ORIGINAL PAPER

Reumatismo, 2021; 73 (4): 208-228

Quality of life measures in Systemic Lupus Erythematosus: A systematic review

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SUMMARY

In this study we systematically investigated the health-related quality of life (HRQoL) tools, which have been most often used over the last five years to evaluate the QoL in patients with systemic lupus erythematosus (SLE), focusing on their items and applications.

A detailed literature search was conducted: the inclusion criteria were as follows:

1) studies including at least 50 patients;
2) studies including at least 25 patients with SLE;
3) quality of life testing with validated measures.

The systematic review was based on 119 studies for a total of 32,449 SLE patients and 3092 controls. A total of 35 different patients-reported quality of life measures, applied in cohorts of patients with SLE, were retrieved with the 36-item Medical Outcome Short Form (SF-36) (63 studies of 119 =52.95%), Lupus Quality of Life (LupusQoL) (17 studies =14.3%) and Lupus Patient-Reported Outcome (LupusPRO) (12 studies =10%) being the most commonly used tools. Overall, this systematic review of the literature indicated that quality of life in patients with SLE appears to be poor and generally lower compared to both the general population and patients with other chronic conditions, as was shown by a few studies that used SF-36 and LupusPRO.

The use of HRQoL scoring in SLE is gaining increasing interest and is used both in randomized controlled trials and in real-life. Future efforts are needed to improve the understanding of the impact of the disease burden on quality of life from the patient's perspective.

Key words: *Systemic lupus erythematosus, systematic review, quality of life, measures, scoring, risk factors.*

Reumatismo, 2021; 73 (4): 208-228

INTRODUCTION

Systemic lupus erythematosus (SLE) is an autoimmune chronic disease characterized by multi-organ involvement. In SLE patients, the production of a heterogeneous group of autoantibodies, which bind to their antigens and generate immune-complexes, can promote inflammatory damage in various organs (1). Additionally, the resulting wide spectrum of clinical manifestations, as well as the occurrence of several comorbidities (2) and possible drugs side effects can significantly impact on all the aspects of health-related quality of life (HRQoL) in SLE patients, in particular the physical, mental and social dimensions (3). Quality of life in SLE patients is lower compared to both the general population and patients with other chronic diseases, thus leading to a loss of trust in the treating clinicians and poor adherence to therapy (4, 5). Hence, it is relevant to consider also HRQoL as an outcome to be evaluated and targeted to improve the management plan and daily life of SLE patients. Consequently, HRQoL is rapidly becoming a fundamental outcome, not only when investigating the well-being of SLE patients, but also when evaluating the efficacy of treatments in randomized controlled trials.

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Over the years, several patients-reported quality of life measures have been developed to assess HRQoL. These measures can be both SLE-specific, such as Lupus Quality of Life Tool (LupusQoL) (6), Quality of Life in Systemic Lupus Erythematosus (L-QoL) (7), Systemic Lupus Erythematosus Quality of Life (SLEQoL) (7), Lupus-Patient-Reported Outcome (LupusPRO) (8) and Lupus Impact Tracker (LIT) (9), or generic, such as the 36-item Medical Outcome Short Form (SF-36) (10), 12-item Medical Outcome Short Form (SF-12) (11) and the Functional Assessment of Chronic Illness Therapy-Fatigue (FACIT-F) (12).

An adequate understanding of their applicability and accuracy in assessing the various dimensions of the HRQoL is crucial, since these tools are based on different measures and have specific advantages and limitations. It is essential to explore the comparability of the different patients-reported quality of life measures to identify the best tool to be used according to the different settings.

Therefore, in this study we investigated systematically the HRQoL tools, which have been most often used over the last five years to evaluate SLE patients, focusing on their items and applications. The aim of our study is to help future researchers investigating QoL in SLE to choose the best tool to use in their studies, learning from past experience gained in worldwide research.

MATERIALS AND METHODS

A detailed literature search was initially conducted to identify articles that reported findings from clinical studies evaluating the QoL in SLE patients. Key words and subject terms included: (“systemic lupus erythematosus” (MeSH Terms) OR (“systemic lupus erythematosus” (All Fields))) AND (“Quality of life” (MeSH Terms) OR “Quality of life” (All Fields)) AND (“2016/01/04” (PDat): “2021/01/04” (PDat)). The search strategy was applied to Ovid MEDLINE, In-Process and Other Non-Indexed Citation and Ovid Medline for the last 5 years (from January 2016 to January 2021). Abstracts from EULAR and ACR/ARHP Annual Meetings (2015-2020) were screened and included in the analysis when meeting the inclusion criteria and not replicating studies published elsewhere. Inclusion criteria were:

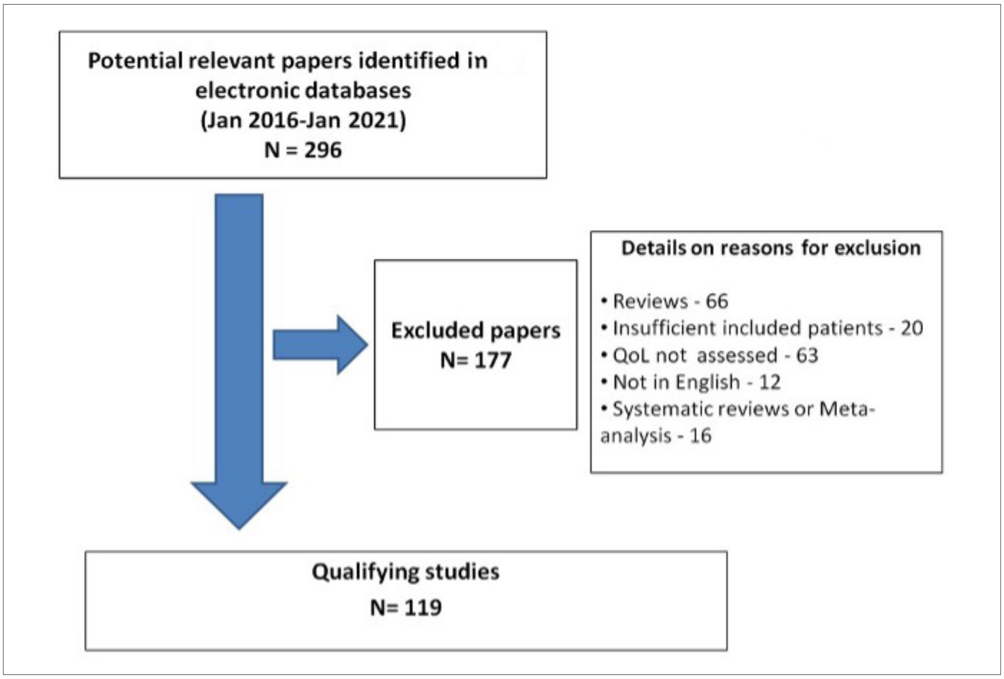

Figure 1 - Literature search strategy and studies’ selection.

1) studies including at least 50 patients;
2) studies including at least 25 patients with SLE;
3) quality of life testing with validated measures [Cross-cultural validated measures were considered, however, for the sake of the study, results are presented with the original scoring measures. Further, different versions of the same score were also considered, but the original version of the score was included in the systematic review].

The studies which met the inclusion criteria were systematically analyzed by two independent reviewers (MR and GEH). Disagreements were resolved by consensus; if it could not be achieved, a third party (SS) provided an assessment of eligibility. Non-English language publications were excluded from the systematic review. The literature search strategy is shown in Figure 1. This study was performed according to PRISMA guidelines (13-15).

■ RESULTS

Literature search

The systematic review included 119 studies considering a total of 32449 SLE patients and 3092 controls (13-131). The included studies had different designs; in particular: 62 studies out of 119 (52%) were cross-sectional, 24 (20.2%) were case-control, 16 (13.5%) were prospective, 11 (9.25%) were randomized clinical trials, 5 (4.2%) were longitudinal and 1 (0.85%) included a retrospective cohort. Only 11 studies out of 119 (9.3%) enrolled controls who were in total 1779 healthy donors (57.6%) and 1313 patients affected by other chronic diseases (42.5%), i.e. 605 patients with rheumatoid arthritis, 226 with cutaneous lupus erythematosus, 147 with Sjögren syndrome, 136 with amyopathic dermatomyositis, 120 with systemic sclerosis and 79 with autoimmune blistering diseases. Table I (19-23, 30, 32-144) summarizes the studies included and their main characteristics.

Patients-reported quality of life measures in systemic lupus erythematosus

A total of 35 different patients-reported quality of life measures applied in cohorts of patients with SLE were retrieved. The 36-item Medical Outcome Short Form (SF-36) (63 studies of 119 =52.95%), Lupus Quality of Life (LupusQoL) (17 studies =14.3%) and Lupus Patient-Reported Outcome (LupusPRO) (12 studies =10%)

Table I - Report of the studies included in the systematic review.

Year	First Author	Study design	N. of SLE patients	N. of controls	Definition of controls (i.e. healthy donors)	QoL instruments used in the study	Ref.
2014	Mirbagher et al.	CC	77	840	Females (20-50 y.o.)	Lupus Quality of Life (LupusQoL)	(33)
2015	Mazzoni et al.	CS	344	N/A	N/A	ProblematicSupport Scale (PSS)	(34)
2015	Oner et al.	CS	113	N/A	N/A	Lupus quality of life (LupusQol) and 36-item ShortForm Health Survey (SF-36)	(35)
2015	Wallace et al.	RCT	203	N/A	N/A	36-item ShortForm Health Survey (SF-36)	(36)
2015	Mazzoni et al.	CS	344	N/A	N/A	Lupus Patient-Reported Outcomes (LupusPRO)	(37)
2016	Hanly et al.	PR	1827	N/A	N/A	36-item ShortForm Health Survey (SF-36)	(38)
2016	Bostrom et al.	RCT	35	N/A	N/A	36-item ShortForm Health Survey (SF-36)	(39)
2016	McElhone et al.	PR	101	N/A	N/A	Lupus quality of life (LupusQol) and 36-item ShortForm Health Survey (SF-36)	(22)
2016	Fidler et al.	CS	110	N/A	N/A	36-item ShortForm Health Survey (SF-36)	(40)
2016	Mahieu et al.	CS	123	N/A	N/A	Patient Reported Outcomes Measurement Information System (PROMIS)	(41)
2016	Jolly et al.	RCT	116	N/A	N/A	36-item ShortForm Health Survey (SF-36)	(42)

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Year	First Author	Study design	N. of SLE patients	N. of controls	Definition of controls (i.e. healthy donors)	QoL instruments used in the study	Ref.
2016	277 Wang et al.	PR	60	N/A	N/A	36-item ShortForm Health Survey (SF36)	(43)
2016	Macedo et al.	CS	216	N/A	N/A	36-item ShortForm Health Survey (SF-36)	(44)
2016	Otter et al.	CS	131	N/A	N/A	Lupus Quality of Life (LupusQol)	(45)
2016	Santos et al.	RCT	120	N/A	N/A	36-item ShortForm Health Survey (SF-36)	(46)
2016	272 Mok et al.	CS	367	N/A	N/A	36-item ShortForm Health Survey (SF36)	(47)
2016	Legge et al.	LG	273	N/A	N/A	36-item ShortForm Health Survey (SF-36)	(48)
2016	Ramondt et al.	CS	106	N/A	N/A	Brief Illness Perception Questionnaire (Brief IPQ)	(49)
2016	Mazzoni et al.	LG	162	N/A	N/A	Lupus Patient-Reported Outcomes (LupusPRO)	(50)
2016	Sebastiani et al.	PR	122	N/A	N/A	Visual analogue scale (VAS)	(51)
2016	Piga et al.	PR	80	N/A	N/A	36-item ShortForm Health Survey (SF-36)	(52)
2016	Williams et al.	LG	50	N/A	N/A	36-item ShortForm Health Survey (SF-36) and Functional Assessment of Chronic Illness Therapy-Fatigue (FACIT-F)	(53)
2016	Devilliers et al.	LG	325	N/A	N/A	Lupus Impact Tracker (LIT), 36-item ShortForm Health Survey (SF-36), and Lupus Quality of Life (LupusQoL)	(21)
2016	Lopez-Pina et al.	CS	232	N/A	N/A	EuroQol-5 dimension (EQ-5D)	(54)
2016	Pinto et al.	CS	39	N/A	N/A	36-item ShortForm Health Survey (SF-36)	(55)
2016	Escobar et al.	CS	147	N/A	N/A	Lupus quality of life (LupusQol) and EuroQol (EQ-5D)	(56)
2016	Chen et al.	CS	541	N/A	N/A	36-item ShortForm Health Survey (SF-36) and EuroQol-5 dimension (EQ-5D)	(57)
2016	Inoue et al.	CS	205	N/A	N/A	Lupus Patient-Reported Outcomes (LupusPRO)	(58)
2017	Jones et al.	LG	100	N/A	N/A	Pediatric Quality of Life Generic Core Scale (PedsQL-GC), Pediatric Quality of Life Rheumatology Module (PedsQL-RM), Functional disability inventory (FDI), Simple Measure of Impact of Lupus Erythematosus in Youngsters (SMILEY), Childhood Health Assessment Questionnaire (C-HAQ), and Child Health Questionnaire (CHQ-PF50)	(59)
2017	Moorthy et al.	PR	467	N/A	N/A	Simple Measure of Impact of Lupus in Youngsters (SMILEY) and Pediatric Quality of Life (PedsQL)	(32)
2017	Antony et al.	CS	73	N/A	N/A	Lupus Impact Tracker (LIT)	(60)
2017	Brandt et al.	CS	860	N/A	N/A	12-item ShortForm health survey questionnaire (SF-12) and Lupus Impact Tracker (LIT)	(61)
2017	Yilmaz-Oner et al.	CC	99	71	No chronic diseases	36-item ShortForm Health Survey (SF36) and Multidimensional Assessment of Fatigue (MAF)	(62)
2017	Calderon et al.	CS	101	N/A	N/A	12-item ShortForm health survey questionnaire (SF-12)	(63)

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Year	First Author	Study design	N. of SLE patients	N. of controls	Definition of controls (i.e. healthy donors)	QoL instruments used in the study	Ref.
2017	Lai et al.	CS	333	N/A	N/A	29-item short form profile (PROMIS-29) and Quality of Life in Neurological Disorders (Neuro-QoL)	(64)
2017	Azizoddin et al.	CS	136	N/A	N/A	Lupus Patient-Reported Outcomes (LupusPRO)	(65)
2017	Etchegaray-Morales et al.	CS	138	N/A	N/A	Lupus Quality of Life (LupusQol)	(66)
2017	Inoue et al.	CS	205	N/A	N/A	Pittsburgh Sleep Quality Index (PSQI), 12-item ShortForm Health Survey (SF-12), and Lupus Patient-Reported Outcomes (LupusPRO)	(67)
2017	Schneider et al.	PR	569	N/A	N/A	Lupus Impact Tracker (LIT)	(68)
2017	Stummvoll et al.	CS	118	N/A	N/A	Self-developed questionnaire	(69)
2017	Chaigne et al.	CC	267	267	Diagnosed with rheumatoid arthritis as per the ACR criteria	36-item ShortForm Health Survey (SF-36)	(70)
2017	212 Taniet al.	CS	50	N/A	N/A	Visual Analog Scale (VAS), Patient's perception of global disease activity and general health (GH), and Health Assessment Questionnaire (HAQ)	(71)
2017	Nantes et al.	CS	78	N/A	N/A	36-item ShortForm Health Survey (SF-36)	(19)
2017	Golder et al.	CS	1422	N/A	N/A	36-item ShortForm Health Survey version 2 (SF-36v2)	(72)
2017	Chaigne et al.	CS	252	N/A	N/A	36-item ShortForm Health Survey (SF-36)	(73)
2017	Magro et al.	PR	232	N/A	N/A	36-item ShortForm Health Survey (SF-36)	(74)
2017	Kent et al.	CS	121	N/A	N/A	Lupus Quality of Life (LupusQol)	(75)
2017	Kasturi et al.	CS	162	N/A	N/A	36-item ShortForm Health Survey (SF-36), Lupus quality of life (LupusQol), and Patient Reported Outcomes Measurement Information System (PROMIS)	(76)
2017	Monahan et al.	PR	248	N/A	N/A	36-item ShortForm Health Survey (SF-36)	(77)
2017	Mok et al.	RC	769	N/A	N/A	36-item ShortForm Health Survey (SF-36) and Lupus Patient-Reported Outcomes (LupusPRO)	(78)
2017	Uzuner et al.	CC	41	49	Healthy children and adolescents from local community	Pediatric quality of life inventory child versions (PedsQL-C)	(79)
2017	Meseguer-Henarejos et al.	CS	223	N/A	N/A	Lupus quality of life (LupusQoL)	(80)
2017	Duruöz et al.	CS	55	N/A	N/A	SLE Quality of Life Questionnaire (L-QoL), Nottingham Health Profile (NHP), and Health Assessment Questionnaire (HAQ)	(81)
2017	Shamekhi et al.	RCT	68	N/A	N/A	12-item ShortForm Health Survey (SF-12)	(82)
2017	Correa et al.	CC	75	78	Subjects without known rheumatic diseases, randomly assigned from a population of workers of the public health services or family and friends of SLE patients	Oral health impact profile (OHIP-49)	(83)

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Year	First Author	Study design	N. of SLE patients	N. of controls	Definition of controls (i.e. healthy donors)	QoL instruments used in the study	Ref.
2017	Contentti et al.	CS	191	N/A	N/A	36-item ShortForm Health Survey (SF-36)	(84)
2017	Margiotta et al.	CS	100	N/A	N/A	36-item ShortForm Health Survey (SF-36)	(85)
2017	Muhammed et al.	CS	101	N/A	N/A	EuroQoL-5dimension (EuroQol-5D)	(86)
2017	Hersh et al.	CS	939	N/A	N/A	Childhood Health Assessment Questionnaire (CHAQ)	(87)
2018	Cosatti et al.	CS	130	N/A	N/A	Lupus quality of life (LupusQol) and Visual Analog Scale (VAS)	(23)
2018	Piga et al.	CC	101	72	Healthy controls enrolled from hospital staff (n=37) and patients classified with rheumatoid arthritis according to the 1987 ACR criteria (n=35)	Functional Assessment of Chronic Illness Therapy-Fatigue (FACIT-F), 36-item ShortForm Health Survey (SF-36), and Heath Assessment Questionnaire (HAQ)	(88)
2018	Iudici et al.	CS	83	N/A	N/A	36-item ShortForm Health Survey (SF-36), Health Assessment Questionnaire Disability Index (HAQ-DI), and Hospital Anxiety and Depression Scale	(89)
2018	Donnelly et al.	CS	50	N/A	N/A	Pediatric Quality Of Life Inventory Generic Core (PedsQL-GC) and Pediatric Quality of Life Rheumatology Module (PedsQL-RM)	(90)
2018	Zeng et al.	CC	104	104	Healthy relatives of SLE patients	36-item ShortForm Health Survey (SF-36)	(91)
2018	Jolly et al.	CS	1259	N/A	N/A	Lupus Patient-Reported Outcome (LupusPRO)	(92)
2018	Golder et al.	CS	105	N/A	N/A	Lupus Impact Tracker (LIT)	(93)
2018	Baba et al.	CS	233	N/A	N/A	36-item ShortForm Health Survey (SF-36)	(94)
2018	Lee et al.	PR	244	N/A	N/A	36-item ShortForm Health Survey (SF-36)	(95)
2018	Azizoddin et al.	CS	131	N/A	N/A	36-item ShortForm Health Survey (SF-36), Functional Assessment of Chronic Illness Therapy-Fatigue (FACIT-F), Insomnia Severity Index (ISI), Patient Health Questionnaire-9 (PHQ-9), and Lupus Patient-Reported Outcome (LupusPRO)	(96)
2018	Jiang et al.	CS	223	N/A	N/A	Systemic Lupus Erythematosus-Specific Quality of Life Questionnaire (SLEQOL) and 36-item ShortForm Health Survey (SF-36)	(97)
2018	Elera-Fitzcarrald et al.	PR	277	N/A	N/A	Lupus quality of Life (Lupus-QoL)	(98)
2018	Azizoddin et al.	CC	116	N/A	N/A	Functional Assessment of Chronic Illness Therapy-Fatigue (FACIT-F), and Lupus Patient-reported Outcome (LupusPRO)	(99)
2018	Tsang-A-Sjoe et al.	CC	154	N/A	N/A	36-item ShortForm Health Survey (SF-36)	(100)
2018	Pereira E Silva et. al	CC	68	27	Primary Sjögren	Overactive bladder questionnaire short form (OABq-SF)	(101)
2018	Strand et al.	RCT	268	N/A	N/A	Functional Assessment of Chronic Illness Therapy-Fatigue (FACIT-F), 36-item ShortForm Health Survey (SF-36)	(102)
2018	Wang et al.	CC	60	N/A	N/A	36-item ShortForm Health Survey (SF-36)	(103)

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Year	First Author	Study design	N. of SLE patients	N. of controls	Definition of controls (i.e. healthy donors)	QoL instruments used in the study	Ref.
2018	Tarazi et al.	CC	165	441	Cutaneous lupus erythematosus (n=226), Amyopathic dermatomyositis (n=136) and autoimmune blistering diseases (n=79)	36-item ShortForm Health Survey (SF-36)	(104)
2018	Groot et al.	CC	111	N/A	N/A	36-item ShortForm Health Survey (SF-36)	(105)
2018	Xie et al.	RCT	125	N/A	N/A	36-item ShortForm Health Survey (SF-36)	(106)
2018	Parodis et al.	PR	69	N/A	N/A	36-item ShortForm Health Survey (SF-36), Functional Assessment of Chronic Illness Therapy-Fatigue (FACIT-F), EuroQol 5-dimension (EQ-5D)	(107)
2018	Jolly et al.	CC	1803	N/A	N/A	Lupus Patient-Reported Outcome (LupusPRO)	(108)
2018	Figueiredo-Braga et al.	CC	72	N/A	N/A	Chalder Fatigue Scale (CFS), 36-item ShortForm Health Survey (SF-36), and Fatigue Severity Scale (FSS)	(109)
2018	Waldheim et al.	PR	84	N/A	N/A	Multidimensional Assessment of Fatigue (MAF), and 36-item ShortForm Health Survey (SF-36)	(110)
2018	Pascual-ramos et al.	CC	245	183	Rheumatoid arthritis	36-item ShortForm Health Survey (SF-36)	(111)
2018	Merrill et al.	RCT	442	N/A	N/A	Lupus quality of life (Lupus QoL)	(112)
2018	Margiotta et al.	CC	93	N/A	N/A	36-item ShortForm Health Survey (SF-36), and Functional Assessment of Chronic Illness Therapy-Fatigue (FACIT-F)	(113)
2018	Kasturi et al.	CC	204	N/A	N/A	Lupus Quality of Life (Lupus QoL), and 36-item ShortForm Health Survey (SF-36)	(114)
2018	Zhao et al.	CC	118	N/A	N/A	Lupus Quality of Life (LupusQoL)	(115)
2018	Nowicka-Sauer et al.	CC	80	N/A	N/A	Fatigue Severity Scale (FSS)	(116)
2018	Aziz et al.	CC	91	N/A	N/A	36-item ShortForm Health Survey (SF-36), and Systemic Lupus Erythematosus specific-quality of life instrument (SLEQOL)	(117)
2019	Seguier et al.	CS	57	N/A	N/A	36-item ShortForm Health Survey (SF-36)	(118)
2019	Margiotta et al.	CS	136	N/A	N/A	36-item ShortForm Health Survey (SF-36)	(119)
2019	Jolly et al.	RCT	867	N/A	N/A	36-item ShortForm Health Survey (SF-36), andFunctional Assessment of Chronic Illness Therapy-Fatigue (FACIT-F)	(120)
2019	Pinto et al.	CS	144	N/A	N/A	Lupus Patient-Reported Outcome (LupusPRO)	(121)
2019	Corneloup et al.	PR	336	N/A	N/A	Lupus Quality of Life (LupusQoL), and Systemic Lupus Erythematosus-specific quality of life instrument (SLEQOL)	(20)
2019	Pinto et al.	CS	112	N/A	N/A	Patient Health Questionnaire 9 (PHQ9), Generalized Anxiety Disorder 7 (GAD7), and Fatigue Severity Scale (FSS)	(122)
2019	Gholizadeh et al.	CS	135	N/A	N/A	Lupus Patient-Reported Outcome (LupusPRO), Hospital anxiety and depression scale (HADS)	(123)

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Year	First Author	Study design	N. of SLE patients	N. of controls	Definition of controls (i.e. healthy donors)	QoL instruments used in the study	Ref.
2019	Wu et al.	RCT	76	N/A	N/A	Fatigue Severity Scale (FSS), and 36-item ShortForm Health Survey (SF36)	(124)
2019	Živković et al.	CS	83	N/A	N/A	Fatigue Severity Scale (FSS), and 36-item ShortForm Health Survey (SF36)	(125)
2019	Kasturi et al.	CS	223	N/A	N/A	PROMIS Global Health Short Form (PROMIS10), and 36-item ShortForm Health Survey (SF-36)	(126)
2019	Poomsalood et al.	CS	237	N/A	N/A	Systemic Lupus Erythematosus-specific Quality of Life questionnaire (SLEQoL)	(127)
2019	Ugarte-Gil et al.	CS	483	N/A	N/A	36-item ShortForm Health Survey (SF-36)	(128)
2019	Ugarte-Gil et al.	CS	243	N/A	N/A	Lupus Quality of Life (LupusQoL)	(129)
2019	Margiotta et al.	CS	130	N/A	N/A	36-item ShortForm Health Survey (SF-36), and Functional Assessment of Chronic Illness Therapy-Fatigue (FACIT-F)	(130)
2019	Goswami et al.	CS	126	N/A	N/A	Fatigue Severity Scale (FSS); and 12-item ShortForm Health Survey (SF-12)	(131)
2019	Geng et al.	CS	201	N/A	N/A	Fatigue Severity Scale (FSS) 9 and 7 items	(132)
2019	Abu Bakar et al.	CS	215	N/A	N/A	36-item ShortForm Health Survey (SF-36)	(133)
2019	Horisberger et al.	CS	73	N/A	N/A	36-item ShortForm Health Survey (SF-36), and Fatigue Assessment Scale (FAS)	(134)
2019	RomànIvorra et al.	CS	190	N/A	N/A	5-level EQ-5D version (EQ-5D-5L)	(135)
2019	Gàvilan-Carrera et al.	CS	70	N/A	N/A	36-item ShortForm Health Survey (SF-36)	(136)
2019	Legge et al.	PR	1683	N/A	N/A	36-item ShortForm Health Survey (SF-36)	(137)
2019	Park et al.	CC	120	960	Systemic sclerosis (n=120), rheumatoid arthritis (n=120), Sjögren syndrome (n=120) and 600 healthy controls	36-item ShortForm Health Survey (SF-36), Short Form Six-Dimensional health index (SF-6D), and EuroQol 5-dimension (EQ-5D)	(138)
2019	Conceição et al.	RCT	80	N/A	N/A	Systemic Lupus Erythematosus-specific quality of life instrument (SLEQOL)	(139)
2019	Castellano Rioja et al.	CC	161	N/A	N/A	SLE Quality of Life Questionnaire (L-QoL)	(140)
2019	Delis et al.	CC	196	N/A	N/A	Lupus Quality of Life (LupusQoL)	(141)
2020	Katz et al.	CS	1066	N/A	N/A	Lupus impact tracker (LIT), 6-item SLE-Family questionnaire, and Healthy Days Core Module (HDCM)	(142)
2020	Ratanasiripong et al.	CS	650	N/A	N/A	Stress Scale (DASS), and Lupus Quality of Life (LupusQoL)	(143)
2020	Louthrenoo et al.	CS	337	N/A	N/A	36-item ShortForm Health Survey (SF-36), and Systemic Lupus Erythematosus-specific quality of life instrument (SLEQOL)	(30)
2020	Legge et al.	PR	1549	N/A	N/A	36-item ShortForm Health Survey (SF-36)	(144)

SLE, systemic lupus erythematosus; CC, case-control; CS, cross-sectional; LG, longitudinal; PR, prospective; RC, retrospective cohort; RCT, randomized clinical trial; N/A, not applicable.

were the most commonly used tools [summarized in Table II (6, 8-12, 27, 145-171)].

36-item Medical Outcome Short Form

The SF-36 was not designed specifically for patients with SLE, but for the general population. Sixty-three studies, i.e. 53% of the total included in our analysis, applied the SF-36. Findings from these studies showed that patients with SLE scored <50 for both the physical component (PCS) and the mental component scores (MCS). The same result was observed in patients affected by other autoimmune conditions considered as controls (evaluated in only three studies out of 63), while healthy controls (only analyzed in two studies out of 63) scored >50 for both PCS and MCS.

Lupus Quality of Life

Lupus Quality of Life (LupusQoL) is a SLE-specific HRQoL tool. It was the second most commonly applied (17 studies accounting for 14.3% of the total) and ranged from 41 to 71.

Lupus Patient-Reported Outcome

The Lupus Patient-Reported Outcome (LupusPRO) also contains non-health related QoL (NHRQoL) domains in addition to HRQoL domains and was used in 12 studies out of 119 (10%). In relation to HRQoL, SLE patients scored from 56 to 75, while they scored from 59 to 72 for NHRQoL domains.

Other measures that were used in the included studies were: Lupus Impact Tracker (LIT) (6 studies =5%), EuroQoL (EQ-5D) (6 studies =5%), 12-item Medical Outcome Short Form (SF-12) (5 studies =4.2%) and Systemic Lupus Erythematosus-Specific Quality of Life Questionnaire (SLEQoL) (5 studies =4.2%). Moreover, 75 studies out of 119 (63%) used only one measure,

Table II - Summary of the quality of life measures used in the studies included in the systematic review.

Measure	N. of items	Domains	Questions Format	Range of scoring	N. of studies that used the measure	Reference
Lupus quality of life (LupusQol)	34	Physical health, emotional health, body image, pain, planning, fatigue, and relationships	5-points scale	1-100	17	(6)
Problematic Support Scale (PSS)	20	Social support, psychosocial adjustment, and disease characteristics	5-points scale	0-60	1	(145)
Short-Form 36 (SF-36)	36	Physical functioning, bodily pain, general health, vitality, social functioning, role of emotional, and mental health	8-scaled scores	1-100	63	(10)
Lupus patient reported outcomes (LupusPRO)	44	Lupus symptoms, Cognition, Lupus medication, Physical health, Pain-vitality, Emotional health, procreation, body image, general health, desires/goals, coping, social support, and satisfaction with care	6-points scale	0-100	12	(8)
Pediatric Quality of Life Inventory™ version 4.0 Generic Core Scales (PedsQL™ 4.0)	23	Physical functioning, emotional functioning, social functioning, and school functioning	5-points scale	0-100	4	(146)
Patient Reported Outcomes Measurement Information System (PROMIS)	56	Pain, fatigue, anger, anxiety, depression, physical function, satisfaction with participation in social roles, and satisfaction with participation in discretionary social activities	5-points scale	0-30	4	(147)

>>> *Continue*

>>> *Continue*

Measure	N. of items	Domains	Questions Format	Range of scoring	N. of studies that used the measure	Reference
Simple Measure of Impact of Lupus Erythematosus in Youngsters (SMILEY)	26	Effects on self, limitations, social life, and burden of SLE	5-points scale	1-100	2	(148)
Childhood Health Assessment Questionnaire (C-HAQ)	30	Dressing and personal care, getting up, eating, walking, hygiene, reach, grip, and activities	4-points scale	0-32	3	(149)
Brief Illness Perception Questionnaire (Brief IPQ)	9	Cognitive illness, emotional representations, illness comprehensibility, and casual representation	11-points scale	0-100	1	(150)
Systemic lupus erythematosus observations of travel burden (SLEOTB)	NA	Reliance on caregivers, meeting financial priorities, and pain and physical limitations	NA	NA	1	(151)
Visual analogue scale (VAS)	NA	NA	NA	0-100	3	(152)
Krupp's fatigue severity scale (FSS)	20	NA	7-points scale	0-60	7	(27)
Functional Assessment of Chronic Illness Therapy-Fatigue (FACIT-F)	27	Physical well-being, Social/Family well-being, Emotional well-being, and Functional well-being	5-points scale	0-100	9	(12)
Lupus Impact Tracker (LIT)	21	Cognition, lupus medications, physical health, pain/fatigue impact, emotional health, body image, and planning/desires/goals	100-points scale	0-100	6	(9)
Short Form health survey questionnaire (SF-12)	12	Physical functioning, role physical, bodily pain, general health, vitality, social functioning, role emotional, and mental health	8-points scale	1-100	5	(11)
Multidimensional assessment of fatigue (MAF) scale	16	NA	10-points scale	0-150	2	(153)
EuroQol (EQ-5D)	5	Mobility, Self-Care, Usual activity, Pain/Discomfort, and Anxiety/ Depression	5 levels	0-100	6	(154)
Neuro-QoL (Quality of Life in Neurological Disorders)	13	Upper extremity function and applied cognition	5-points scale	0-80	1	(155)
Pittsburgh Sleep Quality Index (PSQI)	19	Sleep quality, sleep latency, sleep duration, habitual sleep efficiency, sleep disturbances, use of sleeping medication, and daytime dysfunction	7 component scores	0-21	1	(156)

>>> *Continue*

>>> Continue

Measure	**N. of items**	**Domains**	**Questions Format**	**Range of scoring**	**N. of studies that used the measure**	**Reference**
Self-developed questionnaire	30	Route to diagnosis, therapy, social environment, information, and communication, and demographic data	NA	NA	1	www.lebenmitlupus.org
Health Assessment Questionnaire (HAQ)	20	Dressing and personal care, getting up, eating, walking, hygiene, reach, grip, and activities	4-points scale	0-32	3	(157)
Hospital Anxiety and Depression Scale (HADS)	14	Mood and anxiety	4-points scale	0-100	2	(158)
Perceived Stress Scale (PSS)	10	Family pressure, academic pressure, interpersonal conflicts, physical health problems, and others	5-points scale	0-40	1	(159)
Nottingham Health Profile (NHP)	38	Physical mobility, social isolation, emotional reactions, pain, sleep, and energy	7-points scale	0-100	1	(160)
Oral health impact profile (OHIP-49)	49	Functional limitation, physical pain, psychological discomfort, physical disability, psychological disability, social disability, and handicap	5-points scale	0-70	1	(161)
Insomnia Severity Index	7	NA	5-points scale	0-49	1	(162)
Patient Health Questionnarie-9	9	NA	5-points scale	0-27	2	(163)
Systemic Lupus Erythematosus-Specific Quality of Life Questionnaire (SLEQOL)	40	Physical functioning, activities, symptoms, treatment, mood, and self-image	7-points scale	40-280	5	(164)
6-item SLE-Family questionnaire	6	Fatigue, activity participation, mental health, isolation, love and intimacy, and family roles	6 questions	0-10	1	(165)
Healthy Days Core Module (HDCM)	4	NA	4 questions	0-30	1	(166)
Generalized Anxiety Disorder 7 (GAD7)	7	Anxiety	4-points scale	0-21	1	(167)
Short Form Six-Dimensional health index (SF-6D)	11	Physical functioning, role limitation, social functioning, pain, mental health, and vitality	Continuous measure	0-100	1	(168)
Lupus Erythematosus Quality of Life Questionnaire: CVLEC	36	Functioning, emotions, symptoms, body image, and photosensitivity	5-points scale	36-180	1	(169)
Overactive bladder questionnaire short form (OABq-SF)	19	Symptom bother and health-related quality of life	6-points scale	0-100	1	(170)
Chalder Fatigue Scale (CFS)	11	Physical and mental	4-points scale	0-100	1	(171)

31 out of 119 (26%) used a combination of two measures, 11 out of 119 (9.25%) used a combination of three measures and 2 out of 119 (1.7%) used more than four measures.

DISCUSSION

HRQoL tools are widely used in many studies of SLE patients, from randomized controlled studies to patient management strategy studies, thus gaining progressively more interest in the research community.

As to the overall results of our systematic review, SF-36 was the most widely used generic tool to measure HRQoL in SLE (16). Although SF-36 is diverse, well-validated, and sensitive to change (17), its generic nature may not permit to assess specific dimensions of HRQoL in SLE patients, such as physical appearance and intimate relationships (6). Furthermore, SF-36 does not include the assessment of organ-specific aspects of HRQoL, such as skin or kidney-related complications. Although SF-36 is sensitive to change over time, it might sometimes miss meaningful changes noted in longitudinal studies or trials (18), thus proving more suitable for studies with cross-sectional design.

The LupusQoL is a disease-specific HRQoL tool that was developed and validated in 2007 at the Rheumatology department of Blackburn Royal Infirmary. Four domains of LupusQoL are similar to SF-36, namely emotional health, physical health, pain, and social role. Both LupusQoL and SF-36 can be used to reflect improvement and worsening (19), however the disease-related LupusQoL is considered the most appropriate validated tool for cross-sectional evaluations of HRQoL in SLE (7). Few longitudinal studies in our analysis used the LupusQoL (20-22). Although these studies showed fair sensitivity to change, some domains, such as the body image domain, were irresponsive to change, especially in relation to dermatological or musculoskeletal flares, or treatment (20), It has been previously shown that patients with a more active disease report poorer HRQoL across all LupusQoL domains, except for fatigue (7). This suggests that the use of another HRQoL tool in combination with LupusQoL could be a better approach to assess fatigue (23). Indeed, many tools can be used to assess fatigue among SLE patients. For example, the functional assessment of chronic illness therapy-fatigue (FACIT-F) explores self-reported aspects of physical and mental fatigue and their effects on function and daily living (24). A strong positive correlation was observed between FACIT-F domains and many SF-36 domains, with a similar impact of fatigue on both physical and mental health (25). Along with FACIT-F and visual analogue scale (VAS), the Krupp's fatigue severity scale (FSS) is a frequently used instrument to measure fatigue among patients with SLE (26). FSS has good psychometric properties and was validated in multiple languages. Additionally, it was designed to measure the outcome of fatigue on functional performance such as exercise, motivation, and daily activities (27). Although both the FACIT-F scale and the FSS have good construct validity, when assessing fatigue in SLE patients (28), FSS was reported to have inferior internal consistency and sensitivity than the FACIT-F scale (29). Other less commonly used fatigue assessment tools, such as the multidimensional assessment of fatigue (MAF) scale and Chalder fatigue scale (CFS), were also less studied in SLE, particularly in a prospective fashion, as evidenced in our analysis.

Certain domains of the lupus experience, such as self-image, family planning, or impact of medication, can be neglected by some SLE QoL assessment tools. To address these gaps, the Lupus Patient-Reported Outcome (LupusPRO) was developed in 2012. This tool contains HRQoL domains, such as lupus symptomatology, physical health, and body image, as well as non-HRQoL domains such as desires/goals and satisfaction with care. LupusPRO demonstrates good internal consistency and good test reliability. While this tool is sensitive to longitudinal changes and widely-validated, there are still no data available on its responsiveness using the standardized response means (8). Similar to SF-36, LupusPRO reports greater magnitude of change for improvement than for deterioration (6). However, LupusPRO can better detect organ-specific effects on QoL (8).

Despite all the data considered, it is sometimes difficult to appropriately compare different domains of different tools. For example, SF-36 and LupusQoL have strong correlations among physical health/physical functioning, emotional health/mental health, pain/bodily pain, and fatigue/vitality domains (6). Similarly, SLEQOL and SF-36 correlate well in physical functioning, activities, and symptoms scores (30). However, many aspects, possibly affecting HRQoL in SLE patients and not assessed by certain tools, can affect physical functioning, thus leading to a difference in sensitivity between the tools. Therefore, future clinical trials should use more than one tool to fully capture the experience of patients with SLE and predict which factors can affect which domains.

Our analysis also included several measures of pediatric SLE. These tools vary in their ability to predict change in disease activity over time. The Childhood Health Assessment Questionnaire, used in 2 studies (1.68%) in our analysis, is adequate for assessing physical function and disability in pediatric SLE, but its primary emphasis is on SLE symptoms related to arthritis (31). Among all the measures, the Simple Measure of Impact of Lupus Erythematosus in Youngsters (SMILEY), used in 2 studies (1.68%), is the only disease specific multidimensional measure (31). On the contrary, the Pediatric Quality of Life Inventory (PedsQL), used in 3 studies (2.5%), does not correlate significantly with disease severity, self-concept and socioeconomic status (32), implying that even though the system-specific module encompasses appropriate domains, pediatric SLE patients may require additional items to completely explain the effect of the disease on their QoL.

We acknowledge that this study has some limitations. Although our initial search strategy aimed at identifying all papers relevant to our objectives, it is possible that some studies may not have been retrieved, due to the wide heterogeneity of keywording in this field. Also, aggregation of studies that differ in objectives, terms of intervention or patient type and HRQoL tools used could have led to the generalization of study findings. For instance, the diverse study designs led to the inclusion of both healthy controls and controls affected by other chronic autoimmune conditions and to a disproportionate amount of SLE patients and controls. Moreover, since most studies did not report patients' clinical manifestations, it was not possible to distinguish between different subclasses of SLE. Finally, there are some instruments for cutaneous lupus which could be relevant in patients with SLE who had skin manifestations, but the evaluation of these instruments was beyond the aim of this analysis.

CONCLUSIONS

Based on this systematic review of the literature, quality of life in patients with SLE appears to be poor and overall lower when compared to both the general population and patients with other chronic conditions. Furthermore, some of the tools currently used to measure quality of life (*e.g.*, SF-36) were not specifically developed for the SLE population, and, therefore, may not be capturing all the relevant domains, especially in longitudinal studies. Some others, like the LupusQoL, while specifically developed in patients with SLE, lack prospective validation investigating performances in different geographical settings. SLE specific tools validated prospectively with the ability to detect organ-specific effects on HRQoL, such as LupusPRO, can be occasionally insensitive to treatment-related changes. Therefore, future qualitative studies are needed to improve the understanding of the disease burden on quality of life from the patient's perspective. Similarly, both SLE-specific and not-SLE specifics measures should be included systemically in future prospective studies to investigate comparability and ensure that the universe of items relevant to SLE patients is properly captured.

Acknowledgments
None

Authorship Contributions
MR, GEH, AB searched the literature, assisted with the organization of the manuscript, interpreted and collected data, and wrote and edited the review. DR, IU, AT and SS interpreted and collected data, helped to design the figures and panel, and wrote and edited the review.

Declaration of Interest
None

Ethics approval and consent to participate
None

Consent for publication
None

Availability of data and materials
None

Funding
None

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