Working together
www.rcis.ro

Revista de Cercetare si Interventie Sociala

ISSN: 1583-3410 (print), ISSN: 1584-5397 (electronic)

INVISIBLE ILLNESS, CONTESTED LEGITIMACY, AND GAPS IN PSYCHOSOCIAL SUPPORT: LIVING WITH LUPUS IN ALBANIA

Juliana AJDINI, Aida NDREA

Revista de cercetare și intervenție socială, 2026, vol. 94, pp. 45-58

https://doi.org/10.33788/rcis.94.3

Published by:
Expert Projects Publishing House

expert projects publishing

On behalf of:
„Alexandru Ioan Cuza" University,
Department of Sociology and Social Work
and
HoltIS Association

Invisible Illness, Contested Legitimacy, and Gaps in Psychosocial Support: Living with Lupus in Albania

Juliana AJDINI[1], Aida NDREA[2]

Abstract

Systemic lupus erythematosus (SLE) is a chronic autoimmune condition whose fluctuating and often invisible symptoms can disrupt everyday life. This qualitative exploratory study examined psychosocial experiences of SLE in Albania and professional perspectives on support gaps. Between December 2024 and March 2025, semi-structured interviews were conducted with 15 adults reporting a physician diagnosis of SLE (13 women, 2 men; aged 22–58 years) and four professionals (two rheumatologists, two social workers) in four Albanian cities. Reflexive thematic analysis generated four themes: invisible fatigue and the need to prove illness; stigma, gendered expectations, and social withdrawal; fragmented healthcare relationships and absent psychosocial pathways; and informal coping as both a resource and a response to institutional scarcity. Findings highlight credibility work around invisible symptoms and reliance on informal support where psychosocial pathways are weakly routinised. Implications include psychosocial assessment, explicit referral pathways, patient education, peer support, and stronger health–social-care coordination.

Keywords: systemic lupus erythematosus; invisible illness; stigma; psychosocial support; social intervention; Albania.

Introduction

Systemic lupus erythematosus (SLE) is a chronic autoimmune condition with heterogeneous manifestations and an unpredictable course. It disproportionately affects women and may involve multiple organ systems (Tsokos, 2011). Fatigue, pain, cognitive difficulties, uncertainty, and treatment demands can restrict employment, family roles, and social participation even when outward signs are

[1] Department of Social Work and Social Policy, Faculty of Social Sciences, University of Tirana, ALBANIA. E-mail: jajdini@gmail.com;

[2] Primary Health Care Center No. 6, Durrës, ALBANIA. E-mail: idajdini@hotmail.com

absent (Schmeding & Schneider, 2013; Sutanto, Singh-Grewal, McNeil, Craig, & Tong, 2013). The burden of SLE therefore extends beyond disease activity.

Qualitative research shows that people with SLE often negotiate a discrepancy between how they feel and how they appear. Invisible or fluctuating symptoms can lead others to question the legitimacy of limitations, shaping disclosure, support seeking, and self-perception (Brennan & Creaven, 2016; Petrocchi, Visintini, De Marchi, Quartuccio, & Palese, 2022). Bury's (1982) biographical disruption illuminates disrupted life trajectories, while Goffman's (1963) stigma framework helps explain the management of invisible and visible signs. More recent scholarship describes the communicative labour of being believed and taken seriously as 'credibility work' (Thompson, Babu, & Makos, 2025).

Studies across settings describe altered family and work roles and dependence on informal support (Case et al., 2021; Cornet et al., 2022; Phuti, Schneider, Makan, Tikly, & Hodkinson, 2019). In SLE, Xu and Xiang (2026) show how invisible symptoms, bodily changes, work, and motherhood can produce layered stigma and narrative labour. Mental-health and peer support may also be constrained by stigma, time, cost, and weak referral pathways (Goldschen et al., 2024), while European recommendations emphasise education, psychosocial intervention, self-management, and shared decision-making (Parodis et al., 2024).

These issues remain underexplored in Albania. Gender provides relevant context but should not be assumed to explain individual experience. National evidence shows an unequal distribution of unpaid household and care responsibilities, with women carrying a larger share (INSTAT, 2020). Accordingly, gendered findings in this study are grounded in participants' own accounts, and the small number of men precludes meaningful gender comparison.

This study asked how adults with SLE in Albania experience the psychosocial consequences of an invisible and fluctuating illness, how they describe interactions with health and social-care systems, and how professionals understand support gaps. The aim was contextual understanding for social intervention, not prevalence estimation or representativeness.

Methodology

Design and setting

A qualitative exploratory design examined how adults living with SLE understood the psychosocial consequences of illness and how professionals interpreted support gaps. Reflexive thematic analysis (RTA) was selected for its interpretive focus on patterned meaning and its recognition of the researchers' active role in knowledge production (Braun & Clarke, 2006, 2019, 2021). Goffman's (1963) stigma framework and Bury's (1982) biographical disruption were used as sensitising concepts during interpretation, not as predetermined codes.

Data were collected between December 2024 and March 2025. Interviews were conducted in Tirana, Durrës, Elbasan, and Shkodër. Seven of the 15 patient interviews and all four professional interviews were conducted in Tirana, making it the principal interview setting; the remaining patient interviews took place in Durrës, Elbasan, and Shkodër. These locations are reported only as interview settings and are not used as proxies for place of origin or residence. The study was not designed to compare cities or regions.

Participants and recruitment

The sample comprised 19 participants: 15 adults reporting a physician diagnosis of SLE (13 women and 2 men, aged 22–58 years) and four professionals. The professional group included two rheumatologists (woman, 36; man, 47) and two social workers (women, 39 and 28). Time since reported diagnosis ranged from 2 to 11 years. All patients had previously worked, but none was in paid employment at interview. Eligibility required adulthood, a self-reported physician diagnosis of SLE, capacity to consent, and willingness to discuss illness experience. Professionals were purposively selected for relevant clinical or psychosocial experience.

Patient recruitment used snowball sampling, which can facilitate access to small or weakly organised populations while reproducing existing social networks (Noy, 2008). Recruitment began with one person previously known to the first author professionally. Further participants were identified mainly through people with SLE who had met others with the condition during inpatient care. Referred individuals were contacted separately and informed about the study purpose, voluntary participation, confidentiality, and interview process before written consent was obtained. The interview guide was shared in advance, and the interview was arranged for a later date. Participants were not asked to refer contrasting profiles, and no eligible person who was approached declined participation.

Recruitment proceeded alongside familiarisation with the accumulating interviews and ended when later interviews were no longer contributing substantively new perspectives relevant to the research questions. We therefore describe the stopping point as information sufficiency rather than claiming exhaustive saturation. This decision is consistent with the principle of information power, which relates sample adequacy to the specificity and quality of the material and its contribution to the study aim rather than to statistical representativeness (Malterud, Siersma, & Guassora, 2016). The resulting sample was information-rich but network-based; it should not be understood as representative or as a maximum-variation sample.

Table 1. Characteristics of the study sample

Participant group	Characteristic / code	Description
Patients (S1–S15)	Number	15
	Gender	13 women; 2 men
	Age	22–58 years
	Time since reported physician diagnosis	2–11 years
	Interview settings	Tirana (n=7 patient interviews); remaining patient interviews in Durrës, Elbasan, and Shkodër
	Employment at interview	None in paid employment; all had previous work experience
Professionals (P1–P4)	Interview setting	All four professional interviews were conducted in Tirana
	P1	Rheumatologist; woman; 36 years
	P2	Rheumatologist; man; 47 years
	P3	Social worker; woman; 39 years
	P4	Social worker; woman; 28 years

Note. Interview settings are descriptive and do not indicate place of origin, residence, or regional differences. Patient characteristics are otherwise aggregated to reduce re-identification risk. Codes S1–S15 identify patient interviews and P1–P4 professional interviews and are used consistently throughout the Results. Gender is stated only when known and relevant to interpretation.

Data collection

Semi-structured interviews combined a consistent topic framework with flexibility for participants to elaborate personally salient issues (Kallio, Pietilä, Johnson, & Kangasniemi, 2016). Topics covered symptoms and diagnosis, emotional wellbeing, disclosure and relationships, family and work roles, encounters with health and social services, coping, and desired support. Patient interviews lasted 45–75 minutes and professional interviews 30–60 minutes; 12 were face to face and seven online. All were conducted in Albanian, audio-recorded with permission, transcribed verbatim, and supplemented by field notes.

Analysis and reflexivity

Analysis followed Braun and Clarke's six recursive phases of RTA (2006, 2019, 2021). The first author repeatedly read transcripts and field notes, generated manual codes, compared patterns, and developed candidate themes. Coding

initially remained close to participants' language. For example, being called 'lazy', not being believed, continuing despite exhaustion, and withholding explanations were coded as disbelief, moral judgement, overexertion, and concealment. These codes were grouped around the work required to make invisible illness credible. The resulting pattern was subsequently interpreted through Goffman and the established concept of credibility work (Thompson et al., 2025), rather than using that concept as an a priori code.

The same progression from descriptive coding to interpretation was used across the dataset. Family help, informal peer support, self-management, uncertainty about services, and reliance on personal contacts were initially coded separately. Considered alongside professionals' accounts of weak referral routes and limited interdisciplinary support, these patterns informed 'institutional scarcity', used here as an analytic descriptor for limited availability or routinisation of psychosocial support, referral, coordination, peer support, and service navigation around SLE care, rather than an absence of medical care.

Patient and professional interviews were analysed as related but distinct sources. Patient accounts primarily illuminated lived experience; professional accounts illuminated service organisation and possible explanations for reported gaps. During theme development, the groups were compared for convergence, difference, and tension. The strongest convergence concerned the absence of a routine psychosocial pathway: patients described uncertainty about where to seek help, while professionals described limited time, coordination, protocols, and referral options.

The second author reviewed developing codes and themes, checked interpretations against interview material, and discussed alternative readings with the first author. Consistent with RTA, this was a dialogic reflexive process rather than duplicate coding or inter-coder agreement (Braun & Clarke, 2021). Analysis was manual. All 19 interviews informed theme development. For reporting, patient interviews were assigned unique anonymised codes S1–S15 and professional interviews P1–P4; these codes are used consistently throughout the Results. Only quotations selected for reporting were translated from Albanian into English and checked against the Albanian originals. Minor syntactic adjustments were made for readability while preserving meaning and tone.

Reflexivity was maintained throughout analysis. The first author's social work and social policy background oriented attention toward relationships, exclusion, and institutional response, while the second author's medical and rheumatology background supported clinical contextualisation. Reflective notes and author discussions were used to question assumptions, consider alternative readings, and distinguish participants' descriptions from higher-order interpretations. Reporting was informed by COREQ and SRQR recommendations (Tong, Sainsbury, & Craig, 2007; O'Brien, Harris, Beckman, Reed, & Cook, 2014), without claiming formal checklist compliance.

Ethical considerations

Ethical safeguards were integrated throughout recruitment, interviewing, data handling, and reporting. All participants were adults able to provide informed consent, and the study involved interviews only, with no clinical procedures. Before the interview, participants received written and verbal information about the study purpose, audio-recording, confidentiality, voluntary participation, the right to decline questions, and the right to withdraw. Written informed consent was obtained from every participant before data collection. Individuals identified through referrals were contacted separately so that the decision to participate remained personal and voluntary.

At the time data collection commenced, the research team did not have access to a functioning institutional mechanism for ethical review of the study, and formal institutional approval was therefore not obtained. This is reported transparently. The ethical procedures were guided by the Social Research Association (2021). Identifiers were removed during transcription, anonymised codes were used throughout, and digital files were stored on password-protected devices. Because recruitment occurred through a small illness network, demographic details and quotations were reported conservatively to reduce the risk of deductive disclosure (Kaiser, 2009).

Results

Four interconnected themes were identified: (1) invisible fatigue and the need to prove illness; (2) stigma, gendered expectations, and social withdrawal; (3) fragmented healthcare relationships and absent psychosocial pathways; and (4) informal coping as both a resource and a response to institutional scarcity. The first two were predominantly patient-led; the third drew on both groups; and the fourth linked patient coping with professional descriptions of service limitations. Across themes, legitimacy emerged as a central issue: participants managed symptoms while negotiating whether their consequences were recognised as credible.

Invisible fatigue and the need to prove illness

Fatigue was the most consistently described and least socially intelligible symptom. Patients distinguished it from ordinary tiredness: it could be present on waking, persist despite rest, and make routine tasks difficult even when outward signs were absent. One participant described the period before diagnosis:

> *"I was tired all the time and no one believed me. I was often called lazy. I would wake up more tired than when I went to bed." (S1)*

Another participant emphasised the gap between outward appearance and bodily experience:

> *"No one can see how tired I am. I may look fine from the outside, but my body feels as if it is fighting every day." (S2)*

Others recalled being advised to 'push yourself' or 'eat well' rather than seek assessment for persistent exhaustion. Across accounts, fatigue was sometimes interpreted through moral categories such as effort or laziness. Patients described explaining limitations, defending rest, pushing through symptoms, or deciding not to explain. We use 'credibility work' for this recurring effort to make invisible symptoms believable; the term summarises a data pattern rather than replacing participants' accounts with theory.

Professionals did not describe social disbelief in the same terms, but acknowledged that fatigue can be difficult to address in brief consultations because it is subjective, multi-causal, and not always reflected in visible signs or laboratory results. Convergence was partial: patients described the social consequences of disbelief, while professionals described conditions that can make fatigue difficult to recognise and discuss.

Stigma, gendered expectations, and social withdrawal

Patients described two unstable forms of visibility. When symptoms were hidden, others sometimes minimised the illness; when rashes, hair loss, or treatment effects were visible, participants felt exposed to questions, pity, and assumptions about severity. Disclosure therefore required calculation. One participant described disbelief even within the family:

> *"Even at home they would say, 'Don't exaggerate.' That was the hardest part—when the people closest to me did not believe me." (S5)*

Another participant described the emotional cost of repeatedly explaining an illness that others could not see:

> *"After a while, you stop talking about it because you feel that people do not want to hear the same explanation again." (S6)*

Reflecting on a previous workplace, one participant described how well-intended help could still be experienced as a loss of competence:

> *"At work, the others thought they were helping me by doing my tasks for me, but they did not understand how much I suffered because of that." (S4)*

This account shows how well-intended assistance could affect reciprocity and professional identity. The clearest gendered material concerned motherhood,

fertility, and appearance rather than a general comparison between women and men. One woman described fertility-related loss as especially difficult:

> *"The hardest thing was learning that I could not have more children. Thank God I have my daughter; she is worth the whole world to me." (S7)*

The two men added a different perspective, but their number was too small to support gender comparison. One man described the difficulty of explaining illness-related hair loss and the pity he perceived from others:

> *"When I began losing my hair, people thought I was simply going bald like other men. I found it difficult to explain what I was living with, and I could see pity in their eyes." (S14)*

He also recalled being asked whether he had arranged his inheritance in case he died, an interaction that initially provoked anger but that he later linked partly to poor public knowledge of lupus. These accounts show how disbelief, pity, fertility, appearance, and expected productivity became salient for particular participants without supporting general claims about women or men with SLE in Albania.

Fragmented healthcare relationships and absent psychosocial pathways

Patients generally distinguished clinical expertise from the wider experience of care. Many valued individual physicians and recognised the pressures under which they worked, yet described consultations as concentrated on disease activity and medication. Emotional distress, family strain, employment concerns, and social isolation were rarely described as routinely assessed. One participant described reliance on the University Hospital Centre 'Mother Teresa' (QSUT) in Tirana when navigating specialist care:

> *"We did not know where to go or what to do. Only in Tirana, at QSUT, did we feel that we could find help. Elsewhere, at least they told us to go to Tirana." (S9)*

This statement reflects one participant's service experience and should not be read as evidence that all regional services lack capacity. It nevertheless echoed a broader pattern of reliance on Tirana-based specialist services while psychosocial support remained difficult to identify. Another participant recalled receiving information about the permanence of the diagnosis without equivalent guidance about everyday adaptation:

> *"The doctor told me that I would live with this for the rest of my life, but no one explained how. What was I supposed to do, and where was I supposed to go?" (S10)*

Professional accounts converged most clearly with patients at this point. Across the four professional interviews, psychosocial consequences were described as insufficiently embedded in routine care. Social workers emphasised unclear

routes for emotional and social support, while rheumatologists emphasised short consultations, heavy caseloads, limited coordination, and few referral options. One woman social worker explained:

> *"We do not have specific protocols for lupus patients, especially for emotional support. The focus is medical, and there is no clear route beyond that." (P3)*

One woman rheumatologist similarly described the tension between treating disease and addressing its wider psychosocial consequences:

> *"We treat the body, but there is very little time or space to address the person's wider difficulties." (P1)*

Patients described uncertainty and self-navigation, whereas professionals described organisational conditions that could produce them. This convergence supports a pathway-level interpretation, while the small professional sample prevents generalisation.

Informal coping: resource and response to institutional scarcity

Participants actively adapted to illness by pacing activities, protecting rest, adjusting expectations, using faith or creative practices, and learning bodily limits. Close relatives and friends provided practical and emotional support, and some participants supported others with lupus. One participant described how helping newly diagnosed women also became a source of meaning:

> *"At first, I was alone. Now I try to help women who have just been diagnosed. Helping them has also helped me." (S11)*

Another participant described family as the most dependable form of support:

> *"Thank goodness we have our family. They are the only support. They accept us and stay with us; this has fallen on them as much as on us." (S12)*

A further participant captured the more individual side of adaptation:

> *"I learned to listen to my body and protect my peace." (S13)*

Informal coping had two sides. Peer support restored reciprocity and family support provided continuity, but reliance on personal networks was often necessary because structured alternatives were difficult to identify. Most patients had not accessed a structured SLE support group, psychological counselling linked to rheumatology, or a designated care coordinator; contacts formed during hospital stays therefore became important sources of information and recognition.

This combination of resourcefulness and limited formal support underpins institutional scarcity. Specialist medical care could coexist with weakly routinised

psychosocial support, referral, coordination, peer resources, and navigation, leaving patients and families to assemble much of the emotional and practical response themselves. Resilience was therefore both agency and solidarity and a possible marker of responsibility shifted toward informal networks.

Discussion

Living with SLE involved a double task: managing a fluctuating condition and negotiating whether its effects were recognised as real and consequential. The study does not introduce credibility work as a new concept; it shows how this established communicative labour operates in Albanian SLE experiences and intersects with weakly routinised psychosocial pathways. Institutional scarcity emerged from reliance on informal networks alongside patient and professional accounts of limited psychosocial referral and support.

The findings accord with qualitative syntheses on uncertainty, fatigue, disrupted identity, and unmet support needs in SLE (Petrocchi et al., 2022; Sutanto et al., 2013). They also extend work on illness credibility (Thompson et al., 2025) and recent SLE research on layered stigma and narrative labour (Xu & Xiang, 2026). The Albanian contribution lies in linking these experiences to reliance on Tirana-based specialist care and weakly routinised psychosocial pathways.

Bury's (1982) biographical disruption is visible in altered expectations for work, family, fertility, independence, and the future, and could recur when fatigue interrupted plans or recognition was withdrawn. Goffman's (1963) framework clarifies movement between concealing invisible illness and managing visible signs. The findings add that legitimacy was relational and organisational: recognition also depended on whether families, workplaces, and care systems could respond to fluctuating illness.

Gendered experiences require caution. The clearest gendered material in this sample concerned motherhood, fertility, and appearance, while Albanian gender data provide broader context on unequal household and caring responsibilities (INSTAT, 2020). Because only two men participated and the study was not designed for gender comparison, these findings identify gendered meanings within particular accounts rather than characteristics of Albanian women generally or differences between women and men with SLE.

The patient–professional comparison supports an organisational interpretation: patients described uncertainty about where to seek help, while professionals identified limited protocols, time, coordination, and referral options. This locates the pathway gap in structural constraints rather than individual indifference and accords with evidence on barriers to mental-health support in SLE (Goldschen et al., 2024).

Institutional scarcity is used here as an analytic descriptor, not a judgement of the Albanian health system. Specialist medical care coexisted with reliance on informal networks for emotional support, peer knowledge, family assistance, and navigation. Coping therefore reflected relationships, knowledge, access, and formal support rather than individual resilience alone.

Implications for social intervention

A practical first step would be a minimum psychosocial pathway linked to rheumatology and primary-care contacts. Routine appointments could include a brief check of fatigue, emotional distress, family or work disruption, and available support. This aligns with recommendations that SLE care include education, psychosocial intervention, self-management support, and shared decision-making alongside pharmacological treatment (Parodis et al., 2024).

Second, assessment should connect to an explicit referral map. Rheumatologists, primary-care physicians, social workers, and psychologists should know where referrals can be directed and how follow-up returns to the care team. Where specialist psychological services are limited, trained social workers can provide brief psychosocial assessment, practical guidance, family education, and service navigation, with severe distress referred to mental-health professionals.

Third, facilitated peer groups—in person, online, or hybrid—could provide reliable information and experiential recognition, consistent with SLE research on peer and self-management resources (Case et al., 2021; Cornet et al., 2022). Groups should protect confidentiality, link to professional support when needed, and accommodate fatigue or mobility constraints. Professional development should address invisible symptoms and communication, with people living with SLE involved in intervention design and evaluation.

Strengths and limitations

Including patients and professionals connected lived experience with service-level explanation. Transferability is supported by reporting age, time since physician diagnosis, interview setting, employment status, and professional characteristics while avoiding patient-level combinations that could increase identification risk.

Snowball recruitment may have concentrated participants within hospital-linked networks, and participants were not asked to recruit contrasting profiles. Although no eligible person who was approached declined participation and later interviews added little substantively new information, less connected people may have been missed. Interview settings are descriptive, not comparative. Only two men participated, and the professional sample was small. No patient was in paid employment at interview; this is descriptive and does not establish that SLE caused unemployment. Family members, employers, policymakers, and service managers were not interviewed.

The findings are analytically rather than statistically transferable and are not estimates for all people with SLE or Albanian healthcare settings. Future research should recruit beyond hospital-linked networks, include more men and employed participants, collect relevant geographical and socioeconomic characteristics prospectively, and evaluate regional variation and co-designed referral or peer-support models.

Conclusion

For participants, SLE became socially consequential not only through symptoms and uncertainty but through the need to make illness believable and assemble support without a routine psychosocial pathway. Credibility work captures efforts to explain, conceal, push through, or withdraw when symptoms are doubted; institutional scarcity describes weakly routinised psychosocial support, referral, coordination, and peer resources. Family and peer solidarity supported adaptation but should not obscure burdens shifted to informal networks. Linking routine clinical contact with psychosocial assessment, clear referral, patient education, and facilitated peer support offers a proportionate social-intervention response.

Acknowledgments

The authors thank all participants for sharing their experiences.

Data Availability

De-identified interview data are retained by the authors and may be made available to editors or reviewers on reasonable request, subject to confidentiality constraints. Full transcripts are not publicly deposited because of the risk of deductive disclosure.

References

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, *3*(2), 77–101. https://doi.org/10.1191/1478088706qp063oa

Braun, V., & Clarke, V. (2019). Reflecting on reflexive thematic analysis. *Qualitative Research in Sport, Exercise and Health*, *11*(4), 589–597. https://doi.org/10.1080/2159676X.2019.1628806

Braun, V., & Clarke, V. (2021). One size fits all? What counts as quality practice in (reflexive) thematic analysis? *Qualitative Research in Psychology*, *18*(3), 328–352. https://doi.org/10.1080/14780887.2020.1769238

Brennan, K. A. M., & Creaven, A.-M. (2016). Living with invisible illness: Social support experiences of individuals with systemic lupus erythematosus. *Quality of Life Research*, *25*(5), 1227–1235. https://doi.org/10.1007/s11136-015-1151-z

Bury, M. (1982). Chronic illness as biographical disruption. *Sociology of Health & Illness*, *4*(2), 167–182. https://doi.org/10.1111/1467-9566.ep11339939

Case, S., Sinnette, C., Phillip, C., Grosgogeat, C., Costenbader, K. H., Leatherwood, C., et al. (2021). Patient experiences and strategies for coping with SLE: A qualitative study. *Lupus*, *30*(9), 1405–1414. https://doi.org/10.1177/09612033211016097

Cornet, A., Mazzoni, D., Edwards, A., Monzani, D., Pravettoni, G., Andersen, J., et al. (2022). Coping with systemic lupus erythematosus in patients' words. *Lupus Science & Medicine*, *9*(1), e000656. https://doi.org/10.1136/lupus-2022-000656

Goffman, E. (1963). *Stigma: Notes on the management of spoiled identity*. Prentice-Hall.

Goldschen, L., Peng, C. S., Mufson, M. J., Feldman, C. H., Case, S. M., Costenbader, K. H., et al. (2024). Barriers, facilitators, and preferences for mental health services among patients with systemic lupus erythematosus: A qualitative study. *Arthritis Care & Research*, *76*(7), 914–925. https://doi.org/10.1002/acr.25321

INSTAT. (2020). *Gender Equality Index for the Republic of Albania 2020*. Institute of Statistics, Republic of Albania. https://www.instat.gov.al/en/publications/books/2020/gender-equality-index-for-the-republic-of-albania-2020/

Kaiser, K. (2009). Protecting respondent confidentiality in qualitative research. *Qualitative Health Research*, *19*(11), 1632–1641. https://doi.org/10.1177/1049732309350879

Kallio, H., Pietilä, A.-M., Johnson, M., & Kangasniemi, M. (2016). Systematic methodological review: Developing a framework for a qualitative semi-structured interview guide. *Journal of Advanced Nursing*, *72*(12), 2954–2965. https://doi.org/10.1111/jan.13031

Malterud, K., Siersma, V. D., & Guassora, A. D. (2016). Sample size in qualitative interview studies: Guided by information power. *Qualitative Health Research*, *26*(13), 1753–1760. https://doi.org/10.1177/1049732315617444

Noy, C. (2008). Sampling knowledge: The hermeneutics of snowball sampling in qualitative research. *International Journal of Social Research Methodology*, *11*(4), 327–344. https://doi.org/10.1080/13645570701401305

O'Brien, B. C., Harris, I. B., Beckman, T. J., Reed, D. A., & Cook, D. A. (2014). Standards for reporting qualitative research: A synthesis of recommendations. *Academic Medicine*, *89*(9), 1245–1251. https://doi.org/10.1097/ACM.0000000000000388

Parodis, I., Girard-Guyonvarc'h, C., Arnaud, L., Distler, O., Domján, A., van den Ende, C. H. M., et al. (2024). EULAR recommendations for the non-pharmacological management of systemic lupus erythematosus and systemic sclerosis. *Annals of the Rheumatic Diseases*, *83*(6), 720–729. https://doi.org/10.1136/ard-2023-224416

Petrocchi, V., Visintini, E., De Marchi, G., Quartuccio, L., & Palese, A. (2022). Patient experiences of systemic lupus erythematosus: Findings from a systematic review, meta-summary, and meta-synthesis. *Arthritis Care & Research*, *74*(11), 1813–1821. https://doi.org/10.1002/acr.24639

Phuti, A., Schneider, M., Makan, K., Tikly, M., & Hodkinson, B. (2019). Living with systemic lupus erythematosus in South Africa: A bitter pill to swallow. *Health and Quality of Life Outcomes*, *17*, Article 65. https://doi.org/10.1186/s12955-019-1132-y

Schmeding, A., & Schneider, M. (2013). Fatigue, health-related quality of life and other patient-reported outcomes in systemic lupus erythematosus. *Best Practice & Research Clinical Rheumatology*, *27*(3), 363–375. https://doi.org/10.1016/j.berh.2013.07.009

Social Research Association. (2021). *Research ethics guidance*. https://the-sra.org.uk/common/Uploaded%20files/Resources/SRA%20Ethics%20guidance%202021.pdf

Sutanto, B., Singh-Grewal, D., McNeil, H. P., Craig, J. C., & Tong, A. (2013). Experiences and perspectives of adults living with systemic lupus erythematosus: Thematic synthesis of qualitative studies. *Arthritis Care & Research*, *65*(11), 1752–1765. https://doi.org/10.1002/acr.22032

Thompson, C. M., Babu, S., & Makos, S. (2025). A grounded theory of credibility work and illness: Explication and application to the case of women on trial in health care. *Communication Research*, *52*(8), 1059–1085. https://doi.org/10.1177/00936502231184318

Tong, A., Sainsbury, P., & Craig, J. (2007). Consolidated criteria for reporting qualitative research (COREQ): A 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*, *19*(6), 349–357. https://doi.org/10.1093/intqhc/mzm042

Tsokos, G. C. (2011). Systemic lupus erythematosus. *The New England Journal of Medicine*, *365*(22), 2110–2121. https://doi.org/10.1056/NEJMra1100359

Xu, N., & Xiang, H. (2026). Between visible marks and invisible pain: A qualitative study of multi-layered stigma among women with systemic lupus erythematosus in China. *Behavioral Sciences*, *16*(6), 848. https://doi.org/10.3390/bs16060848