

Self-concept and body image of people living with lupus: A systematic review

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Funding information

This work was supported by Coordination of Improvement of Higher Education Personnel - Brazil (CAPES) no. 88881.188510/2018-01.

Abstract

Aim: To summarize existing evidence regarding body image in patients with systemic lupus erythematosus, with the following considerations: (a) the perceptions patients have of their body changes; (b) how patients cope with changes in their body; (c) and what their perceptions are of body changes.

Method: A systematic review of literature integrating quantitative and qualitative studies. We searched databases (PubMed, CINAHL, Embase, SCOPUS, the Web of Science, Medline, Medline Complete, and Academic Search Premier) and publications from 2010 to 2020 with “Systemic Lupus Erythematosus” AND “Self-Concept” OR “Body Image” AND “Woman” as medical subheading terms. The studies included were subjected to a thematic content analysis, which allowed subjective interpretation of data through a systematic classification process for coding themes or patterns.

Results: We identified 647 studies, of which 22 were analyzed in this study. Our results indicate that changes in the body image of people with lupus and their perception are issues that must be treated as characteristics of the disease; therefore, they need to receive the same attention as is given to physical disabilities and pain. The analysis identified 3 thematic categories: (a) depression and anxiety associated with body changes (hair loss, weight gain); (b) body image reflecting the disease; and (c) confrontations and interventions to promote acceptance and adaptation to the new image.

Conclusions: The dimensions of self-concept and body image are essential for assessing the quality of life of individuals with lupus. The formation of a adjusted self-concept can be managed by health professionals supporting these people.

KEYWORDS

body dissatisfaction, body image, self-concept, systematic review, systemic lupus erythematosus



1 | INTRODUCTION

Body image (BI) refers to the internal representation and perceptions of appearance and behavior and attitudes held by an individual.^{1,2} The attitudinal dimensions of BI, which include the beliefs and values of the individual,^{1,3} can be explored from many perspectives. The perceptual dimensions of BI are focused on the individual's precise judgments of their size, weight, and body shape.¹ Some aspects of BI are associated with efforts made to control or change appearance, adopt behaviors to avoid being judged by others,¹ and achieve a desired or idealized body.^{1,4}

BI disorders can take many forms, including extreme dissatisfaction with appearance and compulsory checking and fear of judgment of appearance.² These disorders have been consistently associated with psychological consequences,⁵ including depressive symptoms⁶ and impaired self-esteem.⁷ BI disturbance (BID) is defined as the distortion of perceptions or cognition related to body weight or shape.⁸ BID plays an important role in anxiety/depression and reduces quality of life (QoL).^{9,10}

BI reflects external appearance and is separate from self-concept, which refers to an individual's view of oneself as a person. In individuals with systemic lupus erythematosus (SLE), self-concept can remain positive, even when BI is negative.¹¹

SLE is a multisystemic disease that can alter body appearance. Its rate of incidence is 9-240 cases/100 000 people and is prevalent in women in reproductive age (the female-to-male ratio is 9:1).^{12,13} The disease has a different presentation in different individuals, with variable levels of severity.¹⁴

In general, clinical manifestations of SLE involve several organs, including the skin, kidneys, lungs, heart, and central nervous system. Affected organs and systems suffer from disease sequelae, and periods of remission may occur without clinical manifestations.^{13,15} SLE manifestations include spots, flushing, and skin rashes, especially on the face, joint changes, hair loss, and weight gain,¹³ which make the disease apparent and can cause changes in BI.

Therefore, this review focuses on the changes and adaptations that occur in the BI of people with SLE as primary interest and in their self-concept as secondary interest and is aimed at summarizing existing evidence regarding BI and self-concept in patients with SLE, with the following considerations: (1) the perceptions patients have of their body changes; (2) how patients cope with changes in their body; (3) and what their perceptions are of body changes. To fulfill these objectives, we will conduct an analysis of both quantitative and qualitative studies.

2 | METHODS

2.1 | Protocol and registration

This review was registered in PROSPERO, under number CRD42019126613. To design the study, the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) checklist was used.¹⁶

2.2 | Inclusion criteria

2.2.1 | Types of patients and conditions

Adult patients (more than 18 years old) diagnosed with SLE, according to the European League Against Rheumatism (EULAR) and the American College of Rheumatology (ACR),¹⁷ were included in the study. The selected studies had to include self-concept and/or BI subjects.

2.2.2 | Types of outcomes

Outcomes are reported for the participants' experience or perception of the influence of SLE on their own persons: the patient's perception of their body; how they interpret and cope with their BI; what kind of symptoms are associated with how the patient feels; and how they see or conceptualize their self.

2.2.3 | Types of studies

Published peer-reviewed journal articles were considered in this review. Qualitative or quantitative designed observational studies (descriptive cross-sectional analyses, case-control analyses, and cohort analyses) and designed experimental studies (randomized and non-randomized) were included. There was no geographical restriction, and studies published in English, Spanish, French, or Portuguese were eligible. The articles were published between 2010 and 2020. We considered for inclusion studies focused on the issue of BI and those that made evident the relationship between BI and other issues, such as QoL as a primary interest, or even self-concept as a secondary interest. Methodological studies for instrument validation, case studies or case reports, and literature reviews were excluded.

2.3 | Search strategy

This systematic review asked the research question what the BI is of people living with lupus. A literature search was performed in February 2019 and updated in June 2020, and used the following electronic databases: US National Library of Medicine - National Institutes of Health (PubMed), Cumulative Index to Nursing and Allied Health Literature (CINAHL), Excerpta Medica (Embase), SCOPUS, the Web of Science, Medline, Medline Complete, and Academic Search Premier. A manual search of lists of selected articles supplemented the electronic search. All studies selected were electronically available.

Two authors (LR and MSS) performed the search. The medical sub-heading (MeSH) terms used were "Systemic Lupus Erythematosus" AND "Self-Concept" OR "Body Image" AND "Woman".

2.4 | Study records

A database was created with the free software EndNote to manage the publications searched. For the exclusion process, the covidence.org tool for organizing systematic reviews (available at <https://www.covidence.org>) was used.

Two reviewers (LR and MSS) independently screened titles and abstracts. At the end of this selection phase, the 2 reviewers discussed cases of disagreement. If there was doubt about eligibility, the article was included until the full textual analysis phase. If doubt remained, a third reviewer (LMS) provided an opinion on the eligibility of the text. The search process is summarized in Figure 1.

2.5 | Bias assessment

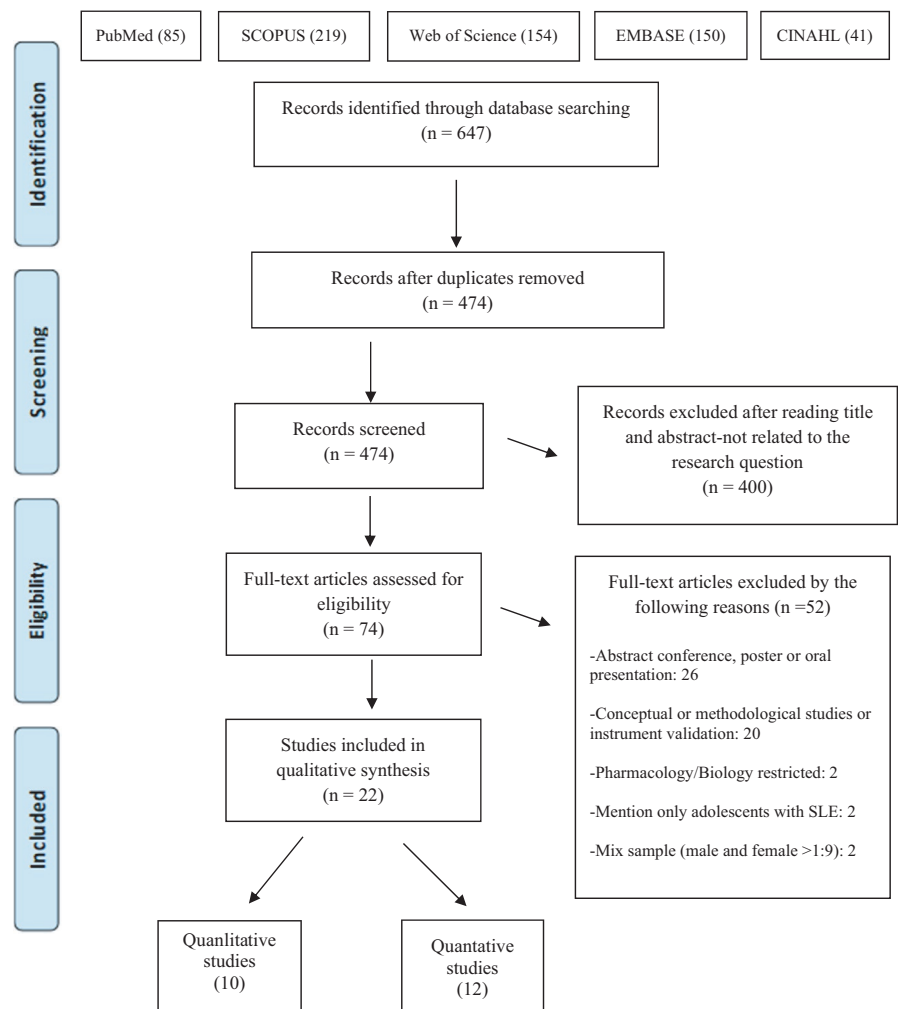
Assessments of the quality of articles were based on checklists developed by Joanna Briggs Institute (JBI) for quasi-experimental, cross-sectional, and qualitative research,¹⁸ available at The System for the Unified Management, Assessment and Review of Information

(SUMMARI). Two authors (LR and MSS) performed the assessments. Disagreements were managed to reach consensus through analysis and discussion with a third author (LMS). The level of evidence provided by the studies was evaluated according to the JBI Model of Evidence Based Healthcare.¹⁹

2.6 | Data analysis

The studies were subjected to thematic content analysis, which allows data to be interpreted through a systematic classification process for coding themes or patterns.¹⁸ To enable analysis of quantitative and qualitative studies, goal aggregation²⁰ was carried out using the following procedures: the high points of the qualitative studies were raised and themes were generated and codified,¹⁸ and the variables in quantitative studies were transformed into similar themes and also codified.²⁰ The analysis culminated in a synthesis of the content, with construction of thematic categories for organization and presentation of the meta-aggregation material.²¹

FIGURE 1 Study search flow diagram



3 | RESULTS

3.1 | Search results

Of the 647 articles identified, 173 were removed as duplicates. The inclusion and exclusion process included a peer review of the titles and abstracts of 474 articles, performed by 2 authors (LR and MSS), to identify studies that potentially met the inclusion criteria, followed by a full-text reading of 74 articles. Disagreements on the eligibility of articles were discussed with the third author (FGS) until consensus was reached. By consensus, 22 articles were finally selected for analysis. The flow chart in Figure 1 shows the studies included in the main analysis.

3.2 | Description of studies

Of the 22 studies, 15 were cross-sectional. Twelve studies had a quantitative approach, and 1 of them had a quasi-experimental design. The remaining 10 had a qualitative design. Figure 2 presents the main topics of the articles. These topics were always related to BI, either as a domain or as a question in a questionnaire or as an emerging theme in comments made by study participants. The results are for a total of 3394 participants. A large variation in sample size was observed, ranging between 6 and 1259 participants.

For the quantitative studies, the alpha coefficients of the applied instruments were .96 for the Body Image QoL Inventory (BIQLI),²² .91 for the depression subscale of the Systemic Lupus Erythematosus Needs Questionnaire (SLENQ),^{23,24} .73 for an adapted version of the

Body Image Questionnaire,¹⁰ and .93 for the Pain & Vitality domain and .94 for the BI domain of the LupusPRO questionnaire.²⁵ In studies that did not calculate Cronbach's alpha, evaluations from previous studies were reported.²⁶⁻³⁰

Quantitative studies carried out bivariate analyses using the following statistical tests: (a) Chi-squared test;^{24,27-29,31} (b) Student's *t* test;^{10,26,30,31} (c) one-way analysis of variance (ANOVA);^{23,24} (d) Mann-Whitney *U* test;^{27,28} and (e) correlations.^{28,30} When indicated, non-parametric tests were applied.^{28,29,31,32} Some studies also performed multivariate analyses.^{10,24-27,30}

Qualitative studies examining the singularity of living experiences, the emerging cascading process, and the revelations of the participants³³ included 4 phenomenological studies,^{11,34-36} 3 conceptual analysis studies based on focus groups,³⁷⁻³⁹ and a content analysis of individual discourse in 3 studies.⁴⁰⁻⁴² The data interpretation process was supported by Dedoose software⁴³ in 1 case³⁸ and NVIVO software⁴⁴ in 2 cases,^{40,42} whereas 7 cases did not clarify whether data were analyzed manually or with software.

Table 1 presents a summary of the structures of the 22 selected articles.

3.3 | Critical appraisal

In addition to the thematic analysis, articles were evaluated for methodological quality and the risk of bias separately by 2 authors (Figure 3). All studies met more than 70% of the criteria for methodological quality, which ranged between moderate and high. In the case of the level of evidence, 50% of the studies were at level 4b, 45.5% at level 3, and 4.5% at level 2c.

2010	2011	2012	2013	2014	2015	2016	2018	2019	2020
USA/UK	USA	USA/Brazil	Brazil Netherlands New Zealand	USA/UK/ Austria/Germany Sweden/Romania	USA/China	USA	USA Denmark	USA South Africa Taiwan	Brazil
Women with Systemic Lupus									
Quality of life related to body image	Psychosocial challenges Impact in physical and emotional well-being association with sociodemographic and medical regimens related to body image	Association with comorbidity and health limitations related to body image To give mean to diagnosis and to reorganize new fronts in daily life related to body image	Conceptions assigned to be illness related to body image Illness and medication perception and association with sociodemographic related to body image	Body-image intervention and health outcomes Social and Interpersonal experiences of immigrants related to body image Daily functionality in rheumatic's patients related to body image	Clinical and Sociodemographic and association with impact on sexual function and related to body image Experience toward diagnosis related to body image	Treatment received by indigents in the public sector vs. non-indigents in the private sector related to body image	Quality of life and unmet needs related to body image Initial experiences toward diagnosis related to body image	Prevalence of symptom perception and association with sleep quality and depression related to body image Quality of life related to body image Experience of south African women about living with LES related to body image	Perceptions of pregnant women about pregnancy and LES related to body image

FIGURE 2 Publication in the last 10 years on various topics related to body image in the discussion of article



TABLE 1 Studies included in this review

Study	Sample	Objective	Study design/ evidence level/ collection/ measures	Main results
Auerback and Beckerman, 2011 ²³ USA	N = 378, 357 female; 13 male Age: 21–60 y	To identify and to clarify the unique psychosocial challenges for those living with SLE	Cross-sectional, descriptive & observational study Level 4b - SLENQ - Psychosocial needs and beliefs. Considering 3 subscales: depression, anxiety, social economic coping (SEC); - MHLOC - Multidimensional Health Locus of Control Scale: 2 subscales: chance and internal	Changes in the body have been associated with depression, as well as limitations with SLE and the side effects of treatment Changes in appearance were also associated with anxiety, as well as the feeling of injustice for being affected by the disease, anger because of SLE, perception of an uncertain future, side effects from treatment
Beckerman et al. 2011 ²⁴ USA	N = 378, 357 female; 13 male Age: 20–67 y	To identify psychosocial experiences To identify what ethnicities may be at risk for which psychosocial stressors	Cross-sectional Approach: quantitative study - Level 4b - SLENQ - Psychosocial needs and beliefs Considering 3 subscales: depression, anxiety, SEC MHLOC Scale: 2 subscales: chance and internal Side effects of medication	There were the following associations with changes in body image: changes in the body with depression; changes in appearance with the perception of the side effect of the medication (greater with the use of hydroxychloroquine and corticosteroids), hair loss with a higher degree of depression; weight gain with greater need for psychosocial care (for Hispanics); hair loss and muscle pain with feelings of depression and anxiety; hair loss with higher levels of anxiety
Beckerman, 2011 ²⁷ USA	N = 32, 29 female; 3 male Age: Under 35 y = 19; over 35 y = 13	The purpose was the further identification and clarification of unique psychosocial challenges for those living with SLE	Qualitative study Meaningfulness for qualitative studies Level 3 Focus group to explore, in an open way, how this disease affected women's lives, in a safe environment to talk about their shared and unique experiences Thematic content analysis was used	Body image, self-concept and the inability to function as before were related to feelings of depression. The reports are that the participants ceased to be who they were before the beginning of SLE
Chiang et al. 2019 ²⁶ Taiwan	N = 75, 67 female; 8 male Mean age 23.0 (range: 9.6–37.2)	Explore prevalence of symptoms perceived by SLE patients Develop groups of symptoms Examine the association of the load of each group of symptoms with sleep quality and depression	Descriptive correlational study Level 4b SSC (SLE Symptom Checklist) PSQI (Pittsburgh sleep quality) BDI (Beck Depression Inventory II) Demographic: treatment information; the medical impact; SFQ (Sexual Functioning Questionnaire); B-IPQ (Brief Illness Perception Questionnaire)	5 groups of symptoms prevailed: symptoms related to body image and circulatory problems, white fingers in the cold, hair loss and sensitivity to sunlight; symptoms related to weight gain: cheeks / face, more appetite and nightmares: symptoms related to pain and itching: aching joints, aching muscles, headache and itching; symptoms related to bruises and stomach complaints: spontaneous hematomas and stomach complaints; symptoms related to fatigue: fatigue, mood swings, loss of concentration, disturbed memory and skin vulnerability

(Continues)



TABLE 1 (Continued)

Study	Sample	Objective	Study design/ evidence level/ collection/ measures	Main results
Cordeiro and Andrade 2012 ³⁴ Brazil	N = 10 female = 100% Age >18 y	Understand the meaning attributed by women to the fact that they have a diagnosis of lupus	Qualitative study with phenomenology meaningfulness for qualitative studies Level 3 Face-to-face interview, with the following question: How do you feel, as a woman, to have a diagnosis of lupus?	Self-image has changes imposed by lupus, participants feel it in the relationship with family and in the development of activities daily Participants need care with clinical manifestations and psychological aspects of this pathology, helping them to develop a positive self-image, guiding them with self-care, control and prevention of possible complications
Daleboudt et al. 2013 ³⁰ The Netherlands New Zealand	N = 106 participants, female = 94.3%; male = 5.7% Mean age = 43.34 y (SD = 14.96)	Access the influence of SLE on sexual function Investigate the association between sexuality and perception of the disease and sociodemographic aspects Compare sexual functions of patients with SLE and other chronic diseases	Cross-sectional approach Quantitative study Level 4b PDSBE (Physical Disability and Sexual and Body Esteem scale) SFQ (Medical Impact Scale of the Sexual Functioning Questionnaire) B-IPQ (Brief Illness Perception Questionnaire)	The perception of changes in body image of patients was to experience negative effects of SLE on their sexual functioning, especially on their sexual and body esteem The perception of the disease was a more important predictor than the sociodemographic and clinical characteristics of sexual functioning The influence of SLE on sexual functioning appears to be disease-specific, unlike other chronic diseases
Gholizadeh et al. 2019 ²⁵ USA	N = 135 female 92.6%; male 7.4% Mean age: 48.54 (13.9)	Examined whether body image (specifically, body image-related quality of life) serves as a mediator of the relationship between pain and depressive symptoms among patients with SLE	Cross-sectional approach Quantitative study Level 4b LupusPRO Pain and Vitality LupusPRO Body Image HADS (Hospital anxiety and Depression Scale)	Body image related quality of life was a significant mediator in the relationship between pain and depressive symptoms
Hale et al. 2015 ¹¹ USA	N = 15; female = 14 (94%); male = 1 (6%) Ages ranged: 22 to 57 y	To understand experiences within a group of patients diagnosed with SLE	Cross-sectional approach Qualitative study Meaningfulness for qualitative studies Level 3 Qualitative mode of enquiry using semi-structured interviews with audio-records: (Q1: what body image and self-image meant to patients; Q2: how they cope about their medication's effects)	Women often refer to the appearance of women and compare themselves to other women Matter with skin, weight or functional problems Participants felt that, when more confident, they were less concerned with the external appearance, emphasizing their self-image Participants feel more prepared to address other people's comments or opinions when they receive interventions on psychosocial issues, such as social skills training

(Continues)



TABLE 1 (Continued)

Study	Sample	Objective	Study design/ evidence level/ collection/ measures	Main results
Jolly et al. 2010 ²⁸ USA	N = 185 patients; female = 174 (94%); male = 11 (6%) Mean age: 42.2 ± 14.5 y	To characterize US patients regarding demographic and LupusQoL-US	Cross-sectional approach Quantitative study Level 4b LupusQoL-US domains: Physical health, Pain, Planning, Intimate Relationships, Burden to others, Emotional health, Body image, and Fatigue	Alpecia correlated with body image, intimate relationships and pain Age was associated with body image domain Skin damage was associated with body image domain in LupusQoL
Jolly et al. 2012 ²² USA	N = 165 participants Control group: 78 healthy (47.27%), experimental group: 87 SLE (52.72%) Age: 42.4 ± 13.1 for SLE and 38.7 ± 13.2 y for non-SLE subjects	To compare body image-related QoL (healthy and SLE patients) To determine associations: Body Image Quality of Life Inventory (BIQLI) and disease features, comorbid conditions and health-related QoL To determine the amount of variation in Health-related QoL (HRQoL) explained by disease activity, damage and body image	Cross-sectional approach Quantitative study Level 4b Body mass index BIQLI HRQoL SF-6D (functional status index; a variant of SF-36) EQ-5D (health status index)	Poor body image is a realistic problem that patients with SLE frequently face, and this needs to be addressed through focused on cutaneous disease activity, damage and depression Patients with SLE have significantly worse body image-related QoL than age-matched non-SLE controls Considering SLE patients, body image-related QoL has negative correlation with alopecia, irreversible cutaneous damage, depression Considering SLE patients, body image-related QoL was positive
Jolly et al. 2014 ³¹ USA	N = 15 Intervention group: 10; control group: 5 Mean age = intervention group 43.2 (12.2), control group 44.4 (8.7)	Determine the feasibility and effectiveness of a novel body image intervention in improving body image - Determine health outcomes among women	Quasi-experimental study approach Quantitative study Level 2c BILS Body-image measures (Body Image in Lupus Scale) MBSRQ (Multidimensional Body Self-relations Questionnaire) Appearance Scale) Psychological health measures: (CES-D Center for Epidemiological Studies Depression; STAI State Trait Anxiety Index) QoL: (LupusPRO)	Major improvements in body image were seen after body image interventions Body image was modified in patients with SLE, improving psychological well-being and QoL, maintaining this improvement over time
Jolly et al. 2018 ³² USA	N: 1259 patients with lupus nephritis (LN) Median age: 41.7 (13.5)	Describe HRQoL (lupus symptoms and medication; cognition; procreation; physical and emotional health; pain vitality; body image) and non-HRQoL (desire goals; social support; satisfaction care)	Cross-sectional approach Quantitative study Level 4b BILS body image measures: (Body Image in Lupus Scale; MBSRQ, Multidimensional Body Self-relations Questionnaire; Appearance Scale) Psychological Health Measures: (CES-D; STAI) QoL: (LupusPRO)	Patients with LN were younger had worse HRQoL and non-HRQoL Specific domains of HRQoL adversely affected include lupus symptoms, medications, procreation, emotional health, body image and desire goals Among patients with LN and active LN, lupus medications and procreation HRQoL are significantly adversely impacted, independent of their age, gender, ethnicity and country

(Continues)



TABLE 1 (Continued)

Study	Sample	Objective	Study design/ evidence level/ collection/ measures	Main results
Larsen et al. 2018 ³⁵ Denmark	N = 15 women Mean age = 45.6	To explore the experience of being diagnosed with SLE as an existential phenomenon	Cross-sectional approach Qualitative study Meaningfulness for qualitative studies Level 3 Semi-structured interview Van Manen's phenomenology of practice	About self-concept, receiving the diagnosis of lupus is an experience that suspends life, increasing uncertainties in the present and in the future, is to find yourself in a whirlwind of events, is to step on uneven ground and be at an inflection point with yourself and with others
Ogunsanya 2018 ³⁸ USA	N = 19, female = 18 (94.7%); male = 1 Mean age: 49 ± 14	To explore patients' views on how cutaneous lupus has affected their lives and the unmet needs with regard to SLE treatment and care	Qualitative study Meaningfulness for qualitative studies Level 3 Focus group discussion guide based on the themes Understanding the impact of SLE on patients' lives; Unmet needs in relation to treatment and care for SLE	Changes in appearance extrapolated the image and patients used several coping mechanisms, both positive and negative, to mitigate the effects of cutaneous lupus Several themes captured the burden of cutaneous lupus in patients; these ranged from disease sequelae and social effects to functioning
Phuti et al. 2019 ⁴⁰ South Africa	N = 25 women Mean age: 30.9 y (range: 22-45)	To explore living experiences, perceptions and unmet needs of South African patients with SLE	Qualitative study Meaningfulness for qualitative studies Level 3 Individual in-depth interviews exploring their physical concerns, emotional health, sexual well-being and fertility	Changes in self-image have been associated with physical disfigurements resulting from lupus as alopecia, skin rashes and weight fluctuations induced by corticosteroids were a major concern. These changes were also associated with affected libido, leading to strained personal relationships
Rodrigues et al. 2020 ⁴² Brazil	N = 26 pregnant women Mean age: 30 (SD 14.85)	To understand the meanings attributed to pregnancy by pregnant women with SLE during prenatal care	Qualitative study Meaningfulness for qualitative studies Level 3 Face-to-face interview with semi-structured script with open-ended questions with the following themes: feelings about being an SLE carrier, experience with carrying this disease while being pregnant, pregnancy monitoring, sexual behaviors after finding out about the illness and pregnancy, and daily life	Changes in self-concept and body image are associated with disease and the side effects of drugs used to control lupus, which can prevent pregnant women with lupus from identifying with themselves. This engenders psychological and social impacts activated by the visibility of the disease. Participants reported experiencing social isolation, sadness, and hopelessness because of their disease-related self-image
Rodriguez-Rivera et al 2016 ²⁹ USA	N = 98 patients disadvantaged = 40; private care = 58 Female = 94 (95.9%); male = 4 (4.1%) Mean age = 44.9 (SD 12)	To determine patient-reported outcomes measures To compare outcomes between public sector patients and private sector patients	Cross-sectional approach Quantitative study Level 4b LupusPRO HRQoL (8 domains; body image is 8th domain) Non-HRQoL (4 domains)	No significant differences were observed for the domains of body image Patients from the public sector reported better coping than the private group

(Continues)



TABLE 1 (Continued)

Study	Sample	Objective	Study design/ evidence level/ collection/ measures	Main results
Rutter and Kiemle 2014 ³⁶ UK	N = 6 female 100% Mean age = 42 (28-47)	To describe interpersonal experiences considering their ethnicity and cultural influences	Cross-sectional approach Qualitative study Meaningfulness for qualitative studies Level 3 Phenomenological interpretative analysis with semi-structured questions: (a) SLE diagnosis, physical effects, social function, sense of self, relationships, intimacy and the future	Body image and changes in the appearance of SLE medications were related to the feeling of helplessness. 5 themes arise: (a) SLE: complexities and ironies; (b) the power of SLE; (c) sense of personal responsibility; (d) essential relationships, qualities and consequences; (e) fighting in the public's view.
Shen et al. 2015 ¹⁰ China	N = 352 participants (26 missing) 156 patients (SLE experimental group) 210 healthy (control group) Female = 142 patients (91%); 176 healthy (89.8%); male = 14 (9%); 20 healthy (10.2%) Mean age = 32.9 (\pm 10.2) patients; 35.0 (\pm 11.4) healthy	To examine the association between BID and sexual function	Cross-sectional approach Quantitative study Level 4b BID Body Image Disturbance (7 subscale) SAS Revised Self-Rating Anxiety Scale SDS Revised Self-Rating Depression Scale SF-36 QoL	In patients group, BID generally, has significant correlations with partner relationship; also BID generally, has significant correlations with sexual function. Patients have higher risk for anxiety than healthy group There were significant differences in sexual relationship impairment between patients and healthy, sexual partner relationships were disturbed by appearance-related concerns
Stamm et al. 2014 ³⁹ Austria	N = 229 patients (21 with SLE) Female = 20 (95%), male = 1 (5%) Age = 21-38 y	To compare and contrast the concepts of functioning in daily life in patients with different rheumatological conditions (multicentric 8 countries)	Cross-sectional approach Qualitative study Meaningfulness for qualitative studies level 3 focus group (3-8 people with SLE) interviews (6 open questions) supported by the who international classification of functioning, disability and health (ICF) (body functions and structures; activities and participation; environmental and personal factors)	Patients report: body image and appearance: changes in the body as a whole, but also specific parts (skin; weight loss) and attitudes of others (based on appearance); (1) positive attitudes recognized by family members, colleagues; (2) negative attitudes recognized by strangers, employers and society in general
Xavier et al. 2013 ⁴¹ Brazil	N = 9 female patients (100%) Age = 21-38 y	To understand the conceptions attributed to the disease process	Cross-sectional approach Qualitative study Meaningfulness for qualitative studies Level 3 Semi-structured interviews (13 questions: life course from getting sick to the moment; patient perspective about treatment; describes the relationship with their doctor; how patient defines her pathology; how patient defines the association between her illness and the specific events in her life)	Body image and lupus as a unknown body: (a) negative feelings (strangeness, horror, anguish, shame); (b) the brand of a new image permanently/ chronically sick 5 themes: (a) the onset of the disease; (b) body and lupus; (c) treatment; (d) lupus and its causes; (e) the doctor's speech about lupus

(Continues)



TABLE 1 (Continued)

Study	Sample	Objective	Study design/ evidence level/ collection/ measures	Main results
Zhao, et al. 2018 ²⁷ China	N = 256 participants; 109 patients (experimental group), 128 healthy (control group) Missing 19 (9 patients; 10 healthy) Female = 101 patients (92.7%); 114 healthy (89.1%); male = 8 patients (7.3%); 14 healthy (10.9%) Mean age = 33 (SD 17) patients; 36.5 (SD 16.8) healthy	To investigate the relationship among psychological status, QoL, self-esteem, social support, BID To explore risk factors of BID	Cross-sectional approach Quantitative study Level 4b IDB (Body Image Disruption), 5 scales; IDB > 0.30 = disturbance HADS Rosenberg self-esteem SSRS (social support rating scale) HRQoL and LupusQoL	BDI higher in patients than in healthy ($P < .05$ in all 7 dimensions) LupusQoL in patients: body image the best score BID association with: personal health insurance, diabetes complication, appearance of new rash, depression, anxiety, self-esteem Risk factors for BID: appearance of new rash, high anxiety

3.4 | Thematic categories

Three thematic categories were created from the themes that emerged from the data to organize and present the meta-aggregation^{20,21} performed during the analysis of the articles: (1) depression and anxiety associates with body changes (hair loss, weight gain); (2) BI reflecting the disease; and (3) confrontations and interventions to promote acceptance and adaptation to the new image.

Within each category, the results of the qualitative and quantitative studies are presented separately for didactic purposes. However, the complementarity of these studies is emphasized in the answer to the question that guides this review. Figure 4 shows the clustering of the studies.

3.4.1 | Depression and anxiety associates with body changes (hair loss, weight gain)

The disease causes body changes and the medications used to treat it cause significant discomfort.

BI, self-concept, and the use of SLE medications

SLE is commonly associated with hair loss and changes in appearance,^{23,40} as well as psychosocial needs³⁷ and symptoms related to vasoconstriction.²⁶ Emotional and sexual life is disturbed,^{10,29} and QoL suffers as a result of the disease.^{22,24} In addition, problems with facial appearance and weight have a strong correlation with BI.^{27,40}

QoL related to BI mediates the relationship between pain and depressive symptoms.²⁵

Medications sometimes made participants feel worse than before treatment, and the discontinuation of treatment or non-adherence to medication due to side effects was not uncommon.¹¹

The process of changes in BI brought about by SLE involves uncertainties, losses, and pain and is permeated by anguish.⁴¹

Visibility of disease and the judgment of others

Gender identity is often influenced by BI. Once an SLE patient compares themselves to stereotypes,¹¹ they experience a sense of lost identity³⁵ and withdraw from social interaction. A sense of having no autonomy in deciding how to get better may also emerge, and the patient may submit themselves to their sick body.³⁶ Furthermore, body shame and low self-esteem can increase feelings of self-destruction.^{27,35}

SLE patients felt they did not recognize themselves when looking in the mirror because they felt that the skin and hair damage altered their appearance, making the disease visible, and, therefore, making the situation more serious.³⁴ There is dissatisfaction related to BI due to the visibility of skin changes, such as scars, alopecia and depigmentation and weight gain (due to the use of steroids).³⁸

	Beckerman 2011	Cordeiro 2013	Hale 2015	Larsen 2018	Ogunsanya 2018	Puthi 2019	Rodrigues 2020	Rutter 2015	Stam 2014	Xavier 2013
1. Is there congruity between the stated philosophical perspective and the research methodology?	●	●	●	●	●	●	●	●	●	●
2. Is there congruity between the research methodology and the research question or objectives?	●	●	●	●	●	●	●	●	●	●
3. Is there congruity between the research methodology and the methods used to collect data?	●	●	●	●	●	●	●	●	●	●
4. Is there congruity between the research methodology and the representation and analysis of data?	●	●	●	●	●	●	●	●	●	●
5. Is there congruity between the research methodology and the interpretation of results?	●	●	●	●	●	●	●	●	●	●
6. Is there a statement locating the researcher culturally or theoretically?	●	●	●	●	●	●	●	●	●	●
7. Is the influence of the researcher on the research, and vice-versa, addressed?	●	●	●	●	●	●	●	●	●	●
8. Are participants, and their voices, adequately represented?	●	●	●	●	●	●	●	●	●	●
9. Is the research ethical according to current criteria or, for recent studies, and is there evidence of ethical approval by an appropriate body?	●	●	●	●	●	●	●	●	●	●
10. Do the conclusions drawn in the research report flow from the analysis, or interpretation, of the data?	●	●	●	●	●	●	●	●	●	●
Total	9/10	8/10	9/10	10/10	10/10	10/10	10/10	9/10	9/10	8/10
%	90	80	90	100	100	100	100	90	90	80

Qualitative Critical Appraisal

	Auerbach 2011	Beckerman 2011	Chiang 2019	Daleboudt 2013	Gholizade 2019	Jolly 2010	Jolly 2012	Jolly 2018	Rodriguez-Rivera 2016	Shen 2015	Zhao 2018
1. Inclusion criteria are defined	●	●	●	●	●	●	●	●	●	●	●
2. Subjects and context detailed	●	●	●	●	●	●	●	●	●	●	●
3. Exposition measured in a valid and reliable way	●	●	●	●	●	●	●	●	●	●	●
4. Objective and standardized criteria used	●	●	●	●	●	●	●	●	●	●	●
5. Confounding factors identified	●	●	●	●	●	●	●	●	●	●	●
6. Strategies declared to deal with confounding factors	●	●	●	●	●	●	●	●	●	●	●
7. Results evaluated in a valid and reliable way	●	●	●	●	●	●	●	●	●	●	●
8. Appropriate statistics texts	●	●	●	●	●	●	●	●	●	●	●
Total	5/7	7/8	6/7	8/8	6/7	5/7	8/8	7/8	6/7	8/8	7/8
%	71.4	87.5	85.7	100	85.7	71.4	100	87.5	85.7	100	87.5

Cross-sectional Critical Appraisal

	Jolly 2014
1. Is it clear "cause" and "effect"	●
2. Participants were in some similar comparison	●
3. Participants had the same treatment	●
4. Control group exists	●
5. Exists multiple measurements before/after intervention	●
6. Follow-up / complete OR differences described and analyzed	●
7. Results included in any comparison measured in the same way	●
8. Results measured reliably	●
9. Appropriate statistics texts	●
Total	9/9
%	100

Quasi-experimental critical appraisal

● NA ● No ● Yes ● Unclear

FIGURE 3 Quality appraisal of the included studies

3.4.2 | BI reflecting the disease

Appearance does not reflect who people with lupus nephritis are.^{29,31} Ethnicity and other individual factors have an impact on the prevalence and severity of the disease, and may generate different feelings about BI in each person.³² Many people with SLE use cosmetics to help their self-image,³¹ a time-consuming and expensive process.²⁹

Pain and swelling in the joints are common for these people, making them unable to participate in activities, which causes insecurity by altering their self-concept.³⁵ Pregnant women in the third trimester feel strange in their own bodies, often experiencing social

isolation, sadness, and hopelessness related to this perception of their BI.⁴² People expressed a desire to have the body they had before the onset of lupus symptoms.³⁸

3.4.3 | Confrontations and interventions to promote acceptance of and adaptation to the new BI

Women with SLE experience major BID; 2 authors explore the relationship between the existence of lupus and BID,^{10,27} and another highlights that women with SLE have a BI related with age but not with time of disease.²⁸ Confrontation with the new BI appears

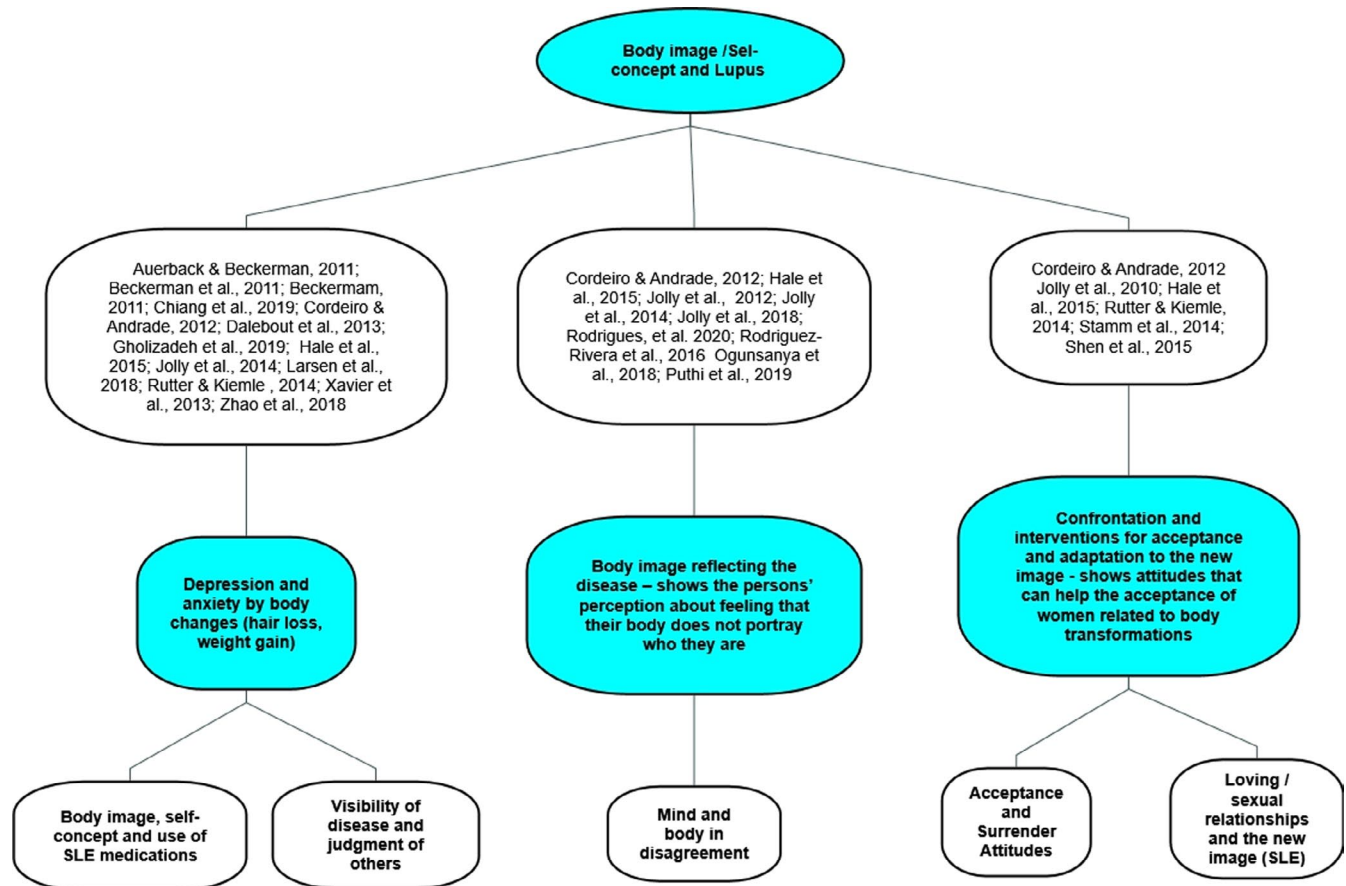


FIGURE 4 Clustering of included studies

to be relevant for the majority of SLE patients, and many change their lifestyles and attitudes to adapt to the disease and to their changing body.³²

3.4.4 | Attitudes of acceptance and surrender

Acceptance of the disease, expressed as surrendered attitudes, suggests an internal lived experience.³⁵ Forms of communication such as irony, to better face the disease and remain unhurt, are common.³⁶ Better acceptance of oneself can be achieved by integrating into patient groups.³⁹

3.4.5 | Loving/sexual relationships and acceptance of the changed body

Appearance-related concerns and sexual problems are associated¹⁰ with SLE patients. Age, marital status, and BID are predictors of impairments between SLE patients and their partners, whereas BID scores and education are more closely associated with impairments in patients' sexual functioning.¹⁰

Unattractiveness is a major feeling reported by women with SLE, compared to those with other chronic diseases.³⁰ However, their

emotions and feeling of coherence could explain the participants' perception of attractiveness.³⁰ Impaired sexual function, related to distress and deficiencies in the patient's social life, suggests a link between physical function and psychological function, which can contribute to sexual health and overall QoL.¹⁰

The female role in marriage intimacy, pertinent to most women, is often not fulfilled once BI issues are exacerbated.³⁶ A restricted life and the loss of experiences and relationships bring feelings of helplessness and small horizons.³⁶ These disease limitations significantly affect relationships.¹⁰

4 | DISCUSSION

4.1 | Considerations of study design and population representativeness

The results of this review are representative in terms of the SLE population. The 3394 participants in the studies came from 5 continents: Asia (Taiwan and China), Africa (South Africa), North and South America (USA and Brazil), Europe (Denmark, UK, Austria, Netherlands), and Oceania (New Zealand). Given the assessment of such a diverse population, it makes sense that BI, a burning problem among people with lupus, should be explored in different cultures.



4.2 | Considerations of measures of self-image

All instruments used in the studies included in this review are validated and widely used in research. However, we emphasize that while some instruments focused on BI,^{10,22,27,31,32} others did not. Instead, they concentrated on issues such as QoL,^{18,25,27-29} psychosocial needs,^{23,24} quality of sleep, and sexual dysfunction,^{26,30} but used BI as a questionnaire domain to measure these factors; therefore, they provide information on BI for discussion, even if indirectly.

4.3 | Synthesis of research findings

Focusing on the changes and adaptations that occur in the BI of people with SLE (primary interest) and on their self-concept (secondary interest) (considering: [a] the perceptions that patients have of their bodily changes; [b] how patients deal with changes in their bodies; and [c] what are their perceptions of bodily changes), 3 thematic categories that were elaborated from the themes emerged from the data: (a) depression and anxiety caused by bodily changes (hair loss and weight gain); (b) BI reflecting the SLE, demonstrating the person's perception that their body does not portray who they are; and (c) coping and interventions for acceptance and adaptation to the new BI, indicating attitudes that can facilitate women's acceptance of bodily transformations.

The most reported and evaluated feelings associated with BI changes were depression,²²⁻²⁷ anxiety,^{10,23,24,27} social isolation,⁴² anguish,⁴¹ and helplessness.³⁶ These feelings can lead to illness if adequate support is not provided for coping with them, leading to aggravation of the condition of the person with SLE.⁴⁵ In addition, a feeling of loss and a lack of functionality related to the chronicity of the disease were reported.³⁹

The condition of individuals with lupus is like that of chronic patients, and the limitations imposed can cause suffering, anguish, uncertainty, loss, and pain.⁴¹ Despite having the same disease, with the same symptoms and even the same treatments (medication and dosage), each patient's experience of SLE is unique;⁴¹ therefore, BI and self-concept can be altered by the conditions imposed by the disease, which may have an impact on sexual behavior²⁷ and personal relationships.¹¹

Having and maintaining a positive attitude under disease conditions can be an actively difficult pursuit, and individuals with SLE must preserve their self-image despite the changes caused by the disease. Therefore, people with lupus report the use of "symbolic masks" to hide, such as keeping a smile on their face or appearing to be strong and cheerful, to meet the expectations of others, even if they are experiencing deep sadness¹¹ as a result of loss of identity,³⁴ which must be reconstructed.

People with lupus report a lack of support for the psychosocial aspects of the disease.¹¹ In the case of physical aspects, they feel that their bodies are no longer reliable compared to when they were healthy; thus, normal functioning becomes strange and activities of everyday life require great effort.³⁴

4.4 | Limitations of primary studies

Although SLE most often affects women, some studies used mixed samples. Therefore, we chose to exclude studies that did not reflect the gender proportion indicated in the literature, which is 1 man to every 9 women with SLE.¹² From a gender perspective, studies should be designed to include only women or only men. However, we ensured that the studies considered in the review predominantly included female subjects; therefore, the themes identified here reflect the responses of women to BI and self-concept. The heterogeneity of the studies did not permit a deeper comparative analysis.

4.5 | Strengths of the systematic review

The present study provides a comprehensive explanation of the phenomena related to BI in SLE. As the participants of the selected studies were women, our review brings a gender perspective that may be different, given society's stereotypes of female BI.

4.6 | Implications for research

We argue that the effects of the psychosocial issues related to BI are essential considerations for health professionals when treating people with SLE.

Ongoing research examining the association of depression and anxiety with BID and SLE and potential associations with other mental disorders remains important.

The use of extensive questionnaires, which can identify different aspects of BI in people with SLE, and the addressing of cultural differences, nuances, and the meanings of each concept are also suggested. We recognize that there are limitations on the description of strategies or interventions that help to adapt to changes in BI of people with lupus; this is an important issue to focus on in research.

4.7 | Implications for clinical practice

The starting point for clinical practice is the consideration by health professionals of the effects of the disease and treatment on the external appearance of patients and recognition of the associations of BI with anxiety and depression. Likewise, professionals need to value the difficulties and psychosocial pressures faced by people with SLE that have an impact on the process of coping with the disease and changes in BI and self-concept. Professionals must value how existential experiences can result in a paradoxical and turbulent period after the individual is diagnosed with SLE. Orientation activities are the initial strategy to deal with this issue.

Knowledge and presentation of therapeutic options can prevent or limit adverse effects and ameliorate the negative impacts of BI on QoL. These options include: (a) the use of sunscreen; (b) early referral, screening, and treatment of active disease, thereby



limiting organ involvement and preventing impairment;^{21,28} (c) training in the use of suitable cosmetics;³¹ (d) early diagnosis, referral, and treatment of depression;^{22,23,25} and (e) coping and self-esteem exercises.^{31,34}

4.8 | Recommendations

We summarize 3 main recommendations for health professionals: (a) the need to value the importance of changes in BI and the self-concept of people with lupus, in the same way that their experience of pain and physical limitations is valued, since the literature exposes the impact of these changes; (b) the need to consider psychosocial problems and early screening for symptoms of illnesses due to depression, anxiety and relationship problems (eg, social isolation and helplessness) as the literature shows that they are associated with BI; and (c) the need to offer products, such as cosmetics, that can assist in coping with BI changes, since good results have been shown in a pilot study.

5 | CONCLUSION

Based on references available in databases, we believe to the best of our knowledge that our study is the first systematic review of BI and self-concept in people suffering from SLE. The most common changes reported were weight gain and changes in skin, hair, and joints, which impacted BI and functionality. The most reported feelings related to these changes were depression, anxiety, social isolation, helplessness, and anguish. Feelings of loss and lack of functionality were also related to the chronicity of the disease.

This study highlights the crucial importance of the dimensions of self-concept and BI for assessing QoL of individuals with lupus. These aspects can reveal the patient's relationship with SLE and how it can impact his/her life, particularly if these issues are not actively addressed by health professionals.

ACKNOWLEDGEMENTS

Providing validation of search: SARHAS'Lab, UEVORA. Providing language help: Cambridge Proofreading.

CONFLICT OF INTEREST

None declared.

ETHICS APPROVAL

Formal ethics approval is not required for this type of study.

STATEMENT REGARDING INFORMED CONSENT

Formal consent is not required for this type of study.

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How to cite this article: Rodrigues L, Sim-Sim MMF, Sousa L, Faria-Schützer DB, Surita FG. Self-concept and body image of people living with lupus: A systematic review. *Int J Rheum Dis*. 2021;00:1-15. <https://doi.org/10.1111/1756-185X.14187>