preference weights are represented in Fig. 2B. They indicate the relative strength of utility for each attribute level, with more positive numbers indicating higher utility, more negative numbers higher disutility. By examin-

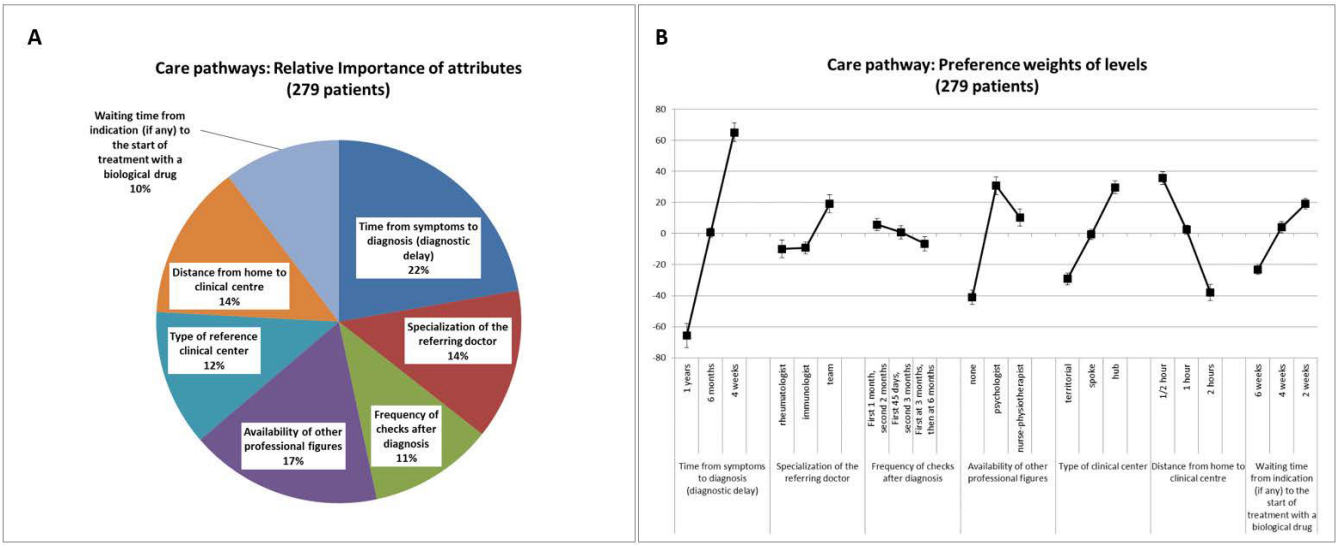

Fig. 1. Integrated Care Pathway for patients with SLE: relative importance of the attributes (**A**) and preferences for attribute levels (**B**).

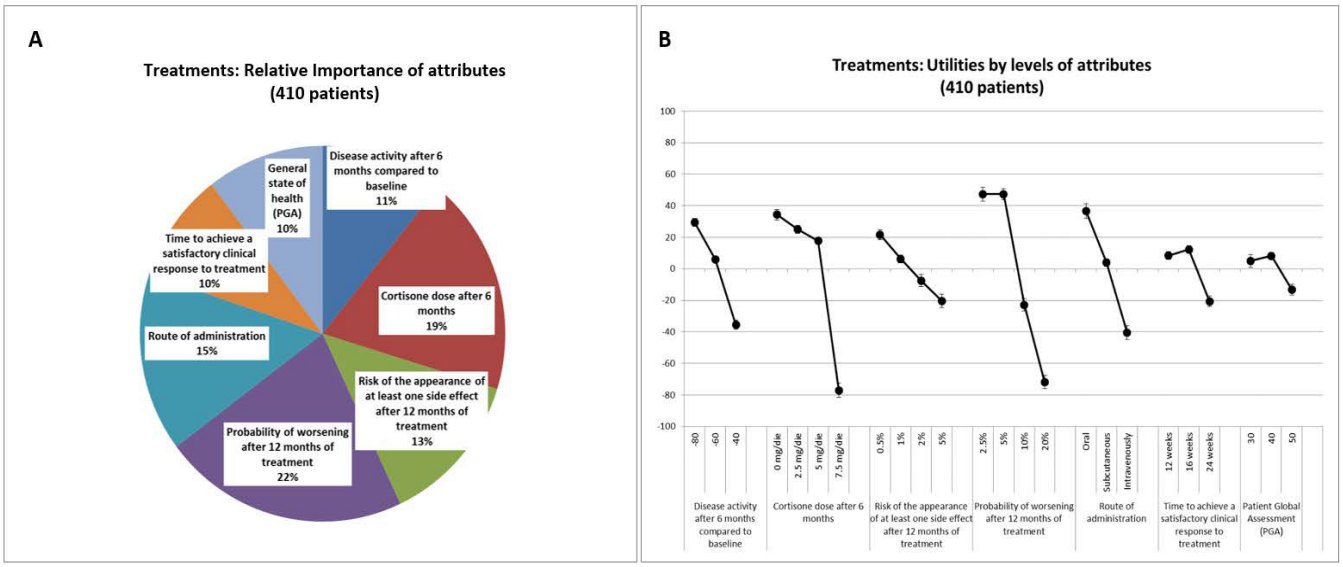

Fig. 2. Therapy for patients with SLE: relative importance of the attributes (**A**) and utilities by level of attributes (**B**).

ing the patterns of each attribute, the following considerations can be made. To limit the probability of worsening represents the first target of patients, who consider similarly beneficial the levels of 2.5% and 5%. Oral intake was largely preferred. With regards to glucocorticoid dose after 6 months since the start of the therapy, only a dose of 7.5 mg/day is considered a disutility and small differences were observed among 0, 2.5 and 5 mg/day (all in the "utility" area above the 0-reference line). The differences across levels of the other attributes are smaller. However, it may be worth to note that: only intra-venous via is considered a disutility among modalities of administration and only a 24-week delay a disutility for the onset of action.

No difference emerged between subgroups defined according to presence/absence of renal and/or neuropsychiatric involvements (Suppl. Fig. S4-S5).

A trade-off analysis was also performed. Patients would accept intravenous administration as long as it involves a reduction in the cortisone dosage from 7.5 to 5 mg/day. In turn, the utility increase (94.7) associated to this cortisone dosage reduction exceeds the utility increase attributed by patients to the reduction of the "probability of worsening after 12 months of treatment" from 10% to 5% (70.2) (Suppl. Fig. S6).

Discussion

Several previously published studies highlighted the unmet need for a thorough understanding of the multidimensional implications of SLE in both the short and long term. This discrete choice experiment (DCE), alongside the one involving clinicians (13), aids in tailoring the approach at each stage of the disease trajectory and evaluating the effectiveness of novel medications based on the direct experiences of patients.

Importantly, clinicians are aware that five main themes summarise the experi-

ences of living with SLE: experiencing waves of emotions due to the unpredictable nature of the disease, trying to live an ordinary life, listening to and obeying the body's limitations, reviewing my life projects and dealing with future uncertainties (19). These themes, by interacting with each other, suggest that living with SLE is a multifaceted and complex experience, posing challenges and emphasising social aspects. SLE has a negative impact on patient experiences, influencing multiple dimensions of their daily lives, with fatigue and pain emerging as the most prevalent symptoms. Living with SLE demands that patients alter their life goals and navigate a continuous state of uncertainty (19).

According to the results of the DCE herein reported, the authors were able to make significant statements about patient quality of life by integrating the most important goals for clinicians and the most important preferences for patients. To the best of our knowledge, this is the first patient-based DCE on SLE, where patients actively selected their preferences. The study's added value lies in the particular determination of diverse options by expert clinicians in the field of SLE. Thus, this methodological approach enables the optimal integration of clinician priorities with patient preferences.

The first notable aspect emerging from this DCE is that diagnostic delay is the most crucial attribute. This aligns with what clinicians also stated in their DCE (12). Obtaining an early diagnosis of SLE in the initial stages is, therefore, imperative when symptoms may be more subtle and non-specific, rendering the diagnosis more challenging. Timely diagnosis of SLE is essential to establish early and proper management. Early management of the disease is indeed crucial to prevent complications, damage accrual and enhance clinical outcomes. Accordingly, this first aspect clearly correlates with the selection of a diagnostic delay of 4 weeks as the major patients' preference. The SLE Risk Probability Index (SLERPI) was published in 2021, which focuses on the clinical characteristics of patients with suspected SLE and uses a simple algorithm for early recognition of the disease. It has been recently applied and compared with different classification scales, showing its usefulness in the early diagnosis of SLE, with good correlation and good sensitivity (20).

The second aspect that emerged from this study is the "Importance of a multidisciplinary care team able to improve clinical outcomes and patient satisfaction", as recently demonstrated by the results of a randomised controlled trial conducted in China by Le Zhang *et al*. (21). In the expert opinion expressed by Fanouriakis *et al*., the importance of having a multidisciplinary team in the care of patients with SLE is emphasised, particularly in cases of renal involvement (22). Moreover, Giorgio Galoppini *et al*. proposed a multidisciplinary (MD) approach as the optimal strategy for optimising care in patients with SLE. This approach demonstrated a positive impact on pregnancy-related complications and disease flares while improving the psychological impact of SLE (23). The importance of having a psychological support has been demonstrated also by Petrocchi *et al*. (19). Counselling and psychoeducational interventions have been reported to hold potential value as adjunctive treatments for patients suffering from the chronicity and unpredictability of the disease. These factors have a psychological impact on planning both short- and long-term aspects of their lives (19). Lupus Clinics are growing worldwide, and they offer a model of care by a multidisciplinary team of experts working in close partnership with community physicians and patients, addressing the need to increase clinical services and fast access to high-level care for lupus patients.

In terms of care pathway, DCE results highlight the third aspect, that is the importance of the clinical centre's close proximity to the patient's home, preferably within 30 minutes of distance from home. Patients prefer care centres that are easily accessible within a short distance, regardless of the type of centre. For this reason, a well-structured network of hub and spoke centres is necessary, seamlessly integrated to manage varying levels of care complexity among different centres. A concrete example is the European Reference Networks (ERNs), launched by the European Commission to address the main challenges related to SLE and other rare and complex diseases. These are virtual networks involving healthcare providers (HCPs) across Europe, offering patients the best expertise and facilitating the timely exchange of life-saving knowledge through healthcare professionals, with a focus on ensuring that knowledge travels more efficiently than patients (24). The management of SLE in Europe has been significantly enhanced by the ERNs, facilitating the pooling of expertise and resources across member states, ensuring patients receive timely access to specialised treatment and cutting-edge medical knowledge. In the context of rare connective tissue and musculoskeletal diseases, the ReCONNET infrastructure aims to bring together patients, clinicians, and other crucial stakeholders to collaborate and work towards improving the lives of individuals affected by diseases such as SLE. Similar studies could be replicated at the European level in order to increase the harmonisation of care of lupus patients.

The fourth aspect important for SLE patients is the opportunity to reduce glucocorticoids/prednisone to a dosage ≤5 mg/day, in accordance with the new EULAR recommendations (25). Additionally, there is a preference for decreasing the likelihood of clinical worsening after one year of treatment. Therefore, patients are aware of being affected by a chronic, long-lasting disease and, consistently with that, the attribute "Time to achieve a satisfactory clinical response to treatment", showed the least level of importance. Reasons for non-adherence were complex and multifaceted; moreover, among the most recognised reasons for non-adherence, two of them are healthcare-related (including poor information about the prescribed medications or the disease), and disease-related (including lacking acceptance of a chronic illness or perceived disease quiescence), thus pointing out the importance of communication between healthcare professionals and patients (26).

The fifth aspect, deemed essential by patients, is related to the route of administration for therapies. As expected, oral and subcutaneous routes are preferred. However, the potential clinical advantage of a glucocorticoid-sparing therapy outweighs the disadvantage of intravenous administration, as patients are already aware. This is true also for patients reporting of suffering of severe SLE, *i.e.* with self-reported renal or neuropsychiatric involvement, and for diseases other than SLE, as reported by Finckh *et al*. (27). For all these reasons, regardless of the specific organ manifestations that require differentiated therapeutic approaches, SLE is recognised by patients as a systemic autoimmune disease that necessitates a comprehensive management approach. Interventions leading to overcome possible barriers to access to reference centres for providing the optimal treatment approach independently from the route of administration are then reinforced.

This DCE study has some limitations. First, the potential patients' possible misunderstanding of attribute importance and its relative selection bias could be influenced by voluntary participation in the study, which cannot guarantee the actual diagnosis of the patient. Patients who voluntarily participated may systematically differ from those who did not, potentially impacting the results. However, the analysed sample does not show differences between patients with more severe manifestations, including nephropathy and/or neuropsychiatric SLE, and those without. Second, patients did not have the option to choose alternative responses to those proposed by clinicians. This was intended to facilitate the comparison between patients and physicians, as preliminarily reported by Piga *et al*. (13). Third, significant imbalances among the choices were not observed, and there was a lack of data on the representativeness of the various Italian regions.

This first DCE study, involving patients, supports clinicians in achieving the goals outlined in the latest EULAR recommendations for SLE, particularly in reducing glucocorticoid dosage and minimising disease damage. Patient preferences contribute to improving the care pathway by optimising disease management, emphasising multidisciplinary and psychological support, and the integration of hub and spoke centres within the international framework of ERN networks. The application of significant results obtained by this study to other contexts, supported by qualitative and longitudinal data, would further expand its implications.

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