







# Experiences and daily limitations of people with systemic lupus erythematosus

## Vivências e limitações cotidianas de pessoas com lúpus eritematoso sistêmico

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### ABSTRACT

**Objective:** to analyze perceptions of people with lupus regarding psychosocial impacts and daily limitations. **Methods:** qualitative, interpretive study conducted in a rheumatology outpatient clinic of a university hospital in Northeastern Brazil. The convenience sample was defined by saturation. Data were collected using a sociodemographic questionnaire and semi-structured interviews. The corpus was analyzed by Descending Hierarchical Classification using IRAMUTEQ and interpreted through Reflexive Thematic Analysis. **Results:** forty-two participants were included, predominantly mixed-race women aged 25–30 years, married, with children. Five thematic classes were identified: coping and adaptation; knowledge and diagnosis; physical manifestations and symptoms; access barriers and social support; and experiences with the healthcare system and medications. Emotional distress, isolation, and uncertainty were associated with chronic pain, fatigue, and functional limitations. Difficulties in accessing consultations, tests, and medications were reported, as well as weaknesses in institutional support. Coping strategies included spirituality, self-care, and support networks. **Conclusion:** lupus impacts extend beyond the biological dimension, involving psychological distress, social limitations, and structural barriers. **Contributions to practice:** findings support nursing interventions focused on psychosocial assessment, mental health screening, and psychoeducational strategies for individualized care.

**Descriptors:** Nursing; Lupus Erythematosus, Systemic; Mental Health; Autoimmune Diseases.

### RESUMO

**Objetivo:** analisar as percepções de pessoas com lúpus sobre os impactos psicossociais e limitações no cotidiano. **Métodos:** estudo qualitativo, interpretativo, realizado em ambulatório de reumatologia de hospital universitário no Nordeste brasileiro. A amostra foi não probabilística por conveniência, definida pelo critério de saturação. A coleta ocorreu por questionário socio-demográfico e entrevistas semiestruturadas. O *corpus* textual foi analisado por Classificação Hierárquica Descendente com auxílio do IRAMUTEQ e interpretado pela Análise Temática Reflexiva. **Resultados:** participaram 42 pessoas, predominantemente mulheres pardas, entre 25 e 30 anos, casadas e com filhos. Identificaram-se cinco classes temáticas: enfrentamento e adaptação à doença; conhecimento e diagnóstico; manifestações físicas e sintomas; barreiras de acesso e suporte social; e experiência com o sistema de saúde e medicamentos. Evidenciaram-se sofrimento emocional, isolamento e incerteza associados à dor crônica, fadiga e limitações funcionais. Relataram-se dificuldades de acesso a consultas, exames e medicamentos, além de fragilidades no suporte institucional. Também emergiram estratégias de enfrentamento, como espiritualidade, autocuidado e redes de apoio. **Conclusão:** os impactos do lúpus ultrapassam a dimensão biológica, envolvendo sofrimento psíquico, limitações sociais e barreiras estruturais. **Contribuições para a prática:** subsidiam intervenções de enfermagem voltadas à avaliação psicossocial, rastreamento em saúde mental e estratégias psicoeducativas para cuidado individualizado.

**Descritores:** Enfermagem; Lúpus Eritematoso Sistêmico; Saúde Mental; Doenças Autoimunes.

## Introduction

Systemic Lupus Erythematosus (SLE) is a chronic, inflammatory, autoimmune disease of multifactorial etiology, characterized by multisystem manifestations and an unpredictable clinical course<sup>(1)</sup>. In addition to its organic repercussions, it is also associated with significant psychosocial impacts, including depressive symptoms, anxiety, cognitive changes, and functional impairment<sup>(2)</sup>.

Factors such as stress, socioeconomic difficulties, and limited social support may intensify disease flares and worsen the quality of life of this population. In this context, self-care interventions, structured social support, and psychoeducational strategies emerge as relevant resources to promote treatment adherence and symptom management<sup>(3-4)</sup>. However, even during periods of clinical remission, people with SLE often experience persistent symptoms, such as pain, fatigue, and sleep disturbances. These physical manifestations are intertwined with subjective dimensions, making the identification and categorization of psychological symptoms a clinical challenge<sup>(5)</sup>. Despite this complexity, these aspects are key determinants of overall well-being and require management that goes beyond the biological dimension.

A high prevalence of psychological distress in this population is recognized<sup>(2-5)</sup>, and studies often prioritize clinical indicators and quantitative outcomes. In this regard, it is important to expand approaches that emphasize the subjective dimensions of illness, particularly in understanding the daily experience of SLE from a qualitative perspective in the Brazilian context. By centering the narratives of this population, this study seeks to deepen knowledge about the subjective dimension of chronic illness, contributing to the debate on the psychosocial impacts of autoimmune diseases and to strengthening nursing practices that are more responsive to the experiences of this population.

Considering that chronic illness involves identi-

ty, emotional, and social processes, this study is based on the premise that understanding the perceptions and meanings attributed to living with SLE may inform care practices that are more responsive to psychosocial dimensions. In this context, the following question is posed: What are the perceptions of people with SLE regarding psychosocial impacts and daily limitations? Therefore, the study aims to analyze perceptions of people with lupus regarding psychosocial impacts and daily limitations.

## Methods

### Study design

This is a qualitative study of an interpretive nature, conducted in the rheumatology outpatient clinic of a university hospital in Northeastern Brazil. To ensure methodological rigor, the Consolidated Criteria for Reporting Qualitative Research (COREQ) protocol was used to structure both the study and the report.

### Population and sample

The eligible population consisted of individuals diagnosed with SLE who were followed at the aforementioned outpatient clinic between April 2024 and May 2025. Individuals aged 18 years or older, of both sexes, receiving regular follow-up at the service and with preserved cognitive function allowing verbal interaction were included. All participants formally consented to participate and completed the interview in full.

The population comprised all patients diagnosed with SLE treated at the hospital. The sample was nonprobabilistic by convenience. The sample size was defined by the criterion of theoretical saturation, understood as the point at which new statements no longer added relevant elements to the analytical categories, with stability observed in meanings and lexical classes<sup>(6-7)</sup>.

## Data collection instrument

Data were collected using a sociodemographic form and a semistructured interview guide, administered in person in a private office at the outpatient clinic to ensure privacy and confidentiality of information. Interviews were conducted by previously trained researchers and audio recorded on a digital device with participants' consent.

The guide included the following questions: How long ago were you diagnosed with SLE? What do you know about lupus? How do you perceive lupus in your life? What does mental health mean to you? How would you describe your emotional experience of living with lupus? What has your treatment follow-up routine been like? What do you highlight about your care process and your relationship with treatment?

The study is grounded in an interpretive epistemological approach of a subjective nature, based on the understanding that the reality of living with SLE is constructed from individuals' singular experiences within their sociocultural contexts. A qualitative approach was adopted to enable an in-depth understanding of the meanings attributed by participants to their perceptions of psychosocial impacts and daily limitations resulting from the condition.

Data collection occurred without prior contact between researchers and participants. Initially, the research team introduced themselves, explained the objectives of the study, and formally invited participation. After reading and signing the Informed Consent Form, individual interviews were conducted.

## Data analysis

Qualitative analysis was performed with the support of the Interface de R pour les Analyses Multidimensionnelles de Textes et de Questionnaires (IRAMUTEQ) software, through the categorization of textual elements obtained from verbatim transcription of the interviews. Each transcribed text composed a corpus, defined as the set of all texts analyzed.

For this study, Descending Hierarchical Classification was used, allowing lexicographic analysis of the textual material by grouping words semantically according to their meanings for subsequent identification of thematic classes<sup>(8)</sup>.

The data were also subjected to Reflexive Thematic Analysis, following six phases ranging from familiarization with the material to the production of the final report, enabling in-depth interpretation and the construction of thematic categories<sup>(9)</sup>. In this process, IRAMUTEQ was used as a complementary tool for corpus processing and data organization, while reflexive analysis remained the central axis of interpretation.

For the presentation of results and to preserve anonymity, participants were identified by alphanumeric codes composed of the letter "P" (participant), followed by the number corresponding to the chronological order of the interviews.

## Ethical aspects

The study followed the criteria established by Resolution 466/2012 of the National Health Council, which regulates research involving human subjects. All participants had access to the Informed Consent Form as a prerequisite for voluntary participation in the study. The research project was submitted to the Research Ethics Committee of the Hospital Universitário Lauro Wanderley, under approval number 6,875,655/2024 and Certificate of Presentation for Ethical Consideration number 79360624.5.0000.5183.

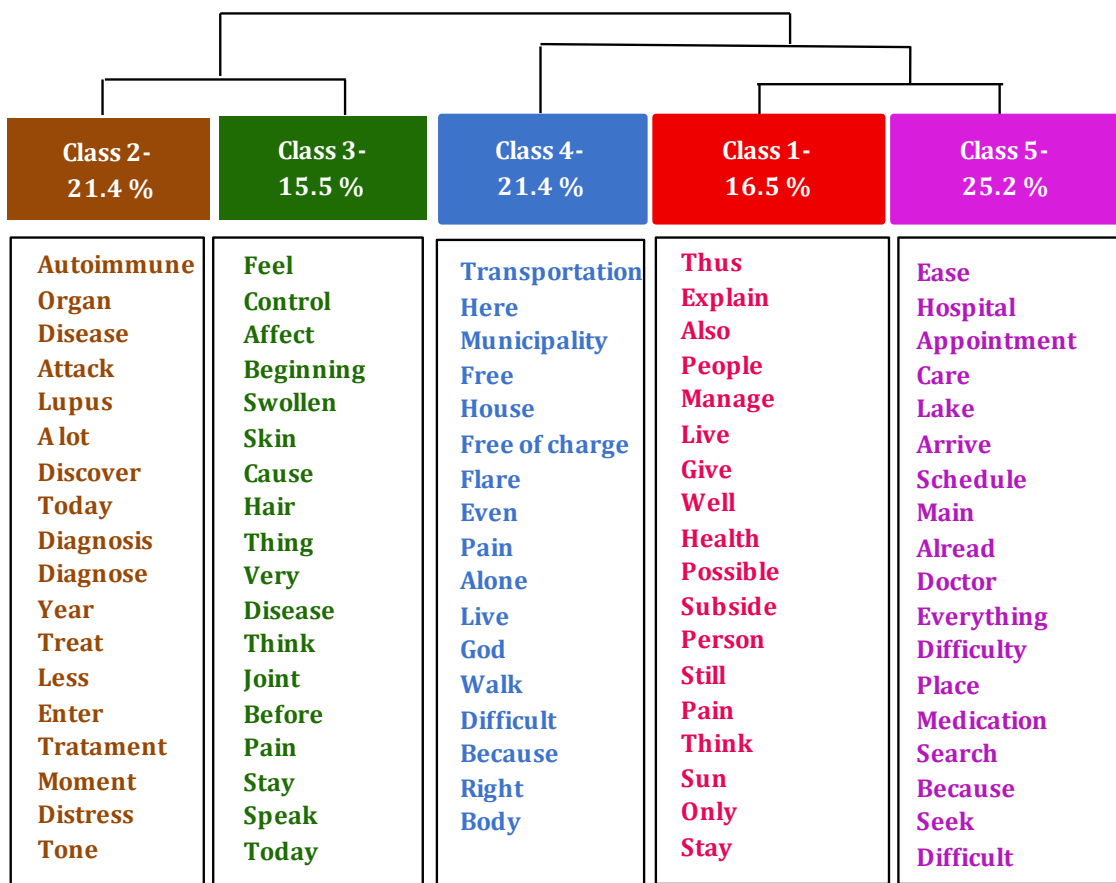
## Results

A total of 42 individuals participated in the study, all aged 18 years or older, interviewed at the rheumatology outpatient clinic of a university hospital in Northeastern Brazil. Regarding sociodemographic characteristics, there was a predominance of women (92.3%), heterosexual individuals (97%), aged between 25 and 30 years (17.3%), mixed-race individuals

(60.7%), married (39.9%), and with children (72%). Religious diversity was observed, with a higher frequency of Catholics (52.2%) and Evangelicals (24.5%).

The lexical analysis of the content obtained using the IRAMUTEQ software showed an analytical corpus consisting of 113 text segments (TS), of which 103 were retained, representing 91.1% of the analyzed content, a value that reflects high internal consistency and thematic cohesion in the material.

Figure 1 presents a dendrogram in vertical format, in which the active forms contained in the TS associated with each class are indicated. Thus, it is observed that the first partition of the corpus gave rise to Class 5 (representing 25.2% of the material), the second partition separated Class 1 (16.5%) and Class 4 (21.4%), and finally, the third partition separated Class 2 (21.4%) and Class 3 (15.5%). Therefore, Class 5 has the highest representativeness in the corpus.



**Figure 1** – Dendrogram of Descending Hierarchical Classification. João Pessoa, PB, Brazil, 2026

The lexical analysis allowed the identification of five thematic classes that express perceptions of psychosocial impacts and daily limitations. The classes were named based on an exhaustive reading of the processed corpus and the application of reflexive thematic analysis, which enabled the interpretation of meanings and the structuring of findings into categories that reflect the experience of illness.

**Class 1 – Coping and adaptation to the disease**

This class reflects how individuals deal with lupus, seeking to understand, adapt, and achieve well-being despite the challenges that include pain and the limitations imposed by the disease. This condition is directly related to the mental aspect of coping: *No one is able to cure or improve lupus; they only seek medications that relieve*



The graphical dimension of the lexical analysis highlights the prominence of the terms “medication” and “flare” as structuring elements of the narratives, followed by “organ,” “control,” “disease,” and “autoimmune,” indicating that the perceptions of people with lupus are centered on the disease as the core of their experiences.

It is observed that the presence of words that qualify these perceptions, such as “depression,” “sad,” “tired,” and “control,” reflects the complexity of the impacts of lupus on the lives of these individuals. This visual organization represents the perceptions of people with lupus as a dense network of suffering that merges aspects inherent to the disease with the social context (“hospital,” “work,” “free”), demonstrating that their experiences extend across key spaces of socialization, as if they were restricted or only permitted by the disease.

The correlation between the dendrogram and the word cloud suggests that lupus is experienced as a biopsychosocial phenomenon. While the healthcare system focuses on “medication” and “appointments,” the patient’s lived world is marked by “fatigue,” the search for “control,” and the fear of “isolation.” Therefore, treatment success depends not only on pharmacological effectiveness but also on the ability of institutions to provide support that encompasses mental health and facilitates access to patients’ rights.

## Discussion

The findings reveal that SLE extends beyond the biomedical dimension, constituting a complex experience shaped by emotional, social, and structural factors. The predominance of women reaffirms the gendered nature of the disease, requiring an intersectional analysis that considers social inequalities and specific vulnerabilities.

Coping did not represent a return to a previous state of normality but rather the construction of new ways of living. Resilience emerged as an active process of existential reorganization. Spirituality, in turn, func-

tioned as a coping strategy and a source of meaning in the face of uncertainty regarding the clinical course<sup>(10)</sup>.

Psychological distress was associated not only with physical symptoms but also with loss of autonomy and social invisibility. In productivity-oriented societies, living with a chronic illness implies a risk of symbolic and social marginalization. Structural difficulties in accessing medications and services highlight persistent inequities in the healthcare system. Such barriers increase suffering and compromise treatment adherence, reinforcing the need to strengthen care networks.

In this context, Nursing plays a strategic role in integrating clinical management and psychosocial support through practices such as active listening, health education, and interventions aimed at promoting autonomy.

Class 1, related to living with the disease and coping, highlighted the embodied nature of illness. The disease was experienced not only as a biological condition but also as a disruption of daily life and a challenge to self-care. In line with other findings, recurrent symptoms and unpredictable flares reinforced the limiting nature of chronic illness and required continuous reorganization of these individuals’ lives<sup>(11)</sup>. This class reinforces coping and adaptation to the disease in daily life. It is observed that the attempt at reorganization expressed by participants does not imply a return to the pre-diagnosis condition but rather the construction of new ways of living with the disease, evidencing a continuous adaptive process.

The adverse effects of medications, such as immunosuppressants and corticosteroids, were also reported in an ambivalent manner because, although considered essential for the clinical control of autoimmune diseases, they were associated with physical and emotional discomfort. This duality between therapeutic necessity and suffering has been described in recent literature, highlighting how the experience of pharmacological treatment may contribute to processes of medicalization and vulnerability, especially in the context of the female body<sup>(12)</sup>.

Furthermore, resilience emerged as a hallmark of the narratives in Class 1, associated with hope, persistence, and the reconstruction of life projects. This resilience does not refer to a return to a previous normality but to the creation of new ways of living with lupus. This perspective aligns with findings on chronic pain, which highlight the importance of active coping, self-care, and adaptation in the face of limitations imposed by the condition, promoting meaningful changes in daily life and the incorporation of new strategies to cope with the persistence of the disease<sup>(11)</sup>.

Class 2, related to knowledge and diagnosis of lupus, highlighted terms indicating that patients had knowledge about SLE and the impact of diagnosis. The findings suggest that, although there is a basic understanding of the disease, the moment of diagnosis remains permeated by fear and insecurity, indicating gaps in communication and informational follow-up throughout treatment. This underscores the need for health education and informational support for patients, strengthening health literacy.

Some studies indicate that concepts of self-care and autonomy facilitate the adoption of health-promoting practices, especially when supported by educational spaces that enable critical reflection on personal experiences and the construction of new meanings for self-care. In addition, Brazilian studies have shown that lack of knowledge about the disease increases suffering and hinders treatment adherence, making the role of Nursing essential in providing sensitive and continuous explanations of the diagnosis<sup>(13-14)</sup>.

Therefore, the data indicate the potential of Nursing to mediate between technical information and the subjective processing of diagnosis, structuring interventions that consider patients' emotional context, promoting understanding of the illness, and strengthening the therapeutic bond based on trust, accessible information, and the reduction of anxiety associated with the impact of diagnosis.

Physical manifestations and symptoms of lupus revealed psychological distress, expressed in Class 3 through feelings of sadness, anxiety, hopelessness, and

isolation. This represents an invisible and often underestimated dimension of illness, which, from the participants' perspective, was as intense as physical pain.

A high prevalence of stress, anxiety, and depression is observed among patients with chronic diseases, conditions that compromise overall health and well-being by intensifying physical symptoms, reducing treatment adherence, and lowering quality of life. Furthermore, various psychosocial factors influence the development of these conditions, such as social isolation, responsibilities as a primary caregiver, length of hospitalization, social relationships, age, marital status, frequency of hospital visits, and patients' lifestyle<sup>(15)</sup>. In the present study, these manifestations do not appear dissociated from bodily limitations but rather as an integrated expression of the experience of living with a chronic and unpredictable condition.

The data reinforce this understanding, highlighting not only depressive symptoms but also the loss of autonomy, self-esteem, and self-image. Exclusion from social and family life, lack of understanding from others, and the stigma associated with the condition contributed to the construction of an identity marked by fragility. It is understood that living in an ill body in a productivity-oriented society entails facing constant risks of marginalization and social exclusion<sup>(16)</sup>.

The narratives grouped in Class 4 revealed tensions related to structural and institutional issues faced by people with lupus in accessing consultations, diagnostic tests, and medications. In this class, reports on social determinants and the support provided by municipalities, such as transportation and support houses, stand out. Limitations in access to services and the importance of municipal management for continuity of treatment were identified. The invisibility of the disease also emerged as a barrier to social recognition of suffering. Reports of stigma and external judgment were also identified.

Some national studies have indicated that patients with SLE experience psychosocial burdens resulting from the invisibility of the disease and structural barriers to accessing healthcare. It is emphasized

that the existence of secondary social support has the potential to improve treatment adherence and strengthen care networks, although its implementation remains uneven across municipalities<sup>(13,16)</sup>.

Therefore, this class highlights how socioeconomic conditions and local institutional support directly influence the experience of treatment. It is incumbent upon public policies and the services of the Unified Health System at the municipal level to strengthen access mechanisms and articulate networks of physical and emotional support, reframing care in an intersectoral manner and promoting resilience and quality of life in this population.

Class 5 exposed the limitations of public policy in ensuring longitudinal, comprehensive, and equitable care for people with rare chronic diseases. Unlike the previous class, which emphasizes social and institutional support, this class focuses on the institutional experience of the healthcare system as a whole.

Difficulties in obtaining specialized consultations, diagnostic tests, and medications constituted a scenario of institutional neglect that reinforced health inequities. As noted in the literature, system fragmentation, lack of coordination, and inequalities in access highlight challenges for consolidating an efficient and equitable model<sup>(17)</sup>. In addition, the narratives revealed a sense of abandonment by public institutions. This subjective dimension of access, marked by frustration, waiting, and fatigue, increased suffering and compromised treatment adherence<sup>(18)</sup>.

It is important to highlight that, although suffering and limitations were present, the participants' narratives were not characterized by victimization. On the contrary, there is an appreciation of self-care, the strengthening of support networks (family, religious, and community), and the active construction of a new identity of living with SLE.

Spirituality appears as a strongly structuring axis of meaning, functioning as emotional support and a form of acceptance of the illness, an aspect also described in other contexts of disease-related uncertainty<sup>(19)</sup>. Understanding the sociodemographic profile of people with SLE is a fundamental element for nursing

practice. This process highlights the importance of recognizing social determinants and their implications in the health-disease process.

The findings therefore demonstrate that living with SLE is associated with feelings of uncertainty, daily limitations, and psychological distress, which compromise well-being and quality of life. In this context, nursing practice can be understood as an articulating element between clinical management and psychosocial support, integrating practices of listening, welcoming, and educational interventions that promote autonomy and adaptation to chronic conditions<sup>(20)</sup>.

## Study limitations

The main limitation refers to the convenience sample, composed exclusively of individuals receiving regular outpatient follow-up. This may exclude the perceptions of those who face barriers to accessing healthcare services or who are experiencing acute clinical decompensation, whose daily experiences may present distinct nuances.

Despite this, the study contributes significantly to understanding perceptions of mental health among people with lupus, providing support for future research and for improving healthcare practices.

## Contributions to practice

The contributions of this study lie in supporting nurses in moving beyond a purely clinical and biological model of care, integrating subjective and social dimensions into the therapeutic plan. By giving visibility to the perceptions and daily limitations of people with lupus, the study equips professionals to deliver individualized, person-centered care, fostering welcoming practices, strengthening therapeutic relationships, and promoting coping strategies that directly impact treatment adherence and quality of life. In addition, it provides a basis for the development of care protocols focused on the mental health of people with autoimmune diseases, enhancing the quality of care delivered in healthcare services.

## Conclusion

The perceptions of people with SLE reveal profound psychosocial impacts and daily limitations that extend beyond the clinical dimension, manifesting through psychological distress, social isolation, and feelings of being misunderstood. The findings show that living with the disease imposes significant emotional, relational, and identity-related challenges, demonstrating that daily limitations are intrinsically linked to subjectivity and to the need for a comprehensive perspective that recognizes illness as a process affecting the individual's life as a whole, beyond physical manifestations.

## Authors' contributions

Conception and design or analysis and interpretation of data: **Holanda MKP, Pessoa MS**. Drafting of the manuscript or critical revision of important intellectual content: **Holanda MKP, Silva FP, Nascimento MC, Pinto IDS, Vasconcelos SC**. Final approval of the version to be published: **Silva FP, Nascimento MC, Pinto IDS, Vasconcelos SC**. Agreement to be accountable for all aspects of the manuscript and to ensure that questions related to the accuracy or integrity of any part are appropriately investigated and resolved: **Holanda MKP, Pessoa MS, Silva FP, Nascimento MC, Pinto IDS, Vasconcelos SC**.

## Data availability

The authors declare that the entire dataset can be requested directly from the corresponding author.

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