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## Systematic Review

# Barriers to medication adherence in self-care management of systemic lupus erythematosus patients: a systematic review

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## ABSTRACT

Aim of the study was to explore stakeholder viewpoints on factors impending compliance to medication among individuals with systemic lupus erythematosus (SLE). An extensive search of literature was carried out in PubMed, Embase, and Scopus databases extending from January 2000 to January 2026. The review encompassed all qualitative, peer-reviewed articles on obstacles to drug compliance, published in English language. Two individual reviewers evaluated study quality using the critical appraisal skills programme (CASP) qualitative checklist. Enhancing transparency in reporting the synthesis of qualitative research (ENTREQ) guidelines was used to synthesize the qualitative information. A total of eleven studies were selected. Prominent patient level barriers encompassed insufficient knowledge of the disease condition, risks of non-compliance, forgetfulness, inadequate social support, and suboptimal health teaching. Challenges associated to the healthcare resources, includes availability, cost, and suitability, which were noted in many articles. Proposed solution in reviewed articles to combat these included forming support networks, using electronic alerts, physical therapy, and specialized elderly care units at community health centres, along with cultural contextual approaches to patient support. Customized strategies focused on individual needs should be created to enhance management in SLE cases.

**Keywords:** Systemic lupus erythematosus, Medication adherence, Barriers, Challenges

## INTRODUCTION

Systemic lupus erythematosus (SLE) is a leading cause of morbidity among autoimmune diseases globally.[1] Over 25% of individual with lupus struggle with regular medication use, which increase the likelihood of disease exacerbation and unfavourable results.[2] Complying with recommended treatments can lower the threat and reduce organ damage.[3] However, nearly 50% of patients with SLE cease to take their medications, typically without alerting their health care team.[4]

As a result, dealing with barriers to medication compliance, has thus been recognized as a key focus in public health priority.[5]

Treatment compliance refers to the extend how a person's behavior closely aligns with the planned treatment plan and clinical recommendations from medical personnel.[5] This includes starting the therapy, maintaining it as directed, and stopping it appropriately. Attention to compliance is growing among healthcare workers and institutions due to its links with poorer life satisfaction, more adverse health events, increased need for medical procedures, elevated mortality, and avoidable costs.[6] Non-compliant SLE individuals experience greater flare frequency relative to those who do.[7] Similarly, rise in frequency of hospital admissions is found in nonadherent individual with SLE.[8] Even with advancements in newer drug therapies and tracking tools, compliance remains a global concern, particularly in regions with economic limitations and restricted medical services.[9]

Barriers to adherence are multifaceted, spanning individual patient aspects, provider behaviours, drug characteristic and health system factors. Patient-related factors include inadequate health literacy, traditional views on medicine efficacy and reliance on spiritual or alternative remedies. Financial pressures, oversight, and worries about drug reliability, ease of use, or importance can further hinder consistency. Lack of knowledge about medication effect, its role, scepticism about its necessity, concerns of side effects, and extended duration of treatment often lead to cessation to therapy. Clinician related determinant includes non-recognition of non-adherence, assigning complicated dosing schedules, ineffective benefit communication, and limited patient involvement in decision-making. Health system factors, such as limited insurance coverage, poor care coordination, and inadequate communication between prescribers, also play a role. Caregiver support is significant, as patients with SLE who have caregivers are more likely to adhere to medications. Pinpointing unique barriers for each patient and implementing targeted solutions is essential for better outcomes. Effective aids encompass counselling from pharmacists, combined-dose pills, staff development, group-based encouragement, and tracking tools for follow-up.

Identifying patient-specific barriers and thus adopting customized techniques to overcome them is critical to improving adherence. Successful facilitators include medication counsellors, single-pill fixed-dose combinations, pharmacist training, peer support groups, and information systems for patient follow-up.

While quantitative studies have extensively explored adherence determinants, they often fail to capture the life circumstances influencing adherence from the patient's perspective. Compiling qualitative evidence offers richer understanding of challenges through direct accounts from patients, clinicians, and family. This method combines insights to assist leaders and practitioners in tackling delicate matters. The present review seeks to analyze views from key groups on compliance hurdles in SLE and suggest ways to resolve them.

## METHODS

This systematic review followed the ENTREQ guidelines to ensure detailed and clear presentation.[10] The protocol was registered in PROSPERO (CRD420251061449) after verifying no similar ongoing work.

### *Inclusion criteria*

Peer-reviewed qualitative studies or mixed-methods studies with extractable qualitative data, patients with SLE, caregivers, healthcare professionals, barriers of medication adherence with or without facilitators, published between January 2000 and January 2026 and English language were included in the study.

### *Exclusion criteria*

Purely quantitative studies, editorials, commentaries, conference abstracts, dissertations and grey literature were excluded from the study.

### *Outcome*

Barriers for medication adherence in SLE, including patient-related, healthcare-related, medication-related, and sociocultural factors, along with solutions to improve compliance.

### *Search strategy*

A structured search plan was created with librarian input, blending controlled terms (MeSH, Emtree) and free keywords via Boolean logic. Search concepts included: "Systemic Lupus Erythematosus" OR "SLE", "Medication adherence" OR "drug compliance" OR "treatment adherence", "Barriers" OR "obstacles" OR "challenges" and "Qualitative" OR "interviews" OR "focus groups" OR "thematic analysis."

Databases searched were PubMed, Embase, Scopus, and Cochrane Library.

**Table 1: Details of search strategy.**

| Date of search | database | Years searched | Records retrieved |
|---|---|---|---|
| **15-09-2025** | PubMed/MEDLINE | 2000-Jan 2026 | 26 |
| **15-09-2025** | Embase | 2000-Jan 2026 | 79 |
| **16-09-2025** | Scopus | 2000-Jan 2026 | 41 |
| **17-09-2025** | Cochrane Library | 2000-Jan 2026 | 0 |
| **Total** | | 146 | |

### *Study selection process*

Two investigators independently screened titles/abstracts and full texts, resolving disagreements through consultation with a third investigator.

### *Data extraction and management*

Two investigators extracted data (author, year, methods, participants, sample size, barriers, solutions) into predetermined format, with accuracy double-checked by a third investigator.

### *Quality assessment*

Two reviewers applied the CASP Qualitative Tool, scoring articles as superior (8-10), moderate (4-7), or inferior (0-3).[11]

### Data analysis

Thematic framework analysis was used, with findings clustered by patients, caregivers and HCWs. The process included:

*Familiarization*

Reviewing studies to identify recurrent themes.

*Thematic framework*

Using a predetermined framework, refined with emergent themes.

*Indexing*

Coding data until saturation, with framework revisions as needed.

*Charting*

Tabulating themes for comparison.

*Mapping and interpretation*

Defining concepts and mapping phenomena to the objectives.

## RESULTS

### Study selection

The database search yielded 146 records; after removal of duplicates and screening, 30 full-text articles were assessed for eligibility.

Ultimately, 11 studies met the inclusion criteria and were included in the qualitative synthesis (Figure 1).

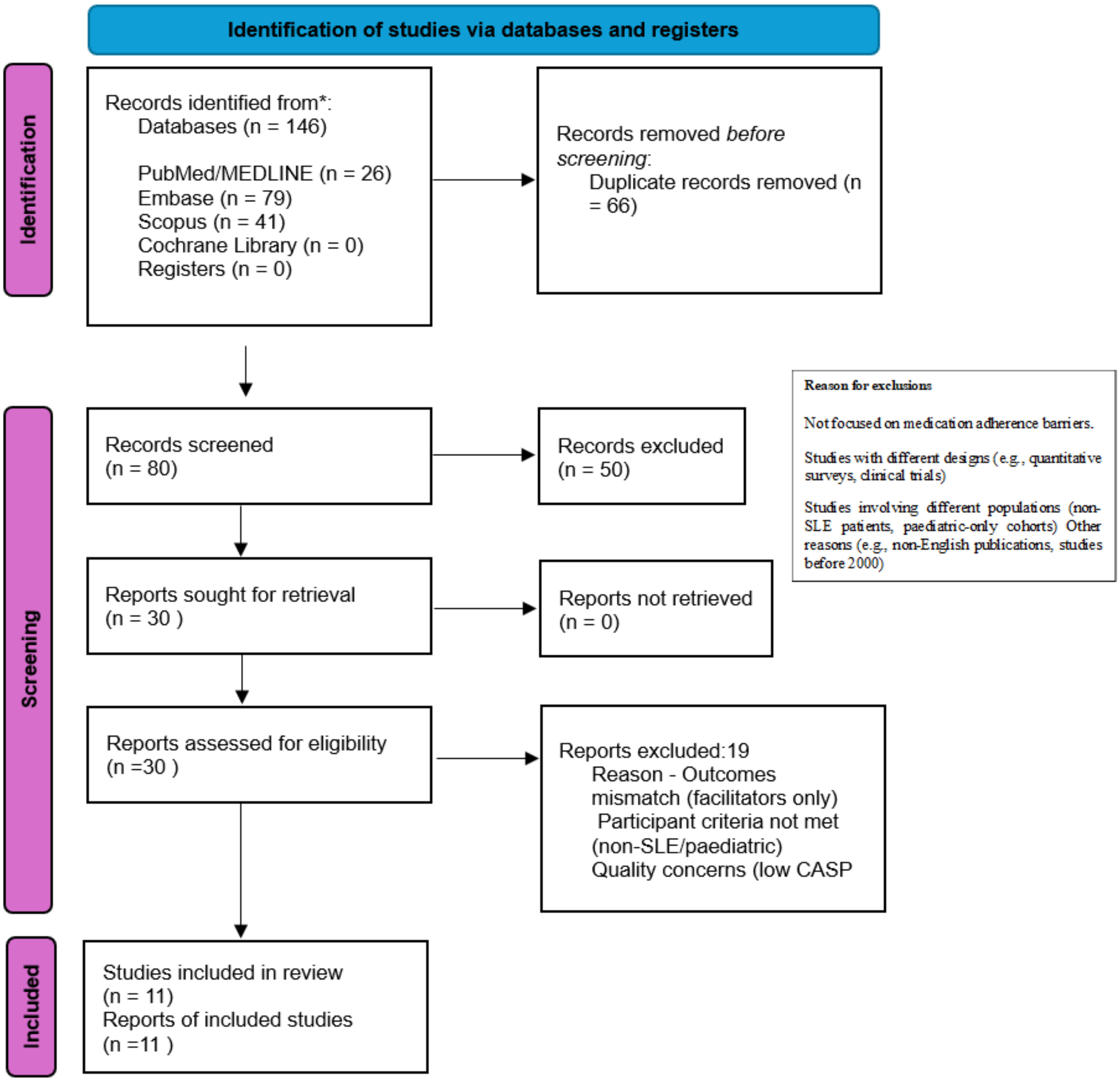

Figure 1: PRISMA flow chart.

### *Characteristics of the studies included*

Table 2 summarizes the characteristics of the 11 included studies. Five (45%) were from the USA, two (18%) from the UK, while others from Sweden, Singapore, and Portugal. The mean age of participants ranged from 16 to 50 years. Studies used IDIs, FGDs, or questionnaires, primarily involving SLE patients and HCWs. Sample sizes ranged from 14 to 31. Seven studies were hospital-based, four community-based. Five used software for analysis, while others used manual methods. Eight studies were high quality.

### *Narrative synthesis*

Findings were grouped under three themes: patient-related, family-related, and health system-related factors. Barriers and suggestions were summarized accordingly.

### *Barriers in medication adherence*

Table 3 presents the thematic framework for barriers. All 11 studies reported barriers. Suggestions to improve medication adherence nine studies suggested options, listed in Table 4

**Table 2: Characteristics of the included studies.**

| Author and year | Country | Data collection method | Study participants | Study setting | Coding | Method of analysis | Sample size | Mean age (in years) | Quality |
|---|---|---|---|---|---|---|---|---|---|
| **Sun et al[12]** | USA | In-depth interviews, thematic analysis | SLE patients, providers | Facility based | Inductive | Manual content analysis | 24 | NR | High |
| **Herndon et al[21]** | USA | In-depth interviews, qualitative descriptive | SLE patients, providers | Facility based | Inductive | Manual content analysis | 24 | NR | High |
| **Emamikia et al[22]** | Sweden | Semi-structured interviews, content analysis | SLE patients | Facility based | Inductive | Manual content analysis | 15 | 32 | High |
| **Tan et al[13]** | Singapore | Semi-structured interviews, thematic analysis | SLE patients | Facility based | Inductive | Manual content analysis | 14 | 16 | Moderate |
| **Chambers et al[14]** | UK | Interviews, questionnaires | SLE patients | Facility based | Inductive | Manual content analysis | 20 | 45 | High |
| **Garg et al[15]** | USA | Focus groups | SLE patients, providers | Facility based | Inductive | Manual content analysis | 20 | NR | High |
| **Sloan et al[16]** | UK | Interviews | SLE patients | Facility based | Inductive | Manual content analysis | 23 | 50 | High |
| **Farinha et al[17]** | Portugal | Semi-structured interviews | SLE patients | Facility based | Inductive | Manual content analysis | 15 | 40 | Moderate |
| **Leung et al[18]** | USA | Interviews | SLE patients | Facility based | Inductive | Manual content analysis | 18 | 35 | High |
| **Mosley Williams et al[19]** | USA | Interviews | SLE patients | Facility based | Inductive | Manual content analysis | 31 | 48 | Moderate |
| **Julian et al[20]** | USA | Interviews | SLE patients | Facility based | Inductive | Manual content analysis | 25 | 44 | High |

**Table 3: Thematic framework of barriers to medication adherence in patients.**

| Main theme | Sub-themes |
|---|---|
| **Patient-related** | Limited knowledge: Inadequate understanding of disease progression, and treatment value among patients.[12]<br>Memory lapses: Failure to follow regimens related to memory lapses amid busy lifestyles.[13]<br>Wrong assumptions: Incorrect ideas about drug effects, dosing schedule.[14]<br>Favoring alternatives: Proclivity towards non-allopathic options like herbal treatments for symptom control.[15]<br>Substance use impact: Impairement with regimen consistency during addiction.[16]<br>Drug reactions: Ceasing treatment without notice upon facing side effects.[17]<br>Psychological pressure: Increased likelihood of missing doses under personal or occupational stress.[18]<br>Social judgment: Hesitance to share SLE details, especially skin symptoms, leading to limited support from close ones.[19] |

Continued.

| Main theme | Sub-themes |
|---|---|
| **Care team** | Support shortcomings: Missing physical or emotional family presence due to work demands, other duties, or personal problems.[20]<br>Weak risk explanation: Inadequate discussion of non-compliance dangers by doctors to patients and families.[21]<br>Clinician behavior: Insufficient compassion, communication, and patient focus from physicians.[22] |

**Table 4: Nine studies provided suggestions.**

| Main theme | Subthemes |
|---|---|
| **Patients** | Peer support groups: patients can motivate each other via self-formed communities.[14,15] |
| | Electronic prompt systems: Using gadgets like phones or watches for dose reminders.[13,18] |
| **Care team** | Community backing: Teaching family to strengthen positive habits, and deter harmful behaviors.[12,16]<br>Monetary assistance: Family assistance to offset medicines and travel expenses.[8]<br>Ongoing provider education: Routine updates for doctors and counselors on best practices.[9]<br>Integrated teams: Unifying traditional medicine, psychological support, rehab, and senior clinics at local levels.[10,11] |
| **Healthcare organisation (infrastructure/resources)** | Care advancements: healthcare workers can make innovations like dedicated day for specific conditions (SLE day, etc), dedicated counselling station/session with additional staff for detailing the importance of adherence and complications related to non-adherence, unique pill dispensing mechanism (colour coding).[12]<br>Information and behavior change efforts: Displaying materials and holding events on compliance in public sites.[14]<br>Electronic health logs: Digitized patient records for enhanced tracking.[8]<br>Multi-drug pills: Highlighting clinical value through workshops and to patients via awareness drives; mainstreaming in routine care.[6] |
| **Environment (regulatory, and policy framework)** | Connections to non-profits and local groups: Training community volunteers, childcare workers, self-aid teams, and NGO staff in patient guidance for better compliance.[10.] |

## DISCUSSION

Compliance with medication in SLE is evolved and sustained by a complex interplay of cognitive, emotional, relational, procedural and structural determinants. This systematic review highlights that inconsistent medication use cannot be blamed only on patient oversight: instead, it arises from ongoing interplays among personal attitudes, clinical interactions, and other systemic conditions.[4-6]

Consistent with broader adherence literature knowledge deficits and misconceptions emerged as central determinants. Many individuals had incomplete grasp of SLE's persistent, immune-driven features.[1,4-6] Misinterpretation of asymptomatic periods as “cure” fostered premature self-abandoning of treatment. Fear of long-term drug toxicity, particularly hydroxychloroquine induced retinal toxicity and corticosteroid-induced cosmetic changes, increased ambivalence toward therapy.[7]

Psychological distress especially depression was an arbiter thereby compounding to intentional non-adherence.[21] Nurses play a major role in screening for sign of psychological distress and timely integration of psychosocial interventions as routine care.[20]

Social connections played a comparable part. Joint planning with compassion notably shaped compliance intentions. Studies demonstrated that dismissive, communication styles fostered disengagement [16]. Instead, collaborative patient centered care planning boosted confidence and ability. These findings align with patient-centred nursing frameworks emphasising therapeutic relation.

Institutional disparities additionally limited consistent treatment. Expense-linked inconsistency is a persistent worldwide challenge.[6,8] Patients reported loss of wages, commuting fees, and inconsistent drug supply. In low-resource contexts, system-level reforms include insurance expansion, local medicine delivery, and online oversight are essential.

Importantly, stigma of autoimmune disease specially with cutaneous expression contributed to concealment and thereby reduced social support. Societal views and alternative remedy use also affected choices. Therefore, guidance attuned to cultural nuances is vital.

Proposed actions in the papers highlighted layered methods: Group networks for shared resilience, tech cues to counter lapses, organized nursing education initiatives, cross-field collaboration (psychological, rehab) and specialized SLE units with compliance advice.

These strategies resonate with chronic care models advocating coordinated, person-centred systems.

From a nursing perspective, treatment adherence should be addressed through comprehensive self-management education, motivational interviewing, and ongoing follow-up. Nurses are uniquely positioned in health care team that bridge communication gaps, reinforce risk communication, and plan interventions to sociocultural contexts.

### *Strengths and limitations*

This is the first review synthesizing qualitative factors associated with barriers to SLE medication adherence, adhering to ENTREQ for transparency. It provides valuable suggestions from patient and provider perspectives, with most studies being high quality, ensuring transferability.[10] Limitations include exclusion of grey literature, potential dissemination bias, and focus on patient/provider perspectives, omitting organizational or political factors. The median sample size (20) was small, though data saturation was achieved.[11]

### *Implications for clinical and public health practice*

Improving adherence is critical to prevent complications. Changeable factors like education shortfalls and service flaws need focus. Relatives can aid by weaving doses into everyday patterns Healthcare providers play a pivotal role, necessitating interventions fitted to cultural and patient-specific contexts.

### *Implications for future research*

Further studies should evaluate the effectiveness of proposed solutions (e.g., digital reminders, polypills). Qualitative research on SLE subgroups under different treatment regimens can contextualize adherence. Employing conceptual models can strengthen proof for focused interventions.

## CONCLUSION

This synthesis shows that medication non-adherence in SLE arises from deeply connected personal, family, and healthcare system challenges. Improving self-care calls for practical, supportive solutions peer groups, phone reminders, open and culturally aware education, and fairer access to care so as empower patients and transform adherence into sustainable, person-centered chronic disease management.

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