

EVALUATING QUALITY OF LIFE IN SYSTEMIC LUPUS ERYTHEMATOSUS: MODERN APPROACHES AND PERSPECTIVES

D. Pencheva^{1,3}, D. Bakalov², VI. Boyadzhieva^{1,2}, M. Ivanova^{1,2}, N. Stoilov^{1,2}

¹Clinic of Rheumatology, University Clinical Hospital "Sv. Ivan Rilski" – Sofia

²Department of Rheumatology, Medical University – Sofia

³Department of Physiology and Pathophysiology, Medical University – Sofia

Abstract. Systemic lupus erythematosus (SLE) is a chronic autoimmune disease with diverse clinical manifestations. Timely diagnosis and accurate assessment of disease activity are essential for determining optimal therapeutic strategies for each patient. Over recent decades, the prognosis for SLE patients has significantly improved. However, even with proper treatment and remission, quality of life (QoL) remains substantially impaired. This underscores the importance of evaluating health-related quality of life (HRQoL) as part of a comprehensive approach to managing SLE patients. A holistic understanding of a patient's overall condition involves not only physical health but also psychological and social well-being. In recent years, numerous QoL questionnaires have been increasingly utilized in rheumatological practice. Generic questionnaires, such as the Short Form-36 (SF-36), facilitate comparisons across different diseases but may lack sensitivity to the specific clinical symptoms of SLE. Conversely, lupus-specific questionnaires, including LupusQoL, SLEQOL, LupusPRO, and L-QoL, offer more precise insights by capturing multiple aspects of the disease from the patient's perspective. Current guidelines emphasize the need to integrate HRQoL assessments into routine clinical practice and research. The literature review highlights the growing role of lupus-specific questionnaires in clinical trials and raises the critical question of their effectiveness and applicability in daily practice to improve medical care.

Key words: systemic lupus erythematosus, quality of Life, lupus-specific questionnaires

INTRODUCTION

Systemic lupus erythematosus (SLE) is a chronic autoimmune disease that significantly impacts health-related quality of life (HRQoL). The disease is characterized by a wide range of clinical manifestations, including fatigue, arthritis, renal and neurological involvement, as well as skin changes, accompanied by laboratory and serological abnormalities. Additional complications, such as spontaneous miscarriages and stillbirths, arterial or venous thrombosis (particularly in the presence of antiphospholipid syndrome), and an increased risk of cardiovascular diseases, contribute to long-term morbidity and cumulative damage. Chronic use of corticosteroids, while often essential for treatment, frequently leads to significant adverse effects that further deteriorate patients' quality of life [1]. Despite the introduction of new molecules from the class of biologic disease-modifying antirheumatic drugs (bDMARDs) and their significant contribution to reducing disease activity, SLE continues to have a serious impact through persistent symptoms such as fatigue and depression [2, 3]. These symptoms often show weak correlation with disease activity but substantially impair HRQoL. Modern models categorize SLE symptoms

into two types: Type 1 – symptoms caused by inflammation that typically respond to immunosuppressive therapy, and Type 2 – symptoms such as fatigue and depression that often persist even when disease activity is low [4]. This distinction may explain the weak association between HRQoL and traditional markers of disease activity, underscoring the need to integrate HRQoL assessments into the comprehensive care of patients with SLE.

CURRENT RECOMMENDATIONS AND RELEVANCE OF HRQoL ASSESSMENTS

The optimal therapeutic goals in SLE include achieving and maintaining remission, as defined by the consensus on the Definition of Remission in SLE (DORIS), or attaining a state of low disease activity (LLDAS) [5, 6]. Alongside these goals, the assessment of HRQoL is becoming increasingly significant in modern clinical recommendations. The guidelines of the European Alliance of Associations for Rheumatology (EULAR) encourage routine HRQoL evaluation at every clinical visit [7]. The "treat-to-target" (T2T) strategy emphasizes optimizing HRQoL

alongside controlling disease activity [8]. In addition to traditional clinical indicators, HRQoL assessment provides a holistic understanding of disease burden and the effectiveness of therapeutic interventions.

QoL EVALUATION

QoL assessments in patients with SLE is conducted using both generic and disease-specific questionnaires. Generic tools, such as the SF-36, are applicable to various populations and allow comparisons between SLE and other diseases. Lupus-specific questionnaires, such as LupusQoL, SLEQoL, and LupusPRO, demonstrate greater sensitivity to the unique characteristics of the disease and changes in its activity, capturing the numerous challenges faced by SLE patients. It is important to distinguish between QoL and HRQoL, as HRQoL focuses on the impact of SLE and its treatment on clinical outcomes, including symptoms and functional limitations. Questionnaires like L-QoL encompass various dimensions of living with SLE and provide a deeper understanding of the disease impact. Integrating these questionnaires into clinical practice and research is essential for optimizing therapeutic strategies [9, 10].

PSYCHOMETRIC PROPERTIES OF QUESTIONNAIRES

When assessing HRQoL, it is essential to understand the psychometric properties of the questionnaire used, namely reliability, validity, and sensitivity. Reliability measures the consistency of the questionnaire through internal consistency (Cronbach's $\alpha > 0.70$) and test-retest reliability (Pearson correlation coefficient, r). Validity determines whether the questionnaire measures its intended purpose and includes various types of validity (content, criterion, convergent, and discriminant validity). Sensitivity refers to the scale's ability to detect changes in the patient's condition over time. Finally, floor and ceiling effects describe participants who achieve the lowest or highest possible scores, which may limit the questionnaire's ability to capture variations. Understanding and applying these psychometric principles ensures the appropriate selection and interpretation of HRQoL assessment tools in clinical and research settings.

The aim of this review is to synthesize existing literature to provide a com-

prehensive understanding of the characteristics, advantages, and limitations of various QoL assessment tools used in SLE.

RESEARCH STRATEGY

A systematic search was conducted in electronic databases (PubMed, Scopus) for published methodologies for assessing quality of life (QoL) in patients with systemic lupus erythematosus (SLE). The search included the terms "systemic lupus erythematosus," "quality of life," and "questionnaires." A total of 1,076 articles were identified, of which 237 duplicates were removed, leaving 839. Articles were excluded if they lacked primary data or were not in English ($n = 226$). Only original research, reviews, and meta-analyses that examined the use of validated QoL assessment tools were included, resulting in the exclusion of 437 articles that did not meet this criterion. In the end, 72 articles were included in the analysis, focusing on generic questionnaires (e.g., SF-36, EuroQol-5D) and lupus-specific questionnaires (e.g., LupusQoL, SLEQoL, LupusPRO, L-QoL). Finally, 104 articles were excluded due to inadequate data quality. An analysis was performed based on the characteristics of the questionnaires, the domains assessed, psychometric properties, and the identified strengths and weaknesses (Figure 1).

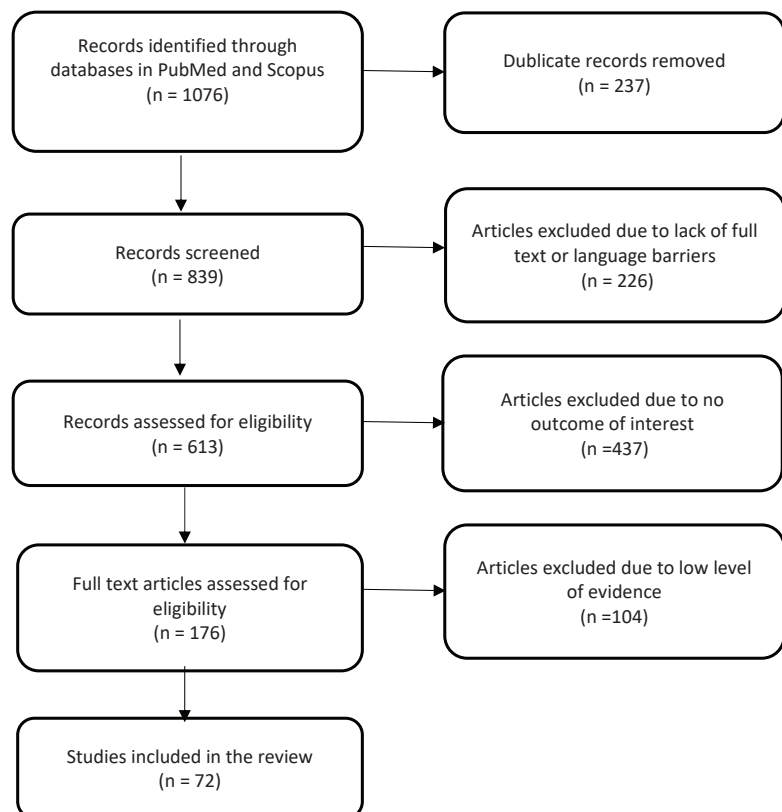


Fig. 1. Selection of included publications

GENERIC QUESTIONNAIRES

Among the most commonly used generic questionnaires are the SF-36v2 (The Short Form Health Survey Version 2), the EQ-5D (EuroQoL 5 Dimensions), PROMIS, and fatigue scales such as FACIT and FSS.

The Short Form Health Survey Version 2 (The SF-36v2) was developed in 1998. It comprises 36 questions assessing quality of life across 8 domains: 1) Physical Functioning (PF), 2) Role Physical (RP): Limitations in activities due to physical health problems, 3) Bodily Pain (BP), 4) General Health (GH), 5) Vitality (VT), 6) Social Functioning (SF), 7) Role Emotional (RE): Limitations in activities due to emotional health problems, 8) Mental Health (MH). The questionnaire evaluates the patient's health status over the preceding 4 weeks, with an additional question assessing changes in health over the past 12 months. Each question is scored on a scale from 0 to 100, where a lower score indicates poorer quality of life, and a higher score reflects better quality of life. A score of 0 corresponds to maximum impairment, whereas 100 indicates no impairment. The SF-36v2 also summarizes results into two components: Physical Component Summary (PCS): Derived from domains related to physical function (PF, RP, BP, GH); Mental Component Summary (MCS): Derived from domains associated with mental health (VT, SF, RE, MH) [12]. The SF-36v2 has been validated for assessing health-related quality of life (HRQoL) in patients with systemic lupus erythematosus (SLE) and is recommended by the British Society for Rheumatology [13]. However, there are concerns about its sensitivity to changes in health status, especially over longer periods. In longitudinal studies, SF-36 does not show significant sensitivity when assessing HRQoL on an annual basis, as the questionnaire reflects only the condition of the previous 4 weeks. Another drawback of SF-36 is the numerous questions, which take more time to complete [14, 15]. In the SLICC (Systemic Lupus International Collaborating Clinics) cohort study, the SF-36 demonstrated improvements across all 8 domains, as well as in PCS and MCS scores, during the first two years after diagnosis, followed by stable results over the subsequent three years. This suggests that the SF-36 is sensitive during the early stages of SLE but not for long-term disease assessment [16].

In the TULIP-1 trial, on day 365, patients treated with Anifrolumab 300 mg showed improvements in PCS and MCS scores by 3.1 (OR CI 1.51 (0.94-2.44)) and 3.8 points (OR CI 1.00-2.79), respectively.

However, these differences were not statistically significant [17]. Thus, the SF-36 is appropriate for short-term studies or newly diagnosed patients with early-stage disease [18]. Additionally, the SF-36 serves as a reference tool for validating new questionnaires, including lupus-specific instruments [19, 20].

Short Form-12 Health Survey (SF-12) is derived from the SF-36 questionnaire and provides comparable data, including summary scores for physical health (PCS) and mental health (MCS). The significantly smaller number of questions for patients ensures easier completion of the questionnaire and its application in daily practice. The SF-12 was used to evaluate predictors of HRQoL in a cohort of 580 patients with systemic lupus erythematosus (SLE) in the LuLa (Lupus-Erythematoses Long-Term Study). Better levels of medical care were associated with higher PCS in the SF-12 [21].

Short Form-20 Health Survey (SF-20) is a condensed version of the SF-36. It comprises 20 questions grouped into six domains: physical functioning (PF), role limitations due to physical problems (RP), social functioning (SF), mental health (MH), health perception (HP), and bodily pain (BP). Scores are assessed on a scale of 0 to 10 and then multiplied by 100 [22].

Short Form-6D (SF-6D) includes 6 domains, based on selected components of the SF-36, using standard methodology. The eight domains of SF-36 are reduced to 6, with the general health domain omitted, and those assessing limitations in activities due to physical and emotional problems combined into one common domain. The final index provides a single numerical value, which may be easier for researchers and clinicians to interpret compared to the summary scores of SF-36 [23]. SF-6D is a validated and reliable tool for assessing HRQoL in a multi-ethnic group of SLE patients in the U.S., with a strong correlation between the final results of EQ-5D and SF-6D [24]. The LUMINA study (Lupus in Minorities, Nature versus Nurture) highlights the ability of SF-6D to predict the accumulation of damage throughout the course of the disease [25].

EQ-5D-5L (EuroQoL 5 Dimensions) is a generic questionnaire developed by the international EuroQoL research group to assess health across five domains: 1) Mobility, 2) Self-care, 3) Usual activities (e.g., work, study, household tasks, family or leisure activities), 4) Pain/discomfort, 5) Anxiety/depression [26]. There are 3 versions of EQ-5D available. The original questionnaire offers 3 levels of response for each domain. The newer version of EQ-5D includes 5 response levels, allowing for better detection of dif-

ferences in health status: no problems, slight problems, moderate problems, severe problems, and unable to perform a specific activity. An adapted version for children, EQ-5D-Y, is also available. In addition, patients assess their current health status with a visual analogue scale (EQ-5D-VAS) ranging from 0 to 100, where 100 represents the best health you can imagine and 0 represents the worst health you can imagine. The similar domains of EQ-5D and SF-36 show strong correlation. Since EQ-5D provides less information compared to multi-domain tools like SF-36, it tends to be shorter and easier to use as EQ-5D consists of only 5 components with a VAS scale and takes about 2 minutes to complete [24]. EQ-5D has been translated into multiple languages and is used in a wide range of diseases, including SLE. EQ-5D shows satisfactory psychometric properties in a group of SLE patients in the U.S., confirming the validity and reliability of the tool in SLE, with the ability to capture discrepancies between HRQoL on one hand and disease activity and damage on the other [27].

Patient-Reported Outcomes Measurement Information System (PROMIS) is a self-assessment tool for health status in adults and children, evaluating various aspects such as fatigue, pain, sleep disturbances, physical functioning, anxiety, depression, and social role satisfaction. It was developed under the initiative of the National Institutes of Health (NIH) [28]. As a generic questionnaire, PROMIS allows for comparison with other disease conditions and with populations of healthy individuals. The individual domains of PROMIS can be adapted to specific health conditions through the use of computerized adaptive tests (CATs) or short formats, such as PROMIS10, which consists of 10 domains assessing physical and mental health in a variety of chronic diseases. The questions in PROMIS are largely adapted from classic questionnaires such as SF-36 and EQ-5D. The psychometric properties of PROMIS-CATs and PROMIS10 have been evaluated in 238 outpatient lupus patients in the U.S., with both questionnaires showing strong correlations with both the generic SF-36 and the lupus-specific LupusQoL [29]. In addition, PROMIS10 has been validated in children with lupus, allowing for assessment and tracking of pediatric patients as they transition into adulthood. This is an advantage of PROMIS10 over well-established questionnaires that are only adapted for this age group [30].

Functional Assessment of Chronic Illness Therapy Scale (FACIT Fatigue Scale/FACIT-F) is one of the most widely used tools for measuring

fatigue in chronic illnesses and has been validated for use in Systemic Lupus Erythematosus (SLE) and lupus nephritis [31, 32]. The short version of the FACIT-F consists of 13 questions that assess patient-reported levels of fatigue and its impact on daily activities and functional capacity over the past 7 days. Fatigue is evaluated using a 4-point Likert scale (4 = no fatigue to 0 = severe fatigue). Higher total scores indicate lower levels of fatigue and, therefore, better quality of life. In post-hoc analyses of the BLISS-52 and BLISS-76 trials, poor quality-of-life outcomes were defined as FACIT-F scores < 30 [32]. The FACIT-F was also employed as one of the tools for assessing fatigue in the LEAF study [33].

Fatigue Severity Scale (FSS) is another instrument used to evaluate fatigue. Originally developed by Krupp, LaRocca, Muir-Nash, and Steinberg in 1989, the FSS consists of 9 items scored on a 7-point Likert scale, where 1 signifies “strongly disagree” and 7 indicates “strongly agree” (35). Different studies have proposed various cut-off values: FSS < 4: Mild fatigue; FSS ≥ 4 and < 5: Moderate/borderline fatigue; FSS ≥ 5: Severe fatigue. The FSS has been successfully validated in SLE populations. It was utilized to assess fatigue in a retrospective study of 332 outpatient SLE patients at the Rheumatology Clinic in Düsseldorf, Germany [36].

SLE-SPECIFIC QUESTIONNAIRES

Several Systemic Lupus Erythematosus (SLE) – specific instruments have been developed to assess health-related quality of life (HRQoL). These include the LupusQoL (Lupus Quality of Life), the SLE-Specific QoL Questionnaire (SLEQOL), the SLE QoL Questionnaire (L-QoL), and Lupus PRO. All these questionnaires have undergone validation processes (Table 1).

Lupus Quality of Life (LupusQoL) questionnaire is the most widely used lupus-specific tool for assessing HRQoL. It was developed by McElhone et al. in 2007 to evaluate the quality of life in SLE patients in the United Kingdom [19]. Since its development, it has been validated in patient cohorts from the United States and adapted into a Spanish version. To date, LupusQoL has been translated into 77 languages and is utilized in 51 countries [37, 38]. The questionnaire consists of 34 items divided into 8 domains: 1) Physical Health, 2) Pain, 3) Planning, 4) Intimate Relationships, 5) Burden to Others, 6) Emotional Health, 7) Body Image, 8) Fatigue. The questions cover the past 4 weeks and are evaluated using a 5-point Likert scale, ranging from “all the time” to “nev-

Table 1. SLE-Specific Questionnaires

SLE-Specific Questionnaires	Number of Questions	Content	Interpretation of Results	Time to Complete	Time Period	Psychometric Properties	Validation in Bulgarian
LupusQoL	34	Physical Health, Pain, Planning, Intimate Relationships, Burden to Others, Emotional Health, Body Image, Fatigue	0-100 Higher score indicates better HRQoL	< 5 min	4 weeks	✓	✓
LupusPRO	43	HRQoL domains: Lupus symptoms, Physical health, Pain-vitality, Emotional health, Body image, Cognitive function, Reproductive health plans, and Lupus treatments. Non-HRQoL domains: Social support and Coping, Desires and Goals, and Satisfaction with medical care.	0-100 Higher score indicates better HRQoL	< 10 min	4 weeks	✓	Translated
SLEQOL	40	Physical functioning, Activities, Symptoms, Treatment, Mood, and Self-image.	40-280 Higher score indicates worse HRQoL	< 5 min	1 week	✓	–
L-QoL	25	A list of questions assessing the overall impact of SLE and its treatment on patients.	0-25 Higher score indicates worse QoL	< 5 min	At the moment	✓	✓

er". The mean scores of the domains are converted into values from 0 to 100, with higher values reflecting better quality of life. Completing the questionnaire takes an average of 4.6 minutes. The original British version of LupusQoL demonstrates excellent psychometric properties. Criterion validity was assessed by comparing the domains with similar domains of the SF-36, with similar results observed in the validation of the American and Spanish versions. LupusQoL has discriminant validity, which allows for the recognition of patients with different disease activity and degrees of organ damage. In the original study in the UK, patients with higher disease activity according to BILAG (British Isles Lupus Assessment Group) demonstrated lower HRQoL values in all domains except for fatigue. In some domains, such as emotional health, appearance, and fatigue, no significant differences were observed between patients with or without organ damage, as defined by SLICC/SDI [19].

LupusPRO is a patient-reported outcome instrument developed in 2012 based on feedback from ethnically diverse groups of SLE patients in the United States. The questionnaire consists of 43 items divided into two domains: health-related quality of life (HRQoL) and non-HRQoL domains. HRQoL domains include lupus symptoms, physical health, pain-vitality, emotional health, body image, cognitive function, reproductive health plans, and lupus treatments. Non-HRQoL domains encompass social support and coping, desires and goals, and satisfaction with medical care. The instrument assesses the patient's condition over the preceding four weeks using a 5-point Likert scale. Scores range from 0 to 100, with higher scores indicating better QoL. In its initial validation cohort,

LupusPRO demonstrated good internal consistency, reliability, and coherence across all domains except the lupus treatment domain [40, 41]. Similar domains within LupusPRO and the SF-36 questionnaire showed strong correlations, supporting the criterion validity of LupusPRO. The instrument also correlated well with disease activity as measured by the British Isles Lupus Assessment Group (BILAG) index and the Safety of Estrogens in Lupus Erythematosus National Assessment-Systemic Lupus Erythematosus Disease Activity Index (SELENA-SLEDAI). LupusPRO has been translated and validated in multiple languages, confirming its applicability across diverse cultures and patient populations with SLE [42, 43]. A psychometric analysis of LupusPRO enabled the extraction of 10 items most representative of lupus' impact on patients' daily lives. This new tool, the Lupus Impact Tracker (LIT), provides a single score and demonstrates strong psychometric properties. Its brevity and ease of use make it a practical option for assessing the impact of lupus on quality of life [44].

SLE-Specific QoL Questionnaire (SLEQoL) was originally developed for English-speaking SLE patients in Singapore by Leong et al. in 2005. The questionnaire consists of 40 items grouped into six domains: physical functioning, activities, symptoms, treatment, mood, and self-image. These components were generated by rheumatologists and nurses rather than by patients. The questions refer to the preceding week, and responses are rated on a 7-point Likert scale. The total score is the sum of all item scores, ranging from 40 to 280. Higher scores indicate poorer quality of life. The questionnaire can be completed in under five minutes. In terms of psy-

chometric properties, SLEQoL demonstrates weak correlations with the SF-36, lupus disease activity, and damage indices. However, it is more sensitive to changes in patient status compared to SF-36. The poor correlation between SLEQoL and SF-36 is attributed to differences in their domains and focus. While SF-36 assesses general health, SLEQoL specifically targets areas affected by lupus [45].

L-QoL is a lupus-specific quality of life (QoL) assessment questionnaire developed based on a needs-based model, which posits that well-being, in the context of QoL, is determined by an individual's ability to meet their needs. The questionnaire has been translated into five languages (Bulgarian, Estonian, Russian, Turkish, and Hungarian) and validated in SLE patient populations in the United Kingdom and, more recently, in Bulgaria [20, 46]. The L-QoL consists of 25 items providing a single, overall measure of the impact of SLE and its treatment on QoL. It was developed through interviews with SLE patients about how the disease affects their lives. Responses are dichotomic ("true" or "false"), yielding a score range of 0 to 25, with higher scores indicating worse QoL. The questionnaire is simple to complete and takes less than 5 minutes. The tool demonstrates excellent internal consistency and test-retest reliability, making it suitable for individual-level assessments. Criterion validity, assessed via patient-reported disease activity and severity, is adequate; patients who perceive their condition as more severe or have higher disease activity report significantly worse overall health status. Unlike other QoL instruments that assess multiple domains, L-QoL provides a single composite score, reflecting the overall impact of SLE and its treatment. This streamlined approach offers a straightforward measure of QoL in SLE patients.

CONCLUSIONS

In summary, the available questionnaires provide a valuable opportunity to conduct a comprehensive assessment of quality of life and highlight its significance in understanding the overall impact of systemic lupus erythematosus and the patients' perspective. A deeper analysis of physical, emotional, and social well-being offers a more precise view of the severity of the disease. This personalized, patient-centered approach helps create individualized care that improves clinical outcomes and optimizes treatment strategies for patients with systemic lupus erythematosus.

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✉ Адрес за кореспонденция:
e-mail: dpencheva@medfac.mu-sofia.bg
<https://orcid.org/0000-0002-6590-7100>

✉ Correspondence address:
e-mail: dpencheva@medfac.mu-sofia.bg
<https://orcid.org/0000-0002-6590-7100>