

Patient-Centered Lupus Erythematosus Mobile Apps: Systematic Search and Evaluation by Patients and Physicians

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Abstract

Background: Lupus erythematosus (LE) is a chronic autoimmune disease that significantly impacts patients' quality of life. Photosensitivity is a key impairment that severely limits the quality of life, especially in cutaneous lupus erythematosus (CLE), where exposure to sunlight can lead to rashes, exacerbations, and pain. In systemic lupus erythematosus (SLE), other manifestations such as joint pain, fatigue, and organ damage may contribute to decreased physical function and emotional distress. Mobile health applications (MHA) offer potential support for comprehensive disease management for the symptoms mentioned above. However, there is a lack of systematic analysis of available lupus management apps.

Objective: This study aims to systematically identify publicly available German or English MHA for lupus management as well as to assess their quality by surveying both patients and physicians.

Methods: A systematic search and assessment of German or English mobile apps for patients with lupus available in the Google Play Store and Apple App Store was conducted independently by two reviewers. The two apps that met all relevant criteria were then reviewed independently by seven physicians using the German Mobile Application Rating Scale (MARS) and the System Usability Scale (SUS). Subsequently, they were reviewed by five patients (three with SLE and two with CLE), using the user version of MARS (uMARS) and SUS. Additionally, the affinity for technology interaction (ATI) scale was collected from both patients and physicians to evaluate the technical affinity in both groups.

Results: In total, 29 apps were available on the Apple Store and 26 on the Google Store, with 18 apps being present and downloadable on both platforms. Of the 18 apps, 16 were excluded because they did not meet the inclusion and exclusion criteria. Only two apps, Lupus Log and Lupus Minder met all the required criteria and were included in the study. The mean MARS scores varied from 2.61/5 to 4.17/5 and mean SUS from 17.5/100 to 100/100 between physicians. The app with the highest mean overall MARS score was Lupus Log, which was rated with 3.91/5 on average by the physicians. Patients evaluated the app with a comparably mean uMARS score (3.95/5). Technical affinity, objectified by ATI, was higher in patients than physicians (3.9 vs 3.68).

Conclusions: Systematic identification and evaluation showed high-quality apps for patient-centered lupus MHA as indicated by MARS and uMARS scores greater than 3 for both Lupus Log and Lupus Minder.

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Abstract

Background

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Conclusion

Systematic identification and evaluation showed high-quality apps for patient-centered lupus MHA as indicated by MARS and uMARS scores greater than 3 for both *Lupus Log* and *Lupus Minder*.

Introduction

Background

Lupus erythematosus (LE) is a chronic autoimmune disorder with great heterogeneity of symptoms. It can affect multiple organs, including skin, kidney, heart, and the nervous system.(1) In cutaneous lupus erythematosus (CLE), inflammation is typically confined to the skin and does not affect internal organs. It is often triggered or worsened by sun exposure.(2) In contrast, systemic lupus erythematosus (SLE) can present with a wide range of clinical symptoms of varying severity, including serious complications such as lupus nephritis, which can lead to kidney failure if left untreated. As a result, patients with SLE are treated with systemic corticosteroids and other immunosuppressants or immunomodulators, which can result in additional morbidity due to side effects. In contrast, for CLE, topical treatments are often sufficient to relieve symptoms.(3)

Due to chronic inflammation, patients experience a variety of physical limitations, including joint pain, fatigue, sleep disorders, photosensitivity as well as cardiovascular and pulmonary symptoms. Mental and emotional health is further impaired with patients showing high prevalence of depression, anxiety, and cognitive disorders.(4) Furthermore, SLE can also directly affect the central nervous system causing a wide variety of psychiatric symptoms.(5) Some patients experience a so called „lupus fog“ with memory loss and difficulty concentrating, which further negatively impacts daily life and social interactions.(6) Corticosteroids and immunosuppressive drugs can cause weight gain, diabetes, osteoporosis, and increased risk of infection that are detrimental to patients' quality of life.(7)

LE poses unique challenges for those living with it. Symptoms such as chronic fatigue, joint pain, and cognitive difficulties often occur unnoticed by others, making it hard for patients to receive understanding and empathy. This invisibility can lead to several emotional and social struggles such as frustration and a feeling of stigmatization.(8) The unpredictable nature of lupus flare-ups is one of its most challenging aspects. Even when the disease appears controlled, symptoms can suddenly return, causing fear and anxiety about the future.(9)

Patients with lupus often experience fluctuating symptoms, which can complicate treatment adherence and monitoring. Mobile health apps (MHA) present an opportunity to support patients in managing their condition by providing accessible information, symptom tracking, and direct communication with healthcare providers.(10) However, there is a lack of robust evidence regarding the effectiveness of these apps for lupus patients, and high-quality clinical trials are essential to assess their impact.(11) To date, pertinent reviews of MHA for lupus management have been limited, (12) often lacking systematic searches and thorough evaluations. To address this lack of evidence, a comprehensive analysis, using established scoring systems, is necessary to collect reliable data on the effectiveness of MHA in supporting lupus patients.

The Affinity for Technology Interaction (ATI) scale provides a reliable method for quantifying an individual's technology affinity.(13) To subjectively assess app quality, the Mobile App Rating Scale (MARS) was developed, evaluating aspects such as engagement, functionality, aesthetics, and information.(14-16) The System Usability Scale (SUS), a 10-item questionnaire, has been widely used to assess the usability of systems, including mobile apps for conditions like dementia, depression, pediatric obesity, and smoking cessation.(17)

Aim of this study

This study aims to systematically identify and assess mobile apps available for lupus management. By using validated tools, such as the MARS and the SUS, this research seeks to provide a comprehensive evaluation of these apps from both professional and CLE as well as SLE patient perspectives.

Methods

Ethics

This study was conducted in accordance with ethical guidelines and standards, with approval from the ethics committee at the University of Würzburg (reference number 20220625 01).

App Selection

A systematic search of German Google Play Store and Apple App Store was performed. The search terms used were: „lupus“, „lupus erythematosus“ „lupus erythematoses“, „systemic lupus“, „cutaneous lupus“. Each app store was searched by two independent reviewers. Inclusion criteria were apps had to be available in both app stores (1), deployed in English or German language (2), specifically designed for patients (3). The exclusion criteria were: apps that were not free of costs (1), advertisements (2) requiring registration or community connections (3). We excluded apps with advertisements to prevent disruptions in users' experiences and to avoid the confounding effects advertisements can have on usability.(18) Advertisements can frustrate users, reduce the clarity and intuitiveness of an app's interface, and make it difficult to compare apps' performance or users' experiences.(19)

The following information available in the app stores and on app websites was collected:

- App name
- Target consumer group (e.g. patients, medical personnel)
- Cost
- Platform
- Advertisement
- Features
- Search term used to identify the app

Evaluation of App Quality

The quality of the identified and included apps was evaluated by 7 physicians using the MARS, which assesses engagement, functionality, aesthetics, and information quality on a 5-point Likert scale. The apps were then further assessed by five patients (three SLE and two CLE patients) using the user version of the MARS (uMARS). The SUS was also used to evaluate the overall usability of the apps.

Evaluation of Technical Affinity

ATI was used in this study to gather information on the physicians' and patients' technical affinity. ATI has been designed to quantify a tendency to actively engage in intensive technology interaction or to avoid it. In both the patient and the physician group, ATI was collected.

Comparative Analysis of Patients' and Physicians' Data

The MARS results represent the physicians' evaluations, as stated above, whereas uMARS results represent patients' evaluation. Both scales utilize a 5-point Likert scale across four sections: "Engagement," "Aesthetics," "Functionality," and "Information." The MARS has been applied in studies evaluating mobile apps related to various chronic diseases, including chronic wounds.(20)

As the next step, Mann-Whitney U test was conducted to determine if there were significant differences between the MARS and uMARS scores, as well as between the median SUS and ATI scale scores of patients and physicians. Comparisons were also made across the five subcategories within the MARS. Wilcoxon signed-rank test was used to determine differences between the included apps. P-values below 0.05 were considered significant. The data analysis was performed using Python, with libraries such as Pandas, SciPy, NumPy, Matplotlib, and Seaborn.

Results

App Selection

In total, 37 apps were identified, of which 18 were available in both App Stores (see Figure 1). Of these 18 apps, 10 were targeted at patients. However, strict criteria were established for app inclusion: the apps needed to be specifically designed for LE, free of charge, and did not require registration/community connections, or advertising. Of the 18 apps, 13 were excluded because they were not specifically designed for LE. Additionally, 4 apps required payment after download or for full access, and 4 apps asked for registration, included ads, or had community connections. Some apps met multiple exclusion criteria. Ultimately, only 2 apps, *Lupus Log* and *Lupus Minder*, met all the required criteria and were included in the study.

Evaluation of App Quality

A total of two apps —*Lupus Log* and *Lupus Minder*—met all inclusion and exclusion criteria and were evaluated by 7 physicians. *Lupus Log* and *Lupus Minder* are designed specifically for lupus patients, offering features tailored to disease management and symptom tracking. The mean MARS scores (and SDs) of the physicians, including subcategory scores and SUS scores, are provided in Table 1.

Lupus Log had the highest mean MARS (mean 3.91, SD 0.42 out of 5) and mean uMARS (mean 3.95, SD 0.62 out of 5). When Wilcoxon signed-rank test was applied *Lupus Log* had a significantly higher MARS score ($p=0.028$) but not significantly higher uMARS scores ($p=0.125$), possibly due to small size (see detailed information on uMARS, SUS and ATI scores of CLE and SLE patients in Multimedia Appendix 1). *Lupus Minder* had a lower mean MARS (mean 3.29, SD 0.38) and mean uMARS (mean 3.31, SD 0.52 out of 5). Mean SUS by physicians and patients scores were 87% and 76% for *Lupus Minder* and 65 and 49% for *Lupus Log*, respectively.

Evaluation of Technical Affinity

ATI scores ranged from 1.22 to 5.78 out of 6. An ATI score of >3 indicates average technology affinity, and a score of >4 indicates high technology affinity. Technical affinity was lower in physicians than in patients (3.68, SD 0.68 vs 3.9, SD 1.82) but this difference was not statistically significant ($P=.74$).

Comparative Analysis of Patients and Physicians Data

Lupus Log MARS (see Table 1) score and uMARS (see Table 2) were almost identical and differences were not statistically significant ($p=0.76$). In the subcategory engagement and information, mean scores differed most. Patients rated engagement with 3.0 lower than physicians 3.69 ($p=0.16$). In contrast, information was rated higher by patients with a mean score of 4.0 than by physicians with a mean score of 3.48 ($p=0.19$).

Lupus Minder's MARS (see Table 1) score and uMARS (see Table 2) were almost identical ($p=0.7$). In the subcategory engagement and aesthetics, mean scores differed most. Patients rated engagement with 2.4 lower than physicians with 2.86 ($p=0.3$). In contrast, aesthetics was rated higher by patients with a mean score of 3.74 than by physicians with a mean score of 3.24 ($p=0.4$).

Table 1: MARS and SUS scores of the *Lupus Log* and *Lupus Minder* app, as assessed by 7 physicians.

	Lupus Log	Lupus Minder
MARS, mean (SD)	3.91 (0.42)	3.29 (0.38)
A: Engagement score, mean (SD)	3.69 (0.58)	2.86 (0.65)
B: Functionality score, mean (SD)	4.46 (0.37)	3.75 (0.46)

C: Aesthetics score, mean (SD)	4.19 (0.72)	3.24 (0.66)
D: Information score, mean (SD)	3.48 (0.65)	3.43 (0.26)
SUS, mean (SD)	87.14 (4.43)	65.36 (27.59)

Table 2: uMARS and SUS scores of the *Lupus Log* and *Lupus Minder* app, as assessed by 5 patients.

	Lupus Log	Lupus Minder
uMARS, mean (SD)	3.95 (0.62)	3.32 (0.52)
A: Engagement score, mean (SD)	3 (0.94)	2.4 (0.52)
B: Functionality score, mean (SD)	4.35 (0.93)	3.8 (1)
C: Aesthetics score, mean (SD)	4.41 (0.44)	3.74 (0.91)
D: Information score, mean (SD)	4 (0.5)	3.56 (0.43)
SUS	76 (29.18)	49.38 (34.18)

Discussion

Principal Findings

In this study, a systematic search was conducted, aimed at identifying and evaluating smartphone apps specifically designed for patients with LE. The quality of these apps was assessed by independent professional raters (physicians) and patients (with CLE and SLE) using different scores—the MARS, uMARS, and SUS. High agreement among assessors, even for subjective measures, is an encouraging indicator of the reliability of the assessment.

This study identified a limited number of high-quality lupus management apps. Both *Lupus Log* and *Lupus Minder* received decent ratings when rated by raters who can be considered affine to technology based on mean ATI scores greater than 3 for physicians and patients. With a mean MARS score of 3.91 (SD 0.42), *Lupus Log* was rated highest by physicians. Likewise, it achieved a mean uMARS score of 3.95 (SD 0.62). Both apps offer diary function to track symptoms and track therapy and rated as functional. In the subcategory 'information', *Lupus Log* was rated higher by patients overall and in the subcategory 'engagement', possibly due to offering additional information on UV index.

Both apps provided a user-friendly interface and allow for the creation of a personalized medication plan. *Lupus Minder* features a structured design with an intuitive layout. It offers general lupus information and a planner for medical appointments, which can be printed or exported. A daily symptom tracker is available, but it only includes a free-text field without predefined options. The app ensures data security through password protection. *Lupus Log* stood out for its well-structured design and includes a real-time, location-based UV index. Its daily symptom tracker allows users to select predefined symptoms, add custom categories (e.g., fatigue, lesions, ulcers), and to attach notes or photos. The app also provides lupus-related tips, news updates, and access to personal health statistics. Additionally, push notifications can remind users to complete the symptom tracker, though medication reminders are not included.

The episodic nature of lupus makes assessing disease activity and severity challenging, as flare-ups are unpredictable and often go unobserved by physicians. Current evaluations rely on patients' memories, subjective reports, and occasional photos, which can lead to misjudgments and suboptimal treatment.

Regular monitoring is essential, as recommended by lupus management guidelines,(21) which advocate for validated tools like LupusQoL (22) and SLAQ (23) to assess disease control. A mobile health app can simplify this process by enabling continuous tracking of symptoms, severity, and flare-ups while providing an overview for both patients and physicians. This improves support, builds confidence, and enhances treatment precision for physicians and patients.

However, there is still insufficient participation by patients in the app development process (24), which was reflected by a low mean score in the subcategory 'engagement' of uMARS when evaluated by patients. Patients as users of MHA need to be involved in the development process.(25, 26) Both patient-centered apps evaluated in this study, provided a diary function which serves both physicians and patients.

Limitations

The study's limitations include a small sample size and the subjective nature of the evaluation tools. Future research should involve larger patient cohorts and consider randomized controlled trials to assess app effectiveness more robustly over a longer period.

Conclusions

Lupus Log and *Lupus Minder* offer practical tools for tracking disease activity in both CLE and SLE.

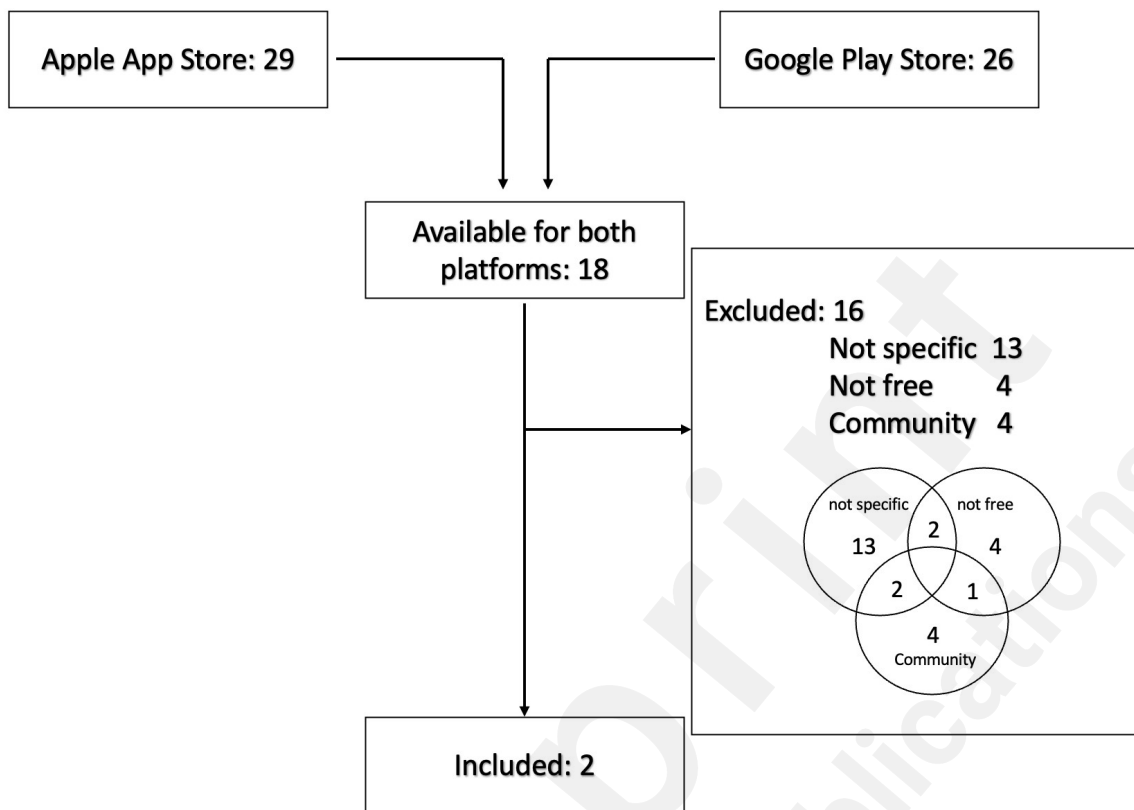
These apps have received positive feedback from patients and physicians, supporting disease control and promoting patient self-management. Their acceptance among patients highlights the need for further studies to evaluate long-term use and adapt the apps to meet the needs of both groups. Involving patients in the app design process can enhance usability and relevance, ultimately leading to better disease management outcomes.

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Figure 1

Flowchart illustrating the screening process for identifying suitable mobile apps.



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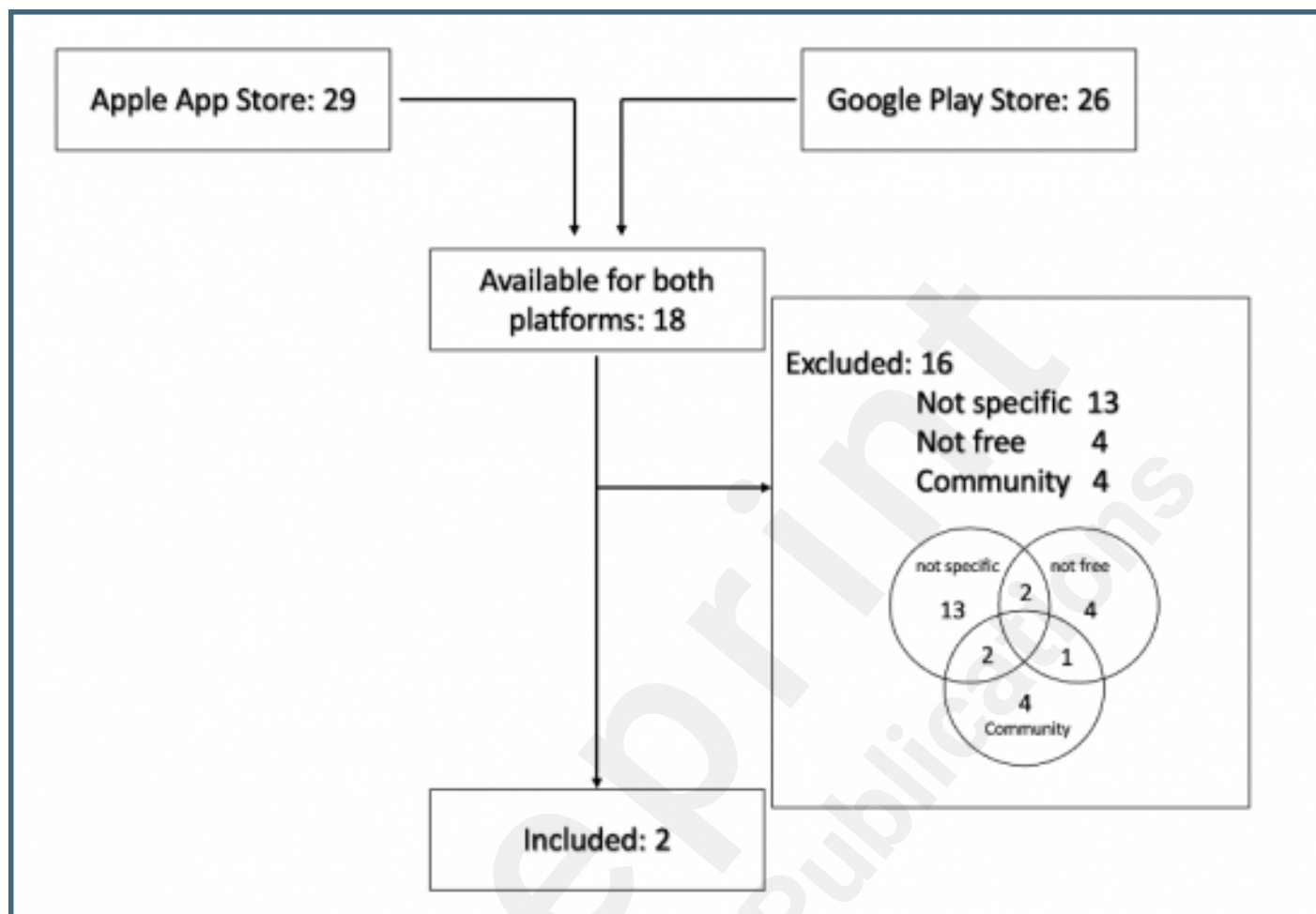
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Supplementary Files

Figures

Flowchart illustrating the screening process for identifying suitable mobile apps.



Multimedia Appendixes

Detailed information on patients' evaluation of both mobile applications.

URL: <http://asset.jmir.pub/assets/407b69b44f8894139767637c28a97731.docx>

