# STUDI LITERATURE: MEKANISME KOPING PADA PASIEN SLE (*SYSTEMIC LUPUS ERYTHEMATOSUS*)

**SKRIPSI**


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**PROGRAM STUDI ILMU KEPERAWATAN**

**INSTITUT TEKNOLOGI KESEHATAN DAN SAINS WIYATA HUSADA SAMARINDA**



**2020**

# STUDI LITERATURE: MEKANISME KOPING PADA PASIEN SLE (*SYSTEMIC LUPUS ERYTHEMATOSUS*)

**SKRIPSI**

Untuk memenuhi sebagai persyaratan untuk mencapai derajat Sarjana Keperawatan (S.Kep) pada Program Studi Ilmu Keperawatan


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Samarinda, 20 Agustus 2020

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# KATA PENGANTAR

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Dengan ini menyetujui dan memberikan hak kepada ITKES Wiyata Husada Samarinda atas karya ilmiah saya yang berjudul:

**Studi Literature: Mekanisme Koping Pada Pasien SLE (Systemic Lupus Erythematosus)**

Beserta perangkat yang ada (jika diperlukan). Dengan ini, ITKES Wiyata husada berhak menyimpan, mengalihmedia/formatkan, mengelola dalam bentuk pangkalan data (database), merawat dan mempublikasikan tugas akhir saya selama tetap mencantumkan nama saya sebagai penulis dan pemilik hak cipta.

Demikian pernyataan ini saya buat dengan sebenar-benarnya.



Samarinda, 20 Agustus 2020

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# ABSTRAK

## STUDI LITERATURE: MEKANISME KOPING PADA PASIEN *SLE (SYSTEMIC LUPUS ERYTHEMATOSUS)*

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**Latar Belakang:** Pasien lupus menggunakan mekanime koping untuk menghadapi situasi yang dirasakan sebagai tekanan dan tidak menyenangkan karena sakitnya. **Tujuan:** Teranalisis mekanisme koping pada penderita SLE (Systemic Lupus Erythematosus). **Metode**: Studi literature yang menggunakan format PICOS fremwork dengan mesin pencari menggunakan tiga *database Pubmed, Springer Link, SAGE Journal*. Seleksi berdasarkan judul, tahun publikasi 2015-2020, full-text, Bahasa Inggris. Didapatkan 8 artikel yang menganalisis mekanisme koping pada pasien SLE. **Hasil:** mekenisme koping pada literature ini yaitu mekanisme koping yang maladaptif dalam literature ini ditunjukkan dengan pasien yang menjaukan dirinya, khawatir dengan kondisinya, perubahan pada fisiknya, kurangnya dukungan sosial, menyalahkan diri sendiri, melarikan diri dan menghindar.**Kesimpulan:** Dengan adanya dukungan sosial yang didapatkan oleh individu, maka individu akan dapat meningkatkan rasa percaya dirinya, memotivasi penderita menjadi lebih baik, lebih semangat dalam menjalani hidup, lebih bisa memaknai hidup sebagai hal yang positif, dan mulai memiliki rasa percaya diri.

**Kata Kunci:** Mekanisme Koping, SLE *(Systemic Lupus Erythematosus)*

## ABSTRACT

### LITERATURE STUDY: MECHANISM OF THE KOPING IN SLE PATIENTS (*SYSTEMIC LUPUS ERYTHEMATOSUS*)



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**Background:** Lupus patients use coping mechanisms to deal with situations that are perceived as stressful and unpleasant because of their illness. **Objective:** To analyze the coping mechanism in patients with SLE (Systemic Lupus Erythematosus**). Method:** Literature studi using PICOS fremwork format with a search engine using three databases Pubmed, Springer Link, SAGE Journal. Selection by title, publication year 2015-2020, full-text, English. There were 8 articles that analyzed the coping mechanisms in SLE patients. **Result:** The coping mechanism in this literature is a maladaptive coping mechanism in this literature shown by patients who distance themselves, are worried about their condition, changes in their physical condition, lack of social support, blame themselves, run away and avoid. **Conclusion:** With social support that is obtained by the individual, the individual will be able to increase his self-confidence, motivate the sufferer to be better, to be more enthusiastic in living life, to be more able to interpret life as a positive thing, and to start having self-confidence.



**Keywords:** Coping Mechanism, SLE *(Systemic Lupus Erythematosus*)

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# BAB I
# PENDAHULUAN

## A. Latar Belakang

Lupus merupakan penyakit imflamasi kronik yang menyerang jaringan ikat dan ditandai dengan adanya perubahan respon imunologi, dimana sistem kekebalan tubuh mulai menyerang jaringan dan organ tubuh sendiri (Pusdatin, 2017). System kekebalan tubuh orang dengan lupus atau odapus (setalah disebut dengan odapus) kehilangan kemampuan untuk membedakan antara substansi asing dengan sel dan jaringan tubuh sendiri, sehingga penyakit ini sering disebut dengan penyakit autoimun. Lupus mengakibatkan iflamasi yang dapat menyerang berbagai organ tubuh, seperti kulit, sendi, sel darah, paru-paru, atau bahkan jantung (Pusdatin, 2017).

Berdasarkan data dari Organisasi Kesehatan Dunia atau WHO yang dikutip oleh Pusdatin (2017) The Lupus Founfation Of America memperikrakan sekitar 1,5 juta kasus terjadi di Amerika dan setidaknya terjadi 5 juta kasus di dunia. Setiap tahun diperkirakan terjadi sekitar 16 ribu kasus baru lupus. Di Indoensia, jumlah penderita penyakit Lupus secara tepat belum diketahui. Prevalensi Systemic Lupus Erythematosus (SLE) di masyarakat berdasarkan survey yang dilakukan oleh Prof. Handono Kalim, dkk diMalang memperlihatkan angka sebesar 0,5% terhadap total populasi (Pusdatin, 2017).

Data dari rumah sakit di Indonesia yang melaporkan datanya pada tahun 2016 (RS Cipto Mangunkusumo, RS Saiful Anwar Malang, RS Muhammad Husin Palembang, RS SardjitoYogyakarta, RS Moewardi Surakarta, RS Sanglah Denpasar, RS Kanujoso Djatiwibowo Balikpapan, dan RSUD Ulin Banjarmasin), menyatakan bahwa terdapat setidaknya 2.166 pasien rawat inap yang didiagnosis penyakit lupus dan 550 diantaranya meninggal dunia (Pusdatin, 2017). Jumlah tersebut mengalami peningkatan sebanyak dua kali lipat dari 2 tahun sebelumnya, dimana pada tahun 2014 terdapat 1.169 kasus dan 200 diantaranya meninggal dunia (Pusdatin, 2017).

Di Kalimantan Timur, sekalipun belum ada jumlah pastinya. Pada tahun 2013 terdata kurang lebih sebanyak 99 odapus yang terdaftar dan tergabung dalam

Support for Odapus (SUFORDA) Kalimantan Timur dan tahun 2019 di RSUD Abdoel Wahab Sjahranie Samarinda terdapat 33 pasien rawat inap yang menderita lupus dan 4 diantaranya meninggal dunia.

Para Odapus harus menghadapi penurunan kondisi fisik dan membutuhkan daya adaptasi yang luar biasa supaya mampu bertahan hidup. Perubahan fisik yang terjadi berupa bercak-bercak kemerahan yang muncul pada wajah, rambut rontok, sensitif terhadap sinar matahari, tubuh mulai bengkak, kulit mulai bersisik dan mulai mengelupas, sariawan di sekitar mulut, rasa nyeri pada persendian tangan dan kaki, sampai pada bagian tubuh yang sulit untuk digerakkan (Prasetyo dan Kustanti, 2014)

Sebagai Odapus, kondisi mereka yang alami akan berdampak besar bagi kehidupan. Mereka tidak hanya merasakan simptom somatis dan kelelahan yang luar biasa. Permasalahan eksistensial, emosi, sosial, dan psikologis, seperti stres, cemas, depresi, serta perubahan peran sosial akibat penyakit juga menjadi permasalahan yang tidak dapat dihindari. Odapus menggunakan mekanime koping untuk menghadapi situasi yang dirasakan sebagai tekanan dan tidak menyenangkan karena sakitnya. Mekanisme yang digunakan ini merupakan cara odapus supaya bisa adaptif dengan sakit yang dideritanya seperti menjaga keseimbangan emosional sehingga tidak terlalu larut dalam masalahnya atau juga menyesuaikan diri dalam kondisi yang mereka alami.

Mekanisme koping dalam penelitian ini mengacu pada berbagai cara yang dilakukan individu untuk menghadapi atau mengatasi stressor yang mengancam baik perilaku dan pikiran yang dilakukan secara sadar untuk mengontrol pengaruh stres yang dialami pada situasi yang tidak menyenangkan dan penuh tekanan. Adapun mekanisme koping yang digunakan Mekanisme koping problem focus, koping cognitively focus dan koping emotion focus.

Berdasarkan hasil peneliti yang digunakan (Cahyaningtyas dan Wisnu,2016) terhadap 6 odapus. Diperoleh hasil bahwa setelah memperoleh diagnosa lupus 83% (5 odapus) mengalami kondisi psikologis seperti drop, sedih, kecewa, perasaan takut di isolasi oleh lingkungan, kaget, pasrah, putus asa, takut dan canggung karena menderita penyakit yang langka, 1 odapus biasa saja. Hasil survei lainnya adalah semua odapus mengalami kondisi tertekan seperti

kehilangan nafsu makan dan tenaga, cepat marah, kehilangan motivasi dan konsentrasi, otot tegang, kepala pusing dan perubahan pola tidur. Selain itu odapus juga harus menghadapi berbagai permasalahan baik dari luar maupun dari dalam diri odapus. Lingkungan yang belum memahami tentang lupus sehingga kurang bisa menerima, dicemooh, dianggap lemah, keluarga kurang peduli, odapus juga mudah merasa lelah sehingga terpaksa harus berhenti dari tempat kerja, hubungan dengan orang terdekat menjadi kurang harmonis, kemudian tidak percaya diri, merasakan demam, nyeri, muncul bintik merah, berat badan meningkat, bantuk dan flu. Setelah melakukan upaya-upaya untuk mengatasi hal tersebut 2 odapus masih mengalami hal yang sama seperti tetap dianggap lemah oleh orang lain dan keluarga tetap tidak peduli, 4 odapus merasa lebih baik.

Berdasarkan fenomena diatas masih adanya Odapus yang belum menerima dirinya sebagai penyandang lupus, rasa malu akibat manisfestasi perubahan penampilan diri baik secara fisik maupun prilaku, belum lagi kepercayaan masyarakat awam yang beranggapan gejala penyakit lupus merupakan penyakit non medis yang hanya dapat disembuhan melalui pengobatan supranatural, terutama pada Odapus yang belum terdeteksi. Berdasarkan fenomena yang telah diuraikan diatas maka perlu dilakukan penelitian yang berjudul "Systematic Literature Review: Mekanisme Koping Pada Pasien SLE (Systemic Lupus Erythematosus)".



## B. Rumusan Masalah

Berdasarkan latar belakang yang dipaparakan, maka dapat dirumuskan masalah penelitian yaitu bagaimana mekanisme koping pada penderita SLE (Systemic Lupus Erythematosus)?

## C. Tujuan Studi Literatur

Teranalisis mekanisme koping pada penderita SLE (Systemic Lupus Erythematosus).

## D. Manfaat Studi Literatur

Manfaat yang diharapkan dari studi literatur ini yaitu :

### 1. Manfaat Teoritis

Studi literatur ini diharapkan dapat memberikan informasi yang dibutuhkan bagi tenaga kesehatan ataupun pemerintah terkait dalam menangani mekanisme koping pada penderita SLE (Systemic Lupus Erythematosus).

### 2. Manfaat Praktis

Secara praktis penelitian ini dapat bermanfaat sebagi berikut:

a. Bagi Peneliti lain

Bagi peneliti lain, data yang didapatkan dari studi literatur ini dapat digunakan untuk penelitian lebih lanjut mengenai mekanisme koping pada penderita SLE (Systemic Lupus Erythematosus)

b. Bagi Institusi Pendidikan

Penelitian ini diharapkan dapat memberi sumbangan positif sebagai bahan acuan untuk insitusi/ yayasan ITKES Wiyata Husada Samarinda dalam rangka meningkatkan mutu pendidikan dimasa yang akan datang serta sebagai dasar pertimbangan terhadap studi literature review mekanisme koping pada penderita SLE (Systemic Lupus Erythematosus)

c. Bagi Peneliti

Sebagai bahan refleksi betapa pentingnya informasi mengenai studi literatur rmekanisme koping pada penderita SLE (Systemic Lupus Erythematosus).

# BAB II
# TINJAUAN PUSTAKA

## A. Telaah Pustaka

### 1. Konsep Penyakit SLE (Systemic Lupus Erythematosus)

#### a. SLE (Systemic Lupus Erythematosus)

SLE adalah gangguan autoimun yang menyerang hampir semua organ dan jaringan (Bertsias et al., 2012).Lupus merupakan penyakit inflamasi kronik sistemik yang menyerang jaringan ikat dan ditandai dengan adanya perubahan respon imunologi, dimana sistem kekebalan tubuh mulai menyerang jaringan dan organ tubuh sendiri (Pusdatin, 2017). Sistem kekebalan tubuh Orang dengan lupus atau Odapus (setelah ini disebut dengan Odapus) kehilangan kemampuan untuk membedakan antara substansi asing dengan sel dan jaringan tubuh sendiri, sehingga penyakit ini sering disebut dengan penyakit autoimun. Lupus mengakibatkan inflamasi yang dapat menyerang berbagai organ tubuh, seperti kulit, sendi, sel darah, paru-paru, atau bahkan jantung (Pusdatin, 2017).



#### b. Faktor Resiko

Penyakit Sistemik Lupus Eritematosus merupakan penyakit inflamasi aotoimun kronis yang belum jelas penyebabnya, memiliki variasi klinis yang luas, dan tampilan perjalanan penyakit yang beragam. Factor genetic, imunologik dan hormonal, serta lingkungan diduga juga berperan dalam perjalanan penyakit.

Faktor resiko penyakit SLE menurut pusdatin (2017) adalah:

1) Faktor genetik: diketahui bahwa sekitar 7% pasien SLE memiliki keluarag dekat (orang tua atau saudara kandung) yang juga terdiagnosis SLE. Oleh karena itu, faktor genetic merupakan salah satu faktor SLE. Sejauh ini diketahui terdapat sekitar 30 variasi gen yang dikaitkan dengan kejadian SLE.
2) Factor lingkungan: infeksi, stress, makanan, antibitik (khususnya kelompok sulfa dan penisilin), cahaya ultraviolet (matahari) dan

penggunaan obat-obat tertentu, merokok, paparan Kristal silica, merupakan faktor pemicu timbulnya SLE.

3) Factor hormonal: perempuan lebih sering terkena penyakit SLE dibandingkan dengan laki-laki. Meningkatnya angka pertumbuhan penyakit SLE sebelum periode menstruasi atau selama kehamilan mendukung dugaan bahwa hormone, khususnya estrogen menjadi pencetus penyakit SLE. Namun, sehingga saat ini belum diketahui secara pasti peran hormone yang menjadi penyebab besarnya prevalensi SLE pada perempuan pada priode tertentu.

**c. Gejala SLE (Systematic Lupus Erythrmatosus)**

Gejala awal kerap mirip dengan penyakit lain sehingga sulit untuk mendiagnosis. Gejala lupus sangat beragam. Ada yang ringan da nada yang bahakan mengancam jiwa. Gejala lupus yang paling sering muncul dari semua pasien tanpa memandang jenis kelamin adalah:

1) Keletihan
2) Sakit kepala
3) Nyeri atau bengkak sendi
4) Demam
5) Anemia (baik karena jumlah sel darah/ haemoglobin kurang, atau karena volume darahnya kurang)
6) Nyeri di dada ketika menarik nafas panjang
7) Ruam kemerahan pada pipi hingga hidung, polanya seperti kupu-kupu
8) Sensitive terhadap cahaya atau cahaya matahari
9) Rambut rontok sampai kebotakan (alopecia)
10) Pendarahan yang tidak biasa
11) Jari-jari berubah pucat atau kebiruan ketika dingin (fenomena Raynaud)
12) Sariawan dimulut atau korang dihidung (Pusdatin, 2017).

**d. Klasifikasi Penyakit Lupus**

Menurut (Pusdatin, 2017) kalsifikasi SLE yaitu :

1) Sistemik Lupus Ertyhematosus (SLE)

Jenis lupus inilah yang paling sering dirujuk masyarakat umum sebagai penyakit lupus. SLE dapat menyerang jaringan organ tubuh mana saja dengan tingkat gejala yang ringan sampai parah. Gejala SLE dapat dating dengan tiba-tiba atau berkembang secara perlahan-lahan atau dapat bertahan lama atau bersifat lebih sementara sebelum akhinya kambuh lagi

Banyak yang hanya merasakan beberapa gejala ringan untuk waktu lama atau bahkan tidak sama sekali sebelum tiba-tiba mengalami serangan yang parah. Gejala-gejala ringan SLE, terutama rasa nyeri dan lelah berkepanjangan, dapat menghambat rutinitas kehidupan, karena itu para penderita SLE bias merasa tertekan, depresi, dan cemas meski hanya mengalami gajala ringan.

2) Lupus Eritematosus Kutaneus (Cuntaneus Lupus Eryhematosus/ CLE)

Dapat dikenali dari ruam yang muncul pada kulit degan berbagai tampilan klinis. Pada lupus jenis ini dapat didiagnosis dengan mengenali gambaran klinis dan beberapa pengujian diantaranya melalui biopsy pada ruam. Pada gambaran biopsi akan terlihat adanya infiltrasi sel inflamasi dan endapan kompleks imun pada batas dermoepidermal yang dikenal dengan lupus band.

3) Lupus Imbas Obat

Efek samping obat beda-beda pada tiap orang. Terdapat lebih dari 100 jenis obat yang dapat menyebabkan efek samping yang mirip dengan gejala lupus pada orang-orang tertentu. Gejala lupus akibat oabt umumnya akan hilang jika berhenti mengonsumsi obat tersebut sehingga tidak perlu menjalani pengobatan khusus. Tetapi perlu diperhatikan untuk tidak lupa berkonsultasi kepada dokter sebelum memutuskan berhenti mengonsumsi obat dengan resep dokter.

4) Sindroma Overla Undifferentiated Connective Tissue (UCTD), dan Mixed Connective Tissue Diasease (MCTD)

Pada sebagian pasein SLE ternyata ditemukan juga menifestasi klinis lain yang memenuhi kriteria diagnostic penyakit autoimun lain seperti artritis rheumatoid, sklerodermam atau myositis. Ada pula pasien SLE yang juga memiliki gejala penyakit autoimun lain namun belum lengkap untuk didiagnosis penyakit autoimun tertentu.

**e. Menifestasi klinis**

1) Konstitusional

Kelelahan merupakan keluhan yang umum pada penderita SLE dan biasanya mendahului berbagai manifestasi klinis lainnya. Penurunan berat badan juga dijumpai pada sebagian penderita SLE disebabkan oleh menurunnya nafsu makan atau diakibatkan gejala gastrointestinal dan terjadi dalam beberapa bulan sebelum diagnosis ditegakkan. Sedangkan demam pada penderita SLE biasanya tidak disertai menggigil (Setiati et al., 2014).

2) Ginjal

Secara klinis penyakit ginjal pada SLE berawal dari proteinuria asimtomatik kemudian berkembang dengan cepat menjadi glomerulonefritis progresif dengan gagal ginjal (Setiati et al., 2014).

3) Sistem Saraf Pusat

Manifestasi SSP terjadi pada sekitar 20% pasien dengan SLE dan biasanya disebabkan oleh vaskulitis serebral atau kerusakan saraf langsung. Manifestasi SSP termasuk psikosis, stroke, kejang, dan mielitis dan berhubungan dengan prognosis keseluruhan yang buruk (Leveno et al., 2009; Manuaba et al., 2008).

4) Muskuloskeletal

Manifestasi muskuloskeletal terjadi sekitar 95% pada pasien SLE dan arthralgia merupakan gejala yang pertama sekitar 50% kasus artritis simetris non erosif paling sering menyerang tangan, pergelangan tangan dan lutut. Selain itu, ditemukan juga mialgia yang terjadi pada 60% kasus (Glick et al., 2008; Levenoet al., 2009).

5) Kulit

Kebanyakan gambaran klinis SLE pada kulit berupa lesi diskoid yang umum bersifat fotosensitif, eritema sedikit meninggi, bersisik, pada wajah bagian pipi dan sekitar hidung yang disebut butterfly rash karena membentuk seperti sayap kupu-kupu (Gambar 2.1.), telinga, dagu, daerah leher, punggung atas, dan bagian ekstensor dari lengan. Manifestasi SLE pada kulit lainnya dapat ditemukan berupa urtikaria rekuren, dermatitis lichen planus-like, bulla, panikulitis (Glick et al., 2008).

**Gambar 2.1.** *Butterfly rash (Web Md, 2013).*



6) Gastrointestinal

Dapat berupa hepatomegali, nyeri perut yang tidak spesifik, splenomegali, peritonitis aseptik, vaskulitis mesenterial, pankreatitis (Perhimpunan Reumatologi Indonesia, 2011; Tsokos et al., 2007).

7) Kardiovaskuler

SLE dapat mengenai perikardium, miokardium, dan endokardium. Perikaditis atau peradangan pada perikardium umum terjadi pada penderita SLE yang mengakibatkan sesak napas dan rasa nyeri tajam seperti di dada seperti terkena serangan jantung (Hamijoyo & Navarra, 2017).

**f. Jenis Terapi Obat Pada Penderita Lupus**

Lupus biasanya ditangani dengan emapt kelompok utama obat, bergantung pada tingkat keparahan penyakitnya. Berikut merupakan obat utama yang dikonsumsi para odapus (orang dengan lupus) (Marriam, 2008).

1) Aspirin dan non-steroid

Adalah obat anti peradangan non-steroid (non-steroidal anti-inflammatory drug, NSAID) digunakan pada pasien yang khususnya menderita nyeri sendi dan otot. Pada pasien yang darahnya kental, aspirin dosis rendah, 75-150 mg setiap hari, digunakan untuk mengencerkan darah.

2) Antimalarial

Obat ini dapat membantu pasien dengan penyakit kulit dan sendi. Antimalarial juga cukup membantu pasien lupus aktif taraf sedang untuk menghindari penggunaan steroid. Hidroksiklorokuin dan mepakrin merupakan jenis antimalarial yang paling banyak digunakan.

3) Steroid

Obat seperti prednisone telah terbukti berperan penting dalam perbaikan lupus dan dapat menyelamatkan nyawa beberapa penderita. Obat ini memberikan dampak yang besar terhadap peradangan dan dapat menekan penyakit lupus. Setelah lupus dapat dikendalikan, penggunaan steroid bias dikurangi secara bertahap dibawah pengawasan dokter.

4) Imunosupresan

Obat ini digunakan dalam terapi penyakit yang lebih berat. Imunosupresan yang paling sering digunakan adalah azatioprin, metotreksat dan siklofosfamid. Individu akan menjalani tes darah secara teratur untuk mengetahui kondisi sumsum tulang dan hati. Individu juga kemungkinan akan menjalani fisioterapi untuk membantu meningkatkan mobilitas sendi yang terserang lupus. Individu harus tetap aktif secara fisik sedapat mungkin. Dengan terapi

ini sebagian besar penderita lupus mampu menjalani kehidupan yang normal dan aktif.

**g. Pemeriksaan Penunjang**

1) Hemoglobin, leukosit, hitung jenis sel, laju endap darah (LED)
2) Urin rutin dan mikroskopik, protein kuantitatif 24 jam, dan bila diperlukan kreatinin urin
3) Kimia darah (ureum, kreatinin, fungsi hati, profil lipid)
4) PT, aPTT pada sindroma antifosfolipid
5) Serologi ANA, anti ds-DNA, komplemen (C3,C4)
6) Foto polos thorax
   a) Pemeriksaan hanya untuk awal diagnosis, tidak diperlukan untuk monitoring
   b) Setiap 3-6 bulan bila stabil
   c) Setiap 3-6 bulan pada pasien dengan penyakit ginjal aktif

Tes imunologik awal yang diperlukan untuk menegakkan diagnosis SLE adalah tes ANA. Tes ANA dikerjakan/diperiksa hanya pada pasien dengan tanda dan gejala mengarah pada SLE. Pada penderita SLE ditemukan tes ANA yang positif sebesar 95-100%, akan tetapi hasil tes ANA dapat positif pada beberapa penyakit lain yang mempunyai gambaran klinis menyerupai SLE misalnya infeksi kronis (tuberkulosis), penyakit autoimun misalnya Mixed Connective Tissue Disease (MCTD), artritis reumatoid, tiroiditis autoimun, atau keganasan.

Jika hasil tes ANA negatif, pengulangan segera tes ANA tidak diperlukan, tetapi perjalanan penyakit reumatik sistemik termasuk SLE seringkali dinamis dan berubah, mungkin diperlukan pengulangan tes ANA pada waktu yang akan datang terutama jika didapatkan gambaran klinis yang mencurigakan.

Test Anti ds-DNA positif menunjang diagnosis SLE, namun jika negatif tidak menyingkirkan diagnosis SLE (Perhimpunan Reumatologi Indonesia, 2011).

## 2. Mekanisme Koping

Mekanisme koping adalah sebagai apa yang dilakukan oleh individu untuk menguasai situasi yang dinilai sebagai suatu tantangan, luka, kehilangan atau ancaman (Siswanto, 2007).

Mekanisme koping lebih mengarah pada yang orang lakukan untuk mengatasi tuntutan – tuntutan yang penuh tekanan atau yang membangkitkan emosi. Penyesuaian diri dalam menghadapi stres, dalam konsep kesehatan mental dikenal dengan istilah koping (Lubis, 2006). Jadi menurut Siswanto dan Lubis mekanisme koping adalah cara yang digunakan individu dalam menyelesaikan masalah, mengatasi perubahan yang terjadi, dan situasi yang mengancam, baik secara kognitif maupun perilaku

### a. Sumber Koping

Sumber koping meliputi aset ekonomi, kemampuan dan keterampilan, teknik pertahanan, dukungan sosial, serta motivasi. (Yusuf, Ah, et al., 2015)



### b. Penggolongan Mekanisme koping

Berdasarkan penggolongannya mekanime koping berpusat pada 3 hal (Stuart & Laraia, 2005):

1) Koping yang berpusat pada masalah (*Problem Focused Coping*)

   Mekanisme ini terdiri atas tugas dan usaha langsung untuk mengatasi ancaman diri. Contoh : negosiasi, konfrontasi dan mencari nasehat.

   a) *Confrontatif* coping adalah mengubah keadaaan yang dianggap menekan dengan cara yang agresif, tingkat kemarahan yang cukup tinggi dan pengambilan resiko.

   b) *Seeking social support* adalah usaha untuk mendapat kenyamanan emosional dan bantuan informasi dari orang lain.

   c) *Planful problem solving* adalah usaha untuk mengubah keadaaan yang dianggap menekan dengan cara hati-hati, bertahap dan analitis.

2) Koping yang berpusat pada kognitif

Mekanisme koping dengan focus kognitif: mekanisme ini merupakan usaha orang untuk mengontrol masalah dan menetralkan masalah tersebut. Misalnya membandingkan secara positif, selektof terhdap ketidaktahuan, dan dievaliasi keinginan objek.

3) Koping yang berpusat pada emosi (*Emotional Focused Coping*)

Usaha mengatasi stress dengan mengatur respon emosional dalam rangka menyesuaikan diri dengan dampak yang ditimbulkan oleh suatu yang dianggap penuh tekanan. Emotional Focused Coping ditunjukan untuk mengatur respon emosional terhadap situasi stress. Stress yang digunakan yaitu; *Sel-Control;* usaha untuk mengatur perasaan ketika menghadapi situasi yang menekan. *Discanting;* usaha untuk tidak terlibat dalam permasalahan, mengindari solah-olah tidak terjadi permasalahan, menciptakan pandangan yang positif. *Positive Reaprisial;* usaha mencari makna positif dari permasalahan dengan berfokus pada pengembangan diri, biasanya bersifat religious. *Escape/Avoidance*; usaha untuk mengatasi situasi menekan dengan lari dari situasi tersebut dan menghindarinya dengan beralih pada hal lain seperti makan, minum, merokok, dan minum-minuman. Pasien menyesuaikan diri terhadap distress emosional secara tidak berlebihan. Contoh menggunakan mekanisme ego seperti denial, supresi atau proyeksi.

**c. Tipe Mekanisme Koping**

Mekanisme koping dibagi menjadi 2 macam, (Stuart & Sundeen, 2013) yaitu:

1) Perilaku berorientasi pada tugas

Perilaku beriorientasi tugas mencangkup penggunaan kemampuan kognitif untuk mengurangi stres, memecahkan masalah, menyelesaikan konflik, dan memenuhi kebutuhan (Stuart & Sundeen, 2005). Perilaku beriorentasi tugas memberdayakan seseorang untuk secara realistic

mengahdapi tuntutan stressor. Tiga tipe umum perilaku beorientasi pada tugas, yaitu;

a) Perilaku menyerang merupakan usaha seseorang mencoba untuk menghilangkan atau mengatasi hambatan dalam rangka memenuhi kebutuhan. Banyak cara dapat dilakukan untuk menyerang masalah, dan reaksi ini bersifat destruktif atau konstruktif. Pola destruktif biasanya disertai dengan perasaaan kemarahan dan permusuhan yang sangat besar. Perasaan ini dapat dinyatakan dengan perilaku negatif atau agresif yang melanggar hak-hak, milik dan kesejahteraan orang lain. Pola konstruktif mencerminkan pendekatan masalah. Mereka secara nyata berperilaku asertif yang menghormati hak-hak orang lain.
b) Perilaku menarik diri dapat dinyatakan secara fisik atau psikologi. Secara fisik, menarik diri melibatkan penghindaran diri dari sumber ancaman, reaksi ini dapat berlaku untuk stresor biologis, seperti kamar penuh asap rokok, paparan radiasi atau kontak dengan penyakit menlar. Seseorang dapat menarik diri dengan cara psikologis, seperti dengan mengakui kekalahan, menjadi apatis, atau menurun aspirasi dan partisipasi, dapat pula seperti reaksi menyerang, reaksi penghindaran yang bersifat konstruktif atau destruktif. Saat seseorang mengisolasi diri dari orang lain akan mengganggu kemampuan bekerja sehingga menimbulkan masalah tambahan.
c) Kompromi melibatkan perubahan cara berfikir seseorang yang biasa tentang hal-hal tertentu, mengganti tujuan atau mengorbankan aspek kebutuhan pribadi.

2) Mekanisme Ego

Mekanisme ego adalah reaksi individu untuk memperlunak kegagalan, menghilangkan kecemasan, mengurangi perasaan yang menyakitkan karena pengalaman yang tidak enak dan juga untuk memoertahankan perasaan layak serta harga diri (W.F.Maramis, 2005). Koping itu sendiri dimaknai sebagai apa yang dilakukan oleh individu

untuk menguasai situasi yang dinilai sebagai suatu tantangan atau luka atau kehilangan atau ancaman. Jadi koping lebih mengarah pada yang orang lakukan untuk mengatasi tuntutan-tuntutan yang penuh dengan tekanan atau yang membangkitkan emosi atau dengan kata lain koping adalah bagaimana reaksi orang ketika menghadapi stress atay tekanan (Siswanto, 2007). Ada banyak nekanisme pertahanan ego, contohnya seperti dibawah ini:

a) Kompensasi: proses dimana seseorang menggunakan kelemahan yang dirasakan dengan penekanan yang kuat atas ciri yang dianggap lebih menyenangkan.
b) Peningkatan: menghindari realitas yang tidak menyenangkan denga mengabaikan atau menolak untuk mengikutinya, mekanisme pertahanan yang paling sederhana dan paling primitive dari semua mekanisme pertahanan ego.
c) Pengalihan: pengalihan emosi yang seharusnya diarahkan kepada objek atau orang tertentu keonjek atau orang yang kurang berbahaya.
d) Disiosasi: pemisahan dari proses kelompok jiwa atau perilaku dari sisa kesadaran atau identitas orang tersebut.
e) Identifikasi: prose dimana orang-orang mencoba untuk menjadi seperti seseorang yang mereka kagumi dengan mengambil pikiran, tingkah laku, atau selera orang itu.
f) Intelektualisasi: penalaran yang berlebihan atau logika yang digunakan untuk menghindari pengalaman peran yang mengganggu.
g) Introjeksi: mengidentifikasi dengan kuat dimana seseorang menggabungkan kualitas atau nilai-nilai orang lain atau kelompok lain kedalam struktur egonya sendiri. Ini adalah salah satu mekanisme paling dini pada anak sehingga penting dalam pembentukan hati nurani.
h) Isolasi: memisahkan komponen emosional dari pikiran, yang mungkin bersifat sementara atau jangka panjang.

i) Proyeksi: menghubungkan pikiran atau implus keorang lain, melalui proses ini seseorang dapat mengubungkan keinginan tak tertahankan, perasaan emosional, atau motivasi kepada orang lain.

j) Reaksi formasi: pengembangan pola sikap dan perilaku yang berlawanan dengan apa yang benar-benar dirasakan atau ingin dilakukan.

k) Rasionalisasi: menawarkan penjelasan yang dapat diterima secara sosial atau tampaknya logis untuk membenarkan atau membuatnya dapat diterima walaupun implus, perasaan, perilaku, dan motif tidak dapat diterima.

l) Regresi: kemunduran karakteristik perilaku pada tingkat perkembangan awal.

m) Represi: penekanan secara tidak sadar hal-hal yang menyakitkan atau konflik pikiran, implus atau memori dan kesadaran. Mekanisme pertahanan ini adalah pertahanan ego utama dan mekanisme lainnya cenderung memperkuatnya.

n) Disosiasi: mengamati orang dan situasi sebagai semua baik atau semua buruk, gagal mengintergarasikan kualitas positif dan negatif dari diri sendiri.

o) Sublimasi: penerimaan tujuan pengganti yang disetujui secara sosial untuk dorongan penyaluran ekspresi norma yang dihambat.

p) Supresi: suatu proses sering didengar sebagai mekanisme pertahanan, tetapi sebenarnya adalah sama dengan represi yang disadari, hal ini merupakan penekanan yang disengaja terhadap hal-hal yang disadari. Kadang-kadang, hal itu dapat menyebabkan represi.

q) Undoing: tindakan untuk komunikasi yang sebagian meniadakan kejadian sebelumnya, mekanisme pertahanan primitif.



**d. Faktor-faktor Yang Mempengaruhi Mekanisme Koping**

Faktor yang mempengaruhi mekanisme koping individu meliputi usia, jenis kelamin, tingkat pendidikan, status perkawinan, kesehtaan fisik,

keyakinan atau pandangan positif, keterampilan memecahkan masalah, keterampilan sosial, dukungan sosial dan materi (Siswanto, 2007).

1) Usia

Usia berpengaruh terhadap cara pandang sesorang dalam kehidupan, masa depan dan pengambilan keputusan.

2) Jenis kelamin

Jenis kelamin sangat mempengaruhi dalam respon terhadap penyakit, stresor, serta penggunaan koping terhadap masalah.

3) Tingkat pendidikan

Pendidikan dapat mempengaruhi seseorang termasuk juga philaka seseorang akan pola hidup terutama dalma memotivasi untuk sikap berperan serta dalam pembangunan kesehatan. Makin tinggi tingkat pendidikan seseorang, makin mudah menerima informasi sehingga makin banyak pula pengetahuan yang dimiliki.

4) Status perkawinan

Yosep (2007) menjelaskan salah satu penyebab stress psikososial yaitu status perkawinan dimana berbagai permasalahan perkawinan merupakan sumber stres yang dialami sesorang, misalnya pertengkaran, perpisahan, perceraian, kematian pasangan. Stresor ini dapat menyebabkan seseorang jatuh dalam depresi dan kecemasan.

5) Kesehatan Fisik

Kesehatan merupakan hal yang penting, karena selama dalam usaha mengatasi stres individu dituntut untuk mengerahkan tenaga yang cukup besar.

6) Keyakinan atau pandangan positif

Keyakinan menjadi sumber daya psikologis yang sangat penting, seperti keyakinan akan nasib yang mengarahkan individu pada penilaian ketidak berdayaan yang akan menurunkan kemampuan strategi koping.

7) Keterampilan memecahkan masalah

Ketempilan ini meliputi kemampuan untuk mencari informasi, menganalisa situasi, mengidentifikasi masalah dengan tujuan untuk

menghasilkan alternatif tindakan, kemudian mempertimbangkan alternatif dan akhirnya melaksanakan rencana dengan melakukan suatu tindakan yang tepat.

8) Keterampilan sosial

Keterampilan ini meliputi kemampuan untuk berkomunikasi dan bertingkah laku dengan cara-cara yang sesuai dengan nilai-nilai sosial yang berlaku dimasyarakat.

9) Dukungan sosial

Meliputi dukungan pemenuhan kebutuhan informasi dan emosioanal pada diri individu yang diberikan oleh orang tua, dan lingkungan masyarakat anggota keluarga lain, saudara, teman, dan lingkungana sekitar

10) Materi

barang atau Dukungan ini meliputi sumber daya berupa uang, barang ala layanan yang biasanya dapat dibeli.



**e. Karakteristik Mekanisme Koping**

Menurut Stuart dan Sundeen (2013), respon mekanisme koping dapat digambarkan sebagai berikut:

Adaptif ⟷ Maladaptif

Jadi karakteristik mekanisme koping adalah sebagi berikut:

1) Mekanisme Koping Adaptif

Mekanisme koping adaptif merupakan suatu kejadian dimana individu dapat mengatur berbagai tugas mempertahankan konsep diri, mempertahankan hubungan dengan orang lain dan mempertahankan emosi serta pengaturan stress (Carpenito, 2001). Karakteristik mekanisme koping adaptif yaitu;

a) Dapat menceritakan secara verbal tentang perasaannya
b) Mengembangkan tujuan realitas
c) Dapat mengidentifikasi sumber koping

d) Dapat menimbulkan mekanisme koping yang efektif
e) Mengidentifikasi alternatif strategi
f) Memilih strategi yang tepat
g) Menerima dukungan

2) Meknisme Koping Maladaptif

Meknisme Koping Maladaptif adalah suatu keadaan dimana individu mempunyai pengalaman atau mengalami keadaan yang beresiko tinggi atau ketidakmampuan untuk mengatasi stressor. Koping maladaptive menggambarkan undividu yang mengalami kesulitan dalam beradaptasi terhadap kejadian-kejadian yang sangat menekan (Carpenito, 2001). Karakteristik mekanisme koping maladaptif yaitu:

a) Merasa tidak mampu menyelesaikan masalah secara efktif
b) Tidak mampu menyelesaikan masalah secara efektif
c) Perasaan lemas, takut, marah, iritable, tegang, gangguan fisiologis adanya stress kehidupan
d) Tidak mampu memenuhi kebutuhan dasar.



**f. Penilaian Koping**

Ada beberapa skal pengukuran koping yang dapat digunakan, yakni sebagai berikut :

1) The Brief COPE

Intrumen ini dikembnagkan oleh Carver (1997) dimana alat ukur ini merupakan adaptasi dari alt ukur COPE yang dibuat Carver. Scheir dan Weintraub (1989). Intrumen ini digunakan untuk melihat cara individu mengatasi maslah dan mengukur respon koping yang penting dan potensial dengan cepat. The bres terdiri 28 item yang mengukur 14 konsep reaksi koping yang berbeda.

2) Coping Srategi Indicator (CSI)

Intrumen ini dibuat oleh Amirkhan (1990) yang terdiri dari item dengan 3 sub skala masing-masing berisi 11 item, skor yans lebih tinggi menujukkan lebih besar menggunakan koping.

3) Ways Of Coping Scale (WOC)

Intrumen ini buat oleh Folkman dan Lazarus (1986) memakai perbedaan Problem Focused Coping dan Emotional Focused Coping. Terdiri dari 66 item pertanyaan mengandung barbagai pikiran dan tindakan seseorang untuk dengan tututan internal dan eksternal stress. Biasanya untuk pengobatan medis atau periksaan akademis.

**Tabel 2.1** *Mekanisme Pertahanan* (Ah.Yusuf, et al 2015)

| Mekanisme Koping | Keterangan |
|---|---|
| Fantasi | Keinginan yang tidak terkabul dipuaskan dalam imajinasi, mengkhayal seolah-olah menjadi seperti yang diinginkan |
| Penyangkalan (denial) | Mekindungi diri terhadap kenyataan yang tak menyenangkan dengan menolak mengahdapi hal itu, yang sering dilakukan dengan cara melarikan diri seperti menjadi “sakit” atau kesibukan lain. Tidak berani melihat dan mengakui kenyataan yang menakutkan. |
| Rasionalisasi | Berusaha membuktikan bahwa perbuatannya (yang sebenarnya tidak baik) rasional adanya, sehingga dapat disetujui dan diterima oleh diri sndiri dan masyarakat. |
| Indentifikasi | Menambah harga diri dengan menyamakan dirinya dengan seseorang atau suatu hal yang dikaguminya. |
| Introyeksi | Indentifikasi yang berbentuk primitive. Menyatukan nilai dan norma luar dengan struktur egonya sehingga individu tidak bergantung pada belas kasihan tentang hal-hal yang dirasakan sebagai ancaman. |
| Reperesi | Secara tidak sadar menekan pikiran yang berbahaya dan menyediakan dari alam sadar kea lam tidak sadar, semacam penyingkiran. |
| Supresi | Individu secara sadar menolak pikirannya keluar dali alam sadarnya dan memikirkan hal yang lain. Supresi tidak begitu berbahaya karena dilakukan secara sengaja dan individu mengetahui apa yang dibuat. |
| Regresi | Mundur ke tingkat perkembangan yang lebih rendah, dengan respons yang kurang matang dan biasanya dengan aspirasi yang kurang |
| Proyeksi | Menyalahkan orang lain mengenai kesulitannya sendiri atau melemparkan kepada orang lain keinginannya yang |

| | |
|---|---|
| | tidak baik. |
| Penyusuanan reaksi (reaksi formasi) | Mencegah keinginan yang berbahaya bila diekspresikan, dengan melebihlebihkan sikap dan perilaku yang berlawanan dan menggunakannya sebagai rintangan. |
| Sublimasi | Mencari pemuasan atau menghilangkan keinginan seksual dalam kegiatan nonseksual. Nafsu yang tidak terpenuhi (terutama seksual) disalurkan kepada kegiatan yang dapat diterima oleh masyarakat. |
| Kompensasi | Menutupi kelemahan dengan menonjolkan sifat yang baik atau frustasu terhadap satu bidang, bias juga mencari kepuasan secara berlebihan dalam bidang lain. |
| Pemindahan (displacement) | Emosi atau fantasi terhadap seseorang atau benda dicurahkan kepada seseorang/benda lain yang biasanya lebih kurang berbahaya dari semula. |
| Pelepasan atau penebusan (undoing) | Meniadakan atau membatalkan suatu pikiran. Kecenderungan atau tindakan (undoing) yang tidak disetujui/tidak bermoral. Bentuk pelepasan/penebusan antara lain meminta maaf, menyesalkan, memberi pilihan, atau melakukan penitensi dan menjalani hukuman. |
| Penyekatan emosional | Mengurangi keterlibatan ego dan menarik diri menjadi pasif untuk melindungi diri sendiri dari kesakitan atau kekecewaan. |
| Isolasi (intelektualisai, disosiasi) | Suatu bentuk penyekatan emosional karena beban emosi dalam suatu keadaan yang menyakitkan, diputuskan, atau diubah (distorsi). |
| Simpatisme | Berusaha mendapatkan simpati dengan cara menceritakan berbagai kesukarannya, misalnya penyakit atau kesusahan yang lain. Oleh karena bila orang simpati maka harga diri meningkat walaupun ada kegagalan. |
| Memberontak (acting out) | Mengurangi kecemasan yang dibangkitkan oleh berbagai keinginan yang terlarang dengan membiarkan ekspresinya dan melakukannya. |

## B. Teori Keperawatan Teori Keperawatan Sister Calista Roy

Sesuai dengan model Roy, tujuan dari keperawatan adalah membantu seseorang untuk beradaptasi terhadap perubahan kebutuhan fisiologis, konsep diri, fungsi peran, dan hubugan interdependensi selama sehat dan sakit (mariner-Tomery, 1994). Kerangka konseptual model adaptasi roy adalah:

1. Sistem adalah kesatuan dari beberapa unit yang saling berhubungan dan membentuk satu kesatuan yang utuh dengan ditandai adanya input, control, proses, output, dan umpan balik.
2. Derajat adaptasi adalah perubahan tetap sebagai hasil dari stimulus fokal, konstektual dan residual dengan standar individual, sehingga manusia dapat berespon adaptif sendiri.
3. Problem adaptasi adalah kejadian atau situasi yang tidak adekuat terhadap penurunan atau peningkatan kebutuhan.
4. Stimulus fokal adalah derajat perubahan atau stimulus yang secara langsung mengharuskan manusia berespon adaptif. Stimulus fokal adalah presipitasi perubahan tingkah laku.
5. Stimulus konstektual adalah seluruh stimulus lain yang menyertai dan memberikan konstribusi terhadap perubahan tingkah laku yang disebabkan atau dirangsang oleh stimulus fokal.
6. Stmulus residual adalah seluruh factor yang mungkin memberikan konstribusi terhadap perubahan tingkah laku, akan tetapi belum dapat di validasi.
7. Regulator adalah subsistem dari mekanisme koping dengan respon otomatik melalui neural, cemikal, dan proses endokrin.
8. Kognator adalah subsistem dari mekanisme koping dengan respon melalui proses yang kompleks dari persepsi informasi, mengambil keputusan dan belajar.
9. Model efektor adaptif adalah kognator yaitu , Fisiologikal, fungsi pean, interdependensi dan konsep diri.
10. Respon adaptif adalah respon yang meningkatkan intergritas manusia dalam mencapai tujuan manusia untuk mempertahankan kehidupan, pertumbuhan reproduksi.
11. Fisiologis adalah kebutuhan fisiologis termasuk kebutuhan dasar dan bagaimana proses adaptasi dilakukan untuk pengaturan cairan dan elektrolit,

aktivits dan istirahat, eliminasi, nutrisi, sirkulasi dan pengaturan terhadap suhu, sensasi, dan proses endokrin/

12. Konsep diri adalah seluruh keyakinan dan perasaan yang dianut individu dalam satu waktu berbentuk : persepsi, partisipasi, terhadap reaksi orang lain dan tingkah laku langsung. Termasuk pandangan terhadap fisiknya (body image dan sensasi diri) kepribadian yang menghasilkan konsistensi diri, ideal diri, atau harapan diri, moral dan etika pribadi.
13. Penampilan peran adalah penampilan fungsi peran yang berhubungan dengan tugasnya di lingkungan social.
14. Interdependensi adalah hubungan individu dengan orang lainyang penting dan sebagai support sistem. Di dalam model ini termasuk bagaimana cara memelihara integritas fisik dengan,pemeliharaan dan pengaruh belajar.

Konsep ini menekankan pentingnya individu untuk mempertahankan prilaku secara adaptif dan mampu merubah perilaku yang maladaptif agar dapat meningkatkan kesehatannya. Apabila individu mampu menggunakan cara-cara penyesuaian diri yang sehat.

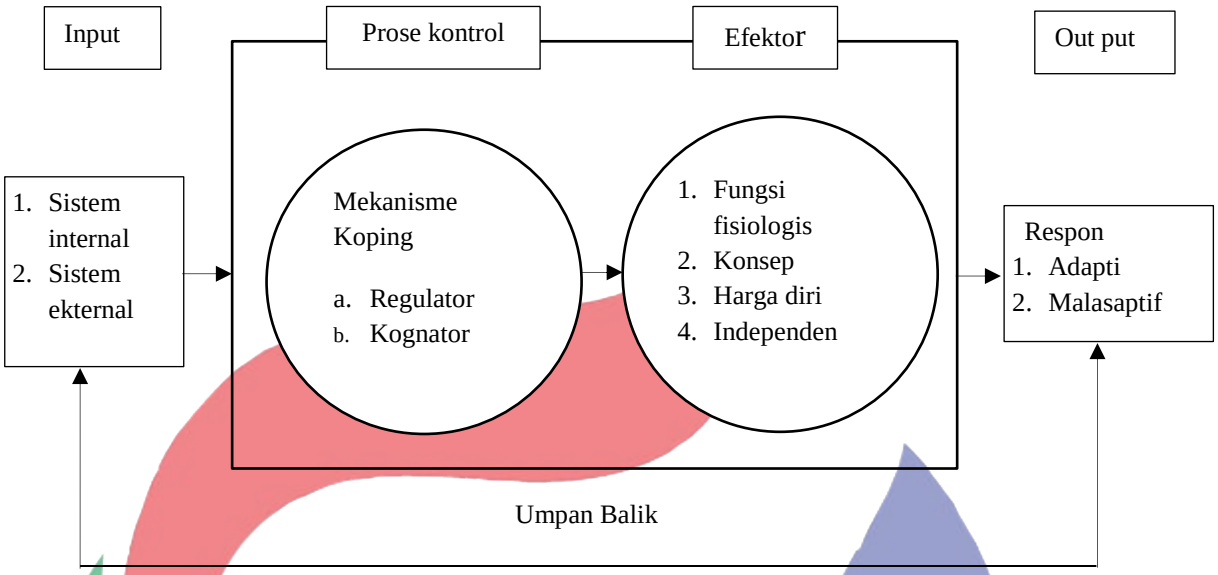


Ekspresi tersebut sering disebut sebagai dukungan emosional yang paling disadari dalam hubungan suami istri. Kategori informasi yang kedua menyebabkan seseorang merasa bahwa dirinya dianggap atau dihargai. Hal ini paling efektif saat ada pengumuman publik mengenai betapa kedudukannya di dalam kelompok cukup terpandang. Keadaan tersebut akan menaikkan perasaan harga diri sehingga disebut sebagai dukungan harga diri. Kategori informasi ketiga membuat seseorang merasa bahwa dirinya merupakan bagian dari jaringan komunikasi dan saling ketergantungan. Informasi disebarkan oleh anggota jaringan, dimana setiap anggota jaringan memahami informasi tersebut dan menyadari bahwa informasi tersebut telah disebarkan diantara mereka. Coba menekankan bahwa dukungan sosial akan meningkatkan kepribadian mandiri, sebaliknya tidak menyebabkan ketergantungan.

Sumber material merupakan dukungan eksternal lain, meliputi barang dan jasa yang dapat dibeli. Mengatasi keterbatasan lingkungan akan lebih mudah bagi individu yang mempunyai sumber finansial yang memadai karena perasaan

ketidakberdayaan terhadap ancaman menjadi berkurang (Brunner & Suddarth,2001).

Model adaptasi Roy (1986) dapat digambarkan sebagai berikut:




**Bagan 2.1** Model Adaptasi Roy



Teori Roy Dijelaskan Sebagai berikut

a. Input

Roy mengidentifikasi bahwa input sebagai stimulus, merupakan kesatuan informasi, bahan-bahan atau energi dari lingkungan yang dapat menimbulkan respon, dimana dibagi dalam tiga tingkatan yaitu stimulus fokal, kontekstual dan stimulus residual.

b. Kontrol

Proses kontrol seseorang menurut Roy adalah bentuk mekanisme koping yang di gunakan. Mekanisme kontrol ini dibagi atas regulator dan kognator yang merupakan subsistem.

1) Subsistem regulator

Subsistem regulator mempunyai komponen-komponen : input-proses dan output. Input stimulus berupa internal atau eksternal. Transmiter regulator sistem adalah kimia, neural atau endokrin. Refleks otonom adalah respon neural dan brain sistem dan spinal cord yang diteruskan sebagai perilaku output dari regulator sistem. Banyak

proses fisiologis yang dapat dinilai sebagai perilaku regulator subsistem.

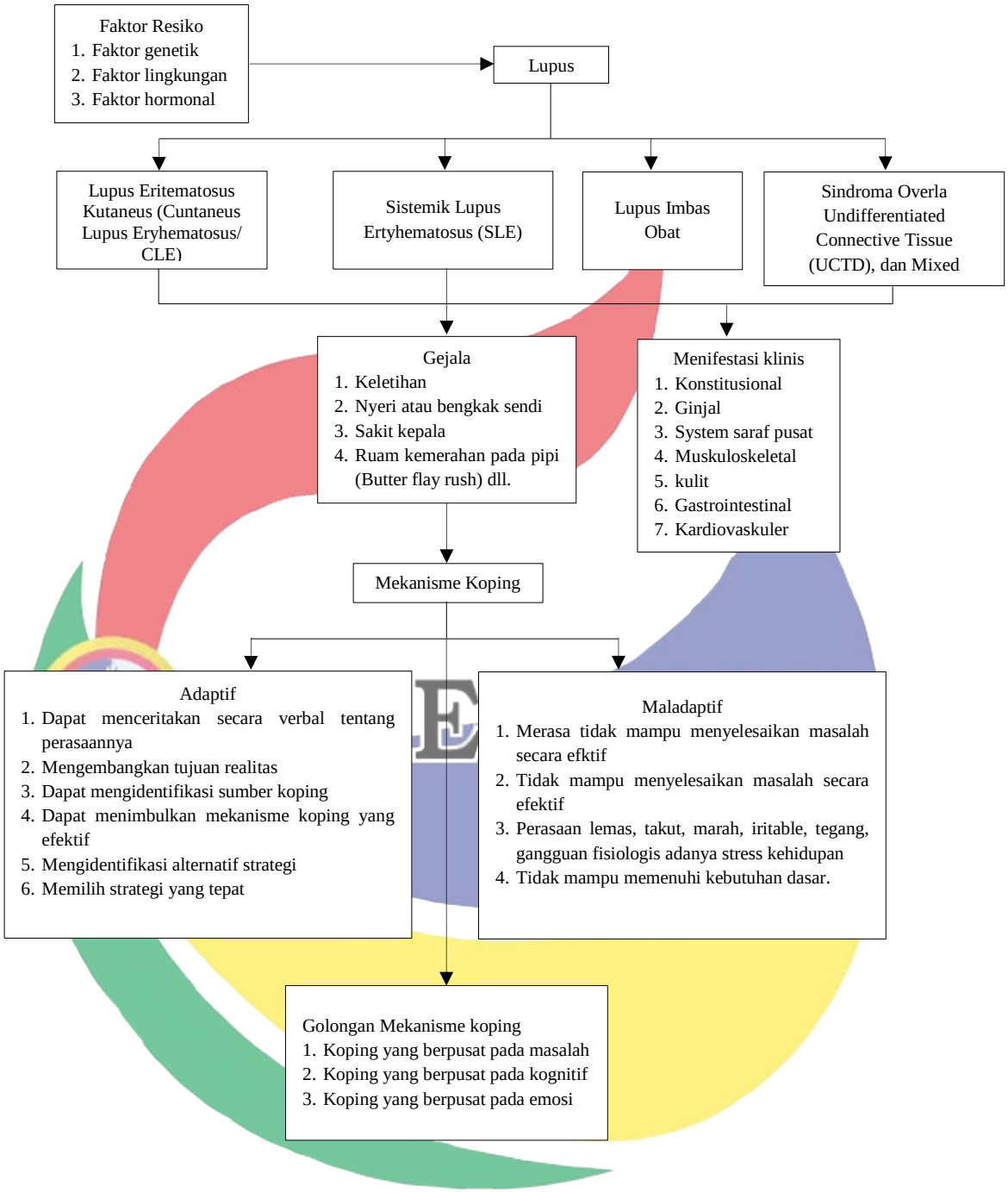
2) Subsistem kognator

Stimulus untuk subsistem kognator dapat eksternal maupun internal. Perilaku output dari regulator subsistem dapat menjadi sumu umpan balik untuk kognator subsistem. Kognator kontrol proses berhubungan dengan fungsi otak dalam memproses informasi, penilaian dan emosi. Persepsi atau proses informasi berhubungan dengan proses internal dalam memilih atensi, mencatat dan mengingat. Belajar berkorelasi dengan proses imitasi, reinforcement (penguatan) dan insight (pengertian yang mendalam). Penyelesaian masalah dan pengambilan keputusan adalah proses internal yang berhubungan dengan penilaian atau analisa. Emosi adalah proses pertahanan untuk mencari keringanan, mempergunakan penilaian kasih sayang.

c. Output

Output dari suatu sistem adalah perilaku yang dapat di amati, diukur atau secara subyektif dapat dilaporkan baik berasal dari dalam maupun dari luar. Roy mengkategorikan output sistem sebagai respon yang adaptif atau respon yang tidak mal-adaptif. Respon yang adaptif dapat meningkatkan integritas seseorang yang secara keseluruhan dapat terlihat bila seseorang tersebut mampu melaksanakan tujuan yang berkenaan dengan kelangsungan hidup, perkembangan, reproduksi dan keunggulan. Sedangkan respon yang mal adaptif perilaku yang tidak mendukung tujuan ini. Roy telah menggunakan bentuk mekanisme koping untuk menjelaskan proses kontrol seseorang sebagai adaptif system.

## C. Krangka Teori




**Bagan 2.2** Krangka Teori
Sumber : Pusdatin(2017), Perhimpunan Reumatologi Indonesia(2011), Stuart dan Sundeen (2013)

## D. Krangka Konsep

Krangka konsep penelitian adalah suatu hubungan atau kaitan antara satu terhadap konsep yang lainnya dari masalah yang ingin diteliti (Notoatmojo, 2012).


**Bagan 2.3** Krangka Konsep

# BAB III
# METODE PENELITIAN

## A. Desain dan Rancanagan Penelitian

Metode yang digunakan dalam penelitian ini adalah Literature review dengan Design penelitian *Studi literature* biasanya disebut *Studi literature review* adalah cara sistematis untuk mengumpulkan, mengevaluasi secara kritis, mengintegrasikan dan menyajikan temuan dari berbagai studi penelitian pada pertanyaan penelitian atau topik yang menarik. *Studi literature* menyediakan cara untuk menilai tingkat kualitas bukti yang ada pada pertanyaan atau topik yang menarik. SLR memberikan tingkat pemahaman yang lebih luas dan lebih akurat dari pada tinjauan literature secara tradisional (Delgado-Rodriguez and Sillero-Arenas, 2018) dalam (Nursalam, 2020).

Studi literature merupakan suatu proses mengidentifikasi, menilai, dan menafsirkan semua bukti penelitian yang tersedia, untuk memberikan jawaban untuk pertanyaan penelitian tertentu (Wahono, 2016). Studi literature ini dilakukan pada buku-buku,jurnal,dan penelitian yang telah dilakukan berkaitan dengan Mekanisme Koping Pada Pasien SLE (*Systemic Lupus Erythematosus*) untuk kemudian dilakukan ulasan atau tinjauan. Output dari *studi literature* ini adalah terkoleksinya referensi yang relevan dengan perumusan masalah. Tujuannya adalah untuk memperkuat keefektifan teori mekanisme koping pada pasien SLE (*Systemic Lupus Erythematosus*) serta sebagai dasar teori dalam melakukan studi dan juga menjadi dasar untuk melakukan desain kendali penerapan mekanisme koping pada pasien SLE (*Systemic Lupus Erythematosus*).

## B. Jenis Pengambilan Data

*Studi literature review* yang merupakan rangkuman menyeluruh beberapa studi penelitian yang ditentukan berdasarkan tema tertentu. Data yang digunakan dalam penelitian ini adalah data sekunder yang diperoleh bukan dari pengamata langsung,akan tetapi diperoleh dari hasil penelitian yang telah dilakukan oleh peneliti-peneliti terdahulu. Sumber data sekunder yang didapat berupa artikel

jurnal bereputasi baik nasional maupun internasional dengan tema yang sudah ditentukan (Nursalam, 2020).

## C. Tahapan Studi Literature

*Studi literature* memiliki 3 tahapan yaitu *Planning*, *conducting*, dan *Reporting* (Wahono, 2016). *Studi literature* melalui tahapan sebagai berikut:

### 1. Planning

*Planning* merupakan tahap pertama dalam *studi literature review* sebagai strategi dalam mencari artikel (Nursalam, 2020). Pada Tahap Planning ini terdapat dua bagian didalamnya yaitu *formulate the review's research question* dan *develop the review's protocol* (Wahono, 2016).

a. Formulate the review's research question

Bagian ini merupakan strategi pertama yang digunakan untuk mencari artikel dengan menyusun pertanyaan penelitian (Research question) kemudian di formulasikan menggunakan PICOC framework (Wahono, 2016). Research question atau pertanyaan penelitian merupakan bagian terpenting dalam setiap *systematic literature review*, research question digunakan untuk memandu proses pencarian dan memandu proses ekstrasi data (Wahono., 2016).

RQ 1 :Jurnal apa yang paling banyak memuat tentang mekanisme koping pada pasien SLE?

RQ 2 : Siapa peneliti yang aktif yang meneliti mekanisme koping pada pasien SLE?

RQ 3 : Metode apa saja yang digunakan dalam penelitian mekanisme koping pada pasien SLE?

RQ 4 : Metode apa yang paling sering digunakan dalam penelitian mekanisme koping pada pasien SLE?

RQ 5 : Metode yang paling bagus yang digunakan dalam penelitian mekanisme koping pada pasien SLE ?

Perumusan Research question pada mekansime koping pada pasen SLE harus sesuai dengan 5 elemen PICOC (Wahono, 2016), yang terdiri

dari: (1) *Population* : Kelompok sasaran untuk kelompok yang sesuai dengan tema dalam studi literature . (2) *Intervention/Issue* : Menentukan aspek investigasi atau masalah yang menarik bagi para peneliti.(3) *Comparation* : Aspek investigasi dengan mana intervensi dibandingkan.(4) *Outcome* : Hasil atau luaran yang diperoleh pada studi terdahulu yang sesuai dengan tema yang sudah ditentukan dalam *systematic review*.(5) *Context*: pengaturan atau lingkungan investigasi.

**Tabel 3.1 Format PICOC *Framework***

| ***PICOC Framework*** | |
|---|---|
| *Population* | Studi yang berfokus pada mekanisme koping pada pasien SLE (systemic lupus erythematosus) |
| *Intervention/issue* | Studi yang berfokus pada mekanisme Koping |
| *Camparator* | Tidak ada |
| *Outcome* | Studi yang menjelaskan kondisi mekanisme koping pada pasien SLE (systemic lupus erythematosus) |
| *Context* | *Nursing,Psychology Health* |



b. Develop the review`s Protocol

Develop the review's protocol merupakan strategi kedua dalam tahap Planning yaitu dengan merencanakan dan menetapkan prosedur dasar peninjauan. Komponen dari strategi ini adalah search terms(kata kunci),seleksi berdasarkan kriterian inklusi dan eksklusi,quality chekslist atau penilaian kualitas (Wahono., 2016).

1) Search Terms (Kata Kunci)

Pencarian Jurnal atau artikel menggunakan keyword dan Boolean operator (AND, OR NOT or AND NOT) digunakan untuk memperluas atau memspesifikkan pencarian sehingga mempermudah dalam penentuan artikel atau jurnal yang digunakan.Kata kunci dalam systematic review disesuaikan dengan *Medical Subject Heading* (MeSH) (Nursalam., 2020) sebagai berikut :

**Tabel 3.2 Kata Kunci Studi Literature**

| Mekanisme Koping | SLE (systemic lupus erythematosus) |
|---|---|
| Coping | OR |
| Strategi Coping | Lupus |
| | OR |
| | Odapus |
| | OR |
| | Autoimmunity |

2) Cara mengakses Jurnal

Mesin pencarian jurnal untuk melihat jurnal tersebut memiliki quartil dan ranking menggunakan mesin pencari yaitu scimagojr.com kemudian didapatkan bahwa jurnal tertinggi yaitu scopus, science direct, springerlink, pubmed (Wahono., 2016).

3) Cara Seleksi Jurnal

Penyeleksian jurnal yang telah dilakukan dengan scimagojr.com kemudian di seleksi dengan kriteria Inklusi dan eksklusi berdasarkan PICOS Framework untuk menyeleksi data. Seleksi berdasarkan judul ,tahun publikasi literature yaitu tahun 2015 – 2020, ful-text, language bahasa inggris (Nursalam., 2020).



**Tabel 3.3 *PICOS Framework***

| PICOS | Inklusi | Eksklusi |
|---|---|---|
| ***Population*** | Studi yang berfokus pada mekanisme koping pada pasien SLE (systemic lupus erythematosus) | Studi yang tidak mengulas tentang mekanisme koping |
| ***Intervention/issue*** | Studi yang berfokus pada mekanisme Koping | Studi yang tidak mengulas mekanisme koping |
| ***Camparator*** | None | None |
| ***Outcomes*** | Studi yang menjelaskan kondisi mekanisme koping | Tidak membahasa tentang mekanisme koping atau |

| | | |
|---|---|---|
| | pada pasien SLE (systemic lupus erythematosus) | issue lain |
| ***Study Design and publication type*** | Cross sectional,randomized control and trial,qualitative research ,etc.<br>Publication type : Journal and book chapter | Tidak ada kriteria eksklusi pada study design<br>Publication type :webpages |
| ***Publication years*** | Post 2015 | Pre 2015 |
| ***Language*** | Bahasa Inggris | Selain bahasa Inggris |

4) *Quality Cheklist* (Penilaian Kualitas)

*Screening literature* menggunakan RAC (*Reasearch appraisal checklist*) untuk menganalisis kualitas metodologi di setiap jurnal sehingga dapat menganalisis kualitas metodologi dalam setiap *study* sesuai dengan metode penelitian yang dilakukan pada penelitian. Instrument ini berisikan ceklist untuk melihat apakah ada kesesuaian, keselarasan dan ketepatan dari judul, desain, sampel, tujuan, hasil dan pembahasan. Ceklist ini kemudian diisi berdasarkan jenis penelitian dan dinilai. Tujuan pengunaan tool instrument *Reasearch appraisal checklist* adalah melihat kualitas jurnal tersebut. Kualitas studi dari masing-masing artikel yang ditetapkan sebagai sumber studi literature ditentukan berdasarkan analisis kualitas *Research Appraisal Checklist* dengan score Tinggi (205-306 poin) dan Sedang (103-204 poin) sehingga didapatkan 8 artikel yang sesuai dengan

**2. Conducting**

a. Ekstrasi data

Pada ekstrasi data menggunakan link www.scimagojr.com untuk menyusun jurnal berdasarkan Quartil jurnal. Quartil jurnal merupakan peringkat jurnal/ Ranking Jurnal. ada Q1,Q2,Q3,Q4 untuk jurnal yang paling baik dengan Quartil 1, menyusun jurnal berdasarkan quartil juga digunakan untuk menjawab research question (RQ) (Wahono., 2016).

**Tabel 3.4** ***Data Extraction properties Mapped to Research Question***

| **Property** | **Research Question** |
|---|---|
| Penelitian dan publikasi | RQ1 dan RQ2 |
| Metode : Mekanisme Koping pada pasien SLE (Syestemic Lupus Erythematosus) | RQ3, RQ4, dan RQ5 |

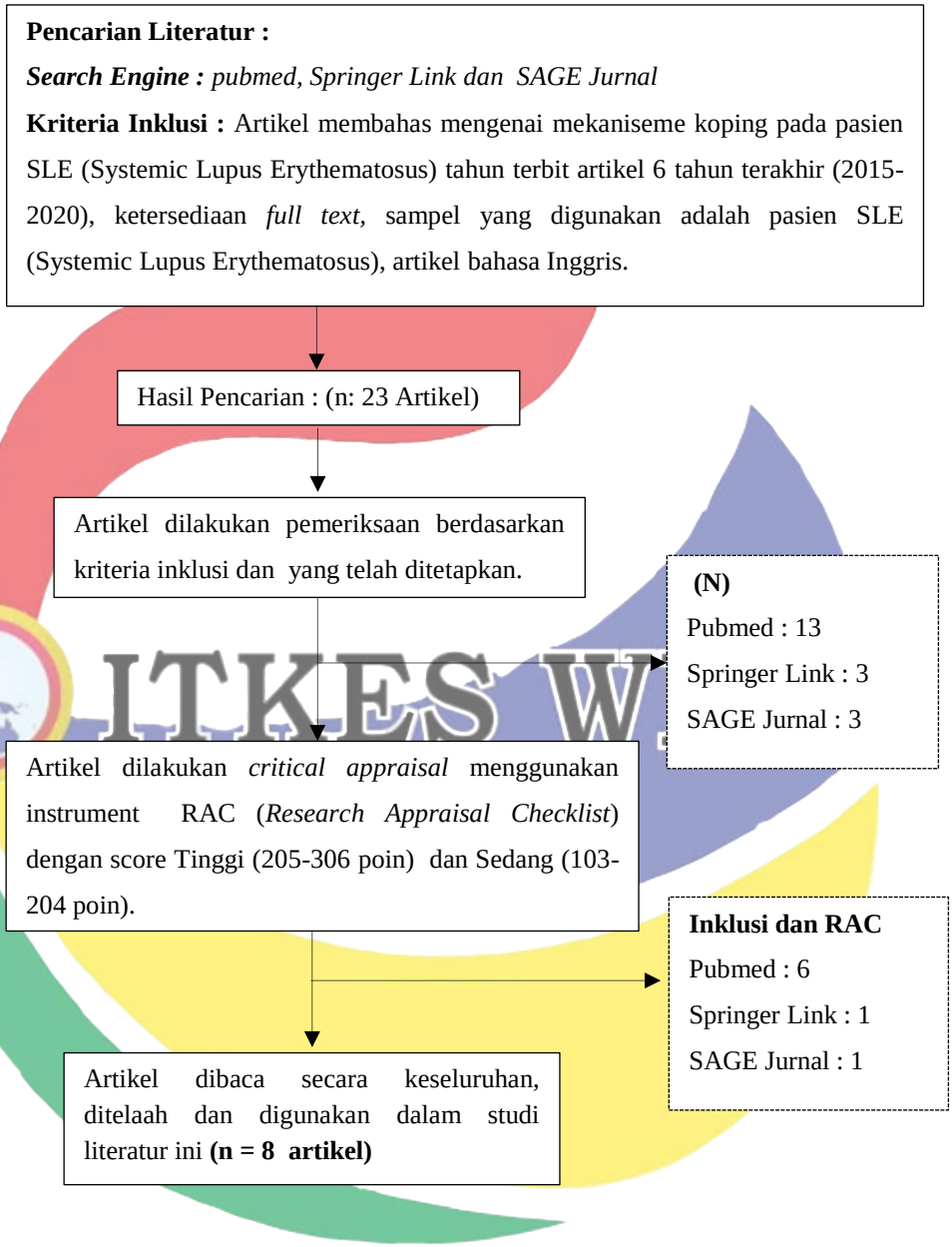
b. Gambaran sintesis

Sintesis pada penelitian ini menggunakan analisis deskriptif yaitu dengan menjelaskan secara narasi hasil temuan artikel ilmiah .pada peneltian ini tidak ditambahkan metode analisis yang lain peneliti hanya merangkum hasil yang ada diartikel dan menganalisisnya sesuai dengan tema (Nursalam., 2020).

**3. Reporting**

Pada tahap terakhir dari SLR peneliti mulai menuliskan hasil dari pengumpulan jurnal yang sudah dianalisis dan juga sudah di rankingkan berdasarkan quartil jurnal (Wahono., 2016), Write up the SLR Paper yaitu *a).Introduction* :Definisi umum tentang penelitian, tujuan ulasan,menekankan menggapa RQ Penting,pentingnya melakukan tinjauan dan bagaimana kontribusi pada pengetahuan di lahan praktik,;*b).Main body* :Pada bagian ini menjelaskan secara singkat tahap-tahap yang diambil untuk melakukan SLR Kemudian menuliskan hasil temuan dari review dan juga tuliskan bagaimana keterlibatan SLR pada penelitian ini untuk praktik dan pengetahuan ;*c).Conclusion*:Bagian paling akhir ditarik kesimpulan.

**Bagan 3.1 Alur Proses Pernyortiran Artikel**



# BAB IV
# HASIL DAN PEMBAHASAN

## A. Hasil Penelitian

### 1. Gambaran Sintesis

Total yang di review adalah 8 artikel yang diperoleh dari strategi pencarian, evaluasi seleksi kriteria inklusi, dan penilaian kualitas metodeolgi dangan kualitas studi dari masing-masing artikel yang ditetapkan sebagai sumber studi literature ditentukan berdasarkan analisis kualitas *Research Appraisal Checklist* dengan score Tinggi (205-306 poin) dan sedang (103-204 poin). Dari 23 artikel, artikel yang dikeluarkan dengan alasan tidak sejalan dengan tujuan penelitian yaitu 15 artikel sehingga ada 8 artikel yang di analisis dengan rincian: cross-sectional study 6, randomized clinical trial 1dan qualitative study 1, hasil pencarian literature yang sudah dianalisis dan di tetapkan dalam studi literature pada penelitian ini adalah sebagai berikut:

**4.1 Hasil Pencarian literature**

| Sumber bahasa | Tahun | Data Base | N | Inklusi dan RAC | Jenis studi penelitian | | |
|---|---|---|---|---|---|---|---|
| | | | | | cross-sectional study | randomized clinical trial | qualitative study |
| English | 2015-2020 | Pubmed | 13 | 6 | 4 | 1 | 1 |
| | | Springer Link | 3 | 1 | 1 | - | - |
| | | SAGE Journal | 3 | 1 | 1 | - | - |
| | **Jumlah** | | **23** | **8** | | | |



### 2. Agregasi review atau pengelompokkan

Agregasi review merupakan pengelompokkan hasil review paper dengan desain kuantitatif dikelompokkan dalam beberapa kategori (tutik, 2010). Pada penelitian ini terdapat pertanyaan penelitian atau research question (RQ) merupakan bagian terpenting dalam setiap studi literature, research question digunakan sebagai kategori, untuk memandu proses pencarian dan memandu

proses ekstrasi data (Wahono, 2016). Pada penelitian ini dari 8 artikel yang teah ditetapkan kemudian di ekstrasi berdasarkan research question untuk dikelompokkan menjadi RQ 1, RQ 2, RQ 3, RQ 4, RQ 5. Pengelompokkan research question dibawah ini, yaitu sebagai berikut:

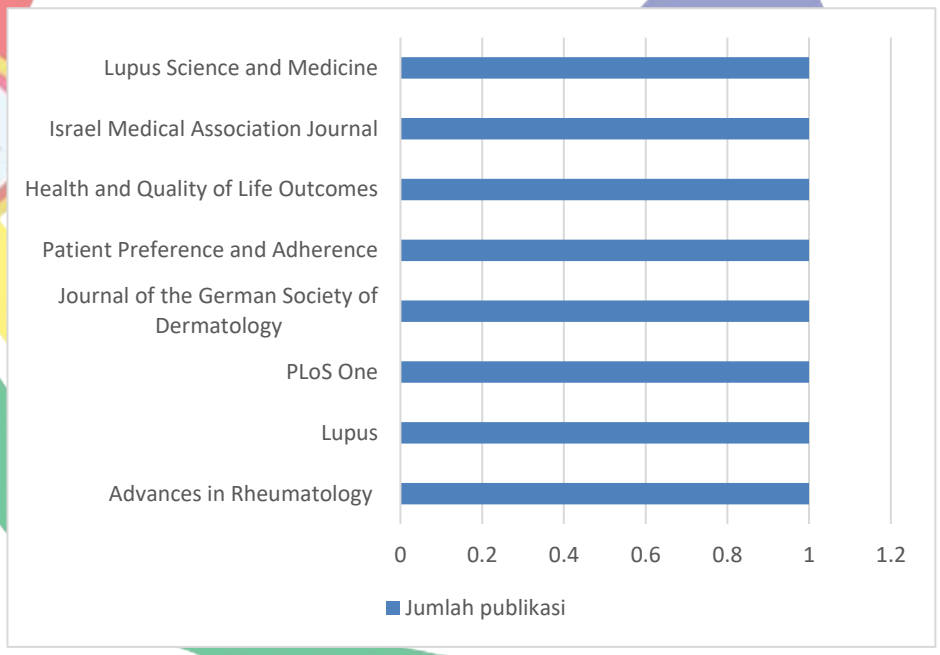
**a. Penelitian dan publikasi**

Berdasarkan poperty pada pengelompokan ekstrasi data pada penelitian dan publikasi berkaitan dengan RQ1 dan RQ2.

1) Research Question (RQ) 1 :Jurnal apa yang paling banyak memuat tentang mekanisme koping pada pasien SLE?

Belum ditemukan jurnal yang paling banyak memuat studi tentang mekanisme koping pada pasien SLE

**Diagram 4.1 Jumlah publikasi**




**Tabel 4.2 Jurnal Publikasi**

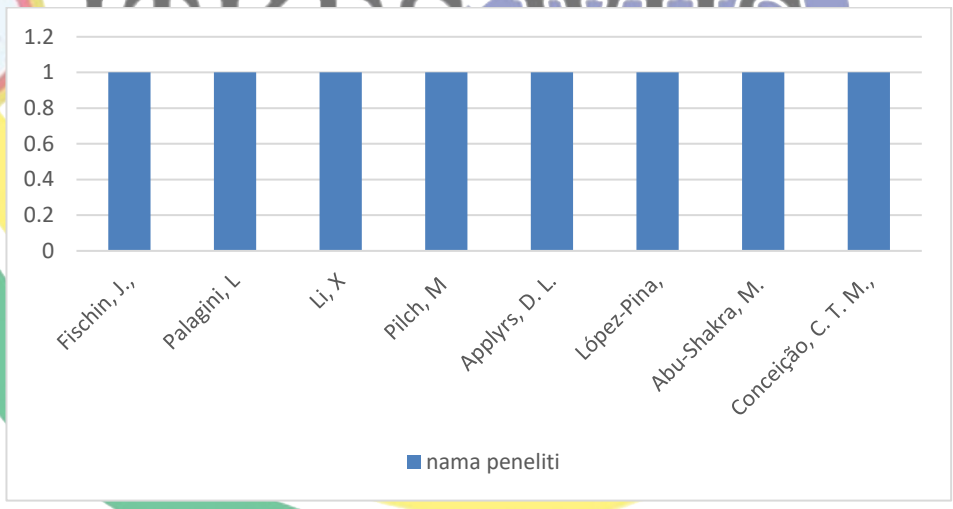
| No | Journal Publications | SJR | Q category | Data Base |
|---|---|---|---|---|
| 1. | Advances in Rheumatology | 0.44 | Q3 | Pubmed |
| 2. | Lupus | 1.02 | Q2 | SAGE Jurnal |
| 3. | PLoS One | 1.02 | Q1 | Pubmed |

| | | | | |
|---|---|---|---|---|
| 4. | Journal of the German Society of Dermatology | 0.45 | Q2 | Pubmed |
| 5. | Patient Preference and Adherence | 0.79 | Q1 | Pubmed |
| 6. | Health and Quality of Life Outcomes | 1 | Q1 | Springer Link |
| 7 | Israel Medical Association Journal | 0.36 | Q3 | Pubmed |
| 8 | Lupus Science and Medicine | 1.5 | Q1 | Pubmed |

2) RQ 2 : Siapa peneliti yang aktif yang meneliti mekanisme koping pada pasien SLE?

Belum ditemukan peneliti yang aktif pada penelitian ini. Adapun peneliti yang berkontribusi pada penelitian ini adalah Fischin, J. , Palagini, L., Li, X., Pilch, M., Applyrs, D. L., López, Abu-Shakra, M., dan Conceição, C.

**Diagram 4.2 Nama Peneliti**



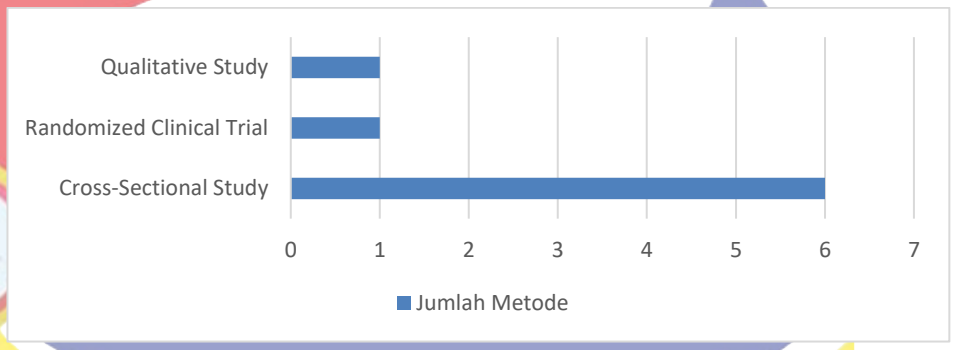

3) RQ 3 : Metode apa saja yang digunakan dalam penelitian mekanisme koping pada pasien SLE?

RQ 4 : Metode apa yang paling sering digunakan dalam penelitian mekanisme koping pada pasien SLE?

RQ 5 : Metode yang paling bagus yang digunakan dalam penelitian mekanisme koping pada pasien SLE ?

Metode yang digunakan pada studi yang memuat tentang mekanisme koping pada pasien SLE (Systemic Lupus Erythematosus) adalah metode *Cross-Sectional Study*, *Randomized Clinical Trial* dan *Qualitative Study*. Metode yang paling sering yang memuat tentang mekanisme koping pada pasien SLE (Systemic Lupus Erythematosus) dalam studi literature ini yaitu metode *Cross-Sectional Study*. Metode yang paling bagus dalam membahas tentang mekanisme koping pada pasien SLE (Systemic Lupus Erythematosus) yaitu *Cross-Sectional Study*.

**Diagram 4.3 Jumlah Metode**




**3. Kualitas dan Resiko Bias**

Setelah melakukan pencarian artikel dengan menggunakan media internet melalui beberapa *search engine*. Penyeleksian jurnal yang telah dilakukan dengan *scimagojr.com*, selanjutnya artikel yang didapatkan akan dilakukan penyortiran untuk mendapatkan artikel yang sesuai dengan topik studi literatur yang dilakukan. Penyortiran dilakukan dengan kriteria inklusi yang ditetapkan yaitu artikel yang membahas "Mekaniseme Koping dan SLE (Systemic Lupus Erythematosus)". Tahun terbit artikel 6 Tahun terakhir (2015-2020), sampel yang digunakan adalah pasien SLE (Systemic Lupus Erythematosus).

Kualitas studi dari masing-masing artikel yang ditetapkan sebagai sumber systematic review ditentukan berdasarkan analisis kualitas *Research Appraisal Checklist* dengan score Tinggi (205-306 poin) dan Sedang (103-204 poin)

sehingga didapatkan 8 artikel yang sesuai dengan systematic review. Hasil pencarian literature yang sudah dianalisis dan ditetapkan dalam systematic review dalah sebagai berikut :

**Tabel 4.2 Hasil Pencarian Literature Untuk Systematic Review**

| Language | Publication years | Data Base | N | Inklusi dan RAC |
|---|---|---|---|---|
| English | 2015-2020 | Pubmed | 13 | 6 |
| | | Springer Link | 3 | 1 |
| | | SAGE Journal | 3 | 1 |
| **Jumlah** | | | **23** | **8** |

**Tabel 4.3 Hasil Score Jurnal Berdasarkan RAC**

| No | Jurnal biografi | Data Base | Score RAC |
|---|---|---|---|
| 1. | Psychoanalytic psychotherapy improves quality of life, depression, anxiety and coping in patients with systemic lupus erythematosus: a controlled randomized clinical trial | Pubmed | 208 (Tinggi) |
| 2. | Insomnia symptoms, perceived stress and coping strategies in patients with systemic lupus erythematosus | SAGE Jurnal | 221 (Tinggi) |
| 3. | Illness uncertainty, social support, and coping mode in hospitalized patients with systemic lupus erythematosus in a hospital in Shaanxi, China | Pubmed | 207 (Tinggi) |
| 4. | Spiritual well-being and coping in scleroderma, lupus erythematosus, and melanoma | Pubmed | 196 (Sedang) |
| 5. | Cultural and quality-of-life considerations when administering corticosteroids as a therapeutic strategy for African American women living with systemic lupus erythematosus | Pubmed | 201 (Sedang) |
| 6. | Measurement properties of the brief resilient coping scale in patients with systemic lupus erythematosus using rasch analysis | Springer Link | 206 (Tinggi) |

| | | | |
|---|---|---|---|
| 7. | Quality of Life, Coping and Depression in Systemic Lupus Erythematosus | Pubmed | 181 (Sedang) |
| 8. | Factors associated with pain coping and catastrophising in patients with systemic lupus erythematosus: a cross-sectional study of the LuLa-cohort | Pubmed | 192 (sedang) |

## B. Hasil Studi

Hasil pencarian literature yang menghasilkan 8 artikel yang sudah dianalisis.. Adapun analisa jurnal yang sesuai dengan inklusi dapat dilihat pada tabel dibawah ini. Hasil studi yang sesuai kriteria studi literature ini adalah sebagai berikut :

**Tabel 4.4 Analisa Jurnal**

| No | Jurnal biografi | Populasi | Tujuan | Hasil | Study design | Score |
|---|---|---|---|---|---|---|
| 1. | Psychoanalytic psychotherapy improves quality of life, depression, anxiety and coping in patients with systemic lupus erythematosus: a controlled randomized clinical trial<br><br>**Author:** Conceição, C. T. M., et al (2019). | 80 Pasien Wanita penderita SLE | Tujuan dari penelitian ini adalah untuk mengevaluasi efektivitas psikoterapi Analitikal Kelompok Singkat untuk meningkatkan kualitas hidup, depresi, kecemasan dan strategi koping pada pasien SLE. | Usia rata-rata pasien adalah 42 tahun; 54% berkulit putih, dengan durasi penyakit rata-rata tahun 12. Pada awal, kedua kelompok itu homogen dalam semua variabel, termasuk obat-obatan. Setelah 20 minggu psikoterapi TG secara signifikan berbeda dari CG, dengan frekuensi gejala yang lebih rendah ( | Randomized Clinical Trial | 208 (Tinggi) |

| | | | | | | |
|---|---|---|---|---|---|---|
| | | | | p = 0,001), tingkat kecemasan yang lebih rendah ( p = 0,019) dan depresi ( p = 0,022), indeks yang lebih baik dalam lima dari enam domain skala kualitas hidup ( hal ≤ 0,005), termasuk total SLEQOL ( p < 0,001) dan dengan strategi pemecahan masalah yang lebih tinggi ( p = 0,017). Tidak ada perubahan dalam skor aktivitas penyakit yang diamati pada kedua kelompok. Psikoterapi psikoanalitik efektif untuk meningkatkan banyak domain kualitas hidup dan satu keterampilan koping yang positif dan untuk mengurangi gejala SLE, kecemasan dan tingkat depresi. | | |
| 2. | Insomnia symptoms, | 90 Wanita SLE | Tujuan dari penelitian ini adalah untuk | Individu dengan gejala insomnia (n | Cross-Sectional | 221 (Tinggi) |

| | | | | | | |
|---|---|---|---|---|---|---|
| | perceived stress and coping strategies in patients with systemic lupus erythematosus<br><br>**Author:** Palagini, L., et al (2016). | | mengevaluasi stres yang dirasakan dan strategi koping pada individu dengan systemic lupus erythematosus (SLE) sesuai dengan adanya gejala insomnia, menggunakan serangkaian variabel yang meliputi evaluasi gejala kecemasan dan depresi. | = 57, 66%) menunjukkan PSS yang lebih tinggi (p <0,001), PSQI (p <0,0001), BDI, (p <0,0001) skor dan menunjukkan strategi koping yang kurang efektif seperti penggunaan pelepasan perilaku. (p = 0,04), menyalahkan diri sendiri (p = 0,02) dan koping yang berfokus pada emosi (p = 0,001). Dalam model multi-regresi, ISI adalah penentu independen PSS tinggi dan pelepasan perilaku; PSQI adalah satu-satunya penentu menyalahkan diri sendiri (p = 0,02) dan koping yang berfokus pada emosi. SLE individu dengan gejala insomnia menunjukkan tingkat stres yang dirasakan dan lebih sering menggunakan | Study | |

| | | | | | | |
|---|---|---|---|---|---|---|
| | | | | strategi coping yang berfokus pada pelepasan dan fokus emosional. | | |
| 3. | Illness uncertainty, social support, and coping mode in hospitalized patients with systemic lupus erythematosus in a hospital in Shaanxi, China<br><br>**Author:**<br>Li, X., He, L., Wang, J., & Wang, M. (2019). | Patients with SLE (N = 200) in a tertiary hospital in Shaanxi. | Tujuan dari penelitian ini adalah untuk menganalisis hubungan antara ketidakpastian penyakit, dukungan sosial, dan model koping pada pasien rawat inap dengan systemic lupus erythematosus (SLE). | Pasien rawat inap dengan SLE menunjukkan tingkat ketidakpastian penyakit yang moderat. Selain itu, ketidakpastian penyakit berkorelasi negatif dengan ketersediaan dukungan (r = -0.161, P = 0,023) dan menghadapi mode koping (r = -0.231, P = 0,001), dan berkorelasi positif dengan mode koping yang menghasilkan (r = 0,249, P <0,001). Temuan ini menunjukkan bahwa ketersediaan dukungan dan mode koping dikaitkan dengan tingkat ketidakpastian penyakit sedang, yang mengindikasikan | Cross-Sectional Study | 207 (Tinggi) |

| | | | | | | |
|---|---|---|---|---|---|---|
| | | | | bahwa dukungan ketersediaan harus mendukung diperkuat pada pasien yang dirawat di rumah sakit untuk secara aktif menghadapi penyakit mereka. Ini selanjutnya meningkatkan kepatuhan pengobatan dan kualitas hidup mereka. | | |
| 4. | Spiritual well-being and coping in scleroderma, lupus erythematosus, and melanoma<br><br>**Author:** Pilch, Michaela, et al. (2016) | Seratus empat puluh sembilan pasien (107 wanita), 44 di antaranya dengan sklerosis sistemik (SSc), 48 dengan lupus erythematosus (LE), dan 57 dengan stadium I atau II melanoma ganas(MM) | Kesejahteraan religius / spiritual (R-S) dikaitkan dengan vitalitas yang lebih besar dan skor depresi yang lebih rendah. Dalam penelitian ini, kami menyelidiki strategi untuk mengatasi penyakit dan peran religiusitas / spiritualitas sehubungan dengan peningkatan | Pada saat diagnosis, beban penyakit lebih besar pada pasien LE daripada pada pasien dengan SSc dan MM. Hanya setelah beberapa tahun pasien SSC dan LE dapat menerima penyakit mereka. Dibandingkan dengan individu yang sehat, skor keseluruhan kesejahteraan R-S secara signifikan lebih rendah pada pasien LE. | Cross-Sectional Study | 196 (Sedang) |

| | | | | | | |
|---|---|---|---|---|---|---|
| 5. | Cultural and quality-of-life considerations when administering corticosteroids as a therapeutic strategy for African American women living with systemic lupus erythematosus<br><br>**Author:**<br>Applyrs, Dorcey L., et al. (2018) | lupus yang dikonfirmasi (n = 224) dan kontrol (n = 60). Sampel terdiri dari 57 orang Kaukasia Amerika, 141 orang Afrika-Amerika Gullah (sub-populasi orang Afrika-Amerika dari Kepulauan Laut Carolina Selatan dan Georgia), dan 86 orang Afrika-Amerika non-Gullah. | Tujuan penelitian ini menyelidiki hubungan antara kortikosteroid, kesehatan emosional, kesehatan fisik, dan aktivitas kerja sehari-hari dalam kehidupan sehari-hari dalam sampel beragam etnis wanita dengan lupus erythematosus sistemik. | Hasil kesehatan emosional lebih baik untuk wanita dengan lupus erythematosus sistemik dibandingkan dengan kontrol. Skor kesehatan emosional yang tinggi dapat dipengaruhi oleh faktor-faktor budaya seperti menutupi emosi, mekanisme penanganan penyakit, agama, dan dukungan keluarga dan sosial yang kuat. Meskipun hubungan yang signifikan tidak terdeteksi antara kesehatan emosional dan pekerjaan / kegiatan rutin kehidupan sehari-hari, hubungan itu signifikan setelah disesuaikan untuk penggunaan kortikosteroid. | Cross-Sectional Study | 201 (Sedang) |

| | | | | | | |
|---|---|---|---|---|---|---|
| 6. | Measurement properties of the brief resilient coping scale in patients with systemic lupus erythematosus using rasch analysis<br><br>**Author:**<br>López-Pina, José-Antonio, et al. (2016) | 232 pasien lupus erythematosus sistemik. | Tujuan dari penelitian ini adalah untuk mengeksplorasi sifat psikometrik dari Skala Penanganan Resiliensi Singkat pada pasien dengan SLE menggunakan analisis Rasch. | Mode skala penilaian (RSM) menunjukkan bahwa empat kategori yang digunakan dalam item BRCS dipesan dengan benar. Keempat item memberikan kesesuaian yang baik dengan model Rasch politytous. Selain itu, parameter cukup dipisahkan untuk mengukur ketahanan pada pasien dengan SLE. BRCS adalah skala unidimensional (nilai eigen = 1.843) dari ketahanan dan item independen secara lokal. Tidak ada DIF antara pria dan wanita dalam sampel. Hanya sedikit perbedaan signifikan tergantung pada tingkat pendidikan yang ditemukan. BRCS menunjukkan validitas | Cross-Sectional Study | 206 (Tinggi) |

| | | | | | | |
|---|---|---|---|---|---|---|
| | | | | diskriminan yang memadai antara kelompok skor. | | |
| 7. | Quality of Life, Coping and Depression in Systemic Lupus Erythematosus<br><br>**Author:**<br>Abu-Shakra, M. (2016). | 36 Pasien | Tujian penelitian ini adalah mengurangi SoC pada wanita SLE mewakili gangguan adaptive coping dan secara independen terkait dengan penurunan kualitas hidup pada wanita dengan SLE. | SLE adalah penyakit kronis yang secara signifikan berhubungan dengan kualitas hidup yang buruk, gangguan SoC dan tingkat depresi yang tinggi. Mengobati fibromyalgia, meningkatkan mekanisme koping, dan mengidentifikasi kecemasan dan depresi harus menjadi bagian integral manajemen terapi pasien dengan SLE. | Qualitative Study | 181 (Sedang) |
| 8. | Factors associated with pain coping and catastrophising in patients with systemic lupus erythematosus: a cross-sectional study | 620 Pasien | Tujuan dari penelitian ini adalah untuk mengidentifikasi faktor-faktor yang berhubungan dengan penanggulangan rasa sakit dan bencana pada pasien dengan systemic lupus erythematosus. | 447 kasus (94,9% perempuan) dianalisis menunjukkan skor bencana rata-rata 1,1 (SD 0,8) dan skor koping rata-rata 2,8 (SD 0,9) dalam PRSS subskala. Kuartil bencana yang lebih | Cross-Sectional Study | 192 (Sedang) |

| | | | | | | |
|---|---|---|---|---|---|---|
| | of the LuLa-cohort<br><br>**Author:**<br>Fischin, Julia, et al. (2015) | | | tinggi terjadi dengan rasa sakit yang lebih tinggi, aktivitas lupus, kelelahan, kerusakan dan penurunan kualitas hidup terkait kesehatan, sedangkan mereka disajikan secara terbalik untuk mengatasi. | | |

## C. Pembahasan

Pada penelitian ini menggunakan total 8 artikel yang digunakan dan ditetapkan sabagai literature yang digunakan dalam systematic literature review. Systematic literature review pada penelitian ini memiliki pertanyaan penelitian atau research question diawali dengan RQ1 yang menjelaskan dominasi jurnal terkait dengan mekanisme koping pada pasien SLE (Systemic Lupus Erythematosus), indeks quartil yang didapatkan 4 artikel dengan Q1, 2 artikel dengan Q2 dan 2 artikel dengan Q3. Belum ditemukan jurnal yang paling banyak memuat studi tentang mekanisme koping pada pasien SLE (Systemic Lupus Erythematosus). RQ2 menjelaskan siapa peneliti yang paling aktif membahas konsep mekanisme koping pada pasien SLE (Systemic Lupus Erythematosus) tetapi peneliti juga tidak mendaptkan siapa peneliti yang paling aktif dalam penelitian ini. RQ3 yang menjelaskan berdasarkan artikel-artikel yang telah dikumpulkan bahwa metode yang digunakan dalam artikel-artikel penelitian yaitu metode Cross-Sectional Study, Randomized Clinical Trial dan Qualitative Study. RQ4 menjelaskan berdasarkan artikel yang telah dikumpulkan dan ditetapkan metode yang sering digunakan adalah metode Cross-Sectional Study. RQ5 menjelasakan metode yang paling bagus yang digunakan dalam penelitian mekanisme koping pada pasien SLE (Systemic Lupus Erythematosus) adalah

Cross-Sectional Study dan ditentukan berdasarkan analisis kualitas Research Appraisal Checklist dengan score Tinggi (205-306 poin) dan Sedang (103-204 poin) sehingga didapatkan 8 artikel yang sesuai dengan studi literature.

Conceição, (2019) pada penelitian "Psychoanalytic psychotherapy improves quality of life, depression, anxiety and coping in patients with systemic lupus erythematosus: a controlled randomized clinical trial" Teknik psikoterapi digunakan dalam penelitian ini, Psikoterapi psikoanalitik dapat membantu pasien menjadi lebih kuat untuk menghadapi penyakit dan peristiwa kehidupan penting lainnya, meringankan penderitaan mereka. pada penelitian ini menunjukan strategi koping pasien SLE dalam kelompok kontrol dan terapi yaitu Confrontive coping menggambarkan usaha-usaha yang bersifat agresif untuk mengubah situasi, Distancing (menjauhkan) menggambarkan usaha-usaha yang dilakukan dengan cara menjaga jarak dengan masalah yang dihadapi, Self-controlling (Kontrol diri) menggambarkan usaha-usaha yang dilakukan untuk mengatur perasaan dan tindakan, Seeking social Support (Mencari Dukungan Sosial) menggambarkan usaha-usaha yang dilakukan dengan cara mencari dukungan, baik berupa informasi, bantuan nyata, maupun dukungan emosional dari orang lain, Accepting responsibility (Menerima tanggung jawab) menggambarkan mengakui atau menerima peran diri dalam permasalahan yang dihadapi dengan mencoba untuk mendudukkan segala sesuatu sebagaimana mestinya, Escape and Avoidance (Melarikan diri dan menghindar) menggambarkan usaha-usaha yang dilakukan individu dengan cara menghindar atau melarikan diri dari masalah yang dihadapi dan berkhayal, Planful problem Solving (Pemecahan masalah yang terencana) menggambarkan usaha-usaha yang berfokus pada masalah untuk mengubah situasi diikuti dengan pendekatan analitis untuk memecahkan masalah dan Positive reappraisal (Penilaian ulang positif) menggambarkan usaha-usaha menciptakan makna positif dengan berfokus pada pertumbuhan pribadi dari masalah yang dihadapi.

Palagini, (2016) pada penelitian "Insomnia symptoms, perceived stress and coping strategies in patients with systemic lupus erythematosus" menunjukan strategi koping dievaluasi menggunakan skala COPE Singkat, yang menilai

respons koping terhadap stresor, dengan skor yang lebih tinggi menunjukkan penggunaan strategi coping yang lebih baik. Strategi koping yang diukur dalam COPE Singkat termasuk penerimaan, agama, perencanaan, pembingkaian positif, menggunakan dukungan instrumental, koping aktif, menggunakan dukungan emosional, humor, selfdistraction, ventilasi emosi, menyalahkan diri sendiri, pelepasan perilaku, penyangkalan dan penggunaan zat. Strategi mengatasi masalah vs emosi berfokus dipertimbangkan. Skor komposit untuk dua strategi koping ini diperoleh dengan menjumlahkan skala mereka: Penerimaan, agama, perencanaan, pembingkaian positif, menggunakan dukungan instrumental, mengatasi aktif, menggunakan dukungan emosional dan humor terdiri dari skor coping yang berfokus pada masalah, sementara self-distraction, venting emosi, menyalahkan diri sendiri, pelepasan perilaku, penolakan dan penggunaan zat terdiri dari skor koping yang berfokus pada emosi.

Li, X., (2019) pada penelitian "Illness uncertainty, social support, and coping mode in hospitalized patients with systemic lupus erythematosus in a hospital in Shaanxi, China" menunjukkan bahwa ketersediaan dukungan dan mode koping. Social support (Dukungan sosial) berkaitan dengan mendapatkan dukungan emosional, informasi, dan/atau dukungan nyata dari orang terdekat, baik dukungan sosial yang diberikan oleh orang tua, saudara, tetangga, dan lain sebagainya. Mode koping yaitu facing (menghadapi), avoiding (menghindar), yielding (menyerah).

Pilch, (2016) pada penelitian "Spiritual well-being and coping in scleroderma, lupus erythematosus, and melanoma" Penelitian ini menunjukkan bahwa, pada saat diagnosis, pasien SLE khususnya merasa sangat terbebani. Hanya setelah bertahun-tahun mereka dapat berdamai dengan penyakit mereka. Pasien menggunakan kedua strategi koping aktif seperti perjalanan ke alam, merawat hewan peliharaan mereka, berkebun, olahraga, dan kegiatan kerajinan tangan, atau memainkan instrumen, serta strategi pasif seperti pergi ke film, menonton TV, dan mendengarkan musik. Mendengarkan pembicaraan tentang penyakit, membaca, dan kelompok pendukung juga merupakan faktor yang relevan. Strategi koping

religius seperti, menghadiri kebaktian gereja, seminar keagamaan dan spiritual, atau meditasi tidak memainkan peranan penting dalam penanganan penyakit.

Applyrs, (2018) pada penelitan "Cultural and quality-of-life considerations when administering corticosteroids as a therapeutic strategy for African American women living with systemic lupus erythematosus" menunjukan E motional health (kesehatan emosional) harus sehat sehingga pekerjaan / aktivitas rutin kehidupan sehari-hari dapat di kerjakan secara ringan saja dan Physical health (kesehatan fisik) bekerja dengan kegiatan rutin sehari-hari (peran fisik) untuk bertahan terhadap penyakitnya.

López-Pina, (2016) pada penelitian "Measurement properties of the brief resilient coping scale in patients with systemic lupus erythematosus using rasch analysis" dari Brief Resilient Coping Scale (BRCS) ukuran unidimensional yang dirancang untuk menangkap sejauh mana seorang individu mengatasi stres dengan cara yang tangguh. Pada penelitian ini pasien SLE menggunakan resilient coping. Skala ini mencerminkan salah satu pola ketahanan, lebih khusus pola situasional, yang sesuai dengan pola koping tangguh. Mengacu pada keuletan, optimisme, kreativitas, dan pendekatan agresif untuk pemecahan masalah, dan komitmen untuk pertumbuhan positif dari situasi sulit. Selain itu, BRCS berkorelasi dengan status kesehatan yang dirasakan pada pasien dengan SLE, memberikan bukti validitas konstruk. Jika intervensi untuk membangun koping tangguh dapat disempurnakan, maka mungkin kualitas hidup dapat ditingkatkan pada populasi ini dengan kondisi kronis yang penuh tekanan. Peningkatan kualitas hidup pada penyakit kronis yang tidak dapat disembuhkan adalah tujuan utama dan sangat penting bagi pasien.

Abu Shakra, (2016) pada penelitian "*Quality of Life, Coping and Depression in Systemic Lupus Erythematosus"* Data penelitian menunjukkan bahwa pasien dengan SLE tidak puas dengan kualitas hidup mereka yang terkait, The sense of coherence (SoC) mengacu pada orientasi global ke lingkungan dalam dan luar seseorang, yang secara signifikan menentukan hubungan antara stres, mengatasi penyakit, dan kesehatan. SoC terdiri dari tiga konsep: kelengkapan, pengelolaan, dan kebermaknaan.

Fischin, (2015) pada penelitian *"Factors associated with pain coping and catastrophising in patients with systemic lupus erythematosus: a cross-sectional study of the LuLa-cohort"* Melakukan aktivitas rekreasi yang seperti menari atau bowling memiliki hubungan positif dengan koping. Sebaliknya, aktivitas fisik terkait kesehatan lainnya dan luasnya tidak berdampak pada koping. dengan meningkatkan partisipasi/aktivitas sosial mungkin berguna untuk mengurangi koping dan akibatnya meningkatkan fungsi fisik dan mental pada SLE.

**1. Mekanisme koping pada pasien SLE (Systemic Lupus Erythematosus)**

Mekanisme koping berisi serangkaian strategi untuk mengelola stress dan meningkatkan persepsi kontrol pribadi. Pengembangan keterampilan koping untuk menghadapi penyakit SLE. Stressor dalam literature review ini dari dalam diri individu sendiri yaitu penyakit lupus (SLE) yang diderita pasien sedangkan stressor yang lain berasal dari luar individu yaitu dari dalam keluarga dan lingkungan sekitar individu.



Dari berbagai kondisi stres yang dialami ternyata memberikan pengaruh positif dan negatif. Dampak positifnya lebih bisa memaknai hidup seperti menjadi rajin beribadah, memperoleh pekerjaan yang baru. Dampak negatifnya yaitu tidak percaya diri, tertutup, dan malu. Hal ini sesuai dengan pernyataan Mashudi (2013) stres dapat memberikan pengaruh positif dan negative terhadap individu. Pengaruh positif dari stres adalah mendorong untuk melakukan sesuatu, membangkitkan kesadaran, dan menghasilkan pengalaman baru. Sedangkan pengaruh negatifnya adalah menimbulkan perasaan-perasaan tidak percaya diri, penolakan, marah atau depresi yang kemudian memicu munculnya penyakit seperti sakit kepala, sakit perut, tekanan darah tinggi dan lain sebagainya.

Kondisi yang dialami oleh penderita lupus membuat dirinya harus mampu mengontrol mekanisme koping untuk mengatasi kondisi sakitnya. Mekanisme koping berdasarkan golongannya dibagi menjadi 2 yaitu mekanisme koping adaptif dan maladaftif (Stuart and Laraia, 2009). Mekanisme koping adaptif mendukung fungsi integrasi, pertumbuhan, belajar dan mencapai tujuan.

Sedangkan mekanisme koping maladaptif menghambat fungsi integrasi, memecah pertumbuhan, menurunkan otonomi dan cenderung menguasai lingkungan.

Mekanisme koping maladaptif dalam literature ini ditunjukkan dengan pasien yang menjaukan dirinya, khawatir dengan kondisinya, perubahan pada fisiknya, kurangnya dukungan sosial, menyalahkan diri sendiri, melarikan diri dan menghindar. Mekanisme koping yang adaptif dalam literature ini ditunjukan dengan upaya pasien untuk mencoba berbicara dengan orang lain, mencoba untuk mencari informasi yang lebih banyak tentang masalah yang dihadapi, menghubungkan situasi atau masalah yang sedang dihadapi dengan kekuatan supranatural seperti melakukan kegiatan ibadah dan berdoa, melakukan latihan fisik untuk mengurangi stressor, membuat berbagai alternatif tindakan untuk mengurangi situasi dan mengambil pelajaran atau pengalaman masa lalu. Dalam mekanisme koping pada SLE bisa menggunakan BRCS (Brief Resilient Coping Scale) ukuran unidimensional yang dirancang untuk menangkap sejauh mana seorang individu mengatasi stres dengan cara yang tangguh. Skala ini mencerminkan salah satu pola ketahanan, lebih khusus pola situasional, yang sesuai dengan pola koping tangguh.

Faktor yang mempengarui mekanisme koping yaitu dukungan sosial yang berasal dari keluarga, teman, teman sesama penderita lupus, tetangga dan dokter juga mempengaruhi pasien dalam melakukan koping. Hal ini sesuai dengan penelitian Nurmalasari dan Putri (2015) Dukungan sosial yang diterima oleh penderita Lupus, dapat berupa beberapa bentuk dukungan antara lain dukungan emosional, dukungan instrumental atau materi, dukungan penghargaan, dukungan informasi dan inte-gritas sosial. Dengan adanya dukungan yang didapatkan oleh individu, maka individu akan dapat meningkatkan rasa percaya dirinya dan memotivasi penderita menjadi lebih baik. Menurut Huffman, Vernoy, & Vernoy (1997) dukungan sosial merupakan salah satu faktor individu dalam melakukan usahanya mengatasi situasi yang menekan dan menimbulkan stres. dengan memperoleh dukungan

sosial pasien lupus lebih semangat dalam menjalani hidup, lebih bisa memaknai hidup sebagai hal yang positif, dan mulai memiliki rasa percaya diri. Dalam hal ini semakin baik dukungan sosial yang diterima maka akan semakin baik pula coping yang dilakukan penderita lupus dan sebaliknya.

**2. Keterbatasan Studi Literature**

Keterbatasan dalam studi literature ini selama pengumpulan literature dan proses perangkuman dilakukan:

a. Masih belum banyaknya studi atau penelitian yang membahas tentang mekanisme koping pada pasien SLE (Systemic Lupus Erythematosus)
b. Studi atau penelitian hanya di ambil dari jurnal internasional belum ada pengambilan studi atau penelitian dari journal Indonesia
c. Peneliti belum menemukan jurnal publikasi yang paling banyak memuat tentang mekanisme koping pada pasien SLE (Systemic Lupus Erythematosus)
d. Peneliti belum menemukan peneliti yang paling aktif dalam membahas mekanisme koping pada pasien SLE (Systemic Lupus Erythematosus).

# BAB V
# PENUTUP

## A. Kesimpulan

Berdasarkan hasil penelitian dari jurnal-jurnal yang telah dikumpulkan dengan jumlah 8 artikel, sytematic literature review ini mengindentifikasi mekensime koping pada SLE (Systemic Lupus Erythematosus) bahwa penderita lupus mengalami mekanisme koping maladaptif. Meknisme koping maladaptif adalah suatu keadaan dimana individu mempunyai pengalaman atau mengalami keadaan yang beresiko tinggi atau ketidakmampuan untuk mengatasi stressor. Koping maladaptif menggambarkan undividu yang mengalami kesulitan dalam beradaptasi terhadap kejadian-kejadian yang sangat menekan. Adpaun mekanisme koping yang maladaptif dalam literature ini ditunjukkan dengan pasien yang menjaukan dirinya, khawatir dengan kondisinya, perubahan pada fisiknya, kurangnya dukungan sosial, menyalahkan diri sendiri, melarikan diri dan menghindar.

Faktor yang mempengarui mekanisme koping yaitu dukungan sosial yang berasal dari keluarga, teman, teman sesama penderita lupus, tetangga dan dokter juga mempengaruhi pasien dalam melakukan koping. Dengan adanya dukungan yang didapatkan oleh individu, maka individu akan dapat meningkatkan rasa percaya dirinya, memotivasi penderita menjadi lebih baik, lebih semangat dalam menjalani hidup, lebih bisa memaknai hidup sebagai hal yang positif, dan mulai memiliki rasa percaya diri.



## B. Saran

Berdasarkan hasil urain pembahasan dan kesimpulan tersebut peneliti memberikan saran:

1. Bagi ilmu keperawatn

   Diharapkan penelitan ini mampu menjadi acuan dalam pengembangan pelaksanaa asuhan keperawatan khususnya dalam mengetahui kondisi mekanisme koping pada pasien SLE (Systemic Lupus Erythematosus). Perawat dapat memahami kondisi mekanisme koping pada pasien SLE (Systemic Lupus Erythematosus), serta perawat semakin dipanggil untuk

memberikan perawatan holistikm menggabungkan dimensi fisikm psikologis, sosial dan spiritual individu.

2. Bagi institusi

   Diharapkan penelitian ini mampu menjadi salah satu informasi tambahan agar digunakan sebagai sumber informasi ilmu pengetahuan bagi mahasiswa lainnya yang dapat memudahkan dalam mempelajari mengenai mekanisme koping pada pasien SLE (Systemic Lupus Erythematosus).

3. Bagi penelitian selanjutnya

   Bagi penelitian selanjutnya diharapkan dapat digunakan sebagai bahan tambahan dan juga selanjutnya untuk melakukan penelitain dengan mereview artikel pada jurnal-jurnal terkait dengan berkaitan dengan bagaimana mekanisme koping pada pasien SLE (Systemic Lupus Erythematosus) pada jurnal-jurnal indonesia dan bagamina meningkatkan kualitas hidup pada pasien SLE.

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**LAMPIRAN 1**

**INSTITUSI TEKNOLOGI KESEHATAN & SAINS (ITKES)**

**WIYATA HUSADA SAMARINDA**

**BIODATA PENELITIAN**

| | |
|---|---|
| Nama | : Tita Miranda |
| Tempat/Tgl. Lahir | : Samarinda, 22 Desember 1997 |
| Jenis Kelamin | : Perempuan |
| Agama | : Islam |
| Alamat | : Jl. Ciptomangunkusumo Harapan, Kec. Loajanan Ilir |
| No.Telp/Hp | : - |
| Email | : Titamiranda322@gmail.com |
| Program Studi | : S1 Ilmu Keperawatan |
| NIM | : 16.0494.829.01 |
| Judul Skripsi | : Studi Literature: Mekanisme Koping Pada Pasien Sle (Systemic Lupus Erythematosus) |
| Dosen Pembimbing | : 1. Ns. Linda Dwi Novial Fitri. Sp.Kep.Jiwa<br>2. Ns. Wahyu Dewi Sulistyarini, M.S |

**PENDIDIKAN FORMAL**

Tahun 2010 : Lulus SDN 010 Samarinda

Tahun 2013 : Lulus SMPN 18 Samarinda

Tahun 2016 : Lulus SMK Farmasi Samarinda

**LAMPIRAN 2**

## PLAN OF ACTION KEGIATAN TUGAS AKHIR 2019/2020

NAMA : TITA MIRANDA

NIM : 16.0494.829.01

JUDUL : STUDI LITERATURE: MEKANISME KOPING PADA PASIEN SLE (*SYSTEMIC LUPUS ERYTHEMATOSUS*)

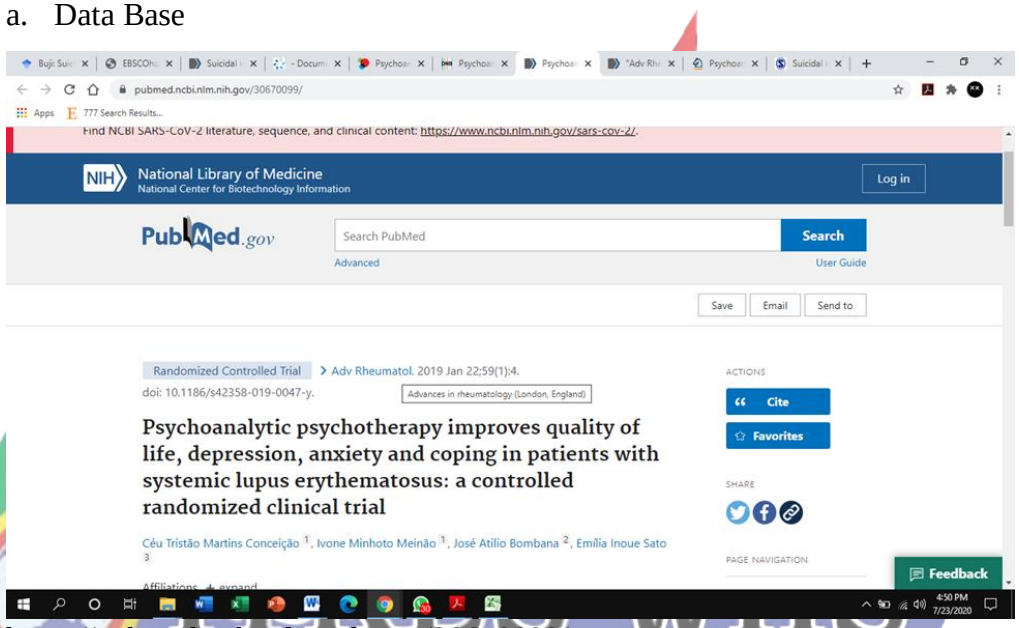
| | | 2019/2020 | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| **No** | **Kegiatan** | **Nov** | **Des** | **Jan** | **Feb** | **Mar** | **Apr** | **Mei** | **Jun** | **Jul** | **Agust** | **Sep** |
| 1 | Pengajuan Judul | | | | | | | | | | | |
| 2 | Penyelesaian Dan Bimbingan Proposal Dari BAB I,II Dan III | | | | | | | | | | | |
| 3 | Sidang Proposal | | | | | | | | | | | |
| 4 | Revisi Proposal | | | | | | | | | | | |
| 5 | Penyelesaian dan Bimbingan Skripsi | | | | | | | | | | | |
| 6 | Sidang Skripsi | | | | | | | | | | | |
| 7 | Yudisium | | | | | | | | | | | |
| 8 | Wisuda | | | | | | | | | | | |

**LAMPIRAN 3**

**DATA BASE DAN SCIMAGORO JOURNAL RANK (SJR)**

1. Psychoanalytic psychotherapy improves quality of life, depression, anxiety and coping in patients with systemic lupus erythematosus: a controlled randomized clinical trial

   a. Data Base

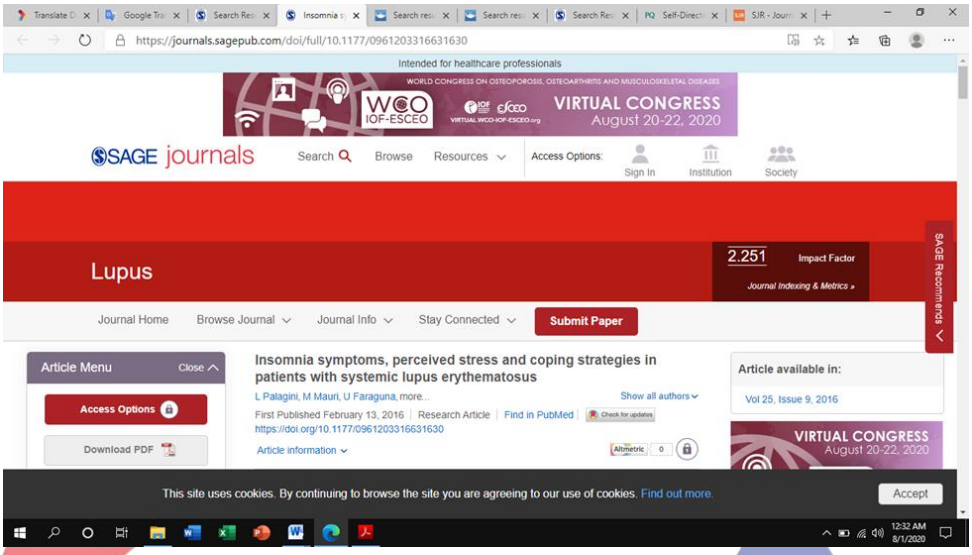



https://pubmed.ncbi.nlm.nih.gov/30670099/

   b. SJR (SCImagoro Journal Rank)

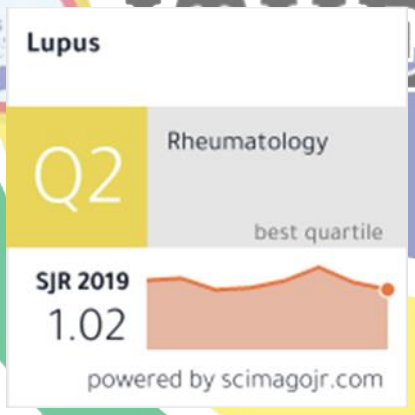
2. Insomnia symptoms, perceived stress and coping strategies in patients with systemic lupus erythematosus

   a. Data Base



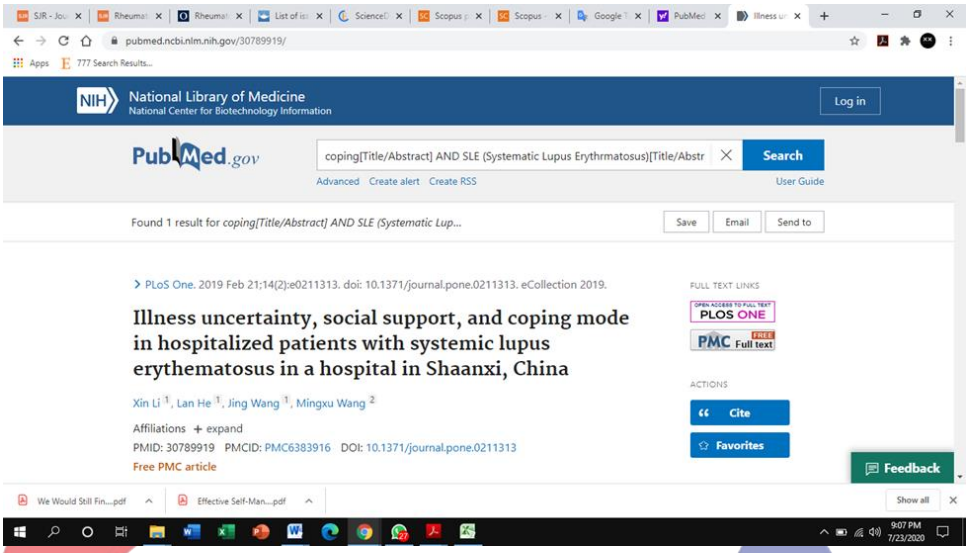

https://journals.sagepub.com/doi/full/10.1177/0961203316631630

   b. SJR (SCImagoro Journal Rank)



3. Illness uncertainty, social support, and coping mode in hospitalized patients with systemic lupus erythematosus in a hospital in Shaanxi, China

   a. Data Base

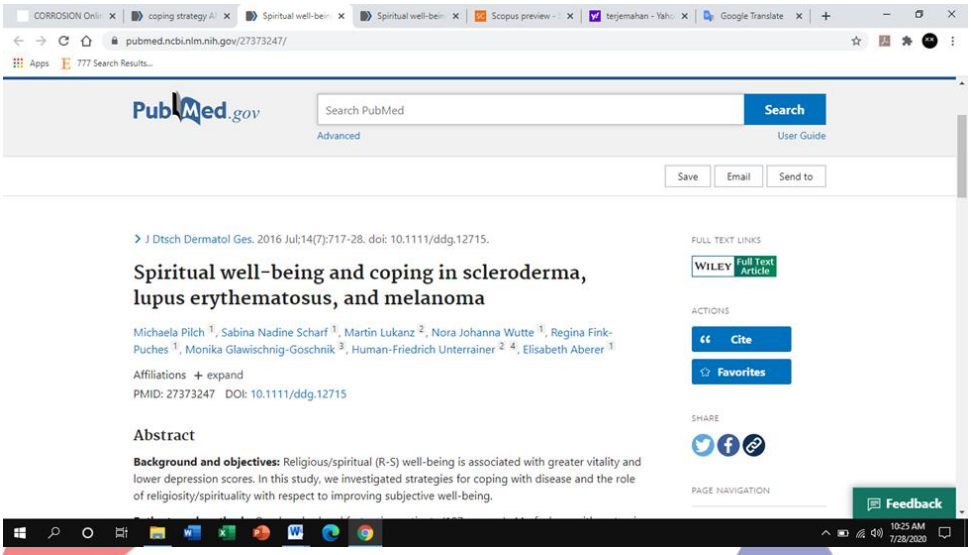



https://pubmed.ncbi.nlm.nih.gov/30789919/

   b. SJR (SCImagoro Journal Rank)

4. Spiritual well-being and coping in scleroderma, lupus erythematosus, and melanoma

   a. Data Base

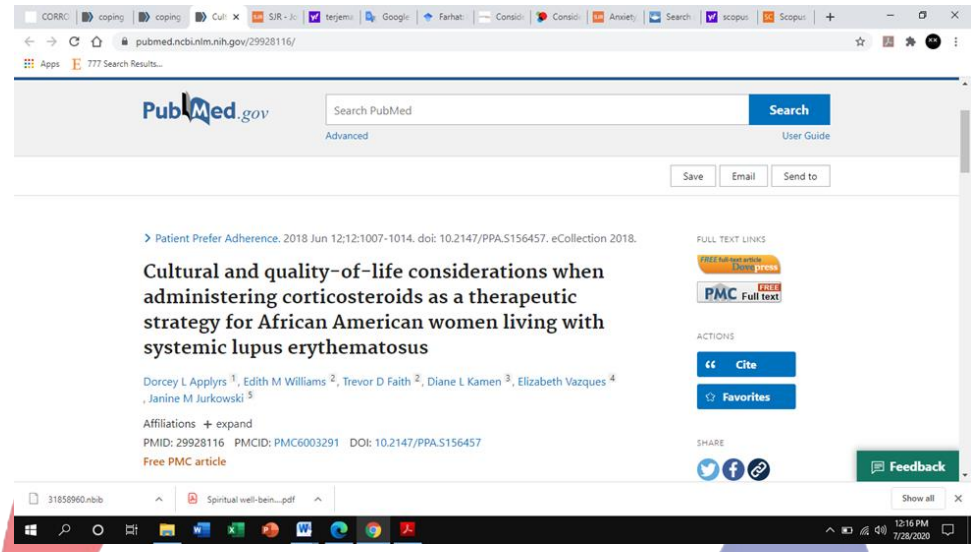



https://pubmed.ncbi.nlm.nih.gov/27373247/

   b. SJR (SCImagoro Journal Rank)

5. Cultural and quality-of-life considerations when administering corticosteroids as a therapeutic strategy for African American women living with systemic lupus erythematosus

   a. Data Base

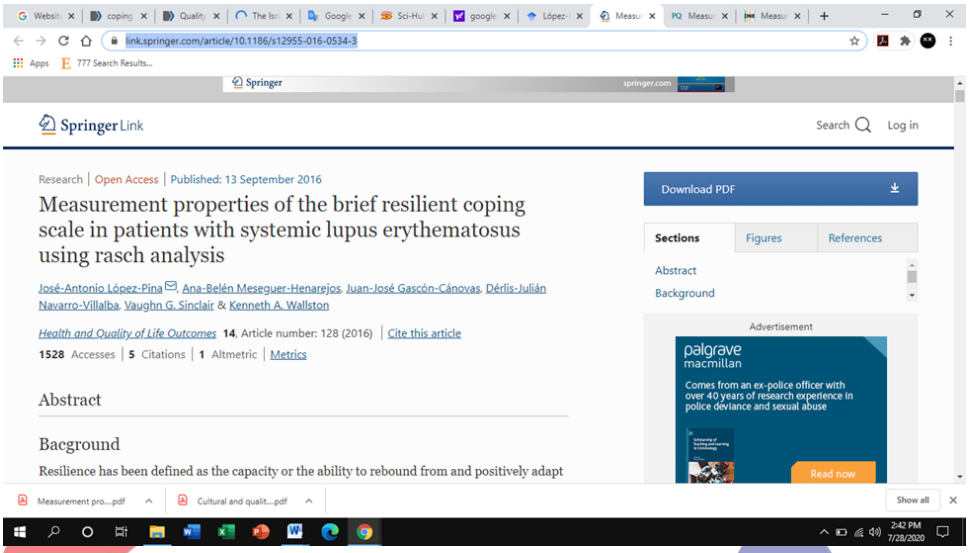



https://pubmed.ncbi.nlm.nih.gov/29928116/

   b. SJR (SCImagoro Journal Rank)

6. Measurement properties of the brief resilient coping scale in patients with systemic lupus erythematosus using rasch analysis

   a. Data Base

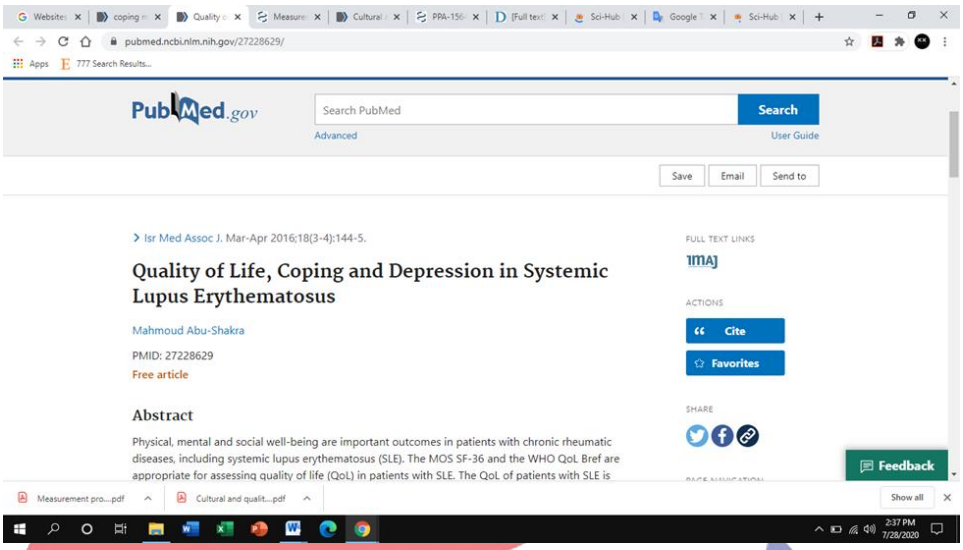



https://link.springer.com/article/10.1186/s12955-016-0534-3

   b. SJR (SCImagoro Journal Rank)

7. Quality of Life, Coping and Depression in Systemic Lupus Erythematosus

   a. Data Base

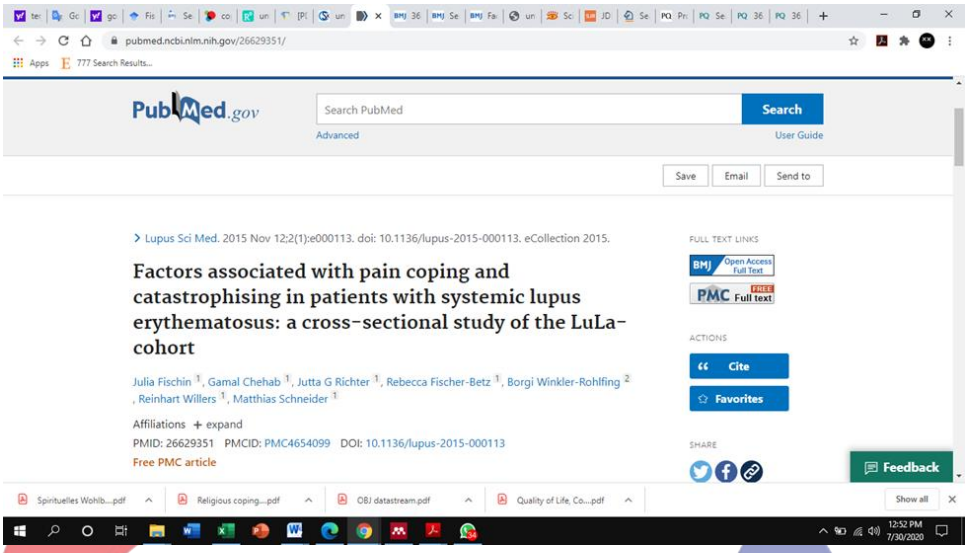



https://pubmed.ncbi.nlm.nih.gov/27228629/

   b. SJR (SCImagoro Journal Rank)

8. Factors associated with pain coping and catastrophising in patients with systemic lupus erythematosus: a cross-sectional study of the LuLa-cohort

   a. Data Base

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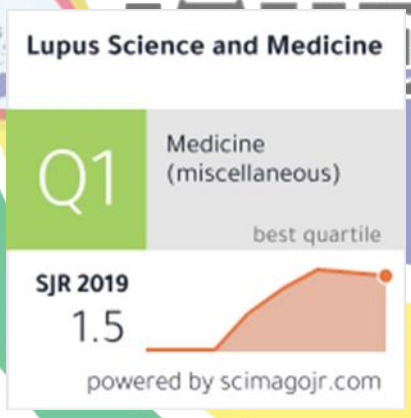
   b. SJR (SCImagoro Journal Rank)



**LAMPIRAN 4**

**RAC (*Research Appraisal Checklist)***

**KUESIONER EVALUASI PENELITIAN**

1. **Psychoanalytic psychotherapy improves quality of life, depression, anxiety and coping in patients with systemic lupus erythematosus: a controlled randomized clinical trial**

Review : Tita Miranda Date & Year : 22 Januari 2019

Author : Conceição, C. T. M., et al DOI: 10.1186/s42358-019-0047-y

| No | Kriteria | Penilaian | | | | | | Jumlah |
|---|---|---|---|---|---|---|---|---|
| | | 1 | 2 | 3 | 4 | 5 | 6 | |
| 1 | Judul mudah dimengerti | | | | | | √ | **6** |
| 2 | Judul jelas | | | | | | √ | **6** |
| 3 | Judul sesuai dengan isi penelitian | | | | | | √ | **6** |
| | **ABSTRAK** | | | | | | | |
| 4 | Abstrak berisi rumusan masalah, dan jika ada, hipotesis dituliskan secara jelas dan ringkas | | | | | | √ | **6** |
| 5 | Metodologi dikemukakan dan dijabarkan secara singkat | | | | | | √ | **6** |
| 6 | Hasil penelitian dipaparkan | | | | | | √ | **6** |
| 7 | Hasil dan/atau simpulan disampaikan | | | | | | √ | **6** |
| | **RUMUSAN MASALAH** | | | | | | | |
| 8 | Rumusan masalah disampaikan pada bagian awal laporan penelitian | | | √ | | | | **3** |
| 9 | Pertanyaan penelitian disampaikan secara tepat | | | √ | | | | **3** |
| 10 | Rumusan masalah diuraikan dengan jelas | | | √ | | | | **3** |
| 11 | Hipotesis yang akan diujikan dapat dibuktikan kebenarannya | | √ | | | | | **2** |
| 12 | Batasan penelitian dapat dikemukakan | | | | √ | | | **4** |
| 13 | Asumsi penelitian dapat dikemukakan | | √ | | | | | **2** |
| 14 | Konsep-konsep terkait penelitian didefinisikan secara operasional | | | √ | | | | **3** |
| 15 | Kontribusi penelitian dikemukakan | | | √ | | | | **3** |
| 16 | Penelitian mampu diuji kebenarannya | | | | | | √ | **6** |
| | **LANDASAN TEORI** | | | | | | | |
| 17 | Teori yang digunakan sesuai dengan rumusan masalah | | | √ | | | | **3** |

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|---|---|---|---|---|---|---|---|---|
| 18 | Teori mendukung alasan penelitian dilakukan | | | | | | √ | **6** |
| 19 | Penelitian dilakukan secara kritis | | | | | √ | | **5** |
| 20 | Keterkaitan rumusan masalah dan penelitian sebelumnya terpapar dengan jelas | | | | √ | | | **4** |
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| | **METODOLOGI** | | | | | | | |
| | **SUBJEK** | | | | | | | |
| 23 | Penjelasan mengenai subjek populasi (kerangka sampling) | | | √ | | | | **3** |
| 24 | Penjelasan mengenai metode pengambilan sampel | | | | √ | | | **4** |
| 25 | Metode pengambilan sampel dijabarkan terutama untuk nonprobability sampling | | | √ | | | | **3** |
| 26 | Ukuran sampel sesuai untuk mengurangi kesalahan tipe II | | √ | | | | | **2** |
| 27 | Mampu mengidentifikasi adanya kemungkinan penyebab terjadinya sampling error | | | | √ | | | **4** |
| 28 | Penjelasan mengenai standar perlindungan bagi subjek penelitian | | | √ | | | | **3** |
| | **INSTRUMEN** | | | | | | | |
| 29 | Menyebutkan reliabilitas data yang sesuai dengan penelitian sebelumnya | | √ | | | | | **2** |
| 30 | Menampilkan reliabilitas data yang sesuai dengan penelitian yang dilakukan | | √ | | | | | **2** |
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| 33 | Metode pengumpulan data dijabarkan agar mencapai kelayakan untuk dipergunakan dalam penelitian ini | | | √ | | | | **3** |
| | **DESAIN PENELITIAN** | | | | | | | |
| 34 | Desain sesuai dengan pertanyaan dan/atau hipotesis penelitian | | √ | | | | | **2** |
| 35 | Apabila diperlukan, kelompok kontrol dapat dimasukkan | | | √ | | | | **3** |
| 36 | Variabel pengganggu / moderasi dapat diidentifikasi | | | √ | | | | **3** |
| 37 | Deskripsi desain dijelaskan cukup eksplisit agar membantu replika penelitian | | | | √ | | | **4** |
| | **ANALISIS DATA** | | | | | | | |
| 38 | Memberikan informasi yang sesuai untuk menjawab pertanyaan penelitian | | | | √ | | | **4** |
| 39 | Melakukan uji statistik | | | | √ | | | **4** |
| 40 | Hasil uji statistik sesuai dengan hipotesis dan pertanyaan penelitian | | | √ | | | | **3** |
| 41 | Tabel dan gambar ditampilkan dalam format yang mudah dipahami serta informatif | | | √ | | | | **3** |
| | **PEMBAHASAN** | | | | | | | |

| | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| 42 | Simpulan diungkapkan dengan jelas | | | | | | √ | **6** |
| 43 | Simpulan didukung dengan bukti-bukti | | | | | | √ | **6** |
| 44 | Hal-hal terkait metodologi penelitian diuraikan dan dibahas | | | | | | √ | **6** |
| 45 | Hasil penelitian secara spesifik dikaitkan dengan konseptual/teoretikal dasar penelitian | | | | | √ | | **5** |
| 46 | Implikasi dari hasil penelitian disebutkan | | | | √ | | | **4** |
| 47 | Melakukan generalisasi hasil penelitian khusus bagi populasi guna menambah khasanah keilmuan | | | | √ | | | **4** |
| 48 | Penyampaian saran bagi penelitian selanjutnya | | | | | | √ | **6** |
| | **BENTUK DAN GAYA PENULISAN** | | | | | | | |
| 49 | Laporan tertulis dengan jelas | | | | | | √ | **6** |
| 50 | Laporan terorganisir secara logis | | | | | | √ | **6** |
| 51 | Laporan tidak bersifat menyimpang, jujur dan berpedoman pada aturan saintifik | | | | | | √ | **6** |
| | **Jumlah** | | | | | | | **208** |

**Jumlah**

**Tinggi (205-306 poin)**

Sedang (103-204 poin)

Di bawah rata-rata (0-102 poin)

**2. Insomnia symptoms, perceived stress and coping strategies in patients with systemic lupus erythematosus**

Review : Tita Miranda Date & Year : 7 January 2016

Author : Palagini, L., et al DOI : 10.1177/0961203316631630

| No | Kriteria | Penilaian | | | | | | Jumlah |
|---|---|---|---|---|---|---|---|---|
| | | 1 | 2 | 3 | 4 | 5 | 6 | |
| 1 | Judul mudah dimengerti | | | | | | √ | **6** |
| 2 | Judul jelas | | | | | | √ | **6** |
| 3 | Judul sesuai dengan isi penelitian | | | | | | √ | **6** |
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| 5 | Metodologi dikemukakan dan dijabarkan secara singkat | | | | | | √ | **6** |
| 6 | Hasil penelitian dipaparkan | | | | | | √ | **6** |
| 7 | Hasil dan/atau simpulan disampaikan | | | | | | √ | **6** |
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| 13 | Asumsi penelitian dapat dikemukakan | | | | √ | | | **4** |
| 14 | Konsep-konsep terkait penelitian didefinisikan secara operasional | | | √ | | | | **3** |
| 15 | Kontribusi penelitian dikemukakan | | | √ | | | | **3** |
| 16 | Penelitian mampu diuji kebenarannya | | | | | | √ | **6** |
| | **LANDASAN TEORI** | | | | | | | |
| 17 | Teori yang digunakan sesuai dengan rumusan masalah | | | √ | | | | **3** |
| 18 | Teori mendukung alasan penelitian dilakukan | | | | | | √ | **6** |
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| 20 | Keterkaitan rumusan masalah dan penelitian sebelumnya terpapar dengan jelas | | | | √ | | | **4** |
| 21 | Kerangka konseptual/ landasan teoretis disampaikan secara jelas | | | √ | | | | **3** |
| 22 | Reviu berisi ringkasan teori yang relevan serta implikasi penelitian | | | √ | | | | **3** |
| | **METODOLOGI** | | | | | | | |
| | **SUBJEK** | | | | | | | |

| | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| 23 | Penjelasan mengenai subjek populasi (kerangka sampling) | | | | | √ | | **5** |
| 24 | Penjelasan mengenai metode pengambilan sampel | | | | √ | | | **4** |
| 25 | Metode pengambilan sampel dijabarkan terutama untuk nonprobability sampling | | | √ | | | | **3** |
| 26 | Ukuran sampel sesuai untuk mengurangi kesalahan tipe II | | | √ | | | | **3** |
| 27 | Mampu mengidentifikasi adanya kemungkinan penyebab terjadinya sampling error | | | √ | | | | **3** |
| 28 | Penjelasan mengenai standar perlindungan bagi subjek penelitian | | | | √ | | | **4** |
| | **INSTRUMEN** | | | | | | | |
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| 33 | Metode pengumpulan data dijabarkan agar mencapai kelayakan untuk dipergunakan dalam penelitian ini | | | | √ | | | **4** |
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| 34 | Desain sesuai dengan pertanyaan dan/atau hipotesis penelitian | | | | | | √ | **6** |
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| 38 | Memberikan informasi yang sesuai untuk menjawab pertanyaan penelitian | | | √ | | | | **3** |
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| 41 | Tabel dan gambar ditampilkan dalam format yang mudah dipahami serta informatif | | √ | | | | | **2** |
| | **PEMBAHASAN** | | | | | | | |
| 42 | Simpulan diungkapkan dengan jelas | | | | | | √ | **6** |
| 43 | Simpulan didukung dengan bukti-bukti | | | | | | √ | **6** |
| 44 | Hal-hal terkait metodologi penelitian diuraikan dan dibahas | | | | | √ | | **5** |
| 45 | Hasil penelitian secara spesifik dikaitkan dengan konseptual/teoretikal dasar penelitian | | | | | √ | | **5** |
| 46 | Implikasi dari hasil penelitian disebutkan | | | | √ | | | **4** |
| 47 | Melakukan generalisasi hasil penelitian khusus bagi populasi guna menambah khasanah keilmuan | | | | | | √ | **6** |
| 48 | Penyampaian saran bagi penelitian selanjutnya | | | | | | √ | **6** |

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| | **BENTUK DAN GAYA PENULISAN** | | | | | | | |
| 49 | Laporan tertulis dengan jelas | | | | | | √ | **6** |
| 50 | Laporan terorganisir secara logis | | | | | | √ | **6** |
| 51 | Laporan tidak bersifat menyimpang, jujur dan berpedoman pada aturan saintifik | | | | | | √ | **6** |
| | **Jumlah** | | | | | | | **221** |

**Jumlah**

**Tinggi (205-306 poin)**

Sedang (103-204 poin)

Di bawah rata-rata (0-102 poin)

**3. Illness uncertainty, social support, and coping mode in hospitalized patients with systemic lupus erythematosus in a hospital in Shaanxi, China**

Review : Tita Miranda Date & Year : 21 Feb 2019

Author : Li, X., He, L., Wang, J., & Wang, M. DOI: 10.1371/journal.pone.0211313

| No | Kriteria | Penilaian | | | | | | Jumlah |
|---|---|---|---|---|---|---|---|---|
| | | 1 | 2 | 3 | 4 | 5 | 6 | |
| 1 | Judul mudah dimengerti | | | | | | √ | **6** |
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| 7 | Hasil dan/atau simpulan disampaikan | | | | | | √ | **6** |
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| 8 | Rumusan masalah disampaikan pada bagian awal laporan penelitian | | √ | | | | | **2** |
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| 10 | Rumusan masalah diuraikan dengan jelas | | | √ | | | | **3** |
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| 12 | Batasan penelitian dapat dikemukakan | | | √ | | | | **3** |
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| 15 | Kontribusi penelitian dikemukakan | | √ | | | | | **2** |
| 16 | Penelitian mampu diuji kebenarannya | | | | | | √ | **6** |
| | **LANDASAN TEORI** | | | | | | | |
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| 18 | Teori mendukung alasan penelitian dilakukan | | | | √ | | | **4** |
| 19 | Penelitian dilakukan secara kritis | | | | √ | | | **4** |
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| 22 | Reviu berisi ringkasan teori yang relevan serta implikasi penelitian | | √ | | | | | **2** |

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|---|---|---|---|---|---|---|---|---|
| | **METODOLOGI** | | | | | | | |
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| 23 | Penjelasan mengenai subjek populasi (kerangka sampling) | | | | √ | | | **4** |
| 24 | Penjelasan mengenai metode pengambilan sampel | | | | √ | | | **4** |
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| 26 | Ukuran sampel sesuai untuk mengurangi kesalahan tipe II | | √ | | | | | **2** |
| 27 | Mampu mengidentifikasi adanya kemungkinan penyebab terjadinya sampling error | | | √ | | | | **3** |
| 28 | Penjelasan mengenai standar perlindungan bagi subjek penelitian | | | | √ | | | **4** |
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| 29 | Menyebutkan reliabilitas data yang sesuai dengan penelitian sebelumnya | | | √ | | | | **3** |
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| 42 | Simpulan diungkapkan dengan jelas | | | | | | √ | **6** |
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| 44 | Hal-hal terkait metodologi penelitian diuraikan dan dibahas | | | | | | √ | **6** |
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| 46 | Implikasi dari hasil penelitian disebutkan | | | | √ | | | **4** |
| 47 | Melakukan generalisasi hasil penelitian khusus | | | | √ | | | **4** |

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|---|---|---|---|---|---|---|---|---|
| | bagi populasi guna menambah khasanah keilmuan | | | | | | | |
| 48 | Penyampaian saran bagi penelitian selanjutnya | | | | | | √ | **6** |
| | **BENTUK DAN GAYA PENULISAN** | | | | | | | |
| 49 | Laporan tertulis dengan jelas | | | | | | √ | **6** |
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| 51 | Laporan tidak bersifat menyimpang, jujur dan berpedoman pada aturan saintifik | | | | | | √ | **6** |
| | **Jumlah** | | | | | | | **207** |

**Jumlah**

**Tinggi (205-306 poin)**

Sedang (103-204 poin)

Di bawah rata-rata (0-102 poin)

**4. Spiritual well-being and coping in scleroderma, lupus erythematosus, and melanoma**

Review : Tita Miranda Date & Year : 14 Juli 2016

Author : Pilch, Michaela, et al DOI: 10.1111/ddg.12715.

| No | Kriteria | Penilaian | | | | | | Jumlah |
|---|---|---|---|---|---|---|---|---|
| | | 1 | 2 | 3 | 4 | 5 | 6 | |
| 1 | Judul mudah dimengerti | | | | | | √ | **6** |
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| | **SUBJEK** | | | | | | | |

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| 28 | Penjelasan mengenai standar perlindungan bagi subjek penelitian | | | √ | | | | **3** |
| | **INSTRUMEN** | | | | | | | |
| 29 | Menyebutkan reliabilitas data yang sesuai dengan penelitian sebelumnya | | | √ | | | | **3** |
| 30 | Menampilkan reliabilitas data yang sesuai dengan penelitian yang dilakukan | | √ | | | | | **2** |
| 31 | Menyebutkan reliabilitas data yang sesuai dengan penelitian sebelumnya | | | √ | | | | **3** |
| 32 | Menampilkan validitas data yang sesuai dengan penelitian yang dilakukan | | √ | | | | | **2** |
| 33 | Metode pengumpulan data dijabarkan agar mencapai kelayakan untuk dipergunakan dalam penelitian ini | | √ | | | | | **2** |
| | **DESAIN PENELITIAN** | | | | | | | |
| 34 | Desain sesuai dengan pertanyaan dan/atau hipotesis penelitian | | | | | √ | | **5** |
| 35 | Apabila diperlukan, kelompok kontrol dapat dimasukkan | | | | √ | | | **4** |
| 36 | Variabel pengganggu / moderasi dapat diidentifikasi | | | √ | | | | **3** |
| 37 | Deskripsi desain dijelaskan cukup eksplisit agar membantu replika penelitian | | | √ | | | | **3** |
| | **ANALISIS DATA** | | | | | | | |
| 38 | Memberikan informasi yang sesuai untuk menjawab pertanyaan penelitian | | | | | √ | | **5** |
| 39 | Melakukan uji statistik | | | | √ | | | **4** |
| 40 | Hasil uji statistik sesuai dengan hipotesis dan pertanyaan penelitian | | | √ | | | | **3** |
| 41 | Tabel dan gambar ditampilkan dalam format yang mudah dipahami serta informatif | | | √ | | | | **3** |
| | **PEMBAHASAN** | | | | | | | |
| 42 | Simpulan diungkapkan dengan jelas | | | | | √ | | **5** |
| 43 | Simpulan didukung dengan bukti-bukti | | | | | √ | | **5** |
| 44 | Hal-hal terkait metodologi penelitian diuraikan dan dibahas | | | | | √ | | **5** |
| 45 | Hasil penelitian secara spesifik dikaitkan dengan konseptual/teoretikal dasar penelitian | | | | √ | | | **4** |
| 46 | Implikasi dari hasil penelitian disebutkan | | | √ | | | | **3** |
| 47 | Melakukan generalisasi hasil penelitian khusus bagi populasi guna menambah khasanah keilmuan | | | √ | | | | **3** |
| 48 | Penyampaian saran bagi penelitian selanjutnya | | | | | √ | | **5** |

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| | **BENTUK DAN GAYA PENULISAN** | | | | | | | |
| 49 | Laporan tertulis dengan jelas | | | | | | √ | **6** |
| 50 | Laporan terorganisir secara logis | | | | | | √ | **6** |
| 51 | Laporan tidak bersifat menyimpang, jujur dan berpedoman pada aturan saintifik | | | | | | √ | **6** |
| | **Jumlah** | | | | | | | **196** |

**Jumlah**

Tinggi (205-306 poin)

**Sedang (103-204 poin)**

Di bawah rata-rata (0-102 poin)

5. **Cultural and quality-of-life considerations when administering corticosteroids as a therapeutic strategy for African American women living with systemic lupus erythematosus**

Review : Tita Miranda
Date & Year : 12 Jun 2018
Author : Dorcey L., et al
DOI: 10.2147/PPA.S156457

| No | Kriteria | Penilaian | | | | | | Jumlah |
|---|---|---|---|---|---|---|---|---|
| | | 1 | 2 | 3 | 4 | 5 | 6 | |
| 1 | Judul mudah dimengerti | | | | | | √ | **6** |
| 2 | Judul jelas | | | | | | √ | **6** |
| 3 | Judul sesuai dengan isi penelitian | | | | | | √ | **6** |
| | **ABSTRAK** | | | | | | | |
| 4 | Abstrak berisi rumusan masalah, dan jika ada, hipotesis dituliskan secara jelas dan ringkas | | | | | | √ | **6** |
| 5 | Metodologi dikemukakan dan dijabarkan secara singkat | | | | | | √ | **6** |
| 6 | Hasil penelitian dipaparkan | | | | | | √ | **6** |
| 7 | Hasil dan/atau simpulan disampaikan | | | | | | √ | **6** |
| | **RUMUSAN MASALAH** | | | | | | | |
| 8 | Rumusan masalah disampaikan pada bagian awal laporan penelitian | | √ | | | | | **2** |
| 9 | Pertanyaan penelitian disampaikan secara tepat | | | √ | | | | **3** |
| 10 | Rumusan masalah diuraikan dengan jelas | | √ | | | | | **2** |
| 11 | Hipotesis yang akan diujikan dapat dibuktikan kebenarannya | | | √ | | | | **3** |
| 12 | Batasan penelitian dapat dikemukakan | | √ | | | | | **2** |
| 13 | Asumsi penelitian dapat dikemukakan | | | | √ | | | **4** |
| 14 | Konsep-konsep terkait penelitian didefinisikan secara operasional | | | √ | | | | **3** |
| 15 | Kontribusi penelitian dikemukakan | | √ | | | | | **2** |
| 16 | Penelitian mampu diuji kebenarannya | | | | | | √ | **6** |
| | **LANDASAN TEORI** | | | | | | | |
| 17 | Teori yang digunakan sesuai dengan rumusan masalah | | | √ | | | | **3** |
| 18 | Teori mendukung alasan penelitian dilakukan | | | √ | | | | **3** |
| 19 | Penelitian dilakukan secara kritis | | | | | √ | | **5** |
| 20 | Keterkaitan rumusan masalah dan penelitian sebelumnya terpapar dengan jelas | | √ | | | | | **2** |
| 21 | Kerangka konseptual/ landasan teoretis disampaikan secara jelas | | | √ | | | | **3** |
| 22 | Reviu berisi ringkasan teori yang relevan serta implikasi penelitian | | | √ | | | | **3** |

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| | **METODOLOGI** | | | | | | | |
| | **SUBJEK** | | | | | | | |
| 23 | Penjelasan mengenai subjek populasi (kerangka sampling) | | | √ | | | | **3** |
| 24 | Penjelasan mengenai metode pengambilan sampel | | | | | √ | | **5** |
| 25 | Metode pengambilan sampel dijabarkan terutama untuk nonprobability sampling | | √ | | | | | **2** |
| 26 | Ukuran sampel sesuai untuk mengurangi kesalahan tipe II | | √ | | | | | **2** |
| 27 | Mampu mengidentifikasi adanya kemungkinan penyebab terjadinya sampling error | | | √ | | | | **3** |
| 28 | Penjelasan mengenai standar perlindungan bagi subjek penelitian | | √ | | | | | **2** |
| | **INSTRUMEN** | | | | | | | |
| 29 | Menyebutkan reliabilitas data yang sesuai dengan penelitian sebelumnya | | | √ | | | | **3** |
| 30 | Menampilkan reliabilitas data yang sesuai dengan penelitian yang dilakukan | | √ | | | | | **2** |
| 31 | Menyebutkan reliabilitas data yang sesuai dengan penelitian sebelumnya | | √ | | | | | **2** |
| 32 | Menampilkan validitas data yang sesuai dengan penelitian yang dilakukan | | | √ | | | | **3** |
| 33 | Metode pengumpulan data dijabarkan agar mencapai kelayakan untuk dipergunakan dalam penelitian ini | | | | √ | | | **4** |
| | **DESAIN PENELITIAN** | | | | | | | |
| 34 | Desain sesuai dengan pertanyaan dan/atau hipotesis penelitian | | | | √ | | | **4** |
| 35 | Apabila diperlukan, kelompok kontrol dapat dimasukkan | | | √ | | | | **3** |
| 36 | Variabel pengganggu / moderasi dapat diidentifikasi | | | √ | | | | **3** |
| 37 | Deskripsi desain dijelaskan cukup eksplisit agar membantu replika penelitian | | √ | | | | | **2** |
| | **ANALISIS DATA** | | | | | | | |
| 38 | Memberikan informasi yang sesuai untuk menjawab pertanyaan penelitian | | | | | √ | | **5** |
| 39 | Melakukan uji statistik | | | | √ | | | **4** |
| 40 | Hasil uji statistik sesuai dengan hipotesis dan pertanyaan penelitian | | | | √ | | | **4** |
| 41 | Tabel dan gambar ditampilkan dalam format yang mudah dipahami serta informatif | | | | | | √ | **6** |
| | **PEMBAHASAN** | | | | | | | |
| 42 | Simpulan diungkapkan dengan jelas | | | | | | √ | **6** |
| 43 | Simpulan didukung dengan bukti-bukti | | | | | | √ | **6** |
| 44 | Hal-hal terkait metodologi penelitian diuraikan dan dibahas | | | | | | √ | **6** |
| 45 | Hasil penelitian secara spesifik dikaitkan dengan konseptual/teoretikal dasar penelitian | | | | √ | | | **4** |
| 46 | Implikasi dari hasil penelitian disebutkan | | | √ | | | | **3** |
| 47 | Melakukan generalisasi hasil penelitian khusus | | √ | | | | | **2** |

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| | bagi populasi guna menambah khasanah keilmuan | | | | | | | |
| 48 | Penyampaian saran bagi penelitian selanjutnya | | | | | | √ | **6** |
| | **BENTUK DAN GAYA PENULISAN** | | | | | | | |
| 49 | Laporan tertulis dengan jelas | | | | | | √ | **6** |
| 50 | Laporan terorganisir secara logis | | | | | | √ | **6** |
| 51 | Laporan tidak bersifat menyimpang, jujur dan berpedoman pada aturan saintifik | | | | | | √ | **6** |
| | **Jumlah** | | | | | | | **201** |

**Jumlah**

Tinggi (205-306 poin)

**Sedang (103-204 poin)**

Di bawah rata-rata (0-102 poin)

**6. Measurement properties of the brief resilient coping scale in patients with systemic lupus erythematosus using rasch analysis**

Review : Tita Miranda  Date & Year : 13 September 2016

Author : López-Pina, José-Antonio  Record Number: 128, vol.14

| No | Kriteria | Penilaian | | | | | | Jumlah |
|---|---|---|---|---|---|---|---|---|
| | | 1 | 2 | 3 | 4 | 5 | 6 | |
| 1 | Judul mudah dimengerti | | | | | | √ | **6** |
| 2 | Judul jelas | | | | | | √ | **6** |
| 3 | Judul sesuai dengan isi penelitian | | | | | | √ | **6** |
| | **ABSTRAK** | | | | | | | |
| 4 | Abstrak berisi rumusan masalah, dan jika ada, hipotesis dituliskan secara jelas dan ringkas | | | | | | √ | **6** |
| 5 | Metodologi dikemukakan dan dijabarkan secara singkat | | | | | | √ | **6** |
| 6 | Hasil penelitian dipaparkan | | | | | | √ | **6** |
| 7 | Hasil dan/atau simpulan disampaikan | | | | | | √ | **6** |
| | **RUMUSAN MASALAH** | | | | | | | |
| 8 | Rumusan masalah disampaikan pada bagian awal laporan penelitian | | √ | | | | | **2** |
| 9 | Pertanyaan penelitian disampaikan secara tepat | | √ | | | | | **2** |
| 10 | Rumusan masalah diuraikan dengan jelas | | √ | | | | | **2** |
| 11 | Hipotesis yang akan diujikan dapat dibuktikan kebenarannya | | √ | | | | | **2** |
| 12 | Batasan penelitian dapat dikemukakan | | | √ | | | | **3** |
| 13 | Asumsi penelitian dapat dikemukakan | | | √ | | | | **3** |
| 14 | Konsep-konsep terkait penelitian didefinisikan secara operasional | | √ | | | | | **2** |
| 15 | Kontribusi penelitian dikemukakan | | √ | | | | | **2** |
| 16 | Penelitian mampu diuji kebenarannya | | | | | | √ | **6** |
| | **LANDASAN TEORI** | | | | | | | |
| 17 | Teori yang digunakan sesuai dengan rumusan masalah | | | | √ | | | **4** |
| 18 | Teori mendukung alasan penelitian dilakukan | | | √ | | | | **3** |
| 19 | Penelitian dilakukan secara kritis | | | √ | | | | **3** |
| 20 | Keterkaitan rumusan masalah dan penelitian sebelumnya terpapar dengan jelas | | √ | | | | | **2** |
| 21 | Kerangka konseptual/ landasan teoretis disampaikan secara jelas | | √ | | | | | **2** |
| 22 | Reviu berisi ringkasan teori yang relevan serta implikasi penelitian | | √ | | | | | **2** |
| | **METODOLOGI** | | | | | | | |

| | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| | **SUBJEK** | | | | | | | |
| 23 | Penjelasan mengenai subjek populasi (kerangka sampling) | | √ | | | | | **2** |
| 24 | Penjelasan mengenai metode pengambilan sampel | | | | √ | | | **4** |
| 25 | Metode pengambilan sampel dijabarkan terutama untuk nonprobability sampling | | | √ | | | | **3** |
| 26 | Ukuran sampel sesuai untuk mengurangi kesalahan tipe II | | √ | | | | | **2** |
| 27 | Mampu mengidentifikasi adanya kemungkinan penyebab terjadinya sampling error | | √ | | | | | **2** |
| 28 | Penjelasan mengenai standar perlindungan bagi subjek penelitian | | | | √ | | | **4** |
| | **INSTRUMEN** | | | | | | | |
| 29 | Menyebutkan reliabilitas data yang sesuai dengan penelitian sebelumnya | | | | √ | | | **4** |
| 30 | Menampilkan reliabilitas data yang sesuai dengan penelitian yang dilakukan | | | √ | | | | **3** |
| 31 | Menyebutkan reliabilitas data yang sesuai dengan penelitian sebelumnya | | | √ | | | | **3** |
| 32 | Menampilkan validitas data yang sesuai dengan penelitian yang dilakukan | | √ | | | | | **2** |
| 33 | Metode pengumpulan data dijabarkan agar mencapai kelayakan untuk dipergunakan dalam penelitian ini | | | √ | | | | **3** |
| | **DESAIN PENELITIAN** | | | | | | | |
| 34 | Desain sesuai dengan pertanyaan dan/atau hipotesis penelitian | | | | √ | | | **4** |
| 35 | Apabila diperlukan, kelompok kontrol dapat dimasukkan | | | | √ | | | **4** |
| 36 | Variabel pengganggu / moderasi dapat diidentifikasi | | | √ | | | | **3** |
| 37 | Deskripsi desain dijelaskan cukup eksplisit agar membantu replika penelitian | | | √ | | | | **3** |
| | **ANALISIS DATA** | | | | | | | |
| 38 | Memberikan informasi yang sesuai untuk menjawab pertanyaan penelitian | | | | | | √ | **6** |
| 39 | Melakukan uji statistik | | | | | √ | | **5** |
| 40 | Hasil uji statistik sesuai dengan hipotesis dan pertanyaan penelitian | | | | | √ | | **5** |
| 41 | Tabel dan gambar ditampilkan dalam format yang mudah dipahami serta informatif | | | | √ | | | **4** |
| | **PEMBAHASAN** | | | | | | | |
| 42 | Simpulan diungkapkan dengan jelas | | | | | | √ | **6** |
| 43 | Simpulan didukung dengan bukti-bukti | | | | | | √ | **6** |
| 44 | Hal-hal terkait metodologi penelitian diuraikan dan dibahas | | | | | | √ | **6** |
| 45 | Hasil penelitian secara spesifik dikaitkan dengan konseptual/teoretikal dasar penelitian | | | | √ | | | **4** |
| 46 | Implikasi dari hasil penelitian disebutkan | | | | | | √ | **3** |
| 47 | Melakukan generalisasi hasil penelitian khusus bagi populasi guna menambah khasanah keilmuan | | | √ | | | | **3** |

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|---|---|---|---|---|---|---|---|---|
| 48 | Penyampaian saran bagi penelitian selanjutnya | | | | | | √ | **6** |
| | **BENTUK DAN GAYA PENULISAN** | | | | | | | |
| 49 | Laporan tertulis dengan jelas | | | | | | √ | **6** |
| 50 | Laporan terorganisir secara logis | | | | | | √ | **6** |
| 51 | Laporan tidak bersifat menyimpang, jujur dan berpedoman pada aturan saintifik | | | | | | √ | **6** |
| | **Jumlah** | | | | | | | **206** |

**Jumlah**

**Tinggi (205-306 poin)**

Sedang (103-204 poin)

Di bawah rata-rata (0-102 poin

## 7. Quality of Life, Coping and Depression in Systemic Lupus Erythematosus

Review : Tita Miranda
Date & Year : Maret-Apr 2016
Author : Abu-Shakra, M.
Record Number: Vol. 18

| No | Kriteria | Penilaian | | | | | | Jumlah |
|---|---|---|---|---|---|---|---|---|
| | | 1 | 2 | 3 | 4 | 5 | 6 | |
| 1 | Judul mudah dimengerti | | | | | | √ | 6 |
| 2 | Judul jelas | | | | | | √ | 6 |
| 3 | Judul sesuai dengan isi penelitian | | | | | | √ | 6 |
| | **ABSTRAK** | | | | | | | |
| 4 | Abstrak berisi rumusan masalah, dan jika ada, hipotesis dituliskan secara jelas dan ringkas | | | | | | √ | 6 |
| 5 | Metodologi dikemukakan dan dijabarkan secara singkat | | | | | | √ | 6 |
| 6 | Hasil penelitian dipaparkan | | | | | | √ | 6 |
| 7 | Hasil dan/atau simpulan disampaikan | | | | | | √ | 6 |
| | **RUMUSAN MASALAH** | | | | | | | |
| 8 | Rumusan masalah disampaikan pada bagian awal laporan penelitian | | | √ | | | | 3 |
| 9 | Pertanyaan penelitian disampaikan secara tepat | | | √ | | | | 3 |
| 10 | Rumusan masalah diuraikan dengan jelas | | √ | | | | | 2 |
| 11 | Hipotesis yang akan diujikan dapat dibuktikan kebenarannya | | √ | | | | | 2 |
| 12 | Batasan penelitian dapat dikemukakan | | | | √ | | | 4 |
| 13 | Asumsi penelitian dapat dikemukakan | | √ | | | | | 2 |
| 14 | Konsep-konsep terkait penelitian didefinisikan secara operasional | | | √ | | | | 3 |
| 15 | Kontribusi penelitian dikemukakan | | √ | | | | | 2 |
| 16 | Penelitian mampu diuji kebenarannya | | | | | | √ | 6 |
| | **LANDASAN TEORI** | | | | | | | |
| 17 | Teori yang digunakan sesuai dengan rumusan masalah | | | √ | | | | 3 |
| 18 | Teori mendukung alasan penelitian dilakukan | | √ | | | | | 2 |
| 19 | Penelitian dilakukan secara kritis | | | √ | | | | 3 |
| 20 | Keterkaitan rumusan masalah dan penelitian sebelumnya terpapar dengan jelas | | √ | | | | | 2 |
| 21 | Kerangka konseptual/ landasan teoretis disampaikan secara jelas | | √ | | | | | 2 |
| 22 | Reviu berisi ringkasan teori yang relevan serta implikasi penelitian | | | √ | | | | 2 |
| | **METODOLOGI** | | | | | | | |
| | **SUBJEK** | | | | | | | |

| | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| 23 | Penjelasan mengenai subjek populasi (kerangka sampling) | | | √ | | | | **3** |
| 24 | Penjelasan mengenai metode pengambilan sampel | | | √ | | | | **3** |
| 25 | Metode pengambilan sampel dijabarkan terutama untuk nonprobability sampling | | √ | | | | | **2** |
| 26 | Ukuran sampel sesuai untuk mengurangi kesalahan tipe II | | √ | | | | | **2** |
| 27 | Mampu mengidentifikasi adanya kemungkinan penyebab terjadinya sampling error | | √ | | | | | **2** |
| 28 | Penjelasan mengenai standar perlindungan bagi subjek penelitian | | | | √ | | | **4** |
| | **INSTRUMEN** | | | | | | | |
| 29 | Menyebutkan reliabilitas data yang sesuai dengan penelitian sebelumnya | | | √ | | | | **3** |
| 30 | Menampilkan reliabilitas data yang sesuai dengan penelitian yang dilakukan | | √ | | | | | **2** |
| 31 | Menyebutkan reliabilitas data yang sesuai dengan penelitian sebelumnya | | √ | | | | | **2** |
| 32 | Menampilkan validitas data yang sesuai dengan penelitian yang dilakukan | | | √ | | | | **3** |
| 33 | Metode pengumpulan data dijabarkan agar mencapai kelayakan untuk dipergunakan dalam penelitian ini | | √ | | | | | **2** |
| | **DESAIN PENELITIAN** | | | | | | | |
| 34 | Desain sesuai dengan pertanyaan dan/atau hipotesis penelitian | | | | √ | | | **4** |
| 35 | Apabila diperlukan, kelompok kontrol dapat dimasukkan | | | | √ | | | **4** |
| 36 | Variabel pengganggu / moderasi dapat diidentifikasi | | | √ | | | | **3** |
| 37 | Deskripsi desain dijelaskan cukup eksplisit agar membantu replika penelitian | | | √ | | | | **3** |
| | **ANALISIS DATA** | | | | | | | |
| 38 | Memberikan informasi yang sesuai untuk menjawab pertanyaan penelitian | | | √ | | | | **3** |
| 39 | Melakukan uji statistik | | | √ | | | | **3** |
| 40 | Hasil uji statistik sesuai dengan hipotesis dan pertanyaan penelitian | | √ | | | | | **2** |
| 41 | Tabel dan gambar ditampilkan dalam format yang mudah dipahami serta informatif | | | √ | | | | **3** |
| | **PEMBAHASAN** | | | | | | | |
| 42 | Simpulan diungkapkan dengan jelas | | | | | √ | | **5** |
| 43 | Simpulan didukung dengan bukti-bukti | | | | √ | | | **4** |
| 44 | Hal-hal terkait metodologi penelitian diuraikan dan dibahas | | | | √ | | | **4** |
| 45 | Hasil penelitian secara spesifik dikaitkan dengan konseptual/teoretikal dasar penelitian | | | √ | | | | **3** |
| 46 | Implikasi dari hasil penelitian disebutkan | | | √ | | | | **3** |
| 47 | Melakukan generalisasi hasil penelitian khusus bagi populasi guna menambah khasanah keilmuan | | √ | | | | | **2** |
| 48 | Penyampaian saran bagi penelitian selanjutnya | | | | | | √ | **6** |

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| | **BENTUK DAN GAYA PENULISAN** | | | | | | | |
| 49 | Laporan tertulis dengan jelas | | | | | | √ | **6** |
| 50 | Laporan terorganisir secara logis | | | | | | √ | **6** |
| 51 | Laporan tidak bersifat menyimpang, jujur dan berpedoman pada aturan saintifik | | | | | | √ | **6** |
| | **Jumlah** | | | | | | | **181** |

**Jumlah**

Tinggi (205-306 poin)

**Sedang (103-204 poin)**

Di bawah rata-rata (0-102 poin

**8. Factors associated with pain coping and catastrophising in patients with systemic lupus erythematosus: a cross-sectional study of the LuLa-cohort**

Review : Tita Miranda Date & Year : 12 Nov 2015

Author : Fischin, Julia, et al. DOI: 10.1136/lupus-2015-000113

| No | Kriteria | Penilaian | | | | | | Jumlah |
|---|---|---|---|---|---|---|---|---|
| | | 1 | 2 | 3 | 4 | 5 | 6 | |
| 1 | Judul mudah dimengerti | | | | | | √ | **6** |
| 2 | Judul jelas | | | | | | √ | **6** |
| 3 | Judul sesuai dengan isi penelitian | | | | | | √ | **6** |
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Sedang (103-204 poin)

Di bawah rata-rata (0-102 poin

Advances in Rheumatology

RESEARCH Open Access

# Psychoanalytic psychotherapy improves quality of life, depression, anxiety and coping in patients with systemic lupus erythematosus: a controlled randomized clinical trial

Céu Tristão Martins Conceição[1], Ivone Minhoto Meinão[1], José Atilio Bombana[2] and Emília Inoue Sato[1*]

## Abstract

**Background:** Systemic Lupus Erythematosus (SLE) is an autoimmune disease which impairs the quality of life. The objective of study was to evaluate the effectiveness of Brief Group Psychoanalytic Psychotherapy to improve quality of life, depression, anxiety and coping strategies in SLE patients.

**Methods:** In a randomized clinical trial, 80 female SLE patients were allocated into two groups: therapy group ($n = 37$) and control group ($n = 43$). Therapy group (TG) attended weekly psychotherapy sessions for 20 weeks; control group (CG) remained on a waiting list. Both groups received standard medical care. Questionnaires and scales were applied by blinded evaluators at baseline (T1) and after 20 weeks (T2): Socioeconomic Status, SLE International Collaborating Clinic/American College of Rheumatology-Damage Index, SLE International Disease Activity, SLE Specific Symptom Checklist, SLE Quality of life, Hospital Anxiety Depression Scale, Coping Strategies Inventory. Intent to treat intra- and inter-group analysis was performed for all variables in T1 and T2 using Qui-square, t-Student, Mann-Whitney and Wilcoxon tests. Analysis of Variance was used to compare categorical variables over time. $P < 0.05$ was considered significant.

**Results:** The mean age of patients was 42 years; 54% were white, with mean disease duration of years 12. At baseline, both groups were homogeneous in all variables, including medications. After 20 weeks of psychotherapy TG was significantly different from CG, with lower frequency of symptoms ($p = 0.001$), lower level of anxiety ($p = 0.019$) and depression ($p = 0.022$), better index in five of six domains of quality of life scale ($p \leq 0.005$), including total SLEQOL ($p < 0.001$) and with higher positive planful problem solving strategy ($p = 0.017$). No change in disease activity score was observed in both groups.

**Conclusions:** Psychoanalytic psychotherapy was effective to improve many domains of quality of life and one positive coping skill and to reduce SLE symptoms, anxiety and depression levels. Brief group psychotherapy can be a useful tool to complement medical care in SLE patients.

**Trial registration:** Number NCT01840709.

**Keywords:** Systemic lupus erythematosus, Quality of life, Depression, Anxiety, Coping strategies, Psychoanalytic psychotherapy

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## Background

Systemic lupus erythematosus (SLE) is an autoimmune disease that can affect several organs and systems. It is more prevalent in females, mainly in the reproductive period of life and has a multifactorial etiology highlighting genetic predisposition, hormonal, environmental and possible infectious factors [1].

The connection between the limbic system, hypothalamic-pituitary-adrenal (HPA) axis and autonomous nervous system has the function to restore body baseline status after exposition to physical or psychological stress [2]. Some authors evaluated the influence of stress as one of the causal factors of SLE and also as a trigger of disease flares [3, 4].

Quality of life (QOL) is considered as being healthy, feeling good and being independent and able to work, according to SLE patient reports [5]. SLE patients have poorer functional status than the general population because specific manifestations of SLE that may decrease quality of life [6, 7]. Feeling of uncertainty about illness, pain and fatigue are important experiences in SLE patients [8], while illness intrusiveness is a stressor that affects QOL [9].

Besides poor QOL in SLE patients, recent studies around the world have shown that anxiety and depression are common symptoms in SLE population. In a systematic review, Palagini et al. found a high variability in the prevalence of depressive disorders in SLE (17–75%) [10]. The incidence of depression in SLE in the Hopkins Lupus Cohort was 29.7 episodes per 1000 person-years [11]. Neuropsychiatric (NP) manifestations occurred in 47.2% and mood disorders in 12.7%, with 38.3% of them attributed to SLE [12]. Ayache and Costa observed prevalence of depression in 65% of SLE patients in Brazil [13].

Coping concept contains a set of strategies to manage stress, reducing its aversive characteristics and increasing the perception of personal control [14]. The development of coping skills to face SLE disease is very important because manifestations of pain and fatigue besides affections in skin and vital organs are stressful events in patient's lives [8, 9]. Coping in SLE patients is usually more passive, with the predominance of acceptance strategies [15].

Haija and Shultz had pointed the necessity of an alternative approach to get more adherence to medical treatment in SLE [16] and psychotherapy has been used to supplement clinical care in several diseases, including cancer [17]. There are few studies evaluating the effectiveness of psychotherapy on autoimmune diseases. These studies have shown improvement in coping, quality of life, depression, anxiety, relationship, self-esteem and general health by psychotherapy and psychosocial support in SLE patients [18–20]. However they presented some weakness like small sample sizes [19, 20], lack of randomization [19] and positive results only in a few domains [18].

The psychotherapy approach performed in our study comes from psychoanalysis, introduced by Freud to alleviate psychic suffering [21–23]. This approach has been modified over time, in relation to the time of analysis (brief duration), number of participants (group therapy) and different types of diseases began to be treated [24–26]. After Alexander's contributions to psychosomatic medicine [27], Pierre Marty developed an influential psychoanalytic theory based on the concept of mentalization which characterizes the psychosomatic functioning [28]. This concept is similar to alexithymia [29] and patients have difficult to express emotions and deal with them. To these patients, the therapy needs to be more directive, only once a week, face-to-face to access body expression, nominate their feelings and unload instinctual excitations [30].

In the Psychiatric Department of *Escola Paulista de Medicina, Universidade Federal de São Paulo*, group psychotherapy has been performed to treat somatoform disorders, adapting the psychoanalytic setting to these patients with good results [31, 32]. We consider that this approach could also help patients with autoimmune diseases.

Until now, there are no studies in Latin America applying psychotherapy techniques in SLE patients. The objective of this study was to evaluate the effectiveness of brief group psychoanalytic psychotherapy (BGPP) to improve quality of life, anxiety, depression and coping skills in Brazilian SLE patients.

## Patients and methods

A controlled, randomized clinical trial was registered at clinicaltrials.gov (number NCT01840709).

### Participants

Patients were recruited from the Autoimmune Rheumatic Disease outpatient clinic of University Hospital through posters affixed on the outpatient clinic. One hundred and five patients declared interest, however 25 dropped out due to difficulty to fulfill the protocol or presented exclusion criteria. Therefore, a total of 80 female SLE patients were enrolled in the study. Patients were randomized by computer table, receiving an assigned number from 1 to 80 and the secretary informed patients to which group they had been allocated. All patients answered the questionnaires at baseline and after 20 weeks, under the supervision of blind evaluators. The physicians involved in the clinical evaluations were also blinded to the patient allocation group.

Inclusion criteria were: female gender, fulfill American College of Rheumatology (ACR) SLE classification criteria [33], age over 18 years and follow-up at the

institution for at least 6 months. All patients signed a consent form approved by the institutional ethics committee (protocol 1655/09).

Exclusion criteria were: illiterate, presence of severe mental diseases (severe cognitive deficit, schizophrenia, bipolar disorder, severe depression), physical conditions that could preclude their weekly participation and patients who were receiving psychological treatment or were participating in other protocols.

Inclusion and exclusion criteria were evaluated by the rheumatologists based on patient's current data and medical records. Only one patient (TG) had a history of psychological treatment many years prior.

The therapy group (TG $n = 37$) was divided into four subgroups, with a maximum of ten patients, according to each patient's preferred schedule (one of four options offered) for psychotherapy attendance. Control group (CG $n = 43$) remained on a waiting list, only receiving standard medical care according to outpatient clinic schedule. The TG was also continuing to receive usual medical treatment throughout the study.

Four patients dropped out of the study (two on CG and two on TG). In CG, one patient died due to SLE activity and one patient was lost to follow-up. In TG, two patients dropped out of the group, reporting difficulty to participate in the weekly meeting. All patients attended at least 15 of 20 sessions (75%), except the two dropouts on TG.

### Assessment instruments

Most of the following questionnaires and scales were self-applied with supervision of blinded assessors for some patients with low educational level and difficulty to understand the questions. The clinical evaluations were performed during the medical appointment. Religion and race were self-nominated. All instruments were validated and adapted to the Portuguese language and were applied at baseline (T1) and after 20 weeks (T2), except SLICC score that was applied only at baseline.

1 – ABIPEME Criteria (*Associação Brasileira de Institutos de Pesquisa de Mercado*) - Socioeconomic questionnaire [34].

The education (years of study) and socioeconomic classification (comfort items at home) are presented in categories.

2 – SLICC/ACR-DI (Systemic Lupus International Collaborating Clinic /American College of Rheumatology - Damage Index) [35].

A measure of the irreversible SLE damage index, present for at least 6 months, evaluating 12 organic systems and calculated by a physician.

3 – SLEDAI (Systemic Lupus Erythematosus International Disease Activity) [36].

A measure of the activity of the disease, scoring each variable of the affected system, evaluated by a physician.

4 – SLE-SSC (Systemic Lupus Erythematosus Specific Symptom Checklist) [37, 38].

A self-related SLE symptom checklist with 38 items evaluating the presence and intensity of several symptoms in the last 30 days. Higher scores indicate worse results.

5 – SLEQOL (Systemic Lupus Erythematosus Quality of Life) [37, 39].

A self-related questionnaire with 40 items in 6 domains evaluating the SLE quality of life. The score of each item varies from 0 to 7 and higher scores correspond to poorer quality of life.

6 – HADS (Hospital Anxiety and Depression Scale) [40, 41].

A self-administered questionnaire evaluating the domains of anxiety and depression (7 questions by domain). Higher scores indicate higher severity of symptoms.

7 – CSI (Coping Strategies Inventory) [42, 43].

A self-applied questionnaire evaluating coping strategies to deal stressful events with 66 items in 8 domains. Each item can be scored from 0 to 3. It can measure mature coping, escape/avoidance and aggressiveness strategies.

### Intervention

Intervention was performed in 90-min sessions once a week for 20 weeks for each subgroup. The psychological technique (BGPP) was a short-term (20 weeks) therapy derived from psychoanalysis, which is based in long-term therapy that has been used in the Psychiatric Department of *Escola Paulista de Medicina, Universidade Federal de Sao Paulo* to treat psychosomatic patients [31, 32]. This technique works according to Marty's model at the Paris School of Psychosomatics [30] and is similar to supportive expressive treatment [44] and to brief dynamic psychotherapy [45], but applied without a manual. The same facilitators managed all the subgroups in this study to guarantee standardization of treatment.

The sessions were organized to achieve the objective to improve the quality of life, coping strategies and emotional balance by the discussion of elected topics. The

group dynamic was free to enable the emergence of important emotional contents, promoting personal integration and increasing relationships in the group. Coping strategies against life stressors, mainly the disease, were trained during the process. All patients in TG did an evaluation about their experience in the group at the end of study. A therapist, an experienced psychologist in this approach (CTMC) and a co-therapist (IMM), who is also a rheumatologist, conducted the intervention. The therapist coordinated and treated the group. The co-therapist was an observer and recorded the group dialogues, behaviors and emotional expressions. A psychoeducational intervention to clarify patients' doubts about the disease was included in the last session.

### Statistical analysis

The sample size (80 patients) was calculated considering SLEQOL questionnaire, with power of 80%, significance level of 5% and standard deviation of total SLEQOL of 52 points [37], assuming as significant difference between groups equal to 35 points.

Intra- and inter-group analysis was performed at baseline (T1) and after 20 weeks (T2). Descriptive statistics were used for sample characterization. The proportion of categorical variables was compared using *Chi*-square test. To compare quantitative variables between groups *t*-Student test was used for those with normal distribution and Mann-Whitney or Wilcoxon test for non-normal distribution. Analysis of variance (ANOVA) test was used to compare categorical variables over time (medication). Medians (minimum-maximum) and means (standard deviation) were used to analyze the data with no normal and normal distribution, respectively. Intent to treat statistical analysis was performed. Statistical Package for the Social Sciences (SPSS), version 17.0 (Chicago, USA) was used for all statistical analysis. $P < 0.05$ was considered significant.

## Results

Demographic and socioeconomic data, SLICC/ACR-DI score and medication of 80 SLE patients are shown in Table 1. At baseline, there was no difference concerning age, disease duration, race, years of education, economic class and religion between CG and TG. At baseline, the medications used to control lupus and neuropsychiatric symptoms were similar between groups, with a mean prednisone dosage of 10.38 mg/day. These medications did not vary significantly during the study (data not shown). In general, the SLICC/ACR-DI score was low, without difference between groups (Table 1). The SLEDAI scores were also homogeneous in either the intra- or inter-groups analysis. Even if a few patients had presented highly active disease in both groups, the mean level of disease activity was low and comparable between TG and CG at baseline and at the end of the study (Table 2).

At baseline, both groups were comparable concerning SLE-SSC scores, but TG patients showed significant reduction on frequency and intensity of self-related symptoms after psychotherapy, making the score lower in TG than CG at T2 ($p < 0.001$) (Table 3).

At T2 we observed improvement in the quality of life in TG, by positive changes in five of six domains of SLEQOL scores (occupational activity, symptoms, treatment, humor and self-image) and in the total score ($p < 0.001$), with significant difference comparing with the CG (Table 4).

TG patients showed a significant reduction on anxiety ($p = 0.019$) and depression ($p = 0.022$) levels at T2, which was not observed in CG, highlighting a significant difference between groups at end of study (Table 5).

Concerning CSI, the inter-group analysis at T2 showed significant difference in the planful problem solving skill. However, in the intra-group analysis in TG, positive changes were also observed in other domains (confrontive, escape and avoidance, planful problem solving and positive reappraisal) at the end of the study (Table 6).

## Discussion

This study aimed to test if BGPP technique could improve quality of life and coping skills, as well, reduce anxiety and depression in SLE female patients attended at a tertiary public service in Brazil. The field of this study is the interface between medicine and psychoanalysis using the psychosomatic concepts and techniques as adjunctive help to patients with physical diseases. Psychotherapeutic treatment can lead patients to better coping with illness and increase the adherence to medical treatment [18–20].

We observed significant improvement in symptoms, quality of life, anxiety, depression and in one positive coping domain. The amount and intensity of symptoms on SLE-SSC scale presented significant reduction in patients after psychoanalytic treatment, improving their quality of life and well-being. After treatment, patients handled their body and disease differently, minimizing the importance of symptoms that were felt before as severe and harmful which interfered in their daily activities. However, this improvement did not reflect in disease activity score, as SLEDAI did not have significant reduction, corroborating previous studies using similar techniques [18–20], concluding that short-time treatment did not have enough power to modify this score.

Patients of the psychotherapy group presented positive changes in quality of life, with improvement in almost all SLEQOL domains: occupational activities, symptoms, humor, self-image and the way to face medical

**Table 1** Social, demographic and clinical data of SLE patients in control and therapy groups

| Patients ($n = 80$) | Control ($n = 43$) | Therapy ($n = 37$) | *P* value |
|---|---|---|---|
| Age mean (SD)* | 42.7 (11.3) | 42.0 (12.3) | 0.798 |
| Disease duration mean (SD)** | 11.6 (8.2) | 12.4 (7.8) | 0.511 |
| Education[a] n (%)*** | | | 0.625 |
| ≤ 3 years | 05 (11.6) | 03 (8.1) | |
| 4–8 years | 16 (37.2) | 10 (27.0) | |
| 9–11 years | 05 (11.6) | 08 (21.6) | |
| 12–15 years | 16 (37.2) | 14 (37.8) | |
| ≥ 16 years | 01 (2.3) | 02 (5.4) | |
| Socioeconomic class[a] n (%)*** | | | 0.846 |
| A/B | 00 (.0) | 00 (.0) | |
| C | 26 (60.5) | 20 (54.1) | |
| D | 12 (27.9) | 12 (32.4) | |
| E | 05 (11.6) | 05 (13.5) | |
| Race n (%)*** | | | 0.642 |
| White | 22 (54.2) | 17 (45.9) | |
| Afro descendants | 21 (45.8) | 20 (54.1) | |
| Religion n (%)*** | | | 0.121 |
| Catholic | 17 (39.5) | 22 (59.5) | |
| Evangelic | 13 (30.2) | 13 (35.1) | |
| Spiritualist | 05 (11.6) | 01 (2.7) | |
| Jehovah witness | 04 (9.3) | 01 (2.7) | |
| Buddhist | 01 (2.3) | 00 (.0) | |
| No religion | 03 (7.0) | 00 (.0) | |
| Lupus medications n (%)*** | | | |
| Azathioprine | 11 (25.6) | 09 (24.3) | 0.897 |
| Hydroxychloroquine | 25 (58.1) | 19 (51.4) | 0.542 |
| Prednisone | 24 (55.8) | 21 (56.8) | 0.932 |
| Neuropsychiatric medications n (%)*** | | | |
| Amitriptyline | 07 (16.3) | 06 (16.2) | 0.994 |
| Cyclobenzaprine | 03 (7.0) | 02 (5.4) | 0.770 |
| Fluoxetine | 09 (20.9) | 07 (18.9) | 0.882 |
| SLICC/ACR-DI [b] n (%)*** | | | 0.055 |
| Zero | 22 (51.2) | 11 (29.7) | |
| 1.00 | 12 (27.9) | 17 (45.9) | |
| 2.00 | 06 (14.0) | 02 (5.4) | |
| 3.00 | 03 (7.0) | 04 (10.8) | |
| 4.00 | 00 (.0) | 03 (8.1) | |

[a]ABIPEME Criteria - Brazilian Association of Market Research Institutes (1995)
[b]SLICC/ACR-DI - Systemic Lupus International Collaborating Clinics/American College of Rheumatology-Damage Index (Range: 0–46)
**t* -Student test; **Mann-Whitney test; ****Chi*-square test



treatment. These results suggest a strong reduction in negative intrusiveness of the disease in treated patient's life, similar to other studies [18–20]. In CG we observed a change in only one SLEQOL domain with worsening of symptoms that likely occurred by chance.

We also found a significant decrease in depression and anxiety levels evaluated by HADS in TG, whereas CG patients did not change. This data revealed the beneficial effects of psychotherapy in their emotional balance. Treated patients began to feel less tense, worried and

**Table 2** Disease activity scores of SLE patients in control and therapy groups over time

| Time | Control ($n = 43$) Median (Min-Max) | Therapy ($n = 37$) Median (Min-Max) | Inter-group $P$* |
|---|---|---|---|
| T1 | .0 (.0–22.0) | 2.0 (.0–19.0) | 0.347 |
| T2 | .0 (.0–20.0) | 2.0 (.0–21.0) | 0.207 |
| Intra-group $P$** | 0.925 | 0.214 | |

*SLEDAI* Systemic Lupus Erythematosus Disease Activity Index (Range: 0–105)
*Mann-Whitney test; **Wilcoxon test

angry. The results are in agreement with Haupt et al. and Navarrete-Navarrete et al. studies [19, 20].

We observed a great improvement in the ability to solve problems but, if we consider the intra-group analyses, changes in four of the eight domains in CSI revealed that psychotherapy improved other coping strategies. These strategies are very important to face daily problems, finding adequate solutions for them and getting enough self-esteem to preserve adequate quality of life. There was a change in the types of coping strategies, trending to face stressors and get emotional balance. Our results are similar to Haupt's study outcomes [19].

At baseline and at the end of the study, the percentage of patients using medications for SLE treatment was similar in both groups and the mean of prednisone dosage used by about 55% of patients was 10.38 mg/day. This medication did not vary significantly during the study. Thus, we do not believe there was a significant influence of the use of prednisone in our results.

Medications for co morbidities, including mild anxiety and depressive symptoms, were also similar between groups at baseline and along the study, reducing the possibility that medications may have contributed to the changes observed in the study. Although severe mental diseases had been excluded, we observed that about 40% of patients were taking antidepressant drugs, used for fibromyalgia or for mild anxiety and depression symptoms, which are frequently present in SLE patients [10–13]. The exclusion of patients with mild psychiatric symptoms could make the study unfeasible, considering the high frequency of these symptoms in SLE patients. Furthermore, previous clinical trials also included patients with depressive and anxiety symptoms and with other mild psychological or psychiatric findings [19, 20] and also was using anxiolytic and antidepressant medications [20].

**Table 3** Symptom checklist scores of SLE patients in control and therapy groups over time

| Time | Control ($n = 43$) Median (Min-Max) | Therapy ($n = 37$) Median (Min-Max) | Inter-group $P$* |
|---|---|---|---|
| T1 | 52.0 (7.0–91.0) | 51.0 (8.0–119.0) | 0.985 |
| T2 | 53.0 (10.0–99.0) | 40.0 (2.0–84.0) | 0.001 |
| Intra-group $P$** | 0.101 | < 0.001 | |

*SLE-SSC* Systemic Lupus Erythematosus Specific Symptom Checklist (Range: 0–152)
*Mann-Whitney test; **Wilcoxon test
$P < 0.05$ significant

In our study, therapeutic intervention helped patients to lead to positive results in psychological measures through the confidence and support atmosphere established in group dynamic. The therapy technique facilitated the patient's integration, increased feeling of willingness to participate and provided social pressure to encourage patients to report symptoms. So, BGPP helped patients to access deep problems and conflicts with the goal of establishing coping strategies to deal with them. During the sessions, patients elected several themes to discuss, such as anxiety and insecurity related to disease, uncertainty about the future, the possibility of death, depressive reactions about life stressors, lack of emotional control, low self-esteem, interpersonal relationship problems, sexual difficulties and reduced quality of life (due to pain and fatigue) beside personal traumatic issues. Thereby, the group functioned as a support to cope with the disease, allowing each patient to handle their anguish and fears and getting more adaptive forms to face stressors improving the quality of life.

Limitations of the study:

1) Low activity and damage scores - As the most of our patients had low SLEDAI and SLICC/ACR-DI scores, these results cannot be generalized to patients with severe disease. For patients with severe disease, it is recommended continued therapy, according to Parth et al. study [46].
2) Additional generalizations - Because of exclusion criteria in our study, we cannot generalize the results to other populations like male gender, illiterate and patients with high education, high socioeconomic status and severe physical and mental diseases. Patients with no personal demand for psychotherapy are also beyond the scope of this study.
3) A restricted choice of coping scales - At the beginning of the study there was only one coping scale translated and validated to the Portuguese language. This questionnaire was considered too complex and long for the majority of our patients.
4) Placebo effect - We consider the possibility of the improvement obtained to be partly due to the general effect of the intervention (more visits to the outpatient clinic to perform the therapy, the special attention of the therapists and the contact with other patients) and not due to specific psychotherapeutic method. This possibility is related to an inherent feature of psychotherapy, which promotes relationships and provides special care for treated patients.

**Table 4** Quality of life scores of SLE patients in control and therapy groups over time

| Domain | Time | Control ($n = 43$) Median (Min-Max) | Therapy ($n = 37$) Median (Min-Max) | Inter-group $P^*$ |
|---|---|---|---|---|
| Physical function | T1 | 12.0 (6.0–34.0) | 10.0 (2.0–39.0) | 0.645 |
| | T2 | 14.0 (6.0–36.0) | 9.0 (6.0–30.0) | 0.023 |
| | Intra-group $P^{**}$ | 0.245 | 0.057 | |
| Occupational activity | T1 | 24.0 (9.0–59.0) | 25.0 (1.0–59.0) | 0.743 |
| | T2 | 31.0 (9.0–61.0) | 17.0 (9.0–42.0) | 0.001 |
| | Intra-group $P^{**}$ | 0.055 | 0.001 | |
| Symptoms | T1 | 22.0 (8.0–49.0) | 23.0 (6.0–51.0) | 0.589 |
| | T2 | 25.0 (8.0–46.0) | 14.0 (8.0–37.0) | 0.001 |
| | Intra-group $P^{**}$ | 0.023 | < 0.001 | |
| Treatment | T1 | 11.0 (4.0–22.0) | 10.0 (3.0–19.0) | 0.591 |
| | T2 | 11.0 (4.0–25.0) | 8.0 (1.0–20.0) | 0.002 |
| | Intra-group $P^{**}$ | 0.093 | 0.008 | |
| Humor | T1 | 14.0 (4.0–28.0) | 15.0 (4.0–28.0) | 0.376 |
| | T2 | 13.0 (4.0–28.0) | 9.0 (4.0–26.0) | 0.005 |
| | Intra-group $P^{**}$ | 0.321 | < 0.001 | |
| Self-Image | T1 | 20.0 (9.0–51.0) | 25.0 (9.0–53.0) | 0.178 |
| | T2 | 20.0 (9.0–54.0) | 15.0 (9.0–33.0) | 0.003 |
| | Intra-group $P^{**}$ | 0.764 | < 0.001 | |
| Total score | T1 | 114.0 (40.0–204.0) | 109.0 (44.0–226.0) | 0.596 |
| | T2 | 113.0 (45.0–236.0) | 71.0 (40.0–153.0) | < 0.001 |
| | Intra-group $P^{**}$ | 0.041 | | |

*SLEQOL* Systemic Lupus Erythematosus Quality of Life (Range: 40–280)
*Mann-Whitney test; **Wilcoxon test
$P < 0.05$ significant



In addition, we have to admit that this type of intervention only works in patients who have personal demand for psychotherapy. In our study, all patients had such a demand and were motivated to accept psychological help. In this case, we believe that psychoanalytic treatment has been able to offer reception and listening to patients' suffering; it has made possible greater self-knowledge for patients and new ways of facing problems arising from the disease.

The psychotherapy technique used in this study did not follow standard manuals because it was similarly conducted by the same therapists in all subgroups. In case of a replication study, we assumed that therapists with similar experience and training in brief group psychoanalytic psychotherapy attendance could reach similar results.

Our single-center sample was smaller than the Canadian multicenter study [18]. However, it was larger than the

**Table 5** Anxiety and depression scores of SLE patients in control and therapy groups over time

| Domain | Time | Control ($n = 43$) Median (Min-Max) | Therapy ($n = 37$) Median (Min-Max) | Inter-group $P^*$ |
|---|---|---|---|---|
| Anxiety | T1 | 6.0 (1.0–16.0) | 9.0 (.0–20.0) | 0.340 |
| | T2 | 8.0 (1.0–18.0) | 6.0 (1.0–16.0) | 0.019 |
| | Intra-group $P^{**}$ | 0.132 | < 0.001 | |
| Depression | T1 | 5.0 (1.0–16.0) | 8.0 (.0–14.0) | 0.264 |
| | T2 | 7.0 (1.0–17.0) | 4.0 (.0–14.0) | 0.022 |
| | Intra-group $P^{**}$ | 0.081 | < 0.001 | |

*HADS* Hospital Anxiety and Depression Scale (Range: 0–21 by domain)
*Mann-Whitney test; **Wilcoxon test
$P < 0.05$ significant

**Table 6** Coping scores of SLE patients in control and therapy groups over time

| Domain | Time | Control ($n = 43$) Median (Min-Max) | Therapy ($n = 37$) Median (Min-Max) | Inter-group $P$* |
|---|---|---|---|---|
| Confrontive | T1 | 0.83 (.00–2.33) | 1.00 (0.33–2.33) | 0.217 |
| | T2 | 1.00 (.00–2.33) | 0.83 (.00–3.00) | 0.638 |
| | Intra-group $P$** | 0.490 | 0.021 | |
| Distancing | T1 | 1.00 (0.29–2.14) | 1.14 (0.14–2.71) | 0.698 |
| | T2 | 0.86 (.00–2.00) | 0.86 (.00–2.29) | 0.790 |
| | Intra-group $P$** | 0.064 | 0.073 | |
| Self-controlling | T1 | 1.40 (0.20–3.00) | 1.40 (0.60–3.00) | 0.804 |
| | T2 | 1.20 (.00–2.80) | 1.60 (0.60–2.40) | 0.186 |
| | Intra-group $P$** | 0.269 | 0.280 | |
| Seeking social Support | T1 | 1.67 (0.33–3.00) | 1.50 (0.33–2.67) | 0.292 |
| | T2 | 1.50 (.00–3.00) | 1.67 (0.17–3.00) | 0.520 |
| | Intra-group $P$** | 0.109 | 0.385 | |
| Accepting responsibility | T1 | 1.71 (0.14–2.71) | 1.43 (0.29–3.00) | 0.153 |
| | T2 | 1.57 (.00–2.71) | 1.57 (0.14–2.71) | 0.262 |
| | Intra-group $P$** | 0.137 | 0.099 | |
| Escape and Avoidance | T1 | 1.50 (.00–3.00) | 1.50 (.00–3.00) | 0.554 |
| | T2 | 1.50 (.00–3.00) | 1.00 (.00–3.50) | 0.124 |
| | Intra-group $P$** | 0.771 | 0.002 | |
| Planful problem Solving | T1 | 1.75 (.00–3.00) | 1.25 (0.50–3.00) | 0.748 |
| | T2 | 1.50 (.00–3.00) | 2.00 (0.75–3.50) | 0.017 |
| | Intra-group $P$** | 0.411 | < 0.001 | |
| Positive reappraisal | T1 | 1.89 (.00–2.89) | 1.56 (0.22–2.67) | 0.218 |
| | T2 | 1.56 (.00–2.78) | 1.78 (0.39–2.67) | 0.063 |
| | Intra-group $P$** | 0.061 | 0.002 | |

*CSI* Coping Strategies Inventory (Range: 0–3 by domain)
*Mann-Whitney test; **Wilcoxon test
$P < 0.05$ significant



samples of German and Spanish single-center studies [19, 20] and reached the estimated sample size to achieve the proposed aims. Concerning age and years of disease duration, our patients had means similar to Edworthy et al. and Navarrete-Navarrete et al. studies [18, 20], and all of them had more chronic disease than the patients of Haupt et al. study [19].

We had two drop-outs in each group of the study. The lost patients had the same demographic and clinical characteristics than the long term participants. We believe that, despite the drop-outs, the homogeneity of the groups was maintained. We used intent to treat analysis, repeating the values of the first access.

More psychoanalytic research is needed to clarify the relationship of the immune system and patient's psychological function. Believing that psychological function can be one of the factors that participate as cause and trigger of SLE flares [3, 4], psychotherapeutic support may be useful to supplement clinical and pharmacological treatments in these patients. Psychotherapy group treatment should be offered at specialized centers to treat SLE patients because it can allow cost reduction and emotional benefits for coexistence and exchange of experiences among patients, besides higher effectiveness than individual treatment, according to a systematic review [47].

## Conclusion

In conclusion, BGPP was effective to improve quality of life, including occupational activity, treatment, humor and self-image as well as to reduce symptoms, depression and anxiety levels in SLE patients, besides lead to some positive change in coping strategies. Psychoanalytic psychotherapy can help patients to become stronger to deal with the disease and other important life events, relieving their suffering.

### Abbreviations

ABIPEME: *Associação Brasileira de Institutos de Pesquisa de Mercado*; ACR: American College of Rheumatology; ANOVA: Analysis of Variance; BGPP: Brief Group Psychoanalytic Psychotherapy; CG: Control Group; CSI: Coping Strategies Inventory; HADS: Hospital Anxiety and Depression Scale; HPA: Hypothalamic-Pituitary-Adrenal; NP: Neuropsychiatric; QOL: Quality Of Life; SLE: Systemic Lupus Erythematosus; SLEDAI: Systemic Lupus Erythematosus International Disease Activity; SLEQOL: Systemic Lupus Erythematosus Quality of Life; SLE-SSC: Systemic Lupus Erythematosus Specific Symptom Checklist; SLICC/ACR-DI: Systemic Lupus International Collaborating Clinic /American College of Rheumatology - Damage Index; SPSS: Statistical Package for the Social Sciences; T1: Baseline; T2: After 20 weeks; TG: Therapy Group

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### Authors' contributions

CTMC had the idea of study, performed the therapy, wrote the manuscript, analyzed and interpreted psychological data. IMM helped the intervention, analyzed clinical data and contributed with the recruitment of patients. JAB supervised the therapy and EIS supervised all study and both reviewed the manuscript. All authors read and approved the final manuscript.

### Ethics approval and consent to participate

We declare that this study has been performed in accordance with Declaration of Helsinki and was approved by the Research Ethics Committee of the Federal University of São Paulo/São Paulo Hospital (protocol 1655/09) and all participants signed the informed consent form.

### Competing interests

All authors declare that they have no competing interests.

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PAPER

# Insomnia symptoms, perceived stress and coping strategies in patients with systemic lupus erythematosus

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**Objective:** The aim of this study is to evaluate perceived stress and coping strategies in individuals with systemic lupus erythematosus (SLE) according to the presence of insomnia symptoms, using a set of variables that include anxiety and depressive symptoms evaluation. **Methods:** Ninety SLE women were evaluated in a cross-sectional study using the Perceived Stress Scale (PSS), Brief COPE, Pittsburgh Sleep Quality Index (PSQI), Insomnia Severity Index (ISI), Beck Depression Inventory (BDI) and Self-rating Anxiety Scale (SAS). **Results:** Individuals with insomnia symptoms ($n = 57$, 66%) presented higher PSS ($p < 0.001$), PSQI ($p < 0.0001$), BDI, ($p < 0.0001$) scores and showed less-effective coping strategies such as the use of behavioral disengagement ($p = 0.04$), self-blame ($p = 0.02$) and emotional-focused coping ($p = 0.001$). In a multi-regression model ISI was the independent determinant of high PSS and of behavioral disengagement; PSQI was the only determinant of self-blame ($p = 0.02$) and emotional-focused coping. **Conclusions:** SLE individuals with insomnia symptoms show high levels of perceived stress and more frequent use of disengaging and emotional-focused coping strategies. This body of evidence suggests that individuals with SLE and comorbid insomnia symptoms may therefore require additional interventions for insomnia. *Lupus* (2016) **0**, 1–9.



**Key words:** Neuropsychiatric lupus; systemic lupus erythematosus; nephritis

## Introduction

Systemic lupus erythematosus (SLE) is a chronic multisystem, inflammatory, autoimmune disorder characterized by a variety of clinical manifestations and organ involvement.[1,2]

Neuropsychiatric manifestations such as depression[3] are frequently observed in SLE and significantly interfere with patients' quality of life, social relationships and productivity.[2–5]

Although earlier diagnosis and better treatment options have improved the survival of SLE patients in recent decades,[6] the course of SLE is characterized by recurrent flares that have been related to stress[7–11] and depression[3] and may lead to progressive disability.[12] Research for prevention and treatment of SLE should thus continue to receive high priority. Insomnia has emerged as a major determinant of psychic and somatic health including rheumatologic disorders[13–19] and SLE.[15–18]

Sleep disorders are an important part of the symptomatology of SLE: they occur in more than half of patients and are associated with disease activity, fatigue and depressive symptoms.[18,20–22] As a role for stress has been hypothesized in the development of flares in SLE,[7,8,10,11,23,24] overactivation of the stress system that has been described in insomnia known as "hyperarousal"[25–27] may be interesting from an SLE point of view. In particular, evidence is accumulating for the hypothesis that conditions of sleep loss, including insomnia, might act as a neurobiologic stressor per se,[28] leading to sympathetic nervous system and hypothalamus-pituitary-adrenal axis over-activation, pro-inflammatory responses that in turn may be involved in the modulation of depression, pain and fatigue in SLE too.[3,20,29]

Despite this evidence, no prior research has examined the possible association between insomnia, stress and the potential impact on SLE individuals.

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According to the appraisal theory, the physiological effects resulting from a stressful event are determined by the individual perception of an event.[30] Appraisal of stress has been related to flares in SLE.[10] Recommendations for lupus patients to reduce perceived stress are based on numerous studies establishing the association between daily stress and disease exacerbation.[7,8,10,11,23,24] Once the event has occurred and been appraised as a stressor, the second process relates to how the individual self-regulates and reduces stress, referred to as "coping."[31] Some of these coping strategies may prove beneficial, while others may instead prove to be "maladaptive" or less effective.[30–32]

A meta-analysis showed emotion-focused strategies, aimed at thinking or feeling in a different way about a stressful situation, to be less effective and to be related to poor mental health[33] with respect to problem-focused coping, aimed at performing something active to modify a stressful situation.[33] In addition, disengagement coping is considered a psychological risk factor or a disadaptive response to stressful events.[34] The course of the disease and the mental well-being of SLE patients have been shown to be influenced by coping strategies applied;[35–37] disengaging and emotional coping styles have been described to interfere with the course of the disease, with the mental well-being and the quality of life in SLE.[11,38]

In the attempt to clarify the relationship between insomnia symptoms and both appraisal and coping of stress in SLE, this study examined a clinical sample of SLE patients who were evaluated according to the presence or absence of insomnia symptoms. Participants were categorized into two groups: 1) SLE patients with insomnia symptoms, and 2) SLE patients without insomnia symptoms. The hypothesis of the study was that SLE participants with insomnia symptoms will show higher rates of stress-appraisal and more maladaptive coping strategies than SLE participants without insomnia symptoms. As insomnia is a risk factor for psychiatric disorders,[39] we also expected to see higher psychological problems in the SLE group with insomnia symptoms.

## Methods

### *Participants*

From January 2012 to December 2013, consecutive outpatients attending the Lupus Clinic of the Rheumatology Unit of the University of Pisa, Italy, were evaluated. Participants underwent a face-to-face evaluation conducted by a medical doctor with expertise in the sleep field (LP). Sleep disorders were assessed by clinical evaluation and the use of sleep-related questionnaires. All enrolled individuals fulfilled at least four of the American College of Rheumatology (ACR) revised criteria for SLE.[40] SLE patients underwent a complete medical evaluation, including a clinical interview to determine the patients' medical, neurologic and psychiatric disorders and pre-existing sleep disorders. Inclusion criteria were age >18 years and written informed consent; exclusion criteria were cognitive impairment that would preclude the completion of the questionnaires; severe medical diseases including end-stage renal disease and active neoplastic disease. Furthermore, patients who were suspected of suffering from another sleep disorder (for example: sleep apnea syndrome, snoring), based on clinical evaluation that was conducted by a medical doctor with expertise in the sleep field (LP) and according to the International Classification of Sleep Disorders, third edition (ICSD-3) criteria,[41] also were excluded. In addition, individuals with a score of 1 or more on item 10 of the Pittsburgh Sleep Quality Index (PSQI)[42] regarding self-reported symptoms or symptoms reported by the patient's roommate were excluded from the study.

### *Clinical evaluations*

After enrollment, participants underwent a standard medical examination. For SLE patients, medical and pharmacological history, previous organ involvement as well as actual disease manifestations and ongoing therapies were recorded. Previous or ongoing neurological manifestations were defined according to the ACR nomenclature and case definitions.[43]

Cumulative glucocorticorticoid (GC) dosages until the assessment time were also computed. Disease activity was evaluated using the European Consensus Lupus Activity Measurement Index (ECLAM) in a range from 0 to 6; a score > 2 was considered as indicative of active disease.[44] Cumulative organ damage was measured using the Systemic Lupus International Collaborating Clinics/ACR Damage Index (SLICC/ACR DI) (range 3–6).[45]

## Questionnaires

### *Measurements of sleep*

#### *PSQI*

Sleep quality was evaluated through the administration of the PSQI. The PSQI is a widely used,

self-rated, standardized questionnaire assessing sleep quality in the previous month. The 19 questions are grouped in seven component scores, each exploring a different sleep feature; the sum yields a global PSQI score[42] used to define poor sleep quality when >5. The following PSQI-derived data were also analyzed: sleep latency (component 2), sleep duration (component 3), habitual sleep efficiency (component 4), and use of medication (component 6).[42]

*Insomnia Severity Index (ISI)*

Insomnia severity was evaluated with the ISI. ISI is a self-reported, seven-item questionnaire that assesses insomnia in the previous two weeks. It is a reliable and valid instrument to index a diagnosis of and severity of insomnia. The sum yields a global score ranging from 0 to 28. Individuals were categorized as having no insomnia if the ISI score ranged from 0 to 7. The presence of insomnia symptoms was defined by an ISI score of 8 or higher.[46]

*Measurements of stress*

*Appraisal of stress: Perceived Stress Scale (PSS)*

Perception of stress was assessed using the PSS.[47] It measures the degree to which events are appraised as stressful. Items were designed to tap how unpredictable, uncontrollable, and overloaded respondents found their lives during the last month. The scale also includes a number of direct queries about current levels of experienced stress. Normative values[47] for 30- to 44-year-old women are >14.

*Coping of stress: Brief COPE*

Coping strategies were evaluated using the Brief COPE scale, which assesses for coping responses to stressors.[32] The Brief COPE specifically referenced coping strategies in which participants engaged in response to stressors. A shortened version of the original instrument, the Brief COPE is a 14 subscale and 28-item multifactorial questionnaire designed to assess levels of engagement in various coping techniques.[32] The 14 subscales are composed of two items each, with higher scores indicating greater use of the respective coping strategy. Coping strategies measured in the Brief COPE include Acceptance, Religion, Planning, Positive Reframing, Using Instrumental Support, Active Coping, Using Emotional Support, Humor, Self-Distraction, Venting of Emotions, Self-blame, Behavioral Disengagement, Denial and Substance Use. Participants were asked to respond to each item on a four-point Likert scale, indicating what they generally do and feel when they experience stressful events (1 = "I have not been doing this at all" – 4 = "I have been doing this a lot").[32] Problem-focused vs. emotion-focused coping strategies were considered. Composite scores for these two strategies of coping were obtained by summing their scales: Acceptance, Religion, Planning, Positive Reframing, Using Instrumental Support, Active Coping, Using Emotional Support and Humor comprised the Problem-focused coping score, while Self-Distraction, Venting of Emotions, Self-blame, Behavioral Disengagement, Denial and Substance Use comprised the Emotion-focused coping score.[48]

*Measurements of psychiatric symptoms*

*Beck Depression Inventory (BDI)*

Depressive symptoms were assessed using the BDI. The BDI is a 21-question inventory for self-assessment, one of the most widely used instruments for measuring the severity of depression. The total score ranges from 0–63. According to the BDI authors' recommendations, a BDI score greater than 9 is indicative of depressive symptoms.[49]

*Self-rating Anxiety Scale (SAS)*

Anxiety symptoms were assessed with the SAS. The SAS is a 20-item self-reported assessment scale based on scoring in four groups of manifestations: cognitive, autonomic, motor and central nervous system symptoms. Each question is scored on a Likert-type scale of 1–4. The total score ranges from 0–80. The presence of clinically relevant anxiety symptoms is defined[50] by SAS scores > 44.

## Statistical analysis

Statistical analysis was performed using NCSS 2008.[51] Results were expressed as mean ± standard deviation (SD). Shapiro-Wilk test was used to check normality of the variables. Differences in means between individuals with or without insomnia symptoms were assessed using *t*-tests for normally distributed variables, or Mann-Whitney *U*/Wilcoxon test for non-normally distributed variables. The Box-Cox transformation was performed for non-normal distributed variables. Categorical variables were analyzed via the $\chi^2$ test. An a priori power estimation analysis returned a sample size of $n = 20$ to reach a power of 0.8. A post hoc power analysis a posteriori was conducted on simple size; a power- > 0.8 was considered significant. Univariate linear regression analysis was performed in order to test the correlates of the PSS, expressed by PSS score,

and of coping strategies, using responses on the Brief COPE subscales. Then multiple linear regression models were built, with the PSS or Brief COPE subscales entered as dependent variables, and as independent variables those measures that were found to be significantly correlated with the dependent variables in the univariate analyses. All the multiple regression models were checked for multicollinearity: a variable was excluded from the model if it had a variance inflation factor greater than 10 and a condition number greater than 100 in the Eigenvalues of Centered Correlations.

## Results

### *Descriptive statistics*

Among the 100 individuals enrolled, all females, those with clinically evaluated or self-reported (or reported by roommate) sleep apneas, snoring, and leg restlessness ($n=6$) or with incomplete data ($n=4$) were excluded. The final analysis was performed on 90 patients. Clinical characteristics of the study population are listed in Table 1. Participants with insomnia symptoms showed significantly higher renal involvement (28 participants = 49.1%, past $p=0.03$) than patients with no insomnia symptoms. No differences in disease activity (ECLAM mean score) were found among the groups (Table 1). Post hoc power analysis a posteriori revealed a power of 0.99.

### *Sleep and psychological characteristics*

Sleep and psychiatric characteristics of the study population are listed in Table 2. Participants with insomnia symptoms exhibited poorer sleep quality, and higher insomnia severity; 29.8% showed a sleep latency >30 minutes ($n=17$, $p=0.02$), 49.1% ($n=28$, $p<0.001$) a short sleep duration (<6 hours), and 64.9% a low sleep efficiency (<85%) ($n=37$, $p=0.01$) compared to SLE patients with no insomnia symptoms (respectively 11.4%, $n=4$; 14.2%, $n=4$; 25.7%, $n=13$). Despite the presence of these sleep problems, the use of sleep medications at least once or twice a week was very limited in the group of SLE patients with insomnia symptoms (15.7%, $n=9$ vs 2% $n=1$, $p=0.006$). Individuals with insomnia also showed higher rates of depressive symptoms than SLE patients with no insomnia symptoms ($p=0.003$); significantly, 40.3% ($n=23$) of the SLE patients with insomnia symptoms showed depressive symptoms.

**Table 1** Clinical characteristics of the study population

| | *Overall* (n = 90) | *No insomnia symptoms* (n = 33) | *With insomnia symptoms* (n = 57) | p *value* |
|---|---|---|---|---|
| Age (years) | 43 ± 11 | 42 ± 11 | 43 ± 11 | 0.23 |
| Education (%) | | | | |
| -Undergraduates | 90. | 91 | 92 | 0.61 |
| -Graduated | 10 | 9 | 8 | 0.55 |
| Employment status (%) | | | | |
| -Unemployed/household | 52 | 52 | 53 | 0.52 |
| -Employed | 48 | 48 | 47 | |
| SLE duration (years) | 15 ± 8 | 14 ± 8 | 15 ± 8 | 0.19 |
| Neurologic involvement (%) | 12 | 10 | 13 | 0.19[a] |
| Renal involvement (%) | 38 | 24.2 | 49.1 | 0.03[a,b] |
| ECLAM mean score | 0.9 ± 1.2 | 0.9 ± 1.0 | 0.9 ± 1.4 | 0.64[a] |
| SLICC mean score | 0.9 ± 1.3 | 0.6 ± 0.8 | 1.0 ± 1.5 | 0.78[a] |
| Glucocorticosteroids (%) | 88 | 90 | 89 | 0.67[a] |
| Immunosuppressive drugs (%) | 42.2 | 36 | 43 | 0.92[a] |
| Cyclophosphamide (%) | 3 | 3 | 3 | 0.72[a] |
| Mycophenolate mofetil (%) | 25 | 18 | 29 | 0.25[a] |
| Azathioprine (%) | 7 | 3 | 7 | 0.69[a] |
| Cyclosporine (%) | 5 | 6 | 5 | 0.84[a] |
| Methotrexate (%) | 3 | 4 | 2 | 0.67[a] |
| Fibromyalgia (%) | 15 | 11 | 13 | 0.25[a] |

Results were expressed in mean ± standard deviation (SD). SLE: systemic lupus erythematosus; *ECLAM: European Consensus Lupus Activity Measurement; SLICC = System Lupus International Collaborating Clinics/ACR Damage Index for Systemic Lupus Erythematosus.* [a]*Mann-Whitney U*/Wilcoxon test for non-normally distributed variables, [b]$p<0.05$.

### *Perceived stress and coping strategies*

PSS scores were significantly higher in SLE patients with insomnia symptoms in comparison to those without insomnia symptoms ($p=0.001$) (Table 3).

Participants with insomnia symptoms reported more use of behavioral disengagement (2.7 ± 1.2 vs 2.3 ± 0.7, $p=0.04$), self-blame (5.6 ± 1.8 vs 4.8 ± 1.6, $p=0.02$) and emotional-focused strategies (22.9 ± 2.8 vs 20.8 ± 2.8, $p=0.001$) than participants without insomnia symptoms (see Table 3).

### *Determinants of perceived stress*

In the univariate analysis perceived stress (PSS score) was significantly related to insomnia severity ($p<0.001$), sleep quality ($p<0.001$) and depressive symptoms ($p<0.02$) (Table 4). It was not related to education level ($p=0.10$), employment status ($p=0.22$), SLE duration ($p=0.20$), neurologic involvement ($p=0.50$), renal involvement ($p=0.64$), ECLAM index ($p=0.49$) or SLICC index ($p=0.41$). In the multiple linear regression analysis, including renal involvement, according

**Table 2** Sleep and psychological characteristics of the study population

| | *Overall* | *No insomnia symptoms* | *With insomnia symptoms* | p *value* |
|---|---|---|---|---|
| ISI score | 8.9 ± 5.0 | 5 (0–7) | 10 (8–14) | 0.001[a,c] |
| PSQI score | 7.5 ± 3.9 | 4 (4–5) | 8 (6–13) | 0.001[a,c] |
| PSQI SL > 30 minutes | | 11.4% | 29.8% | 0.02[a,b] |
| PSQI SD < 6 hours | | 14.2% | 49.1% | <0.001[a,c] |
| PSQI SE < 85% | | 25.7% | 4.9% | 0.01[a,b] |
| PSQI USM | | 2% | 15.7% | 0.006[a,c] |
| SAS score | 31.6 ± 14 | 20 (20–32) | 20 (20–20) | 0.07[a] |
| BDI score | 5.6 ± 7.3 | 1 (0–3) | 5 (1–13) | 0.001[a,c] |

Results of the overall sample are expressed mean ± standard deviation, while values for subgroups based on the presence of insomnia symptoms are expressed as median (25%–75%). *ISI: Insomnia Severity Index; PSQI: Pittsburgh Sleep Quality Index; PSQI subscales: SL: Sleep Latency; SD: Sleep Duration; SE: Sleep Efficiency; USM: use of sleep medication; SAS: Self-Rating Anxiety Scale; BDI: Beck Depression Inventory*. [a]*Mann-Whitney U*/Wilcoxon test for non-normally distributed variables. Significance: [b]$p < 0.05$, [c]$p < 0.001$.

**Table 3** Perceived stress scale and Brief COPE scores

| | *Overall* | *No insomnia symptoms* | *With insomnia symptoms* | p *value* |
|---|---|---|---|---|
| Perceived Stress Scale score | 17.4 ± 4.8 | 12 (10–17) | 19 (17–22) | 0.001[a,c] |
| Brief COPE subscales | | | | |
| Positive reframing | 5.2 ± 1.5 | 5.4 ± 2.1 | 5.4 ± 1 | 0.83 |
| Self-distraction | 4.5 ± 1.3 | 4.6 ± 1.2 | 4.0 ± 1.3 | 0.92 |
| Venting | 5.4 ± 2.3 | 5.2 ± 1.8 | 5.6 ± 1.7 | 0.43[a] |
| Use of instrumental support | 5.4 ± 2.3 | 5.5 ± 2.1 | 5.4 ± 2.3 | 0.56 |
| Active coping | 7.2 ± 1.4 | 7.1 ± 1.5 | 7.4 ± 0.9 | 0.23 |
| Denial | 2.2 ± 0.7 | 2.2 ± 0.7 | 2.2 ± 0.8 | 0.24 |
| Religion | 4.6 ± 2.5 | 5. ± 2.1 | 4.3 ± 2.6 | 0.47 |
| Humor | 4.2 ± 1.7 | 4.2 ± 1.7 | 4.3 ± 1.8 | 0.82 |
| Behavioral disengagement | 2.5 ± 1.1 | 2.3 ± 0.7 | 2.7 ± 1.2 | 0.04[b] |
| Use of emotional support | 5.3 ± 2.4 | 5.5 ± 2.4 | 5.0 ± 2.3 | 0.33 |
| Substance use | 2.0 ± 0.1 | 2.0 ± 0.1 | 2.0 ± 0.0 | 0.19[a] |
| Acceptance | 7.2 ± 2.0 | 7.2 ± 1.4 | 7.2 ± 1.2 | 0.94 |
| Planning | 7.3 ± 1.1 | 7.3 ± 1.0 | 7.1 ± 1.4 | 0.29 |
| Self-blame | 5.3 ± 1.8 | 4.8 ± 1.6 | 5.6 ± 1.8 | 0.02[b] |
| Emotion-focused | 22.1 ± 2.9 | 20.8 ± 2.8 | 22.9 ± 2.8 | 0.001[c] |
| Problem-focused | 46.8 ± 8.7 | 45.8 ± 7.7 | 46.5 ± 9.1 | 0.25 |

Results were expressed in mean ± standard deviation-SD and as median (25%–75%). [a]*Mann-Whitney U*/Wilcoxon test for non-normally distributed variables. Significance: [b]$p < 0.05$, [c]$p < 0.001$.

to the ISI, PSQI, and BDI, only insomnia symptoms ($p = 0.008$) (Figure 1, Table 4) were significantly associated with higher perceived stress (Table 4).

**Table 4** Determinants of perceived stress

| | *Univariate linear regression* | | *Multiple linear regression* | |
|---|---|---|---|---|
| *PSS* | *Coeff* | p *value* | *Coeff* | p *value* |
| Education | 0.16 | 0.10 | – | – |
| Employment status | 0.09 | 0.22 | – | – |
| SLE duration | 0.07 | 0.20 | – | – |
| Neurologic involvement | 0.01 | 0.50 | – | – |
| Renal involvement | 0.40 | 0.64 | – | – |
| ECLAM | 0.20 | 0.49 | – | – |
| SLICC | 0.30 | 0.41 | – | – |
| ISI | 0.49 | <0.0001[b] | 0.34 | 0.008[b] |
| PSQI | 0.62 | <0.0001[b] | 0.23 | 0.17 |
| SAS | −0.04 | 0.16 | | |
| BDI | 0.25 | 0.02[a] | 0.08 | 0.38 |

Results of the univariate linear regression and of the multiple linear regression model with Perceived Stress Scale (PSS) *as a dependent variable and the other clinical, sleep and* psychological *variables as independent variables. SLE: systemic lupus erythematosus*; ECLAM: European Consensus Lupus Activity Measurement; SLICC: System Lupus International Collaborating Clinics/American College of Rheumatology (ACR) Damage Index for Systemic Lupus Erythematosus; *ISI: Insomnia Severity Index; PSQI: Pittsburgh Sleep Quality Index; SAS: Self-Rating Anxiety Scale; BDI: Beck Depression Inventory*. Significant correlations: [a]$p < 0.05$, [b]$p < 0.01$.

### *Determinants of coping strategies*

In the univariate analysis behavioral disengagement was significantly related to insomnia severity ($p = 0.01$), sleep quality ($p = 0.003$) and depressive symptoms ($p = 0.01$). In the multiple linear regression analysis including ISI, PSQI, and BDI, the only independent determinant of behavioral disengagement was poor sleep quality ($p = 0.01$) (Table 5).

In the univariate analysis the use of self-blame was positively related to insomnia severity ($p = 0.006$) and poor sleep quality ($p = 0.05$) (Table 5). In the multiple linear regression analysis including ISI and PSQI, insomnia severity ($p = 0.04$) was the only determinant of the use of self-blame.

In the univariate analysis the use of emotional-focused coping strategies was related to insomnia severity ($p = 0.01$), poor sleep quality ($p = 0.002$) and perceived stress ($p = 0.03$). In the multiple linear regression analysis including ISI, PSQI and PSS, poor sleep quality ($p = 0.04$) was the only determinant of the use of self-blame (Table 5).

## Discussion

The present study investigated the perceived stress and coping strategies in patients with SLE according to the presence or absence of insomnia

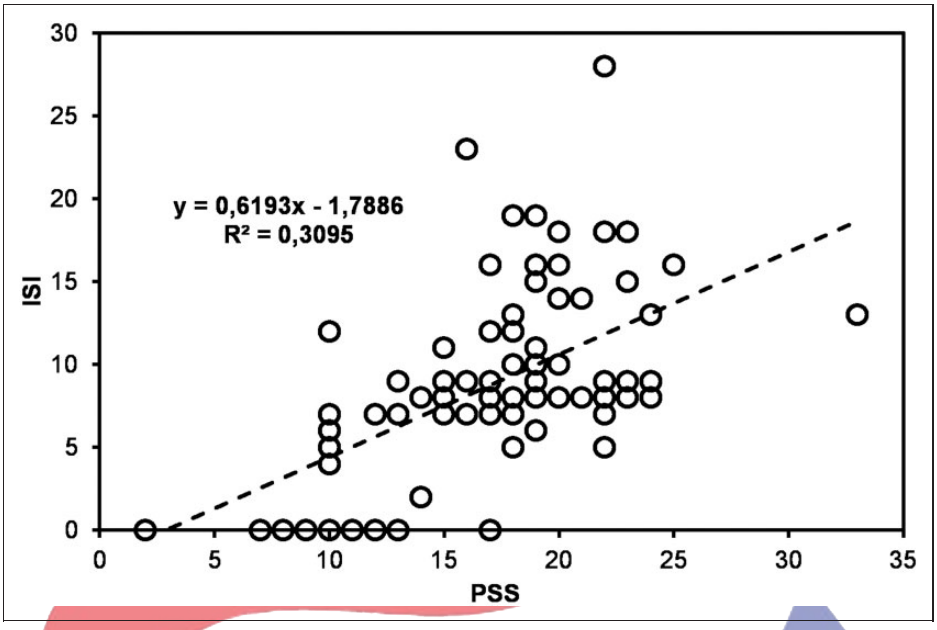


**Figure 1** Scatter plot representing the correlation between Perceived Stress Score (PSS) and insomnia severity in SLE. SLE: systemic lupus erythematosus; ISI: Insomnia Severity Index.

symptoms. The main finding of the study was that SLE patients with insomnia symptoms showed increased perceived stress, less-effective coping strategies, and higher rates of psychiatric symptoms, especially depressive symptoms, compared to SLE patients with no insomnia symptoms. Although in the present study a cause-effect relationship cannot be established because of its cross-sectional nature, we may hypothesize insomnia symptoms play a role in the perception of stress in SLE and, indirectly, in coping strategies in SLE.

Insomnia symptoms were frequent in patients with SLE, afflicting 63% of the sample, thus confirming previous findings showing disturbed sleep to be common in SLE patients.[18,20–22]

Interestingly, these patients showed more frequently a renal involvement, compared to SLE patients with no insomnia symptoms. It is well established that chronic kidney disease is associated per se with a variety of sleep disorders.[52,53] However, renal damage could simply reflect a greater degree of disease severity in SLE patients with insomnia symptoms. We may hypothesize insomnia symptoms to play a role in disease severity as it was previously hypothesized or, conversely, we may hypothesize that patients with more severe disease could be at higher risk for insomnia.[18,20]

Longitudinal design studies may examine if SLE individuals with symptoms of insomnia who receive sleep interventions may require less medications or may improve disease severity compared to those who do not receive sleep interventions.

Individuals with insomnia symptoms showed higher levels of comorbid psychiatric symptoms especially depressive symptoms as seen previously in other studies.[20,21,29] The presence of insomnia symptoms may thus be associated with high levels of depressive symptoms in SLE patients: depression is a very common complaint and it is included in the SLE neuropsychiatric manifestations.[3,54] This finding was expected as insomnia is considered a risk factor for depression[39,55] and insomnia and depression have been shown to be in a causal bidirectional relationship.[56,57] Based on this point of view, sleep interventions may be required in SLE patients in order to favor depressive symptom prevention and treatment.

Patients with insomnia symptoms showed a higher level of perceived stress than non-insomniacs, which may be related to the presence of insomnia symptoms. This finding may suggest that SLE individuals with symptoms of insomnia are more likely to perceive challenging events as stressful. This is in line with previous studies regarding patients with insomnia showing high level of perceived stress.[58–60] This is an important issue as high perceived stress has been related to flares in SLE[10] and numerous studies have demonstrated the associations between daily stress and SLE disease exacerbation.[7,8,10,11,23,24]

**Table 5** Determinants of coping strategies

| | *Univariate linear regression* | | *Multiple linear regression* | |
|---|---|---|---|---|
| *Behavioral disengagement* | *Coeff* | p *value* | *Coeff* | p *value* |
| ISI | *0.05* | 0.01[a] | 0.06 | 0.08 |
| PSQI | 0.08 | 0.003[b] | 0.07 | 0.01[a] |
| SAS | 0.04 | 0.08 | – | |
| BDI | 0.03 | 0.01[a] | 0.02 | 0.06 |
| PSS | 0.04 | 0.09 | – | |
| *Self-Blame* | Coeff. | p-value | Coeff. | p-value |
| ISI | *0.090* | 0.006[b] | *0.11* | 0.04[a] |
| PSQI | 0.093 | 0.05[a] | 0.20 | 0.77 |
| SAS | −0.007 | 0.59 | – | – |
| BDI | −0.003 | 0.91 | – | – |
| PSS | −0.06 | 0.12 | – | – |
| *Emotional focused coping* | Coeff | *p* value | Coeff | *p* value |
| ISI | 0.18 | 0.01[a] | 0.10 | 0.28 |
| PSQI | *0.24* | 0.002[b] | 0.18 | 0.04[a] |
| SAS | *0.01* | 0.57 | – | |
| BDI | 0.03 | 0.39 | – | |
| PSS | 0.16 | 0.03[a] | 0.07 | 0.36 |

Results of the univariate linear regression analysis and the multiple linear regression with coping strategies considered as dependent variables *and the other sleep and* psychological *variables as independent variables. ISI: Insomnia Severity Index; PSQI: Pittsburgh Sleep Quality Index; SAS: Self-Rating Anxiety Scale; BDI: Beck Depression Inventory; PSS: Perceived Stress Scale.* Significant correlations: [a]$p < 0.05$, [b]$p < 0.01$.

Possible mechanisms accounting for such an association were beyond the aim of our study.

However, these results may be consistent with the hypothesis that the condition of sleep loss might act as a neurobiologic stressor leading to sympathetic nervous system and hypothalamus-pituitary-adrenal axis over-activation and pro-inflammatory responses.[28] Pathophysiological mechanisms such as the over-activation (or "hyperarousal") of the sympathetic nervous system and the hypothalamic-pituitary-adrenal axis described in insomnia[25–27] may be involved in modulating stress perception in SLE patients with insomnia. A longitudinal study design should establish in this kind of patients the cause-effect relationship among insomnia symptoms and appraisal of stress.

Another important aspect of the present study is that patients with comorbid insomnia symptoms and SLE also exhibited less-effective coping strategies, such as disengaging coping or emotional-focused coping. Particularly, SLE patients with insomnia symptoms showed a higher use of behavioral disengagement, which is a coping style that has previously been described in individuals with insomnia.[60] In this SLE sample the use of behavioral disengagement was related to poor sleep quality, thus confirming previous observations in insomnia patients.

Self-blame was another disengaging coping strategy observed in this group of SLE patients with insomnia symptoms, and was related to poor sleep related to insomnia severity. In previous research the use of self-blame has been related to poor psychosocial adjustment to the chronic illness and to poorer functional status in SLE, thus resulting in particularly maladaptive behavior in SLE.[61–63]

Individuals with insomnia symptoms also showed a higher use of emotional-focused coping strategies. Emotion-focused coping has also been associated with poor adjustment to the chronic illness and increased levels of depression in rheumatologic disorders[61,62] including SLE,[9] resulting thus in maladaptive behavior in SLE.

Although a cause-effect relationship cannot be established, we may hypothesize insomnia symptoms to play a role in the appraisal of stress and, in turn, to negatively influence coping strategies in SLE. As previously seen, the course of the disease and the mental well-being of SLE patients may be influenced by the kinds of coping strategy engaged, thus the main implication of these results reinforces the idea that insomnia symptoms should be an important target of treatment in SLE patients.

In conclusion, this study suggests that insomnia symptoms are frequent in SLE individuals. Insomnia symptoms may contribute to disease severity and to higher levels of neuropsychiatric manifestations, especially depression. SLE individuals with insomnia symptoms showed high levels of perceived stress in conjunction with more frequent use of disengaging and emotional-focused coping strategies that were related to insomnia severity and poor sleep quality. These data suggest that individuals with comorbid SLE and insomnia symptoms may be at higher risk for further negative health outcomes, and may therefore require additional interventions for insomnia. These results may confirm the hypothesis according to which conditions of sleep loss might act as a neurobiologic stressor per se, leading to sympathetic nervous system and hypothalamus-pituitary-adrenal axis overactivation and pro-inflammatory responses.[28] Prevention and treatment of insomnia symptoms should receive attention in patients with SLE, since insomnia treatments may be relevant for reducing SLE severity including neuropsychiatric manifestations, and may be involved in the perception of stress and in the coping strategies engage in by SLE patients.

We should acknowledge several limitations of the study. The study employed a cross-sectional

design, so the cause-effect relationship between variables cannot be established.

Future studies should employ a longitudinal design and should incorporate clinical methods designed to treat insomnia symptoms. Other limitations include the small sample size and the fact that patients were selected from a single SLE center: future studies should be designed to include multiple SLE centers in order to select greater samples of SLE patients. In addition the present study did not evaluate a control group: the inclusion of a control group of individuals with another chronic disorder may be useful in order to understand if the presence of insomnia symptoms may affect in the same way individuals with SLE or patients with other chronic disease. Further studies should also include patients with other sleep disorders, such as obstructive sleep apnea syndrome, in order to generalize these findings.

## Declaration of Conflicting Interests

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PLOS ONE

RESEARCH ARTICLE

# Illness uncertainty, social support, and coping mode in hospitalized patients with systemic lupus erythematosus in a hospital in Shaanxi, China

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## Abstract

### Objective

To analyze the relationships between illness uncertainty, social support, and coping mode in hospitalized patients with systematic lupus erythematosus (SLE).

### Methods

The General Health Questionnaire, Mishel Uncertainty in Illness Scale, Social Support Rating Scale, and Medical Coping Modes Questionnaire were to the hospitalized patients with SLE (N = 200) in a tertiary hospital in Shaanxi.

### Results

The hospitalized patients with SLE showed a moderate level of illness uncertainty. Furthermore, illness uncertainty was negatively correlated with support availability ($r$ = -0.161, $P$ = 0.023) and facing coping mode ($r$ = -0.231, $P$ = 0.001), and was positively correlated with the yielding coping mode ($r$ = 0.249, $P$ < 0.001).

### Conclusion

These findings suggest that support availability and coping modes were associated with moderate level of illness uncertainty, indicating that support availability support should be strengthened in hospitalized patients to actively face their disease. This subsequently improves their treatment compliance and quality of life.

## Introduction

Systemic lupus erythematosus (SLE) is an autoimmune disease of the connective tissue. It is characterized by tissue injury and displays clinical manifestations in multiple systems and organs due to the occurrence of large numbers of pathogenic autoantibodies and immune

complexes [1]. SLE presents with a chronic, alternating recurrence and the remission process showed considerable heterogeneity in clinical manifestations and severities, making the patients unable to predict the disease process or prognosis [2]. This in turn leads to a greater illness uncertainty, and is defined as lack of capacity to accurately discern the disease-related events or assess the significance and predict the outcomes of such events [3].

Education level, coping style, social support, and information support are considered the four main factors that influence the illness uncertainty [4]. Awareness of illness uncertainty can influence patients' emotions, coping modes, psychology, social adaptivity, and other issues [5], as well as their treatment compliance behavior and quality of life [6–7]. Social support can help improve SLE patients' coping and capacity to adapt with the psychological stress brought on by their disease [8]. At present, research on illness uncertainty involved tumors, heart disease and chronic disease [9–13]. Both domestically and abroad, there are very few studies exploring the illness uncertainty of SLE patients, and all these studies that exist consist of small sample sizes [14–17]. Hence the present study investigated the relationships between illness uncertainty, social support, and coping modes among 200 SLE patients who have been hospitalized for over a week in a tertiary hospital in Shaanxi province, China, providing a theoretical basis for developing intervention measures to lessen illness uncertainty in such patients.

## Materials resource and methods

### Subjects

SLE patients with SLE hospitalized from December 2015 to July 2016 in a tertiary hospital in Shaanxi Province, China, were selected by simple random sampling. This study was approved by the ethics committee of the First Affiliated Hospital of Xi'an, Jiaotong University (approval no. 2015012010). Written informed consent was obtained from all the participants. The criteria used for patient selection and exclusion are shown in Table 1.



### Instruments

The researchers explained the research objective to the participants when handing out the questionnaires. After obtaining the participants' informed consent, they were asked to complete the questionnaires. For patients with dyslexia, questionnaire items were read out one by one by the researchers, and then recorded their responses. All questionnaires were collected on the spot and checked for effectiveness.

### General characteristics

This questionnaire assessed participants' age, gender, ethnicity, occupation, educational level, marital status, family relationships, disease duration, self-perceived severity of disease, medical fee payment method, and family income.

**Table 1. Inclusion and exclusion criteria of SLE patients.**

| | Inclusion Criteria | Exclusion Criteria |
|---|---|---|
| 1 | conformed to the SLE classification criteria as revised in 1997 by the American College of Rheumatology (ACR) | having disorders of consciousness and communication |
| 2 | hospitalized for at least a week | using psychotropic drugs such as antidepressants and tranquilizers |
| 3 | being able to communicate and comprehend the questionnaires | having neuropsychiatric SLE |
| 4 | provided their written informed consent, or from parents/ guardians for minors | having severe dyslexia caused by SLE |

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### Mishel Uncertainty in Illness Scale (MUIS)

This is a contains 33-item scale and measures the four dimensions of illness uncertainty, including unpredictability, complexity, ambiguity, and lack of information. The 15th item is not attributed to any dimension; and hence, it was not included in the final results. The total score of the MUIS ranges from 32 to 160, and was defined as 3 levels. The range of 32 to 74.7 was defined as low level, 74.8 to 117.4 as moderate level, 117.5 to 160 as high level, and higher scores indicating a higher degree of uncertainty in illness[18]. The Cronbach's alpha of the scale was 0.865 and the content validity index (CVI) was 0.92 [19].

### Social Support Rating Scale (SSRS)

This is a 10-item scale and is divided into 3 subscales: objective support, subjective support, and social support availability. The total score ranges from 12 to 60, and higher scores indicate better social support [20]. The Cronbach's alpha coefficient of the scale was 0.814.

### Medical Coping Modes Questionnaires (MCMQ)

The questionnaire contained 20 items in 3 subscales: facing, avoiding, and yielding. The Cronbach's alpha coefficient of the scale was 0.69, 0.60 and 0.76. Higher scores indicated that the patient was more likely to choose the coping mode [21].

### Statistical analysis

The software package EpiData 3.1 (EpiData Entry version, Denmark) was employed to conduct double entry verification of the collected data and analyzed with PASW Statistics 18.0. (SPSS Inc., Chicago, IL). Continuous data were expressed as means ± SD ($\bar{x} \pm s$), while categorical data were expressed as numbers and percentages (%).Demographic characteristics were compared between the groups using one-way analysis (ANOVA) of variance and differences within each group were compared using multivariate analysis of variance. The date of two groups were compared using independent sample *t*-test to detect the significance. Linear correlation between the variables was assessed by Spearman correlation test. A significance level of $P < 0.01$ was considered to be statistically significant in multiple testing and a significance level of $P < 0.05$ was considered statistically significant in other analysis.

## Results

### General characteristics

During the study period, total of 268 SLE patients were admitted to the hospital. According to the inclusion and exclusion criteria, 236 patients were enrolled in the study. These patients were numbered according to their admission sequence, and 210 hospitalized patients with SLE were randomly selected by using a random number table. A total of 210 questionnaires were distributed among the patients. Seven people signed the informed consent of the questionnaires but refused to fill in the questionnaires were removed from the total number of the study. Of the 203 patients, 3 hospitalized female patients submitted invalid questionnaires as less than 20% of total survey projects were finished. The proportion of missing data in the study was less than 5%. The patients who completed the questionnaires showed no significant differences between the groups in age, disease duration, educational level, marital status, and medical fee payment method.

Majority of the hospitalized patients with SLE were female and from Shaanxi Province. The age of the patients ranged from 13 to 74 years old, and the average age was 38.27±13.51. All the patients belonged to the Han ethnicity. The specific results are shown in Table 2.

**Table 2. Differences in the MUIS scores across each demographic characteristics among SLE patients*.**

| Characteristics | SLE Patients (n = 200) | MUIS Scores | P-Value** |
|---|---|---|---|
| **Gender, n(%)** | | | 0.966 |
| **Male** | 23 (11.50) | 97.19 ± 9.77 | |
| **Female** | 177 (88.50) | 97.08 ± 11.62 | |
| **Marital Status, n(%)** | | | 0.044 |
| **Unmarried** | 47 (23.50) | 93.15 ± 12.59 | |
| **Married** | 140 (70.00) | 98.23 ± 11.00 | |
| **Divorced, separated or widowed** | 13 (6.50) | 98.60 ± 8.08 | |
| **Educational level, n(%)** | | | <0.001§ |
| **Primary school and below** | 18 (9.00) | 100.87 ± 7.29 | |
| **Junior middle school** | 58 (29.00) | 100.62 ± 9.52 | |
| **Senior high school or special middle school** | 56 (28.00) | 97.33 ± 10.28 | |
| **Junior College** | 33 (16.50) | 95.46 ± 10.98 | |
| **Bachelor degree or above** | 35 (17.50) | 90.94 ± 14.72 | |
| **Work status, n(%)** | | | 0.600 |
| **Full-time** | 90 (45.00) | 96.21 ± 12.84 | |
| **Part-time** | 10 (5.00) | 96.50 ± 11.91 | |
| **Retired or unemployed** | 100 (50.00) | 97.99 ± 9.84 | |
| **Family relationship, n(%)** | | | 0.929 |
| **Good** | 163 (81.50) | 96.96 ± 11.54 | |
| **Common** | 32 (16.00) | 97.88 ± 11.09 | |
| **Bad** | 5 (2.50) | 96.75 ± 9.81 | |
| **Disease duration (years), n(%)** | | | 0.292 |
| **<1** | 67 (33.50) | 98.15 ± 10.98 | |
| **1–5** | 68 (34.00) | 97.20 ± 11.58 | |
| **6–10** | 32 (16.00) | 93.23 ± 10.77 | |
| **>10** | 33 (16.50) | 98.10 ± 12.13 | |
| **Self-perceived severity of disease, n(%)** | | | 0.012 |
| **Very severe** | 70 (35.00) | 100.53 ± 9.54 | |
| **Severe** | 101 (50.50) | 95.67 ± 11.59 | |
| **Less severe** | 29 (14.50) | 93.96 ± 13.09 | |
| **Payment of medicine, n(%)** | | | 0.048 |
| **Full or part of public funds/insurance** | 8 (4.00) | 95.63 ± 5.29 | |
| **Medicare or social security** | 94 (47.00) | 94.96 ± 12.78 | |
| **NCMS** | 74 (37.00) | 100.24 ± 9.99 | |
| **Self-financed** | 24 (12.00) | 96.95 ± 9.01 | |
| **Family income (Yuan/month), n(%)** | | | 0.001♀ |
| **≤1,000** | 31 (15.50) | 101.78 ± 9.37 | |
| **1,001–2,000** | 55 (27.50) | 100.30 ± 10.26 | |
| **2,001–3,000** | 62 (31.00) | 96.00 ± 10.41 | |
| **≥3,001** | 52 (26.00) | 92.52 ± 12.78 | |

MUIS, Mishel Uncertainty in Illness Scale; NCMS, New rural Cooperative Medical System.

*Values are expressed as mean ± standard deviation unless otherwise specified.

**$P$ Values for the analysis was performed using one-way ANOVA test and a significance level of $P < 0.01$ was considered statistically significant.

§Five groups of educational level of hospitalized SLE patients with uncertainty of illness scores using multivariate analysis of variance of the $P$ values was <0.001.

♀Four groups of family income of hospitalized SLE patients with uncertainty of illness scores using multivariate analysis of variance of the $P$ values was 0.001.

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**Table 3. MUIS Total and Subscale Scores.**

| Items | Possible range in total score | Score Range | $\bar{x} \pm s$ |
|---|---|---|---|
| **Unpredictability** | 5–25 | 7–25 | 16.07 ± 3.05 |
| **Complexity** | 7–35 | 7–26 | 16.70 ± 2.88 |
| **Indeterminacy** | 13–65 | 18–59 | 41.79 ± 7.01 |
| **Lack of information** | 7–35 | 10–32 | 23.04 ± 4.48 |
| **Total** | 32–160 | 55–121 | 97.60 ± 11.24 |

MUIS, Mishel Uncertainty in Illness Scale.

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## Illness uncertainty

In 190 hospitalized patients (95%) with SLE, the MUIS scores were greater than 80. The mean score was 97.60 ± 11.24, indicating that majority of the patients had a moderate level uncertainty. The MUIS total and subscale scores are shown in Table 3.

## Comparison of illness uncertainty by demographic characteristics

We examined the influence of demographic characteristics on illness uncertainty using one-way analysis of variance. Results indicated that illness uncertainty in SLE patients differed significantly by educational level ($F = 4.492$, $P = 0.002$), and family income ($F = 5.978$, $P = 0.001$). In order to exclude the potential confounders in demographic factors, the five groups of educational level of hospitalized SLE patients with illness uncertainty scores using multivariate analysis of variance significantly differed ($F = 5.243$, $P<0.001$), and the four groups of family income of the SLE patients with illness uncertainty scores using multivariate analysis of variance also differed significantly. ($F = 5.578$, $P = 0.001$). All results are shown in Table 2.



## Social support

The SSRS scores of patients with SLE ranged from 17 to 58, with a mean of 39.32 ± 7.43. Table 4 presented a comparison of the SSRS scores in each subscale in our study with the Chinese norms [22]. The Chinese norm referred to social support scores in healthy people as measured by Chinese experts.

## Coping modes

A comparison of MCMQ scores in our study with the scores of general patients as reported by Shen [21] (norm) are shown in Table 5.

**Table 4. Comparison of Scores in each Dimension of Social Support between SLE Patients and Chinese Norm*.**

| Variables | SLE Patients (n = 200) | Norm (n = 307) | *P*—Value** |
|---|---|---|---|
| **Objective support** | 8.85 ± 3.17 | 12.68 ± 3.47 | <0.001 |
| **Subjective support** | 23.46 ± 4.99 | 23.81 ± 4.75 | 0.286 |
| **Support availability** | 7.01 ± 1.84 | 9.38 ± 2.40 | <0.001 |
| **Total** | 39.32 ± 7.42 | 44.34 ± 8.38 | <0.001 |

*Values are expressed as mean ± standard deviation unless otherwise specified.

**$P$ value were calculated using independent sample $t$-test to detect the significance.

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**Table 5. Comparison of MCMQ scores in Patients with SLE and Patient Norm from Shen*.**

| Variables | SLE Patients (n = 200) | Norm (n = 701) | *P* -Value** |
|---|---|---|---|
| **Facing** | 18.58 ± 3.36 | 19.97 ± 3.81 | <0.001 |
| **Avoiding** | 15.95 ± 3.50 | 14.44 ± 2.97 | <0.001 |
| **Yielding** | 9.30 ± 2.66 | 8.81 ± 3.17 | <0.001 |

MCMQ, Medical Coping Modes Questionnaires.

*Values are expressed as mean ± standard deviation unless otherwise noted.

***P* values were calculated using independent sample *t*-test to detect the significance.

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## Correlation of MUIS and SSRS scores

Spearman correlation analysis revealed that the total MUIS scores of patients with SLE were negatively correlated with support availability scores (Fig 1A, $r$ = -0.161, $P$ = 0.023). The indeterminacy and lack of information of MUIS also were negatively correlated with support availability score (Fig 1B and 1C, $r$ = -0.176, -0.152, $P$ = 0.013, 0.031), suggesting an increased support availability, and decreased illness uncertainty in patients with SLE.

## Correlation of MUIS and MCMQ scores

Spearman correlation analysis indicated that MUIS scores were negatively correlated with the coping modes of facing up the disease (Fig 2A, $r$ = - 0.231, $P$ = 0.001), and positively correlated with the yielding coping mode (Fig 2B, $r$ = 0.249, $P$ <0.001). In other words, illness uncertainty was increased in patients who tended to yield as a coping mode, but decreased in many patients who were engaged in facing up the disease.



# Discussion

## Main findings

Our findings demonstrated that the illness uncertainty of 200 hospitalized SLE patients under investigation was in moderate level. Unpredictable disease process and prognosis as well as unclear symptoms are the main sources of illness uncertainty, and educational level and family income are the major influencing factors. Our study indicated that most of the patients with high illness uncertainty were those with junior-senior high school education level and monthly income below 3000 yuan.

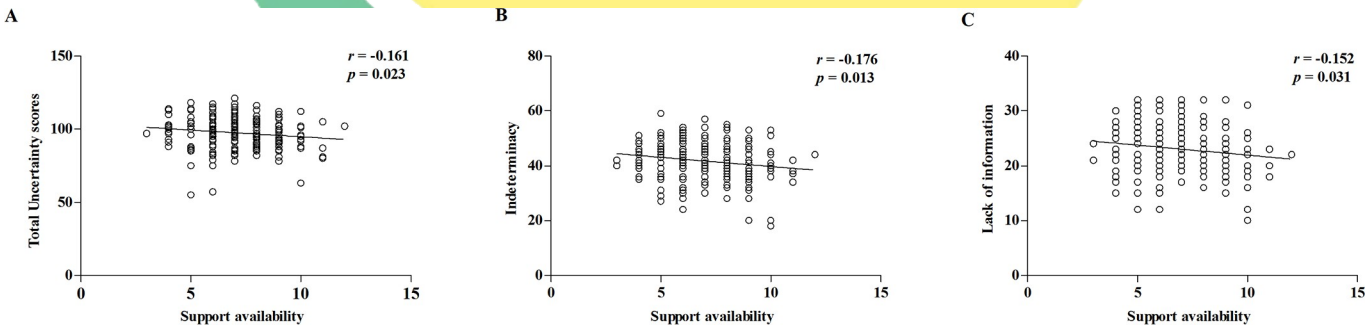


**Fig 1. Correlation of MUIS and SSRS scores.** (A): Support availability was negatively correlated with total MUIS scores of hospitalized patients with SLE. (B-C): Analysis of the sub-items in the MUIS and Social Support Scale showed a negative correlation between support availability and the indeterminacy and lack of information in the MUIS scale. The confounders as gender, marital status, educational level, disease duration, self-perceived severity of disease, payment of medicine and family income were adjusted during the analysis.

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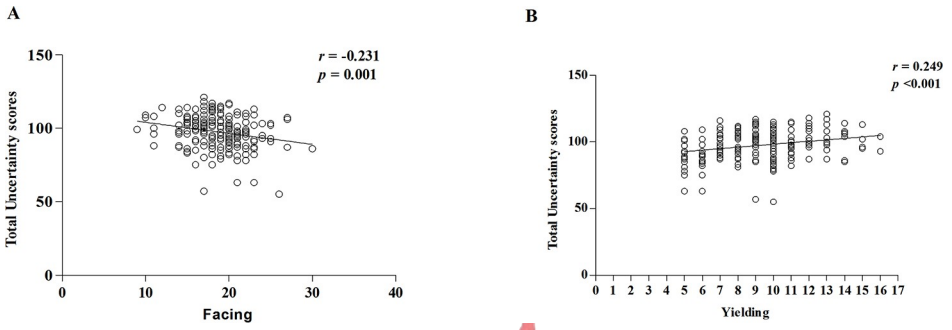


**Fig 2. Correlation of MUIS and MCMQ scores.** (A): Total uncertainty scores were negatively correlated with the coping modes of facing up the disease in the hospitalized patients with SLE. (B): Total uncertainty scores were positively correlated with the yielding coping mode. The confounders as gender, marital status, educational level, disease duration, self-perceived severity of disease, payment of medicine and family income were adjusted during the analysis.

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The 200 hospitalized SLE patients had lower social support score than that of Chinese healthy norm. The total scores of illness uncertainty, the scores of indeterminacy and lock of information were negatively correlated with support availability, suggesting that the hospitalized SLE patients had less social support. Thus, improved social support can possibly reduce the illness uncertainty of SLE patients.

Compared with general patients, hospitalized SLE patients had lower scores of facing, but higher scores of avoiding and yielding, indicating that the patients could not actively face the disease, but often show avoidance and yieldingness in response to the disease. Illness uncertainty was positively correlated with scores of yielding, but negatively correlated with facing. This suggested that there was a high possibility of hospitalized SLE patients to yielding when the scores of illness uncertainty were higher, and highly possible to facing when the scores of illness uncertainty were lower.

## Comparison to other studies

Illness uncertainty not only interfere the ability of seeking for relevant information in patients, but also influence the appropriate decision making under health care. Meanwhile, it may also cause anxiety in patients, influencing their mental adaptive ability, leading to decrease in quality of life, level of hope and disease response capacity, and further influencing rehabilitation process and quality of life [19,23]. The average score of illness uncertainty among the 200 SLE patients was 97.60±11.24, which was in moderate level. In the 4 dimensions, the scores of unpredictability and indeterminacy were relatively high, and scores of lack of information and complexity were relatively low, and these results were in line with Xu et al.'s study from China [15].

In our study, the total score of social support in SLE patients was lower than that of Chinese healthy norm, which was consistent with the results of previous studies [6, 18]. This might be due to the low family income in most of the SLE patients' families. Our study indicated that the families of SLE patients' with total monthly income lower than 4000 yuan accounted for 74%, the ratio of patients under new rural co-operative medical system and self-supporting was 49%, and the medical reimbursement ratio of patients under new rural co-operative medical system during hospitalization was 50%. Some of the therapeutic drugs belong to the limited medical insurance reimbursement. SLE is a rheuma immune systemic chronic disease, and so the patients need long-term persistent medication. The economic support from family and

society are limited, and patients cannot persistently afford the huge medical costs, leading to the decreased objective support. SLE was highly evident in female population of child-bearing period, which remains important stage for most of the patients attending school, trying to get a job and planning to build a family, and also the key stage for those who need to take family responsibility. However, the disease conditions of these patients are chronic and persistent, and so, long-term medication is needed. Thus, the patients had no normal ability of working, living or giving birth to babies, the physical and social function is limited, and the economic and family status were also reduced [24,25]. Furthermore, our study included SLE patients with high school education or below, accounting for 66%, and so, the approaches of looking for help were limited. The feeling of control on live and disease-related issues was reduced, so that they could not actively ask for help from social support and fully use the social resource, leading to the decrease in objective support and support availability. Mishel [26] believed that social support was one of the important factors that predict the illness uncertainty, and social support could directly influence the indeterminacy, complexity and unpredictability of illness uncertainty factors. Our study showed that utilization of support had negative correlation with illness uncertainty in hospitalized SLE patients. Although our results were not consistent with Mishel's study, similar results were shown in other diseases, such as cancer [27] and diabetes [28], indicating that it was associated with population and racial differences. Results of Wei et al [29] study also proved that good social support and its utilization degree could help decrease the illness uncertainty of patients. He et al. [20] study proved that the higher the support availability was, the lower the illness uncertainty would be.

Compared with Shen et al.'s study [21], the score of active facing disease of the hospitalized SLE patients was lower, but the scores of avoiding and yielding were significantly increased. The possible reason for this is that SLE is a chronic and persistent disease and its clinical course is usually unpredictable, with exacerbations and periods of remission. The mental health in SLE appeared to be influenced by perceived stress, disease duration, disease activity and cumulative organ damage [30]. Depression and anxiety were common in "non-NPSLE" [31]. During the long-term therapy of the disease, there lacked understanding and confidence, and hence, the patients could not face the influence of disease and therapy on study, work and live correctly. Especially under weak self-willpower or insufficient external support, patients often give up on themselves, bow to the inevitable or unwillingly face the reality. Furthermore, they may accept the negative influence subconsciously to seek the way out of disease, when they are unable to find a way out [26]. Our study showed that illness uncertainty had negative correlation with the coping modes of facing, but had positive correlation with yielding coping mode, which was in line with the results of Huang et al.'s study [32]. This suggested that the illness uncertainty might decrease if the SLE patients actively face the reality, communicate with medical staff, and obtain the disease-related knowledge by various ways. If the patients lose confidence on their disease and health, the yieldingness to the disease, and care on the self-health will decrease. They in turn will stop to look for relevant information of the disease, and become laissez-faire on the process and prognosis of the disease. Thus, the increased illness uncertainty possibly accelerates the development of the disease.

## Limitations of the study

The samples of our study were obtained from the SLE patients who were hospitalized over 1 week. Although the samples were representative of SLE, it still could not completely represent all the SLE patients. Objectively, the investigation was limited to manpower and financial resources and material resources, and so a multicentric study was not conducted. Also the sample size was limited.

## Clinical and research implications

In this study, 200 hospitalized SLE patients received illness uncertainty scale, social support rating scale and medical coping modes questionnaire. Results suggested that the illness uncertainty of the patients should receive more attention from the medical staff. During the diagnosis and treatment of the disease, the medical staff not only explore the patients by medical methods, but also pay attention to the influence of psychological, social and cultural factors on patients' disease. For disease evaluation, illness uncertainty, social support system and coping modes should be focused on. Different patients should be helped to fully use the existing and feasible social support system. All the available support system should be mobilized to encourage the patients to expand the society associates and participate in social activities, depending on the help from family members, friends, collages, work unit and organic groups. Thus, the patients can obtain help, support, understanding and respect in every aspect, and in turn can obtain maximum social support, with reduced illness uncertainty, and improved quality of life. Patients should be guided to avoid yielding, but face the disease with positive attitude, and actively coordinate the treatment to improve therapeutic compliance. Meanwhile, it also strengthens the community building, allocates the medical staff to guide the patients' health, fully play the role of family, encourage family members to participate in the care of the patients, making them feel concern and love from various aspects. Thus, hospital care is continuously conducted to decrease the depressive emotion of the patients with disease, promote healthy behavior, build nursing services that cover physiology, psychology, society and culture, and integrates hospital and community, achieving more effective and safer therapeutic effects.

## Conclusion

In summary, a moderate level illness uncertainty is common in hospitalized patients with SLE, which in turn influences the mental adaptation ability and the quality of life. Medical staff should pay full attention to patients' illness uncertainty, and help maximize their use of social support, as well as guide them in facing up their disease in order to reduce the uncertainty. This in turn improves the treatment compliance and quality of life of the patients.

## Author Contributions

**Data curation:** Xin Li, Jing Wang.

**Formal analysis:** Xin Li.

**Funding acquisition:** Mingxu Wang.

**Investigation:** Xin Li.

**Methodology:** Xin Li, Jing Wang.

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# Spiritual well-being and coping in scleroderma, lupus erythematosus, and melanoma

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## Summary

**Background and objectives:** Religious/spiritual (R-S) well-being is associated with greater vitality and lower depression scores. In this study, we investigated strategies for coping with disease and the role of religiosity/spirituality with respect to improving subjective well-being.

**Patients and methods:** One hundred and forty-nine patients (107 women), 44 of whom with systemic sclerosis (SSc), 48 with lupus erythematosus (LE), and 57 with stage I or II malignant melanoma (MM) were surveyed using a self-designed questionnaire, which addressed subjective well-being and disease-related circumstances, as well as the Multidimensional Inventory for Religious/Spiritual Well-Being (MI-RSWB).

**Results:** At the time of diagnosis, disease burden is greater in LE patients than in patients with SSc and MM. Only after several years are SSc and LE patients able to accept their disease. Compared with healthy individuals, the overall score of R-S well-being is significantly lower in LE patients. In LE, photosensitivity and joint pain are inversely correlated with the ability to forgive. SSc patients with facial lesions and pulmonary involvement show greater religiosity. MM patients display significantly higher values for transcendental hope.

**Conclusion:** Talks about the disease and psychological support are the most important needs of patients with SSc, LE, and MM. At present, programs aimed at improving R-S coping skills do not seem to play a significant role, but could be an important resource that should be addressed in the future.



## Introduction

Scleroderma (SSc) and lupus erythematosus (LE) are autoimmune disorders whose initial manifestations usually occur in early adulthood. While scleroderma is a chronic progressive disease, lupus is characterized by exacerbations and remissions. There is still no cure for either of these chronic diseases [1, 2]. Affecting individuals of all age groups, malignant melanoma (MM) is a potentially life-threatening disease with a recent increase in incidence [3, 4]. In patients with SSc, cold, impaired hand mobility, as well as difficulties swallowing and breathing have an impact not only on the physical but also on the psychological well-being [5]. In LE, photosensitivity has a negative impact on everyday life [6]. In both diseases, organ involvement, pain, fatigue, and skin lesions on exposed body parts result in diminished health-related quality of life (QoL) [7–10]. In MM, a reduced QoL is primarily caused by the psychological burden and only to a lesser extent by surgical interventions and various other therapies [4].

The biopsychosocial model of health and disease integrates biological, psychosocial, and socio-economic aspects of disease [11]. However, it fails to address certain aspects that may also play an important role. The WHO has defined the spiritual well-being as an important element of health [12, 13]. Some authors, for example, have proposed the spiritual component as an additional dimension [14]. Religiosity and spirituality (R-S) are becoming increasingly important in healthcare. Faith can play an important role in the disease acceptance and coping. Among others, various authors have examined the effect of R-S on patients with end-stage renal disease (ESRD) [15], chronic pain [16, 17], cancer [16–19], and depression [20, 21].

There are various definitions of R-S [22]. While religiosity is associated with institutions and traditions, spirituality is a broader concept without denominational borders [23]. The extent to which patients with chronic skin disorders exhibit this particular dimension of human existence has not yet been investigated.

The objective of our study was to examine the spiritual well-being in patients with SSc, LE, and MM. Using standardized and self-designed questionnaires, we aimed to ascertain whether R-S played a role in patients compared to healthy individuals. We also compared and contrasted the aforementioned diseases in this regard. Furthermore, we identified factors that play a part in disease acceptance and coping.

## Patients and Methods

Between March and October 2013, patients with SSc, LE, and MM were surveyed at our autoimmune and skin cancer clinic and day clinic using two questionnaires addressing everyday mood and spiritual well-being. The study was approved by the Ethics Committee of the Medical University of Graz.

A total of 242 patients were invited to participate; 182 individuals agreed to do so in writing. Because some patients did not return the questionnaires or filled them out incompletely, and one patient had to be subsequently excluded due to distant metastasis, the data of 149 patients (SSc [n = 44], LE [n = 48], MM [n = 57]) were eventually analyzed. Reasons for nonparticipation or drop-out also included the subjective perception that the questions were too burdensome or difficult to answer. Some patients reported that they were unable to answer the MI-RSB questions, because they had never considered such issues before.

Inclusion criteria were defined as a minimum age of 18, signed informed consent, and the presence of the following medical conditions: undifferentiated, limited or diffuse systemic sclerosis, primary Raynaud's phenomenon (RP) as possible initial manifestation of SSc, cutaneous and systemic LE, and stage IA-IIC MM. Exclusion criteria included metastatic MM and MM with sentinel lymph node involvement (stage III and IV MM), as well as other malignancies within the past five years.

Prior to the start of the study, a sample size estimation according to Cohen 1992 [24] was conducted. Accordingly, variance analysis with three different groups requires at least 322 individuals per group in order to be able to calculate small differences; 52, for moderate differences; and 21, for large differences. Thus, the number of patients at our department merely allowed for the identification of large differences.

The Le Roy criteria were used as diagnostic criteria for SSc [25]. Cutaneous LE was classified according to the Düsseldorf criteria [26], and SLE according to the criteria of the American College of Rheumatology (ACR) [27, 28]. Disease activity in LE was measured using the CLASI score [29]; in SSc, using the Rodnan skin score (RSS) [30]. MM patients had histologically proven stage I and II disease. Clinical data was documented by case report forms (CRF).

Using indirect personal information (ID number), the evaluation was done with the statistical program SPSS.21. Nominal variables of sociodemographic data were analyzed for significance ($p > 0.05$) using the chi-square test; the metric variable 'age', using monofactorial variance analysis. Differences in the R-S well-being (including subscales) between the standard sample and the three disease groups were calculated by means of multivariate variance analysis. Correlations between the clinical data of SSc and LE patients and the R-S well-being were examined using Pearson's correlation coefficient.

### Questionnaires

The patients enrolled in the study completed two questionnaires either independently or assisted by two senior students: a self-designed questionnaire on subjective well-being and coping strategies as well as the Multidimensional Inventory for Religious/Spiritual Well-Being (MI-RSB). The health-related quality of life (HRQL) was measured using the Short Form 36 (SF-36) [31], but is not subject of this article.

The self-designed questionnaire aims to get a general overview of the socio-demographic data and life circumstances of the study participants. Among others, it includes questions on age, education, marital status, disease duration, and religious denomination as well as on disease symptoms and the burden resulting from the diagnosis. It also contains questions about whom patients turn to when seeking consolation and support, how they deal with stigmatization, and what strategies and programs they deem helpful in coping with their illness.

The MI-RSB is a validated questionnaire for the evaluation of R-S well-being. It has been used in psychiatric patients

with affective, neurotic, and somatoform disorders or stress disorders [32]. With regard to the Austrian general population, age and gender-specific normal values have been developed [33]. The MI-RSB consists of six subscales, three relating to the immanent sphere (biopsychosocial), the other three to the transcendental sphere (religious and spiritual). Each subscale contains eight questions, which are answered using a Likert scale. The subscales of the immanent sphere include "Hope Immanent" ("I look to the future with optimism"), "Forgiveness" ("There are things that I cannot forgive"; reverse coding) and "Experiencing Meaning and Sense" ("I have experienced the authenticity of feelings"). The subscales of transcendental sphere include "Hope Transcendental" ("I often think that I have to leave my loved ones behind"; reverse coding), "General Religiosity" ("My faith gives me a sense of security"), and "Interconnectedness" ("I have had an experience in which my person seems to be taken up in something greater").

Adding up the various subscales subsequently yields information about the R-S well-being. The maximum score for each subscale is 48; overall, a maximum score of 288 points can be achieved. Cronbach's alpha is 0.89 for MI-RSB, and at least 0.7 for each individual subscale [33–35].

## Results

### Patients, disease acceptance, and disease burden

Of the 149 patients surveyed, 44 had SSc; 48, LE; and 57, MM. Most SSc patients (59 %) had the limited form of SSc; 16 %, diffuse systemic sclerosis; 14 %, the undifferentiated variant; and 11 %, primary RP (Table 1). Fifty percent had fingertip ulcers/scarring; 39 %, joint involvement; 36 %, pulmonary involvement; and 34 %, involvement of the esophagus. At the time of the survey, the majority of patients had either stable (67 %) or improved (26 %) disease.

Seventy-one percent of LE patients displayed the cutaneous form of LE, with 38 % affected by the chronic discoid type (CDLE). Regarding ACR criteria, 79 % of patients had photosensitivity; 46 %, characteristic skin lesions; and 31 %, non-erosive arthritis. The face, arms, and décolleté were most commonly affected.

More than one-third of MM patients had stage 1A disease. Thirty-four patients (62 %) had undergone sentinel lymph node dissection without any evidence of metastasis. Nine patients (16 %) were receiving interferon therapy, with flu-like symptoms (83 %) being the most common side effect (fatigue, 67 %; depression, 33 %).

Compared to MM patients (51 %), the percentage of women was significantly higher among SSc (84 %) and LE (85 %) patients. The average age showed a similar distribution (Table 2). There were significant differences regarding disease duration among the various disease groups. SSc and MM patients were more frequently married or in a stable relationship than LE patients (SSc 74 %; MM 75 %; LE 65 %) and also significantly more likely to have children. SSc patients were more commonly committed to a denomination (93 %) than LE (77 %) and MM patients (80 %).

While the majority of SSc (72 %) and LE patients (74 %) were able to come to terms with their disease within one year, MM patients were able to do so within three months. Compared to MM patients, a significantly greater percentage of LE patients were confronted with a very large disease burden when informed about their diagnosis (LE 49 % vs. MM 25 %) (SSc 31 %) (Figure 1). At the time of the survey, however, most patients experienced a low to moderate burden (31 % of MM patients experienced no burden at all).

### Confrontation, ramifications, and living with the disease

Almost all patients considered it important to obtain detailed information about the disease, either through physicians or online. The main sources of support and comfort were partners or family (SSc 64 %, LE 62 %, and MM 74 %). The affected patients were comforted by detailed discussions about their disease, by display of physical affection such as hugs, and by shared activities (Table 3). Although not all patients reported that they had received consolation from the people around them, 100 % of LE, 95 % of MM and 81 % of SSc patients nevertheless felt that their relatives and family stood by them.

SSc and LE patients are primarily afraid of physical symptoms and pain as well as prolonged suffering in the future (SSc 73 %/54 %; LE 70 %/59 %). MM patients predominantly fear prolonged suffering and long hospital stays (54 %/36 %), with many of them also worried about their families (36 %). With respect to the future, the majority of SSc and LE patients hope to be able to live well with the disease (SSc 74 %, LE 81 %), and to be able to sooner or later accept it as part of life. In MM patients, the hope for a cure is paramount (82 %).

SSc and LE patients experience a significant impact of the disease on the relationship with their partners (SSc 24 %, LE 26 %, MM 8 %), characterized by tensions (SSc 30 %, LE 37 %, MM 2 %), intensification of the relationship (SSc 43 %, LE 34 %, MM 49 %), or breakups (SSc 8 %, LE 7 %, MM 0 %).

Vacation planning is a similarly difficult task in all three disease groups, among others marked by the fear that UV light, heat, or cold might be detrimental to health (SSc 21 %, LE 48 %, MM 25 %). In addition, 21 % of SSc and 12 % of LE patients exhibit severe fatigue, making a vacation away from home too strenuous. Relaxing during a vacation is deemed very important (SSc 57 %, LE 60 %, MM 62 %).

**Table 1** Patient characteristics.

| SSc (n = 44) | | LE (n = 48) | | MM (n = 57) | |
|---|---|---|---|---|---|
| **Classification** | **Number (%) RSS (min.–max.)** | **Classification** | **Number (%)** | **Classification** | **Number (%)** |
| Primary Raynaud's phenomenon | 5 (11 %)<br>0 | Acute cutaneous lupus erythematosus (butterfly rash) | 0 | Stage 0 | 2 (4 %) |
| Raynaud's phenomenon, positive antibodies | 6 (14 %)<br>3 (0–6) | Subacute cutaneous lupus erythematosus | 8 (17 %) | Stage IA | 21 (37 %) |
| Limited systemic sclerosis | 26 (59 %)<br>4.9 (0–16) | Lupus erythematosus profundus | 2 (4 %) | Stage IB | 13 (23 %) |
| Diffuse systemic sclerosis | 7 (16 %)<br>17.4 (7–27) | Chronic discoid lupus erythematosus | 18 (38 %) | Stage IIA | 11 (19 %) |
| | | Chilblain lupus erythematosus | 2 (4 %) | Stage IIB | 8 (14 %) |
| | | Tumid lupus erythematosus | 4 (8 %) | Stage IIC | 2 (4 %) |
| | | Systemic lupus erythematosus | 14 (29 %) | Sentinel node examined | 34 (62 %) |
| *Clinical findings* | | *Location* | | *Location* | |
| Finger ulcers/scars | 21 (50 %) | Scalp | 5 (10 %) | Face | 8 (15 %) |
| Raynaud's phenomenon | 42 (96 %) | Face | 29 (60 %) | Extremities | 29 (53 %) |
| Facial telangiectasia | 11 (26 %) | Décolleté | 16 (33 %) | Trunk | 17 (31 %) |
| Microstomia | 12 (29 %) | Back | 11 (23 %) | Buttocks | 1 (2 %) |
| Finger contractures | 6 (14 %) | Upper extremities | 27 (56 %) | | |
| Puffy fingers | 28 (65 %) | Lower extremities | 4 (8 %) | | |
| | | Oral mucosa | 3 (6 %) | | |
| *Organ involvement* | | *ACR Criteria* | | | |
| Lungs (PAH/fibrosis) | 16 (36 %) | ≥ 4 | 14 (29 %) | | |
| Esophagus | 15 (34 %) | Cytopenia | 14 (29 %) | | |
| Heart | 0 | dsDNA antibodies, antiphospholipid antibodies | 14 (29 %) | | |
| Kidneys | 1 (2 %) | Butterfly rash | 2 (4 %) | | |
| Joints | 17 (39 %) | CDLE lesions | 22 (46 %) | | |
| | | Photosensitivity | 38 (79 %) | | |
| *Lab tests* | | Mouth ulcers | 10 (21 %) | | |
| Antinuclear antibodies | 31 (71 %) | Nonerosive arthritis | 15 (31 %) | | |
| CENP antibodies | 14 (41 %) | Serositis | 1 (2%) | | |
| Scl70 antibodies | 8 (25 %) | Kidney involvement | 2 (4%) | | |
| Other antibodies | 8 (24 %) | Central nervous system | 1 (2%) | | |
| | | Antinuclear antibodies | 21 (33%) | | |

*Abbr.*: SSc, scleroderma; LE, lupus erythematosus; MM, malignant melanoma; RSS, Rodnan Skin Score; PAH, pulmonary arterial hypertension; ACR, American College of Rheumatology; CDLE, chronic discoid lupus erythematosus; CENP, centromere protein; dsDNA, double-stranded DNA.
Percent = valid percent.

**Table 2** Sociodemographic data.

| | | SSc | LE | MM | Total | P value |
|---|---|---|---|---|---|---|
| | | Number (%) | Number (%) | Number (%) | Number (%) | P |
| Gender | *Female* | 37 (84 %) | 41 (85 %) | 29 (51 %) | 107 (72 %) | *0.01 |
| | *Male* | 7 (16 %) | 7 (15 %) | 28 (49 %) | 42 (28 %) | |
| Age (years) | *Mean (min.–max.)* | 55 (23–80) | 50 (24–78) | 56 (23–80) | 54 (23–80) | n.s. |
| Disease duration (years) | *< 1* | 4 (9 %) | 0 (0 %) | 27 (47 %) | 31 (21 %) | *0.01 |
| | *> 1* | 6 (14 %) | 17 (35 %) | 17 (30 %) | 40 (27 %) | |
| | *> 5* | 20 (46 %) | 9 (19 %) | 6 (11 %) | 35 (24 %) | |
| | *> 10* | 14 (32 %) | 22 (46 %) | 7 (12 %) | 43 (29 %) | |
| Marital status | *Married/stable relationship* | 32 (74 %) | 31 (65 %) | 43 (75 %) | 106 (72 %) | 0.42 |
| Children | *Yes* | 34 (77 %) | 31 (65 %) | 49 (86 %) | 114 (77 %) | *0.05 |
| | *Minors* | 8 (18 %) | 10 (21 %) | 11 (20 %) | 29 (20 %) | |
| Education | *Compulsory school* | 22 (73 %) | 22 (69 %) | 39 (72 %) | 83 (72 %) | 1.00 |
| | *High school certificate* | 5 (17 %) | 6 (19 %) | 9 (17 %) | 20 (17 %) | |
| | *University degree* | 3 (10 %) | 4 (13 %) | 6 (11 %) | 13 (11 %) | |
| Denomination | *With denomination* | 40 (93 %) | 36 (77 %) | 46 (81 %) | 122 (83 %) | 0.10 |
| | *Without denomination* | 3 (7 %) | 11 (23 %) | 11 (19 %) | 25 (17 %) | |

*Abbr.*: SSc, scleroderma; LE, lupus erythematosus; MM, malignant melanoma; *significant; n.s., non- significant



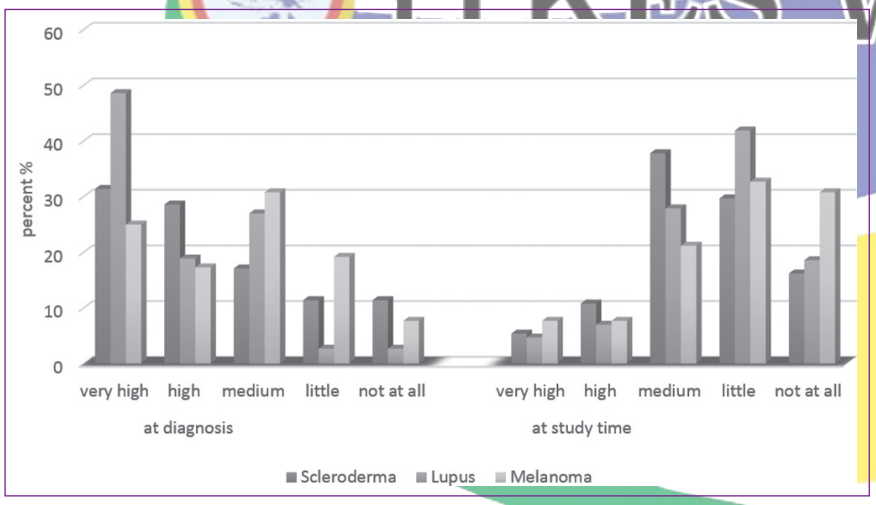


**Figure 1** Disease burden significant (p = 0.02), in post hoc testing, lupus erythematosus > malignant melanoma.

## Social stigma

Stigma plays an important role especially for LE patients. Nearly one-half (48 %) of those affected fear that their disease could be repulsive to others. While more than one-quarter (26 %) of SSc patients are confronted with such fears and reactions, stigma plays practically no role in MM patients (7 %) (Table 4). The majority of SSc and LE patients are able to either ignore the stares (SSc 42 %, LE 63 %) or respond with a smile (SSc 58 %, LE 50 %).

## Coping strategies

Coping strategies used by the majority of patients include a trip into nature (SSc 77 %, LE 63 %, MM 63 %), followed by hobbies such as listening to music or playing an instrument,

**Table 3** Consolation.

| | | SSc | LE | MM | Total |
|---|---|---|---|---|---|
| | | Number (%) | Number (%) | Number (%) | Number (%) |
| Who offered you consolation? | *Nobody* | 8 (18 %) | 3 (6 %) | 3 (5 %) | 14 (10 %) |
| | *Partner* | 28 (64 %) | 29 (62 %) | 42 (74 %) | 99 (67 %) |
| | *Siblings* | 15 (34 %) | 21 (45 %) | 20 (35 %) | 56 (38 %) |
| | *Parents* | 13 (30 %) | 26 (55 %) | 18 (32 %) | 57 (39 %) |
| | *Children* | 21 (48 %) | 19 (40 %) | 28 (49 %) | 68 (46 %) |
| | *Friends* | 21 (48 %) | 26 (55 %) | 24 (42 %) | 71 (48 %) |
| | *Acquaintances* | 10 (23 %) | 11 (23 %) | 9 (16 %) | 30 (20 %) |
| | *Support group* | 4 (9%) | 5 (11 %) | 0 | 9 (6 %) |
| What kind of consolation? | *Hugging* | 15 (34 %) | 23 (52 %) | 19 (33 %) | 57 (39 %) |
| | *Conversation* | 36 (82 %) | 40 (91 %) | 53 (93 %) | 129 (89 %) |
| | *Invitation* | 8 (18 %) | 8 (18 %) | 5 (9 %) | 21 (15 %) |
| | *Shared activity* | 19 (43 %) | 17 (39 %) | 16 (28 %) | 52 (36 %) |

*Abbr.*: SSc, scleroderma; LE, lupus erythematosus; MM, malignant melanoma.
Question 1: SSc (n = 44), LE (n = 46), MM (n = 56), total (n = 146)
Question 2: SSc (n = 36), LE (n = 43), MM (n = 53), total (n = 132)

**Table 4** Stigmatization caused by the disease.

| | | SSc | LE | MM | Total |
|---|---|---|---|---|---|
| | | Number (%) | Number (%) | Number (%) | Number (%) |
| Are you afraid your skin disease might be repulsive to others? | Yes | 11 (26 %) | 21 (48 %) | 4 (7 %) | 36 (25 %) |
| | No | 31 (74 %) | 23 (52 %) | 52 (93 %) | 106 (75 %) |
| Do you have the feeling that people stare at you? | Yes | 12 (29 %) | 18 (41 %) | 2 (4 %) | 32 (22 %) |
| | No | 30 (71 %) | 26 (59 %) | 55 (97 %) | 111 (78 %) |
| If yes, what's your reaction? | I look away. | 3 (25 %) | 1 (6 %) | 0 | 4 (13 %) |
| | I am annoyed. | 1 (8 %) | 3 (19 %) | 0 | 4 (13 %) |
| | I smile. | 7 (58 %) | 8 (50 %) | 0 | 15 (50 %) |
| | I ignore it. | 5 (42 %) | 10 (63 %) | 2 (100 %) | 17 (57 %) |

*Abbr.*: SSc, scleroderma; LE, lupus erythematosus; MM, malignant melanoma.

singing, or reading (Table 5). Religious coping strategies such as praying and attending church services seem to have more meaning for SSc patients (23 % and 14 %, respectively) than for those with LE and MM (LE 13 %/4 %, MM 7 %/7 %). Overall, 14 % of SSc, 4 % of LE, and 5 % of MM patients resort to meditation to find inner peace. All three disease groups consider information about the disease, roundtables, and psychological support (among others) important (Table 6). Fourteen percent of LE patients show an interest in R-S programs (SSc 9 %, MM 5 %).

## Multidimensional inventory of religious-spiritual well-being

Compared with the general population, SSc and MM patients have a similar total score with respect to religious and

**Table 5** Activities offering comforting and distraction.

| | SSc | LE | MM | Total |
|---|---|---|---|---|
| | Number (%) | Number (%) | Number (%) | Number (%) |
| Trips into nature | 33 (77 %) | 29 (63 %) | 35 (63 %) | 97 (67 %) |
| Music | 29 (67 %) | 25 (54 %) | 31 (55 %) | 85 (59 %) |
| Cinema, television | 26 (61 %) | 26 (57 %) | 22 (39 %) | 74 (51 %) |
| Reading | 24 (56 %) | 29 (63 %) | 20 (36 %) | 73 (50 %) |
| Gardening | 17 (40 %) | 21 (46 %) | 22 (39 %) | 60 (41 %) |
| Traveling | 20 (47 %) | 14 (30 %) | 17 (30 %) | 51 (35 %) |
| Wining and dining | 17 (40 %) | 21 (46 %) | 10 (18 %) | 48 (33 %) |
| Pets | 12 (28 %) | 21 (46 %) | 13 (23 %) | 46 (32 %) |
| Sports | 12 (28 %) | 6 (13 %) | 20 (36 %) | 38 (26 %) |
| Cooking | 17 (40 %) | 9 (20 %) | 10 (18 %) | 36 (25 %) |
| Handicraft, painting, needlework | 8 (19 %) | 12 (26 %) | 11 (20 %) | 31 (21 %) |
| Theater, opera | 9 (21 %) | 9 (20 %) | 4 (7 %) | 22 (15 %) |
| Praying | 10 (23 %) | 6 (13 %) | 4 (7 %) | 20 (14 %) |
| Cleaning, tidying up | 7 (16 %) | 7 (15 %) | 5 (9 %) | 19 (13 %) |
| Church service | 6 (14 %) | 2 (4 %) | 4 (7 %) | 12 (8 %) |
| Meditation | 6 (14 %) | 2 (4 %) | 3 (5 %) | 11 (8 %) |
| Club membership, charity work | 4 (9 %) | 2 (4 %) | 5 (9 %) | 11 (8 %) |
| Alcohol, smoking | 2 (5 %) | 4 (9 %) | 3 (5 %) | 9 (6 %) |
| Fasting | 0 | 1 (2 %) | 1 (2 %) | 2 (1 %) |
| Other | 6 (14 %) | 5 (11 %) | 7 (13 %) | 18 (12 %) |

*Abbr.*: SSc, scleroderma; LE, lupus erythematosus; MM, malignant melanoma.
SSc (n = 43), LE (n = 46), MM (n = 56), total (n = 145)

spiritual well-being (Table 7). However, they achieve significantly lower scores in the subscale "Experiencing Meaning and Sense". By contrast, LE patients have a significantly lower overall score than the normal population. On the other hand, they show higher sores in "Forgiveness" and similar values regarding "Hope Transcendental" as the general population. MM patients display significantly lower scores in the subscales "Experiencing Meaning and Sense", "General Religiosity" and "Interconnectedness", but significantly higher scores in the subscales "Forgiveness" and "Hope Transcendental".

As for the total score and the subscales of the MI-RSB, the differences found related to individual disease symptoms (Table 8). Given that we expected a significant effect on the MI-RSB in SSc patients with pulmonary involvement, the level of significance in the analysis was raised from 5 % to 10 %. SSc patients with facial lesions or lung involvement showed significantly higher scores in the subscale "General Religiosity".

In LE patients with photosensitivity and joint pain, significantly lower scores were observed in the subscale "Forgiveness". On the other hand, patients with joint pain display significantly high values in the subscale "General Religiosity". Unlike SSc patients, disease activity in LE patients does have an impact on the MI-RSB and shows a negative correlation with overall R-S well-being.

Apart from the Rodnan score in SSc and the CLASI score in LE, we divided the various disorders into subgroups according to disease severity. There were three groups of SSc patients: Raynaud's phenomenon and undifferentiated SSc, limited SSc, and diffuse SSc. LE patients were divided into cutaneous LE and SLE, and MM patients into those with or without sentinel lymph node dissection. Here, we observed no significant correlation between disease severity and the

**Table 6** Things patients may find helpful.

| | SSc | LE | MM | Total |
|---|---|---|---|---|
| | Number (%) | Number (%) | Number (%) | Number (%) |
| Lecture/talk | 21 (60 %) | 15 (42 %) | 17 (43 %) | 53 (48 %) |
| Group discussions | 12 (34 %) | 13 (37 %) | 13 (33 %) | 38 (35 %) |
| Psychological support | 7 (20 %) | 11 (31 %) | 9 (23 %) | 27 (24 %) |
| Music therapy | 9 (26 %) | 5 (14 %) | 9 (23 %) | 23 (21 %) |
| Meditation | 9 (26 %) | 6 (17 %) | 6 (15 %) | 21 (19 %) |
| Support group | 10 (29 %) | 7 (19 %) | 2 (5 %) | 19 (17 %) |
| Volunteer work | 3 (9 %) | 2 (6 %) | 7 (18 %) | 12 (11 %) |
| Religious/spiritual programs | 3 (9%) | 5 (14 %) | 2 (5 %) | 10 (9 %) |
| Church service, prayers | 5 (14 %) | 2 (6 %) | 4 (10 %) | 11 (10 %) |
| Pastor | 3 (9 %) | 2 (6 %) | 1 (3 %) | 6 (5 %) |
| Social worker | 2 (6 %) | 2 (6 %) | 0 | 4 (4 %) |
| Parish activities | 1 (3 %) | 0 | 2 (5 %) | 3 (3 %) |
| Family support worker | 0 | 1 (3 %) | 0 | 1 (1 %) |
| Other | 2 (6 %) | 8 (22 %) | 2 (5 %) | 12 (11 %) |

*Abbr.*: SSc, scleroderma; LE, lupus erythematosus; MM, malignant melanoma.



total score of the MI-RSB or its subscales (data not shown in tabular form).

Using MANCOVA, the influence of the three disease groups and a control variable (religious denomination: yes/no) on the total score of the MI-RSB and its six sub-scales was investigated. The results revealed that individual disease groups differed significantly with respect to religious-spiritual well-being and the subscales of the MI-RSB ($F = 1.98$, $p < 0.05$)

## Discussion

The present study shows that, at the time of diagnosis, LE and SSc patients in particular feel greatly burdened. Only after many years are they able to come to terms with their disease, whereas the majority of MM patients do so after merely three months. Only 65 % of LE patients are in stable relationships, compared to 75 % of SSc and MM patients. A study by the German LE Support Group (LULA Study) has shown that a spouse or a long-term partner has a positive impact on the mental and physical quality of life [36]. Compared with other chronic dermatological disorders such as psoriasis or atopic dermatitis, patients with LE and SSc generally have the poorest quality of life [8].

Conversations are deemed most important by the surveyed patient group, followed by hugs and shared activities. However, sixteen percent of SSc patients do not derive any consolation from the people around them. A possible reason for this could be that relatives and acquaintances have difficulties grasping the true extent of the disease.

Patients use both active coping strategies such as trips into nature, caring for their pets, gardening, sports, and craft activities, or playing an instrument, as well as passive strategies such as going to movies, watching TV, and listening to music. Listening to talks about the disease, reading, and support groups are also relevant factors. Spiritual activities such as praying, attending church services, religious and spiritual seminars, or meditation play no significant part in disease coping.

Recent studies in SSc patients have shown that the doctor-patient rapport is crucial [37, 38]. Important aspects in coping include disease acceptance, focusing on positive aspects of life, humor, but also faith [38]. By analyzing patient descriptions about their experience, McElhone et al. were able to ascertain the following important aspects: prognosis, disease course, physical appearance, inability to make life plans due to the unpredictability of the disease, and socio-economic factors [39].

Three-quarters of our LE patients had purely cutaneous lupus, 60 % of whom also had facial lesions. The altered appearance leads to embarrassment and discrimination,

**Table 7** Religious/spiritual well-being of patients compared to the general population.

| | N | | SSc | | LE | | MM | | F | P value | post |
|---|---|---|---|---|---|---|---|---|---|---|---|
| | M | SD | M | SD | M | SD | M | SD | | | |
| Religious/spiritual well-being (total score) | 194.44 | 31.70 | 189.02 | 33.01 | 183.64 | 26.35 | 187.46 | 30.11 | 2.94 | ≤ 0.05 | N = S, N = M, N > L |
| Hope immanent | 35.76 | 7.53 | 34.27 | 10.01 | 33.57 | 8.52 | 35.95 | 9,67 | 1.73 | n.s. | |
| Forgiveness | 34.66 | 9.27 | 35.32 | 9.36 | 38.60 | 6.32 | 38.86 | 7.58 | 6.47 | ≤ 0.01 | N = S, N < M, N < L |
| Experiencing meaning and sense | 37.75 | 6.78 | 35.57 | 8.06 | 35.43 | 7.52 | 33.67 | 8.83 | 9.05 | ≤ 0.01 | N > S, N > M, N > L |
| Hope transcendental | 30.39 | 8.15 | 32.09 | 7.87 | 32.09 | 6.88 | 33.96 | 7.31 | 4.66 | ≤ 0.01 | N = S, N = L, N < M |
| General religiosity | 28.73 | 12.26 | 26.89 | 11.55 | 20.85 | 11.69 | 23.39 | 12.60 | 9.67 | ≤ 0.01 | N = S, N > M, N > L, S > L |
| Interconnectedness | 27.15 | 8.95 | 24.48 | 10.59 | 22.98 | 9.40 | 20.84 | 8.39 | 12.86 | ≤ 0.01 | N = S, N > M, N > L, M < S |

*Abbr.*: N, healthy population; SSc(S), scleroderma; LE(L), lupus erythematosus; MM(M), malignant melanoma; n.s., non-significant.

flare-ups may cause social problems [40]. As a consequence of stigmatization, nearly one-half of the patients perceive their disease as repulsive. Verma et al. found no correlation between QoL and the severity of skin lesions (CLASI) [41]. In our LE patients, a high CLASI score correlated negatively with R-S well-being. It is known that appearance plays an important role in SSc patients; it has a significant effect on the incidence of depression and the quality of life [37, 38]. SSc patients are more preoccupied with their appearance than with the awareness that they might die from their disease [42].

Although spiritual and psychological well-being is strongly associated, the spiritual quality of life nevertheless has its own significance. Finding meaning and inner peace is more important with respect to QoL, ranking higher than existential and social factors [43]. In our study, "Experiencing meaning and Sense" was significantly reduced in all patients.

Kenneth Pargament defines religiosity or spirituality as a "search for meaning in ways related to the sacred" [22]. Patients have different views on religion and spirituality. Faith and religious experience cannot always be expressed in words [18, 44]. The WHO defines QoL as individual perception of the position in life, in the context of the culture and value system in which one lives, in terms of objectives, expectations, needs, and concerns [45]. The study by O'Connell KA has shown that spiritual QoL is not above all other aspects of QoL, but is rather an integral part of any kind of QoL [12]. Our SSc and MM patients displayed similar religious and spiritual well-being as the healthy population, whereas LE patients exhibited significantly poorer spiritual well-being. One reason for this may be the fact that almost one-quarter of that particular patient group was nondenominational, whereas 93 % of SSc and 80 % of MM patients associate with a religious community. Patients with SSc have a slowly progressive disease with potential organ involvement and deterioration over the course of years. Given its gradual onset, SSc initially goes unnoticed by other people. The changes in physical appearance but also dysphagia and dyspnea suggest that the disease is potentially life-limiting, which is reflected

**Table 8** Religious/spiritual well-being in relation to disease symptoms.

| | Scleroderma | | | | Lupus erythematosus | | | | |
|---|---|---|---|---|---|---|---|---|---|
| | | SL | | | Visible | Invisible | Photosen- | Joint | |
| | SL face | Hands | Lungs | RSS | SL | SL | sitivity | pain | CLASI |
| Total score RSWB | 0.06 | 0 | 0.21 | 0.16 | 0.14 | 0.10 | 0.14 | 0.22 | −0.25 |
| Existential well-being | | | | | | | | | |
| *Hope immanent* | −0.13 | −0.07 | 0.10 | 0.09 | 0.01 | 0.13 | 0.11 | −0.09 | −0.19 |
| *Forgiveness* | 0.17 | 0.25 | 0.05 | 0.26 | 0.07 | −0.07 | ***−31** | ***−0.29** | −0.10 |
| *Experiencing meaning and sense* | −0.20 | −0.20 | 0.08 | 0.03 | 0.70 | 0.18 | 0.17 | 0.21 | −0.04 |
| Religious well-being | | | | | | | | | |
| *Hope transcendental* | 0.02 | −0.02 | −0.01 | 0.21 | −0.06 | 0.14 | 0.02 | −0.10 | −0.02 |
| *General religiosity* | ***0.32** | −0.07 | ***0.28** | 0.07 | 0.22 | −0.13 | 0.19 | ***0.38** | −0.22 |
| *Interconnectedness* | 0.12 | −0.01 | 0.15 | −0.06 | 0.17 | 0.07 | 0.15 | 0.24 | −0.02 |

*Abbr.*: RSWB, religious/spiritual well-being; SL, skin lesions; RSS, Rodnan Skin Score; CLASI, Cutaneous Lupus Erythematosus Disease Area and Severity Index; *significant, bold letters.

in significantly higher religiosity observed in patients with pulmonary involvement. Likewise, SSc patients with facial changes are significantly more religious.

LE patients are adversely affected by unpredictable flare-ups and especially by the varying clinical picture and involvement of various organ systems. Despite effective therapeutic options, it often takes several weeks for patients to clinically respond. One may only speculate whether this is reflected in fewer stable relationships/marriages compared to SSc and MM patients. Disease flare-ups lead to emotional changes, but affective disorders may also be disease-related. LE patients are characterized by significantly decreased spiritual well-being. However, they achieve a significantly higher score than the general population in the subscale "Ability to Forgive", except for those patients who are photosensitive and those who have joint pain.

For their entire lives, MM patients are burdened by the uncertainty as to whether the disease has been cured with removal of the tumor. A limitation to the study was the fact that all MM patients surveyed were at an early disease stage (I-II) and without metastases; one-third of the patients even only had stage IA disease, and thus the risk for developing metastases was low. Hence, the religious-spiritual well-being seems to be similar to that in the general population. Nevertheless, MM patients have a way better ability to forgive and achieve significantly higher scores for transcendental hope. This could also mean that they have to come to terms with their disease in the present life, and hope for a better life after death.

Dermatologists are familiar with the diseases examined in this study and respective treatment options, but they are not quite as familiar with the impact on patients' lives. Apart from taking into account findings obtained from technical procedures and lab tests, as well as the possibilities offered by 'repair medicine', the physician's qualities as a human being are called upon. A trusting doctor-patient rapport can alleviate the fear and suffering of patients. Our findings should sensitize physicians to these complex issues. The bio-psycho-socio-spiritual model should therefore play an important role in healthcare. Interventions aimed at mobilizing religious-spiritual resources could have a positive impact on disease coping and quality of life. This should be investigated in future studies.

### Limitations

Some questions remained unanswered in both questionnaires. In the self-designed questionnaire on subjective well-being and coping strategies, we therefore stated absolute numbers and percentages.

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Patient Preference and Adherence

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ORIGINAL RESEARCH

# Cultural and quality-of-life considerations when administering corticosteroids as a therapeutic strategy for African American women living with systemic lupus erythematosus

This article was published in the following Dove Press journal:
Patient Preference and Adherence

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**Objective:** This study investigated the association among corticosteroids, emotional health, physical health, and work/regular activities of daily living in an ethnically diverse sample of women with systemic lupus erythematosus.

**Methods:** A secondary analysis of data from the Medical University of South Carolina Lupus Database was conducted between confirmed cases of lupus (n = 224) and controls (n = 60). The sample comprised 57 Caucasian Americans, 141 Gullah African Americans (a subpopulation of African Americans from the Sea Islands of South Carolina and Georgia), and 86 non-Gullah African Americans.

**Results:** Emotional health outcomes were better for women with systemic lupus erythematosus compared with controls. High emotional health scores may be influenced by cultural factors such as masking emotion, disease-coping mechanisms, religion, and strong familial and social support. Although a significant association was not detected between emotional health and work/regular activities of daily living, relationships were significant after adjusting for corticosteroid use.

**Conclusion:** These findings suggest corticosteroid use does influence the strength of the association between emotional health and work/regular activities of daily living.

**Keywords:** systemic lupus erythematosus, emotional health, physical health, Gullah, corticosteroids, quality of life

## Introduction

Systemic lupus erythematosus (SLE) is a chronic autoimmune condition with significant morbidity and mortality.[1] Currently, there are more than 250,000 Americans living with SLE.[2] The disease is more prevalent in women than in men, with a ratio of 9:1.[1] Moreover, African American women are disproportionately impacted by SLE, with the incidence and prevalence of the disease three to four times higher in African Americans than in Caucasian Americans.[1,2] The diverse symptoms of SLE can contribute to poor emotional and physical health.[3] For example, patients experiencing hair loss and scarring skin rashes from SLE may perceive themselves as unattractive, resulting in low self-esteem, isolation, and poor emotional health. Patients often experience measurable physical symptoms such as severe joint pain and fatigue, contributing to limited mobility and exercise tolerance.

In addition to the physical and functional disability attributable to SLE, the corticosteroids very commonly used to treat active SLE, often in high doses for severe disease, are associated with short-term side effects and long-term damage as well as

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early mortality among patients with SLE. In the short term, corticosteroid use has been known to cause elevated mood (also known as steroid euphoria), or conversely, steroid psychosis and associated mental deficiencies.[4–8] These comorbidities are disproportionately experienced by African American women with SLE and can compromise women's ability to perform work/regular activities of daily living with resultant high healthcare costs for patients, their families, and society.[9–13] Furthermore, because SLE affects women during their most productive years of life, it causes them and their families to experience increased financial hardship and significantly decreases their ability to accumulate wealth due to the financial burden associated with the disease and its treatment.[12–14]

Emotional health and physical health can affect work and daily activities; however, no study has explored these health-related quality-of-life (HRQoL) factors in relation to corticosteroid use in an ethnically diverse sample of women with SLE.

## Materials and methods

### Patients and inclusion criteria

A secondary analysis of data from the Medical University of South Carolina (MUSC) Lupus Database was conducted to assess the associations among corticosteroid use, emotional and physical health, and work/regular activities of daily living in an ethnically diverse sample. Subjects included in the current study were patients with SLE who were participating in a longitudinal, observational, web-based SLE database at the MUSC. Of the 402 patients enrolled, 224 women with SLE had complete data available for this study. Patients were seen on a regular basis in the MUSC lupus clinics. All patients had American College of Rheumatology (ACR) criteria and disease activity information available, as well as quality-of-life measures obtained in the database questionnaire. All SLE patients met at least four of the 1997 ACR revised classification criteria for SLE. Of the 224 patients with SLE in this study, 167 are African American, and 107 of these are Gullah African American from the Sea Islands of South Carolina and Georgia. Additionally, as part of the associated SLE in Gullah Health study,[15] 60 unrelated gender-matched Gullah controls are enrolled and included in this study. This study was conducted with approval from the MUSC Institutional Review Board (approval no HR15014). All participants provided written informed consent for study participation.

### Measures and instruments

Work/regular activities of daily living were conceptualized as paid work or daily activities that included, but were not limited to, house cleaning, gardening, cooking, laundry, and grocery shopping. Work/regular activities of daily living were measured using two separate scales: one measured the degree to which emotion affected women as they undertook work/regular activities of daily living, and the other measured how physical ailments affected work/regular activities of daily living. Both scales were derived from the SF-36, v2 – a generic self-administered instrument designed to measure the impact of disease on quality of life – and is valid and reliable for use on individuals living with SLE.[16–18] The SF-36 consists of 36 items that have been constructed into eight scales: Physical Functioning (PF), Role-Physical (RP), Bodily Pain (BP), General Health (GH), Vitality (VT), Social Functioning (SF), Role Emotional (RE), and Mental Health (MH).[19,20] These eight scales are combined into two summary measures: Physical Component Summary and Mental Component Summary. Several studies have used the SF-36 with samples from various racial and ethnic backgrounds including both non-Gullah African American and Gullah African American women with SLE. In these studies, the Cronbach's α exceeded the criterion of 0.70.[21–24]

The role of emotion and its effect on work/regular activities of daily living was measured using a three-item, five-point Likert scale with a range from one (all of the time) to five (none of the time) and a score ranging from 0 to 15 points. A high score indicated a positive outcome for work/regular activities of daily living. The effect of physical illness on work/regular activities of daily living was measured using a four-item, five-point Likert scale with a range from one (all of the time) to five (none of the time). Scores range from 0 to 20 points, with a high score indicating a positive outcome for work/regular activities of daily living.

Emotional health was conceptualized as a state of being, in terms of feelings, and an individual's personal outlook on life. Emotional health was measured using a five-item, five-point Likert scale with a range from one (all of the time) to five (none of the time) and a score range from 0 to 25. This scale was taken from the SF-36, v2 Mental Health subscale. Items have a positive connotation (eg, "How much of the time during the past 4 weeks have you felt calm and peaceful?") or a negative connotation (eg, "How much of the time during the past 4 weeks have you felt so down in the dumps that nothing could cheer you up?"). Items with a negative connotation were recoded so that a high composite score indicated good emotional health.

Physical health was conceptualized as the ability to carry out activities that involve muscle strength. Physical health was measured as a categorical variable on a 10-item, three-choice scale which ranged from one (yes, limited a lot) to three

(no, not limited at all). The score ranged from 0 to 30. This scale was taken from the SF-36, v2 Physical Functioning subscale. A high composite score indicated good physical health.

Demographic data were collected on selected individual characteristics including, race/ethnicity, age, education, and employment status. Clinical data included corticosteroid use and comorbid medical conditions. Race/ethnicity was measured as a categorical variable by using two items from the subject registration form. Subjects who answered either African American or Caucasian for self-identified race were included and other races were excluded from this analysis due to the small sample size. African American subjects identified as either Gullah or non-Gullah African Americans. For purposes of data analysis, ethnicity was recoded using dummy variables with non-Gullah African Americans used as the referent group.

Corticosteroids use was measured as a continuous variable to establish the mean duration of treatment (in years). However, for purposes of data analysis, corticosteroid use was recorded as a dichotomous variable yes (corticosteroid use) or no (no corticosteroid use). Comorbid medical conditions were ascertained using a past medical history form that listed 16 diseases, including diabetes, stroke, fibromyalgia, and cancer. For data analysis, comorbid medical conditions were measured using a dichotomous variable yes (at least one comorbid medical condition) or no (no comorbid medical condition).

Disease damage caused by SLE was measured by the Systemic Lupus International Collaborating Clinics/American College of Rheumatology Damage Index (SLICC/ACR DI) – an indicator of bodily damage from the time of disease diagnosis. Damage has been described as an irreversible change, unrelated to active inflammation, occurring since the onset/diagnosis of lupus, ascertained by clinical assessment and present for at least 6 months, unless otherwise stated.[25] It is a summary scale that uses 12 categories representative of organ systems: ocular, neuropsychiatric, renal, pulmonary, cardiovascular, peripheral vascular, gastrointestinal, musculoskeletal, skin, premature gonadal failure, diabetes, and malignancy. The summary scores ranged from 0 (no damage) to 46 (maximum damage).[25]

## Statistical analyses

All analyses were conducted using the Statistical Analysis System software, version 9.3. Descriptive analysis was conducted to examine sample characteristics. Bivariate analysis using the chi-square test was conducted to assess associations between the following variables: emotional health versus work/regular activities of daily living (role physical) and physical health versus work/regular activities of daily living (role emotional). The two-sample Student's *t*-test was used for continuous variables to assess unadjusted differences in the means of the summary scores between groups.

Linear regression analyses were conducted to assess associations among corticosteroid use, emotional health, physical health, and work/regular activities of daily living (role physical). The following three regression equations were tested: 1) whether there was an association between emotional health and work/regular activities of daily living (role physical); 2) whether there was an association between physical health and work/regular activities of daily living (role emotional); and 3) whether the association between emotional health and regular activities of daily living (role physical) was exacerbated by corticosteroid use.

To further evaluate significant associations, the Tukey–Kramer post hoc test was used to determine whether the means of the three ethnic groups differed significantly. Group comparisons among women with SLE using the chi-square test, the one-way analysis of variance, and the Kruskal–Wallis test included the covariates: corticosteroids, education, disability status, age, depression, and hypertension.

# Results

Descriptive statistics on the characteristics of the study sample are presented in Table 1. Patients with SLE were



**Table 1** Characteristics of participants (N = 284)

| Characteristics | SLE cases (n = 224) | Related controls (n = 60) |
|---|---|---|
| Mean age (years) SD | 39 ± 14 | 42 ± 15.4 |
| **Race/ethnicity** | | |
| Non-Gullah African American n (%) | 84 (38%) | 2 (3%) |
| Gullah African American n (%) | 87 (39%) | 54 (90%) |
| Caucasian American n (%) | 53 (24%) | 4 (7%) |
| **Education** | | |
| Less than high school n (%) | 2 (0.81%) | 2 (3.33%) |
| High school n (%) | 76 (31%) | 16 (26.67%) |
| Some college n (%) | 27 (11%) | 18 (30%) |
| College n (%) | 28 (11%) | 9 (15%) |
| Technical college or trade n (%) | 37 (15%) | 8 (13.33%) |
| Postgraduate n (%) | 17 (7%) | 4 (6.67%) |
| **Employment status** | | |
| Working n (%) | 82 (36%) | 39 (65%) |
| Retired n (%) | 15 (7%) | 5 (8%) |
| Homemaker n (%) | 9 (4%) | 2 (3%) |
| Disabled n (%) | 62 (28%) | 1 (2%) |
| Unemployed n (%) | 30 (13%) | 9 (15%) |
| Other n (%) | 18 (8%) | 5 (8%) |
| **Corticosteroid use** | | |
| Mean duration years ± SD | 5.57 ± 4.83 | – |
| **SLICC Disease Damage Index** | | |
| Mean ± SD | 2.41 ± 1.7 | – |

**Abbreviations:** SLICC, Systemic Lupus International Collaborating Clinics; SLE, Systemic lupus erythematosus.

generally similar in age and education level to subjects in the control group, whereas the groups varied somewhat in race (control group was disproportionately Gullah African American) and employment status (individuals in the control group were more likely to be working and not disabled).

Table 2 shows correlation coefficients of emotional health, physical health, and work with regular activities of daily living (role physical) and work/regular activities of daily living (role emotional), both before and after adjusting for corticosteroid use. Higher emotional health scores were correlated with higher scores for work/regular activities of daily living (role physical; r-estimate = 0.17, $p < 0.01$). After adjusting for corticosteroid use, emotional health remained significantly correlated with work/regular activities of daily living (role physical; r-estimate = 0.40, $p < 0.01$). Similarly, higher physical health scores were correlated with higher scores for work/regular activities of daily living (role emotional; r-estimate = 0.60, $p < 0.01$).

The group comparisons using the Student's *t*-test, and the Wilcoxon rank sum test demonstrated that women with SLE reported higher emotional health scores than controls (18.16 vs 11.08, $p < 0.01$). In contrast, women with SLE reported lower scores in the areas of physical health (22.02 vs 26.22, $p < 0.01$), work/regular activities of daily living (role physical; 13.40 vs 16.91, $p < 0.01$) and work/regular activities of daily living (role emotional; 11.58 vs 12.62, $p < 0.05$) compared with controls.

Table 3 shows the unadjusted linear regression analyses for the association between variables of interest: emotional health, physical health, work/regular activities of daily living (role emotional), and work/regular activities of daily living (role physical). Model 1 demonstrates that higher physical health scores were associated with higher work/regular activities of daily living (role emotional) scores ($\beta = 0.36$, $p < 0.01$). Model 2 found that emotional health was not significantly associated with work/regular activities of daily living (role physical; $\beta = 0.04$, $p = 0.43$). Model 3 was restricted to women with SLE only. After adjusting for corticosteroid use, emotional health was significantly associated with work/regular activities of daily living (role physical; $\beta = 0.38$, $p < 0.01$).

**Table 2** Differences in HRQoL scores between women with SLE and controls

| Characteristics | SLE cases (n = 244) | Controls (n = 60) | *p*-value |
|---|---|---|---|
| | Mean ± SD | Mean ± SD | |
| Emotional health | 18.16 ± 4.80 | 11.80 ± 7.32 | <0.01* |
| Physical health | 22.20 ± 5.89 | 26.50 ± 5.53 | <0.01# |
| Work/regular activities of daily living | | | |
| Role physical | 13.40 ± 4.94 | 16.91 ± 4.52 | <0.01# |
| Role emotional | 11.58 ± 3.67 | 12.62 ± 3.60 | 0.02# |

**Notes:** *Significant difference based on a Student's *t*-test. #Significant difference based on Wilcoxon rank sum test.
**Abbreviation:** SLE, Systemic lupus erythematosus.

**Table 3** Linear regression models for the association between emotional health, physical health, and work/regular activities of daily living before and after adjusting for corticosteroid use

| Model | Variables | Work/regular activities of daily living (role emotional) | | Work/regular activities of daily living (role physical) | |
|---|---|---|---|---|---|
| | | *β* | *p*-value | *β* | *p*-value |
| 1 | Physical health | 0.36 | <0.01* | – | – |
| 2 | Emotional health | – | – | 0.04 | 0.43 |
| 3 | Emotional health | – | – | 0.38 | <0.01* |
| | Corticosteroids | | | −1.80 | 0.51 |

**Notes:** Models 1 and 2: unadjusted; Model 3: adjusted. *Significant difference detected.

As shown in Table 4, racial and ethnic differences were observed for emotional health ($p < 0.004$) and work/regular activities of daily living (role physical) scores ($p < 0.04$). Significant ethnic differences in mental health were observed between both non-Gullah African Americans and Caucasian American women with SLE and the Gullah African American and Caucasian American women with SLE (post hoc $p = 0.004$). Overall, non-Gullah African Americans reported similar emotional health scores compared to Gullah African Americans and lower scores when compared to Caucasian American women with SLE (17.46; 17.70 vs 20.10). For work/regular activities of daily living (role physical), significant ethnic differences were observed between non-Gullah African American and Caucasian American women with SLE (post hoc $p < 0.03$). Non-Gullah African Americans had lower scores in work/regular activities of daily living (role physical) compared to Caucasian American women with SLE (12.74 vs 14.94).

Table 5 shows unadjusted and adjusted linear regression analyses for emotional health and work/regular activities of daily living (role physical). Race/ethnicity acted as a moderator between emotional health and work/regular activities of daily living (role physical; $p < 0.01$), and the association between emotional health and work/regular activities of daily living remained significant ($\beta = 0.37$, $p < 0.01$). After adjusting for ethnicity, education, age, disability status, stroke, dialysis, and depression, the association between emotional health and work/regular activities of daily living (role physical) remained significant but was decreased ($\beta = 0.23$, $p < 0.01$).

**Table 4** Ethnic differences in HRQoL scores among women with SLE

| Characteristics | Non-Gullah African Americans (n = 79) | Gullah African Americans (n = 83) | Caucasian Americans (n = 50) | *p*-value |
|---|---|---|---|---|
| | Mean ± SD | Mean ± SD | Mean ± SD | |
| Emotional health | 17.46 ± 4.70 | 17.70 ± 5.18 | 20.10 ± 3.80 | 0.004* |
| Work/regular activities of daily living | | | | |
| Role physical | 12.74 ± 5.03 | 13.52 ± 4.65 | 14.94 ± 4.84 | 0.04* |

**Notes:** *Significant differences were observed for non-Gullah African Americans and Caucasian American women and Gullah African Americans and Caucasian American women with SLE (post hoc $p < 0.05$).
**Abbreviation:** SLE, Systemic lupus erythematosus.

## Discussion

This study explored the relationships among variables related to everyday life for women with SLE. Our results indicate that physical health has a significantly greater association with decreased work/regular activities of daily living compared with emotional health. Additionally, significant ethnic differences exist in the association between emotional health and work/regular activities of daily living among women with SLE. Among the women with SLE in our study, non-Gullah African Americans had similar emotional health scores compared with Gullah African Americans and lower scores compared with Caucasian Americans. However, non-Gullah African American women with SLE had lower scores for work/regular activities of daily living compared with Gullah African American and Caucasian American women with SLE. Emotional health outcomes were better for women with SLE overall, when compared with controls; however, it is important to note that these groups varied in their demographic characteristics, which could account for variations in emotional coping styles.

High emotional health scores reported by non-Gullah and Gullah African American women with SLE are novel and contrary to the phenomena that we thought we understood in the SLE scientific literature. The negative effects of SLE on emotional health are well documented. Our findings suggest there may be emotional health protective factors that are culturally unique among this population of African American women with SLE residing in the Sea Island regions of coastal South Carolina. This further justifies examination into the impact of racial and ethnic sociocultural influences on disease status within this population.

Whereas side effects of corticosteroid use could be a confounding factor, psychiatric side effects are generally present in a subsect of the population, thereby reducing their ability to cause significant variation.[4–8] Thus, we suspect that the pervasive sociocultural factors influencing this outcome include masking emotion,[26] disease-coping mechanisms, religion, and strong familial and social support due to the high prevalence of multi-patient families with SLE among the Gullah.[16] There may be an interplay between these cultural factors and the adoption of a Superwoman role by Gullah African Americans and non-Gullah African Americans who collectively comprised the majority of women with SLE (77%) in the study sample. The Superwoman role – a survival mechanism adopted by African American women to cope with racism and oppression[27] – could have manifested in the form of stress-relating coping strategies such as an obligation to manifest strength, an obligation to suppress emotions, and resistance to being vulnerable. African American women, both non-Gullah and Gullah, who adopt the Superwoman role are more likely to engage in emotional suppression, which can lead to detrimental changes in immune functioning, illness, and mortality.[27,28] Despite the negative impact of certain aspects of the Superwoman role on health outcomes,

**Table 5** Linear regression models for the association between emotional health, physical health, and work/regular activities of daily living before and after adjusting for corticosteroid use

| Models | Work/regular activities of daily living | | |
|---|---|---|---|
| | Role physical | | |
| | Variables | *β* | *p*-value |
| 1 | Emotional health | 0.40 | <0.01* |
| 2 | Emotional health | 0.40 | <0.01* |
| | Caucasian American | 1.46 | 0.09 |
| | Gullah African American | 1.13 | 0.12 |
| 3 | Emotional health | 0.37 | <0.01* |
| | Caucasian American | 1.24 | 0.19 |
| | Gullah African American | 1.39 | 0.12 |
| | Corticosteroid use | 0.07 | 0.38 |
| 4 | Emotional health | 0.23 | <0.01* |
| | Caucasian American | 0.13 | 0.26 |
| | Gullah African American | 1.66 | 0.03* |
| | Education | 0.72 | 0.29 |
| | Age | −0.04 | 0.05* |
| | Disability status | −3.21 | <0.01* |
| | Stroke | −0.60 | 0.43 |
| | Dialysis | 1.33 | −0.26 |
| | Depression | −1.77 | 0.02* |

**Notes:** Model 1: unadjusted; Models 2–4: adjusted. *Significant difference was observed.

there are positive aspects of this phenomenon; these positive impacts have benefited African American women who have managed historically to demonstrate strength in the face of adversity and tremendous hardship.[27] The lack of a significant association detected between emotional health and work/regular activities of daily living (role physical) was consistent with other findings.[29]

This study attempted to extend previous examinations of the association of emotional health and work/regular activities of daily living among cases and controls[13,29,30] by assessing the moderating effect of corticosteroids – a common treatment in SLE known to cause emotional distress, mood disorders, and psychiatric disorders.[4–8,31] Despite the well-documented side effects of corticosteroid use, prior studies assessing the effects of corticosteroids and the associations between SLE and emotional health and work/regular activities of daily living are scarce.[3] Whereas a significant association was not detected for emotional health and work/regular activities of daily living after adjusting for corticosteroid use, a significant association between emotional health and work/regular activities of daily living (role physical) was detected. These findings suggest that corticosteroid use does influence the strength of the association between emotional health and work/regular activities of daily living; however, it cannot be stated with certainty if this variation is due to the intended treatment effects of the drug or the psychiatric side effects.

This study was limited by the dichotomous coding of corticosteroid use, without accounting for dose, and did not account for the influence of steroid-sparing immunosuppressing medications often used to treat SLE and allowing corticosteroids to be tapered off. From our experience with patients followed in this cohort, a significant proportion of patients continue on corticosteroid therapy for SLE despite trials of other therapies. Our findings will help add support to maximizing steroid-sparing treatments with the goal of tapering off even low doses of corticosteroids. Another notable limitation of this study is the between-group demographic variations; this limits the power of the associations observed; however the current study provides a preliminary and novel inference. Similarly, due to the unique demographic makeup of this population (being largely African American and/or Gullah), the conclusions drawn from the data are not generalizable and should not be applied to other populations.

The finding that racial and ethnic differences were detected for emotional health scores among women with SLE, but not among controls, and that non-Gullah African American women reported poorer emotional health compared to Gullah African Americans and Caucasian American women with SLE are consistent with other research that compared Hispanics from Texas, Hispanics from Puerto Rico, African Americans, and Caucasian Americans (n = 1,351).[32] According to Alarcón et al, the African American race is associated with poorer emotional health compared with other racial/ethnic groups. Although there are unique cultural differences between these two groups, significant differences in emotional health may not have been observed due to shared racial and sociocultural experiences, environmental stressors, coping strategies, and disproportionate disease activity and damage.[1,26,27]

This study revealed that physical health had a greater association with work/regular activities of daily living compared with emotional health, which is similar to empirical findings that declines in physical health and work/regular activities of daily living accompany SLE in the broader population.[10,33–37]

Finally, non-Gullah African Americans experienced more deficits in work/regular activities of daily living compared with their Caucasian American counterparts. These findings are consistent with previous research[13,14] that revealed African Americans were more likely to report work disability.



## Conclusion

Our findings highlight the importance of considering the negative impact of corticosteroids on emotional health among women with SLE – particularly among African American women who disproportionately experience poor health outcomes, yet often require high doses of corticosteroids for treating life-threatening lupus manifestations such as kidney and brain involvement. Although this therapeutic strategy improves physical health, the emotional health implications should not be overlooked. Improvements in SLE outcomes can only be accomplished if racial and ethnic sociocultural factors are examined in research and accounted for in the administering of corticosteroids and the development and implementation of interventions. Despite the diversity that exists within the African American population, cultural differences are not always considered in SLE research and interventions; however, it is known that there are ethnic variations in SLE incidence, prevalence, disease damage, and mortality, and this study assessed ethnic differences. This study provides novel insight into the cultural differences among African Americans, their interplay with

corticosteroid use, and how these can affect quality-of-life outcomes.

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## Disclosure

The authors report no conflicts of interest in this work.

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# Measurement properties of the brief resilient coping scale in patients with systemic lupus erythematosus using rasch analysis

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## Abstract

**Bacground:** Resilience has been defined as the capacity or the ability to rebound from and positively adapt to significant stressors, despite experiences of significant adversity or trauma. To capture to what extent an individual copes with stress in a resilient fashion the Brief Resilient Coping Scale (BRCS) was developed. This tool was validated in people with chronic disease, such as rheumatoid arthritis using standard psychometric techniques of classical test theory, but not yet in patients with Systemic lupus erythematosus (SLE). The aim of this study was to explore the psychometric properties of the Brief Resilient Coping Scale in patients with SLE using Rasch analysis.

**Method:** This study used cross-sectional data. The BRCS was administered to 232 patients with systemic lupus erythematosus. The aspects analyzed were unidimensionality, local independence and differential item functioning (DIF) to construct an interpretative scale of scores with the Rasch model.

**Results:** Rating scale mode (RSM) showed that the four categories used in the items of the BRCS are properly ordered. The four items provided a good fit to the polytomous Rasch model. Moreover, the parameters were sufficiently separated to measure resilience in patients with SLE. BRCS is a unidimensional scale (eigenvalue = 1.843) of resilience and the items were locally independent. There was no DIF between males and females in the sample. Only marginally significant differences depending on the level of education were found. The BRCS showed adequate discriminant validity between groups of scores.

**Conclusions:** BRCS is a suitable scale for measuring resilience in patients with SLE. This scale might be useful for clinicians to obtain information concerning the degree of resilience that each patient has, allowing individuals with low resilience to be identified who need interventions aimed at developing coping skills.

**Keywords:** Systemic lupus erythematosus, Resilient coping, Rasch analysis, Quality of life



## Background

Systemic lupus erythematosus (SLE) is a chronic autoimmune rheumatic disease, characterized by widespread inflammation of blood vessels and connective tissue [1]. The severity of symptoms, the secondary effects of medication, its unpredictability and early onset along with the chronic evolution of the disease are stress factors that provoke medium and long term psychological disorders in many sufferers [2, 3]. Such orders include anxiety and depression [4–7].

These may undermine the adaptation capacity of the patient, and their ability to maintain or regain mental health. This capacity of adaptation or facing up to the disease will largely depend on the patient's psychological capacity, upon which is based the concept of resilience, which has been defined as the capacity or the ability to rebound from and positively adapt to significant

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stressors [8, 9], despite experiences of significant adversity or trauma [10].

Resilience was originally used in the field of physics to refer to the capacity of a material or systems to return to equilibrium after displacement, and has been adapted and developed in psychology as a theoretical construct of mental health protection, promotion and recovery processes [11]. Currently, this concept is increasingly used in the area of clinical medicine, especially, in patients with chronic diseases. Furthermore, some scientific research focuses on the role of resilience in chronic patients' adaptation to their disease [12–14].

In this sense, in certain chronic diseases, such as cancer or Parkinson's, patients with high levels of resilience have a better functional capacity, higher stability and better adaptation to their social environment. Also, the clinical symptomatology of these subjects is less severe, their pain threshold is higher, and they are less tired and are less likely to suffer from anxiety and depression, which leads to a better life quality [15, 16].

Because of this, evaluation of the degree of resilience is very important in subjects with chronic disease such as SLE, enabling deficit situations to be detected and improved [17, 18].

Resilience has been assessed mainly through self-report measures such as the Brief Resilient Coping Scale (BCRS), a 4-item measure that has been validated for people with rheumatoid arthritis, university students and ageing persons [19–21] using standard psychometric techniques of classical test theory. However, until now this scale has not been validated for people with SLE, nor has its psychometric properties been evaluated by item response theory [22].

For this reason, the aim of the present paper is to validate the Brief Resilient Coping Scale in patients with SLE using the Rasch model, testing unidimensionality, local independence, differential item functioning (DIF), and constructing an interpretative scale of scores obtained with the fitted model.

## Methods

### Participants and procedure

A cross-sectional study was developed in the province of Murcia (south-eastern Spain) with patients who met the revised American College of Rheumatology classification criteria for SLE diagnosis [23]. The BRCS and EQ-5D scales were administered, from July to August 2014, by postal survey to 450 eligible subjects selected randomly from the rare disease database of the Murcia Health Service. The study conforms to the principles of the Declaration of Helsinki [24] and was approved by the Research Bioethics Committee of the University of Murcia (Spain) (ID 1204/2015; 4/11/2015).

### Instruments

The Brief Resilient Coping Scale (BRCS) is a 4-item, unidimensional outcome measure designed to capture to what extent an individual copes with stress in a resilient fashion. In the original version, the items have a response format with five options, where 1 means the statement "does not describe you at all" and 5 means "it describes you very well", but in this work the number of categories was reduced to four because the central category was removed to force decision-making of patients (Appendix). The BRCS meets the minimal standard for reliability and validity of a resilience instrument. In this study, the internal consistency coefficient was 0.82 and the Spearman-Brown coefficient was 0.81. The concurrent validity coefficient for BRCS was 0.34 with EQ-5D and 0.34 with EQ-VAS.

The EuroQol (EQ-5D) is a generic health index which comprises a five-part questionnaire (mobility, self-care, usual activities, pain/discomfort, anxiety/depression) to calculate a 'utility' or health index value between "0" and "1", and a visual analogue self-rating scale (EQ-VAS) which ranges from 0 (minimum score) to 100 (maximum score). The EQ-5D is a reliable and valid instrument for measure quality of life [25, 26].

### Rasch analysis

The Rasch family of models transforms ordinal scores to interval scales (logits) [27]. For this it is necessary to specify a model according to the structure of the items in the scale. If the data fit the model specified, then independent item and ability parameters will be estimated. Also, applying the Rasch model involves evaluating the order of the item categories, fitting of the items, the separability of the parameters, and DIF. If all the analyses indicate that the scale forms a unidimensional rule of resilience, it will be possible to construct a more interpretative transformed scale.

There are two models in the Rasch family of models to estimate the location parameters of the items: the partial credit model (PCM) [28] and the rating scale model (RSM) [29]. Both models determine the parameters of the transitions between the categories of the items, but PCM allows each item to have a different unordered threshold, while RSM permits equal transitions between categories for each item. Therefore, a first evaluation of the appropriate model to explain the BRCS results involves examining whether the average score of the people who have answered each category in each item increases monotonically. A second evaluation involves comparing the fit in both models with the deviance ($G^2$) which follows an approximately normal distribution with *df* equal to the difference between the free parameters estimated in each of the models. If the difference between deviances in both models is not significant at

$p < .05$, then the simplest model is selected to explain the matrix of responses to the BRCS.

To estimate the parameters of the Rasch models ConQuest v. 3.0 [30] was used, and for descriptive statistics and convergent validity we used SPSS v. 19.0.

### Item fit

To assess the goodness of fit of the data to the Rasch model Conquest uses two statistics based on residuals of mean square (MNSQ). The unweighted mean square detect unexpected responses pattern when ability parameter is far to the item location parameter, while weighted mean square detect unexpected responses when ability parameter is very close to the item location parameter. An item shows a good fit to Rasch models if the unweighted or weighted item fit is found in the interval 0.6 to 1.4 [31].

### Reliability

Conquest also provides a separability coefficient of the parameters that makes it possible to evaluate whether the localization parameters of the items are sufficiently separate to cover the whole interval of the ability. In this case, the parameters are separate enough if the reliability coefficient is equal to or higher than 0.90 or $\chi^2$ is significant.

### Unidimensionality and local independence

In the Rasch model the items must form a unidimensional scale. Unidimensionality was tested with a principal components analysis (PCA) of residuals. It was considered that the BRCS was unidimensional if at least the first principal component explained a 50 % of the variance and the eigenvalue was higher than 1.5. Local independence was examined with inter-item residual correlation matrix. The items were locally independent if inter-item residual correlations was lower than 0.70.

### DIF

DIF is evidence that the probabilities of the response of the groups can vary through the continuum of ability. Therefore, DIF exists if a group has a higher probability of offering an answer rather than another one systematically though all the levels of ability. In the present study DIF has been tested with regard to gender, a difference between male and female no greater than 0.50 has been taken as a criterion of non-DIF [32].

### Wright map

A Wright map [27] allows ability parameters to be compared with item localization parameters on the BRCS in terms of logits. The Wright map to assess whether the calibration sample is appropriate for the group of items selected and has been useful or not. In both cases, this imbalance would cast doubt on the results of the calibration of the scale.

### Differences between groups

After fitting the data to the Rasch model, the differences in resilience as regards gender, education and age interval were determined by Student's $t$ test or ANOVA, depending on the number of levels of each independent variable. Statistical significance was taken as $p < 0.05$.

### Convergent validity

To explore convergent validity we hypothesized that resilience would be higher among those SLE patients who have a greater quality of life, as shown by literature studies [33–35]. Subjects were first divided into 3 categories (low, moderate, high) using tertiles of HRQoL level as cut-off points. We then used ANOVA followed by the MSD *post hoc* test to compare mean scores from the BRCS across these 3 categories as a way to infer discriminant ability regarding HRQoL.

## Results

Age, gender, disease duration, educational level and comorbidity with other illness in the sample appear in Table 1. The sample consisted of 232 cases (88.2 % females) who returned their postal survey, a response rate of 51.5 %. The average age was 48.6 years (SD = 13.3)

**Table 1** Patients' characteristics ($N = 232$)

| | Mean (SD) | N(%) |
|---|---|---|
| *Age* (years) | 48.6(13.3) | |
| *Disease duration* (years) | 15.9(9.1) | |
| *Gender* | | |
| Female | | 202(88.2) |
| Male | | 30(11.8) |
| *Education* | | |
| No schooling | | 22(9.7) |
| Primary Education | | 86(37.9) |
| Secondary Education | | 75(33.0) |
| Higher Education | | 44(19.4) |
| *Comorbidity* | | |
| Osteoporosis | | 58(25.3) |
| Depression | | 88(38.4) |
| Diabetes | | 23(10.0) |
| Osteoarthritis | | 63(27.5) |
| Anaemia | | 87(38.0) |
| Peripheral vascular desease | | 60(26.2) |
| Vertebral fractures | | 20(8.7) |
| Kidney failure | | 60(26.2) |
| Lung failure | | 45(19.7) |

**Table 2** Frequencies(%) distribution for each item of the Brief Resilient Coping Scale

| | Categories | | | |
|---|---|---|---|---|
| Item | 0 | 1 | 2 | 3 |
| I look for creative ways to alter difficult situations. | 19(8.3 %) | 55(24.1 %) | 78(34.2 %) | 76(33.3 %) |
| *Average score within category* | 1.47 | 4.53 | 7.18 | 10.34 |
| *SD Score within category* | 1.58 | 1.64 | 1.62 | 1.54 |
| Regardless of what happens to me, I believe I can control my reaction to it. | 39(17.1 %) | 69(30.3 %) | 78(34.2 %) | 42(18.4 %) |
| *Average score within of category* | 2.87 | 5.51 | 8.71 | 10.76 |
| *SD Score within of category* | 2.03 | 1.86 | 1.64 | 1.56 |
| I believe i can grow in positive ways by dealing with difficult situations | 28(12.3 %) | 65(28.5 %) | 82(35.9 %) | 53(23.3 %) |
| *Average score within of category* | 2.00 | 5.38 | 7.83 | 10.85 |
| *SD Score within of category* | 1.66 | 1.83 | 1.70 | 1.42 |
| I actively look for ways to replace the losses I encounter in life. | 16(7.0 %) | 49(21.5 %) | 93(40.8 %) | 70(30.7 %) |
| *Average score within of category* | 1.75 | 4.35 | 7.01 | 10.43 |
| *SD Score within of category* | 2.24 | 1.83 | 1.87 | 1.57 |

and the average duration of the illness was 15.9 years (SD = 9.1).

### Ordering of categories

Table 2 shows the mean and typical deviation of the item scores regarding the categories. The gradual increase of the means in each category signifies that the categories are well ordered and no unexpected violations have occurred.

### Which model is better?

Which is the best model to explain the response matrix was tested by comparing deviance of PCM vs. RSM. Deviance for PCM was 1954.767 with $df = 13$, and for RSM was 1957.619 with $df = 7$. The difference was 2.852 ($df = 6$), which was not statistically significant ($p > 0.05$). So, RSM was chosen as the most appropriate model for the BRCS. The location parameters appear in Table 3.

As expected from a scale constructed based on the classic test model, the four items had high homogeneity (0.83 to 0.87) and the localization parameters were very close to the mean resilience of the sample used during the study. Items 2 and 3 were indicative of high resilience, while items 1 and 4 were below average parameters. The thresholds between categories were in order and sufficiently separated, indicating that they fulfilled their expected function of representing the degree of resilience in this sample, as shown in the Wright map (Fig. 1).

### Item fit

Both the unweighted and weighted mean square for the items and the categories were in the specified interval [0.6, 1.4], so it is safe to say that the responses on the BRCS scale follow the RSM (Table 3).

### Separation reliability coefficient

The separation coefficient of the parameters was .98 ($\chi^2 = 112.3$, $df = 3$, $p < 0.001$), which indicates that the thresholds of the four items were able to cover the

**Table 3** Parameters of location and fitting statistics for the items and thresholds parameters of the Brief Resilient Coping Scale

| | | | | Unweighted fit | | | Weighted fit | | |
|---|---|---|---|---|---|---|---|---|---|
| Item | Location parameter | Standard error | $R_{jX}$ | MNSQ | CI | T | MNSQ | CI | T |
| 1 | −0.431 | 0.082 | .87 | 0.87 | [0.82, 1.18] | −1.4 | 0.95 | [0.81–1.19] | −0.6 |
| 2 | 0.706 | 0.081 | .83 | 1.11 | [0.82, 1.18] | 1.2 | 1.09 | [0.82, 1.18] | 0.9 |
| 3 | 0.237 | 0.081 | .85 | 0.94 | [0.82, 1.18] | −0.6 | 0.96 | [0.82, 1.18] | −0.5 |
| 4 | −0.512[a] | 0.141 | .83 | 0.98 | [0.82, 1.18] | −0.1 | 1.01 | [0.81, 1.19] | 0.1 |
| Categories | | | | | | | | | |
| 0 | | | | 0.94 | [0.82, 1.18] | −0.7 | 1.11 | [0.70, 1.30] | 0.7 |
| 1 | −2.30 | 0.083 | | 1.24 | [0.82, 1.18] | 2.4 | 1.23 | [0.80, 1.20] | 2.1 |
| 2 | −0.81 | 0.077 | | 1.25 | [0.82, 1.18] | 2.5 | 1.27 | [0.82, 1.18] | 2.7 |
| 3 | 2.39[a] | | | 1.12 | [0.82, 1.18] | 1.3 | 1.16 | [0.77, 1.23] | 1.3 |

*Notes*: [a]the parameter is constrained, $R_{jX}$ item-test corrected correlation, *MNSQ* Mean square, *CI* Confidence Interval, *T* Transformation Wilson-Hilferty

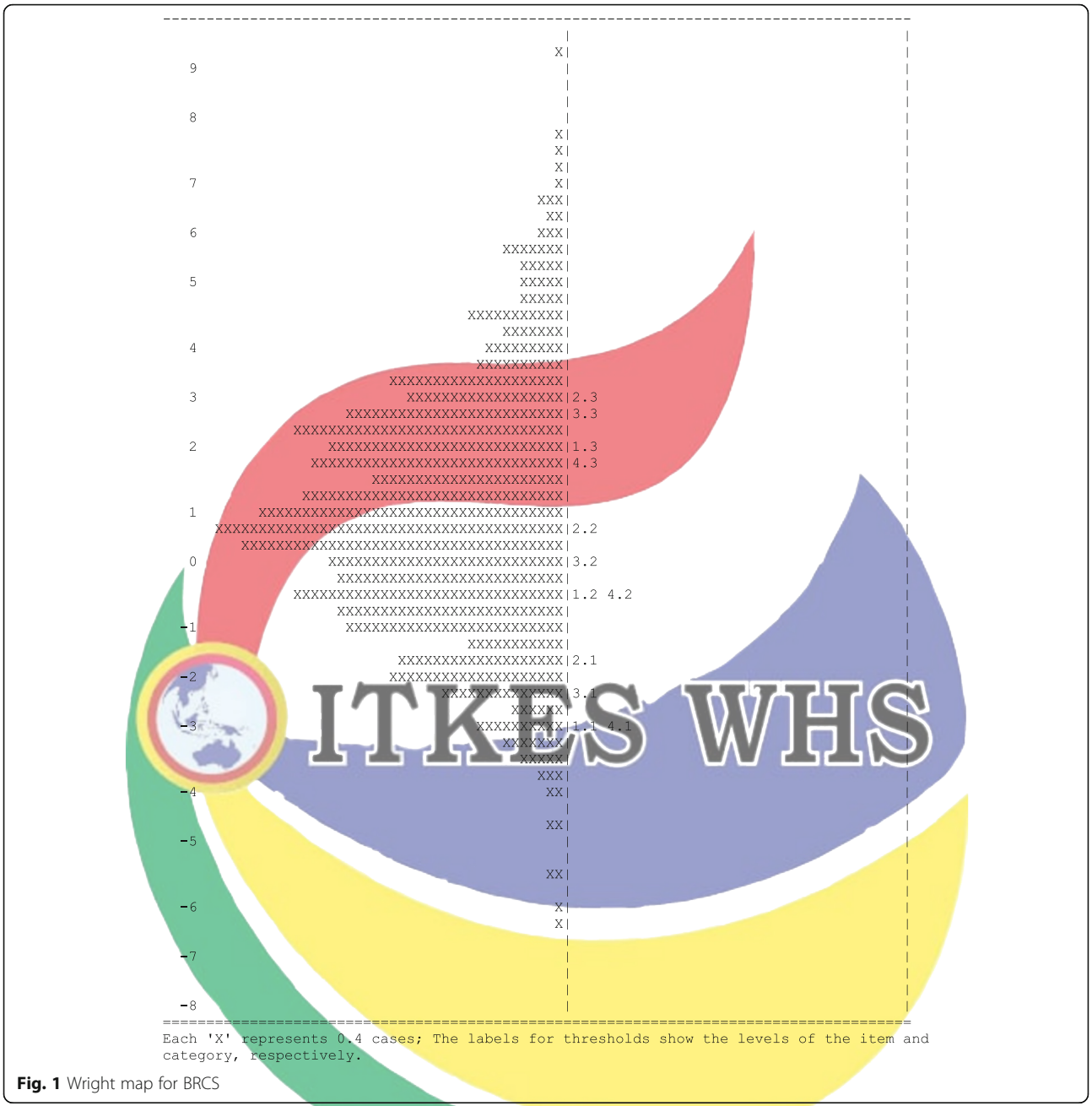


**Fig. 1** Wright map for BRCS

interval of resilience of the sample in which the scale was calibrated, in spite of the small number of items of the BRCS.

### Dimensionality and local independence

Dimensionality of the BRCS was tested with a residual PCA. The small number of items of the scale prevented the first factor from obtaining the expected salience as in other larger scales, but the first main component explained 46.08 % of total variance (eigenvalue = 1.843) so the scale was considered to be essentially unidimensional.

Local independence was obtained through correlations of the standardised residuals of the items which varied between −0.06 and −0.49, never reaching the limit of 0.70, so that the responses to the items were also considered to be locally independent.

### DIF

The difference between males and females in the localization parameters of the four items was 0.11, never surpassing 0.50, so DIF was not significant for any item.

### Differences between groups

After fitting the BRCS to RSM, the resilience parameters for the sample were estimated. No significant differences were found with respect to gender or age interval, but marginally significant differences ($p = .061$) were found between educational levels, the mean of the resilience parameters increasing with educational level. Thus, the group of patients who had only studied primary education obtained a mean of resilience of 0.146 (SD = 2.69), while those who had received higher education obtained a mean of 1.307 (SD = 2.40) (Table 4).

### Convergent validity

Table 5 presents the BRCS scores by HRQoL level. Scores increased significantly with increasing either EQ-5D or EQ-VAS levels. The mean score obtained by the group of patients with a high level of EQ-VAS (60.2 to 100) was 69.7, which is 39.4 % per cent higher than the low-level category ($p < 0.001$), these differences were also observed when comparison between extreme groups was made using the "utility" values obtained by means of EQ-5D (41.2 %) providing, in both cases, evidence of the construct validity of the BRCS.

## Discussion

This is the first study that gives evidence of the reliability and validity of the BCRS using Rasch analysis, in a sample of patients with SLE. Good support was established for the psychometric properties of the BRCS with a good fit to the RSM, and no DIF was found. There was good internal consistency and support for the unidimensionality and local independence of the items on the scale. These results are in agreement with other produced with classical test theory [19–21].

The studies made to date in which resilient coping has been studied in patients with SLE have used the resilience scale (RS) [36, 37]. This scale has 25 items and was developed for the general population. However, the brevity of the BCRS allows it to be completed quickly and easily by patients with conditions such as SLE, and that it can be administered multiple times in longitudinal studies as well as in large surveys. Validation of this scale using the Rasch model also points to its potential usefulness in daily clinical practice in patients with systematic erythematosus lupus.

Study of the dimensionality showed that the BRCS forms a unidimensional scale with localization parameters of the items and thresholds of the categories which clearly separate the resilience of the evaluated patients. There was no evidence of local dependence in the answers to the items.

This scale reflects one of the patterns of resilience, more specifically the situational pattern, which corresponds to resilient coping patterns [10]. Items in this measure refer to tenacity, optimism, creativity, and aggressive approach to problem solving, and commitment to positive growth from difficult situations [19]. By administering this scale to the patients, we obtain information concerning the degree of resilience that each patient has, allowing individuals with low resilience to be identified who need interventions aimed at developing coping skills. In this way, patients who receive treatment will develop abilities to face stressing situations daily, lessening the possibility of a psychological crisis. In fact, in the study of Sinclair & Wallston [19] where BRCS was validated in a sample of rheumatoid arthritis in the US, it was observed that resilient coping showed significant improvement after a cognitive-behavioral intervention designed to enhance adaptive coping, which indicates that levels of resilient coping can be improved.

**Table 4** Differences between groups (Student's t /ANOVA)

| | Mean (SD) | *t/F* | *df* | *P* |
|---|---|---|---|---|
| Gender | | | | |
| Male | 1.28 (2.07) | 1.10 | 226 | 0.271 |
| Female | 0.74 (2.39) | | | |
| Educational level | | | | |
| No schooling | 0.15 (2.69) | 2.50 | (3, 226) | 0.061[a] |
| Primary education | 0.40 (2.40) | | | |
| Secundary education | 1.01 (2.08) | | | |
| Higher education | 1.31 (2.40) | | | |
| Age Interval | | | | |
| 1 (<45 años) | 0.93 (2.36) | .22 | (2, 226) | 0.800 |
| 2 (45–65 años) | 0.75 (2.22) | | | |
| 3 (>65 años) | 0.63 (2.70) | | | |

[a]Marginally significant

**Table 5** Convergent validity of the Brief Resilient Scale (BRCS) regarding HRQol (Euroqol test)[a]

| | BRCS Scores | |
|---|---|---|
| | n | Mean [0–100] (CI 95 %) |
| *EQ visual analogue scale (EQ-VAS)Tertiles* | | |
| Low (T1) [≤40.0] | 75 | 50.9 (45.2-56.6) |
| Moderate (T2) [40.1–60.1] | 66 | 60.1 (54.1-66.1) |
| High (T3) [60.2–100.0] | 69 | 69.7 (62.9-76.5) |
| Overall mean | 210 | 60.0 (56.3-63.7) |
| *EQ-5D descriptive system Tertiles* | | |
| Low (T1) [≤0.08] | 75 | 49.1 (43.5-54.7) |
| Moderate (T2) [0.08–0.31] | 77 | 60.2 (54.2-66.2) |
| High (T3) [0.32–1.00] | 73 | 69.5 (63.3-75.7) |
| Overall mean | 225 | 59.5 (55.9-63.1) |

[a]One-way analysis of variance followed by post hoc test. *EQ* EuroQol, EQ-VAS: Ho: T1 *vs* T2= > $p = 0.03$; Ho: T1 *vs* T3= > <0.001: Ho: T2 *vs* T3= > $p = 0.03$. EQ-5D: Ho: T1 *vs* T2= > $p = 0.009$; Ho: T1 *vs* T3= > <0.001: Ho: T2 *vs* T3= > $p = 0.02$

In addition the BRCS correlates with perceived health status in patients with SLE, providing evidence of its construct validity. If interventions to build resilient coping could be refined, then perhaps quality of life could be improved in this population with a stressful chronic condition. The improvement of the quality of life in an incurable chronic illness is a primary objective and very important for patients. It would be advisable to consider cognitive-behavioral interventions aimed at enhancing resilient coping as a no-pharmacological treatment important for patients with SLE. This recommendation has been suggested in a study with Parkinson's patients, where resilient coping is considered one of the determining factors of disability and quality of life [16].

The length of the scale, only 4 items, may be considered a limiting factor of the quality of the scores, although its brevity means it can be used in clinical contexts where patients might not answer other longer resilience scales ("short but sweet").

Future research will study the properties of the BRCS in other clinical samples with chronic (e.g., fibromyalgia, diabetes, atopic dermatitis) or degenerative disease (e.g., Parkinson's disease, Multiple sclerosis).

## Conclusions

The BRCS is a suitable scale for measuring resilience in patients with SLE. This scale might be useful for clinicians can obtain information concerning the degree of resilience that each patient has, allowing individuals with low resilience to be identified who need interventions aimed at developing coping skills.

## Appendix

**Table 6** BRC scale

| *Consider how well the following statements describe your behavior and actions* | | | | |
|---|---|---|---|---|
| 1. I look for creative ways to alter difficult situations. | 0<br>Does not describe me at all | 1<br>Does not describe me | 2<br>Describes me | 3<br>Describes me very well |
| 2. Regardless of what happens to me, I believe I can control my reaction to it. | 0<br>Does not describe me at all | 1<br>Does not describe me | 2<br>Describes me | 4<br>Describes me very well |
| 3. I believe that I can grow in positive ways by dealing with difficult situations. | 0<br>Does not describe me at all | 1<br>Does not describe me | 2<br>Describes me | 3<br>Describes me very well |
| 4. I actively look for ways to replace the losses I encounter in life. | 0<br>Does not describe me at all | 1<br>Does not describe me | 2<br>Describes me | 3<br>Describes me very well |

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JALP, ABMH and JJGC participated in conception and design, data analysis and interpretation, drafting and revising the manuscript. DJNV participated in acquisition of data and revising the manuscript. VGS and KAW participated in revising the manuscript. All authors approving the final version of the manuscript submitted for review and for publication.

**Competing interest**
The authors declare that they have no competing interests.

**Consent for publication**
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# Quality of Life, Coping and Depression in Systemic Lupus Erythematosus

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**ABSTRACT:** Physical, mental and social well-being are important outcomes in patients with chronic rheumatic diseases, including systemic lupus erythematosus (SLE). The MOS SF-36 and the WHO QoL Bref are appropriate for assessing quality of life (QoL) in patients with SLE. The QoL of patients with SLE is impaired compared with that of controls. Fibromyalgia adversely affects the QoL of SLE patients. Women with SLE had significantly lower scores on subscales of the sense of coherence (SoC) compared with matched controls. This reduced SoC in SLE women represents impaired adaptive coping and is independently associated with reduced QoL in women with SLE. Depression and anxiety are common among SLE patients, and the frequency is similar to that in patients with rheumatoid arthritis. A reciprocal longitudinal relationship between depression and illness intrusiveness was found in patients with SLE. Disease activity and damage are not associated with depression. The subjective experience, not the illness per se, causes depression.

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**KEY WORDS:** systemic lupus erythematosus (SLE), quality of life (QoL), sense of coherence (SoC)

Systemic lupus erythematosus (SLE) is a chronic illness with a wide spectrum of disability and morbidity. The chronic illness state of patients with SLE leads to impaired psychological coping, development of depressive symptoms and anxiety, and impaired quality of life (QoL). Those features may occur in all age groups of patients with SLE.

During the last three decades several studies were performed at the Soroka University Medical Center lupus clinic to study the association between QoL, coping mechanisms, depression and measures of SLE activity and damage. The data of those studies are summarized in this review.

## QUALITY OF LIFE AND SLE

Systemic lupus erythematosus is a chronic autoimmune disease that is characterized by a high prevalence of neuropsychiatric manifestations, unpredictable course, and variable patterns of organ involvement. Quality of life is defined as the general well-being of individuals and societies, based on the individual's culture and life values with respect to that individual's objectives, expectation and standards.

Health-related QoL is the impact of disease and its treatment on the individual's ability to function based on physical, mental and social well-being. Variables that may affect the QoL of SLE patients include: disease activity, damage, fibromyalgia (FM), co-morbidity, medical therapy, education, illness intrusiveness (extent to which chronic illness interferes with routines, activities and interests), self-criticism, illness-related interpersonal relationships, and physician-patient relationship.

In a previous study [1] we compared the QoL of 75 SLE female patients with that of healthy women and women with primary FM using the QoL scale. The data of the study indicated that patients with SLE were dissatisfied with their health-related QoL. Compared with the heathy women, patients with SLE had lower scores for the health, work, active recreation and independence items. Fibromyalgia has a major effect on QoL of patients with SLE [2]. Patients with SLE and FM had significantly lower scores for the health-related items compared to patients with SLE without FM. The QoL scores were not associated with the SLE disease activity scores (SLEDAI).

In a subsequent study [3], the QoL of patients with SLE was assessed by the Medical Outcome Study (MOS) short form SF-36 and by the World Health Organization (WHO) QoL Bref scale. The MOS SF-36 has eight health scales, each of which measures a health concept: physical functioning, role functioning-physical, role functioning-emotional, social functioning, bodily pain, mental health, vitality, and general health perceptions. In addition, the scores of the eight subscales were computed into two summary scores: physical component summary (PCS) and mental component summary (MCS).

The World Health Organization QoL-Bref scale is composed of 26 items that encompass 5 health scales: general, environmental, social, physical, and psychological. The mean scores for the eight individual health scales and for the physical and mental health summary scores of the MOS SF-36 scales and the mean scores of the five individual health subscales of the WHO QOL-Bref for women with SLE were

significantly lower compared to controls. No linear correlation was identified between the SLEDAI and SLE damage scores (SDI) and the scores of the five subscales of the WHO QoL-Bref scale. An inverse correlation was detected between SLEDAI and the physical functioning scale of the SF-36. The SDI score was inversely correlated with the scores for physical functioning, role functioning-physical, social functioning, general health perception and PCS.

### SENSE OF COHERENCE AND SLE

The sense of coherence (SoC) construct refers to a global orientation to one's inner and outer environment, which significantly determines the link between stressors, coping with disease, and health. This construct is driven by the adaptive coping of human beings with continuous stressors and by generalized resistance resources. The salutogenic theory maintains that people are able to cope with stressful situations insofar as they can make sense of the world around them. It claims that the SoC is a construct that predicts success in coping with stressors along the continuum from 'disease' to 'ease', and makes conflict resolution possible. The SoC comprises three concepts: comprehensibility, manageability, and meaningfulness.

The association between SoC and QoL scores (SF-36, WHO QoL-24) and measures of disease activity and damage were studied in a group of 60 women [3]. Women with SLE had a significantly lower overall SoC score and lower scores for the comprehensibility and meaningfulness subscales. No significant correlation was seen between SoC scores and measures of disease activity or end-organ damage. The results of the study [3] indicate that education, age, SDI and SoC are independently associated with QoL in women with SLE. The SoC scores were directly associated with the QoL scores. Multivariate analyses models found that age, SoC and SDI significantly affected PCS scores of QoL, and SoC was the only independent variable for the MCS score of MOS SF-36. Education and SoC were significantly associated with the general WHO QOL-Bref.

### DEPRESSION IN SLE

Depressive episodes occur in 9%–35% of chronically ill patients. Up to 32% of patients with congestive heart failure develop depression, and patients with diabetes mellitus had a twofold increased risk of depression. The occurrence of depression among patients with chronic diseases is associated with increased morbidity and mortality.

We compared the prevalence of anxiety and depression in 56 SLE patients and 58 women with rheumatoid arthritis (RA) (unpublished data). The Montgomery Asberg depression rating scale and the Hamilton anxiety scale were used. We found that the prevalence of current depression, past depression and generalized anxiety were not statistically different between SLE and RA patients. Current depression was reported in 17.8% of SLE patients compared to 24.1% among RA patients. The frequencies of past depression and generalized anxiety were 35.7% vs. 36.2% and 35.7% vs. 39.2% in the SLE and RA patients, respectively. Regression models revealed that depression, anxiety and dysthemia were not associated with SLEDAI, SDI, steroid therapy, and/or non-steroidal anti-inflammatory therapy.

In a subsequent qualitative study [4], patients with SLE were interviewed according to the Giorgi method, which sums up the participant's illness experience. The main finding was that participants constructed their illness as an 'object' that explains various aspects of their experience. This means that patients with SLE assign the illness the role of a principal character (protagonist) and SLE is personified, implying the existence of 'traits' ascribed to the illness.

In a longitudinal study [5], various predictors of depression were assessed in patients with SLE. Those variables included illness intrusiveness, self-criticism (described themselves as perfectionists, driven by high and demanding internal standards), illness-related interpersonal relationships, and physician-patient relationship. Illness intrusiveness, self-criticism and symptom concealment were predictors of depression in SLE. Disease activity and damage were not part of this relationship. The subjective experience, not the illness per se, was found to cause depression.

### CONCLUSIONS

SLE is a chronic disease that is significantly associated with poor QoL, impaired SoC and a high rate of depression. Treating fibromyalgia, improving coping mechanisms, and identifying anxiety and depression should be an integral part of the therapeutic management of patients with SLE.

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LUPUS SCIENCE & MEDICINE™

# Factors associated with pain coping and catastrophising in patients with systemic lupus erythematosus: a cross-sectional study of the LuLa-cohort

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## ABSTRACT

**Objective:** The aim of this study was to identify factors associated with pain coping and catastrophising in patients with systemic lupus erythematosus.

**Methods:** All patients were participants of the lupus erythematosus long-term study, which is based on patient-reported data assessed among members of the German Lupus Erythematosus Self-Help Organization. Assessments were performed by means of a questionnaire. Among self-reported clinical data the Pain-Related Self Statements Scale (PRSS) was included. To depict significant differences univariable analyses were carried out using non-parametrical rank tests. To examine factors influencing our outcome variables, we performed a multivariable stepwise regression model including variables that presented significantly in the univariable analysis.

**Results:** 447 cases (94.9% female) were analysed showing a mean catastrophising score of 1.1 (SD 0.8) and a mean coping score of 2.8 (SD 0.9) in the PRSS subscales. Higher catastrophising quartiles went along with higher experienced pain, lupus activity, fatigue, damage and decreased health related quality of life, whereas they presented inversely for coping. In our multivariable model, factors associated with catastrophising were: number of lupus-specific drugs (p value 0.004), pain in the last 7 days (p value 0.034), the Short Form 12 Health Survey Mental Component Summary (p value <0.001) and disease activity measured by the Systemic Lupus Activity Questionnaire (p value 0.042). Social participation reflected by performed leisure activities such as dancing or bowling had a positive association with coping (p value 0.006). In contrast, other health related physical activities and their extent had no impact on coping. A direct association between the amount of pain coping and catastrophising, as well as a great impact of the catastrophising, respectively, coping level on physical and mental functioning could be shown.

**Conclusions:** Reduction or increase of detected factors might lead to a modification of pain coping and catastrophising and offer an approach to more effective care in patients with SLE.

## KEY MESSAGES

- More pain, damage and lupus-specific drugs as well as worse mental health go along with higher levels of pain catastrophising.
- Social participation/activity might enhance pain coping and reduce catastrophising.

## INTRODUCTION

Patients with systemic lupus erythematosus (SLE) suffer from possible involvement of numerous organ systems, and often from pain,[1–3] fatigue,[1 4–6] sleep disorders,[1 5 7 8] fear,[9] depression[9–13] and cognitive deficits.[14–19] These complaints, either as an independent condition or associated or aggravated by the disease, are frequently linked to physical and mental restraints. Coping describes a set of intentional, goal-directed efforts people engage in to minimise physical, psychological or social harm of an event or a situation.[20] It encompasses behavioural and psychological strategies. These strategies can help in dealing with stress caused by the disease and are associated with a better health related quality of life (HRQoL) in patients with SLE.[21] In this work we subsume the beneficial effects of coping with pain under the term 'coping'. In contrast catastrophising represents a maladaptive cognitive style employed by patients and is associated with an irrationally negative forecast of future events.

Coping is more efficient in an existing reliable social network, which may provide socio-emotional support.[22] The latter has a high impact on disease activity, damage and quality of life.[23] As patients with SLE frequently report a poorer social support than healthy controls,[24] it represents a modifiable option to enhance coping behaviour. Former studies demonstrated positive influence of

physical activity on fatigue in SLE[25–27] and pain as well as physical function in other rheumatic diseases.[28] Referring to these results we hypothesised that physical activity might have an influence on coping strategies as well.

In contrast it is known that catastrophising may have serious impact on chronically ill patients in general and patients with SLE in particular.[29] Maladaptive coping characterised by catastrophising is associated with increased pain experience[30] and predicts higher levels of pain in patients with chronic rheumatic diseases (eg, fibromyalgia syndrome and rheumatoid arthritis).[31] Furthermore, catastrophising and maladaptive coping strategies are linked to higher levels of functional impairment and depression in rheumatoid arthritis[32] and SLE.[33] Numerous other studies verified the negative influence of catastrophising, respectively, suboptimal coping strategies on the outcome of various other chronic diseases by occurrence of depressive symptoms,[34 35] reduced cognitive performance[36] or even an increased risk for suicide.[37]

As psychological interventions and education are able to increase coping abilities in patients with SLE and can thus improve their quality of life,[38] it is of major importance to explore the main stressors that affect coping behaviour.

The aim of this study was to identify factors that are associated with our outcomes pain coping and catastrophising in patients with long-standing SLE and to detect possible susceptible targets for intervention. Therefore, we analysed several demographic parameters, disease related outcomes, physical activity, physical and mental functioning, social participation and their impact on pain coping and catastrophising.

## METHODS

The data was collected within the lupus erythematosus long-term study (LuLa-study), a prospective, patient-centred study investigating the long-term management and course of disease as well as quality of life in patients with SLE. Data collection started in 2001 with annual postal questionnaires among members of the German Lupus Erythematosus Self-Help Organisation. Inclusion criteria were a reported diagnosis of SLE, being a member of the German Lupus Erythematosus Self-Help Organisation and having returned the completed questionnaire. Prior evaluation of the LuLa cohort showed that its data is comparable to physician-reported data and thereby is representative of patients with SLE in Germany.[39] In 2009 we surveyed for 18 comorbidities (hypertension, myocardial infarction, stroke, chronic kidney damage, diabetes, cancer, chronic respiratory disease, chronic liver damage, chronic gastrointestinal disorders, hypercholesterolaemia, mental illness, arthrosis, scarring changes of skin, osteoporosis, fibromyalgia, thrombosis, miscarriages, early menopause), lupus-specific drugs, sociodemographic characteristics, inability to work, degree of disability (%), HRQoL measured by the Short Form 12 Health Survey (SF-12),[40] 'pain in the last 7 days' (NRS 0–10), 'impairment in the last 7 days' (NRS 0–10), disease flares during the last 3 months, disease activity measured by the Systemic Lupus Activity Questionnaire (SLAQ),[41] health related physical activity assessed by the Freiburg Questionnaire for Physical Activity (FFkA),[42] situation-specific aspects of the patients' cognitive coping with pain ('catastrophising' and 'coping'), measured by the Pain-Related Self Statements Scale (PRSS),[43] fatigue measured by the Vanderbilt Fatigue Score (VFS),[44] and the Systemic Lupus International Collaborating Clinics/American College of Rheumatology Damage Index (SLICC/ACR DI).[45–47] Most assessments were self-reported, only for the SLICC/ACR DI patients were asked to let their physician complete the questionnaire. All questionnaire items were assessed at the same time. Due to the questionnaire's length specific instruments regarding socioemotional support had to be omitted. Therefore we used a construct using other variables.

### Measures

#### Pain-Related Self Statements Scale

Detection of coping strategies was carried out by the German version of the PRSS, which is intended to assess situation-specific cognitions that either promote or hinder attempts to cope with pain. The PRSS includes 18 items, which are subsumed into two nine-item subscales, termed 'catastrophising' and 'coping'. Items are rated on a numerical rating scale, describing how often a statement enters the patients' minds when they experience severe pain (0=almost never to 5=almost always). Questionnaire's reliability, validity and sensitivity to change were proven by Flor *et al*[43] in a sample of 415 patients including 120 patients with chronic pain suffering from various rheumatic disorders, 213 patients suffering from chronic back pain, 44 patients with temporomandibular pain and dysfunction (TMPD) and 38 healthy controls.

Both subscales demonstrated to be valid and sensitive to change, and to be closely related to pain intensity and interference from pain experiences. There are no cut-off-values defined for high or low coping, respectively, catastrophising, but results from healthy controls showed a relatively low catastrophising score of 0.9 (SD 0.8) and a relatively high coping score of 3.4 (SD 1.1).[43] In comparison patients with chronic back pain depicted a catastrophising score of 2.0 (SD 1.2) and a coping score of 3.0 (SD 0.9) and patients with TMPD a catastrophising score of 2.3 (SD 1.0) and a coping score of 2.8 (SD 0.7).[43]

#### Short-Form 12 Health Survey

The 12-item short-form (SF-12) is based on the 36-item short-form (SF-36)[40] and is used to survey a population's health status. The SF-12 provides comparable results to the SF-36.[48 49] Two subscales can be extracted: The

Physical Component Summary (PCS) and the Mental Component Summary (MCS). Because of the questionnaire's size limitations we adopted the MCS as a substitute for a more extensive inquiry of the individual factors affecting mental health (eg, depression, anxiety disorders). The MCS has repeatedly proven to be a valid instrument for identifying and assessing the severity of depression and anxiety.[50] Additionally the physical functioning index of the SF-36 (SF-36-pfi)[51] was assessed.

### Systemic Lupus Activity Questionnaire

In order to screen for current disease activity the SLAQ, which is based on the Systemic Lupus Activity Measure,[52] was applied. The SLAQ is a patient-reported questionnaire consisting of 24 items, which aims at detection of disease activity in patients with SLE.[41] In large observational, community-based cohorts of people with SLE it demonstrated to have an adequate reliability, construct validity and responsiveness.[53 54] Additionally, we used the supplemental SLAQ item 1 which assesses the occurrence and severity of disease flares (no/mild/moderate/severe flare) during the last 3 months.

### Systemic Lupus International Collaborating Clinics/American College of Rheumatology Damage Index

In order to detect damage in patients with SLE the SLICC/ACR DI was used.[45–47] It records damage in nine different organ systems, which accrued since disease onset and persisted for at least 6 months.

### Freiburg Questionnaire for Physical Activity

The cohort's health related physical activity was assessed by the FFkA.[42] It consists of 12 questions related to the duration of performed basic activities, recreational activities and sport activities per week. In the context of this study, a calculation of leisure activity was carried out using the items 'dancing' and 'bowling'. As these two social leisure activities, contrary to walking, using exercise machines, and so on, can only be performed in company, we considered them as a proxy measure for patients' 'social participation'.

Further questions considered the incidence of sick leave during the past 12 months, the number of weeks on sick leave and the degree of disability. The degree of disability is a standardised official governmental approval of non-temporary bodily or psychological disability that is due to an irregular state. Severity is graded from 20% to 100%.

### Statistical analysis

Collected data were analysed with the statistical software programme IBM SPSS Statistics V.19. A descriptive analysis was carried out by the calculation of mean, median, SD, minimum and maximum, where applicable.

By means of the PRSS the 'catastrophising' and 'coping' subscales were calculated. To assess the association between the two subscales and other outcome parameters quantitatively, we studied the four quartiles of the subscales (lower quartile <25%, 25–50%, 50–75%, upper quartile >75%) in relation to each outcome parameter. Spearman's correlations were used for ordinal-scaled and Pearson's correlations for interval-scaled data. Because of the subscales skew distribution univariable analyses (UVA) were carried out using non-parametrical rank tests to depict significant differences. In cases of two independent samples the Mann-Whitney U test and in cases of multiple independent samples the Kruskal-Wallis test was applied. p Values less than 0.05 were considered statistically significant for all tests. In order to prevent an α error due to multiple testing, adjustment of the p values by means of the Bonferroni correction was performed. Consequently, levels of statistical significance were defined at $p<\alpha/k$ ($\alpha=0.05/k$=number of tests).

To examine factors influencing our outcome variables 'catastrophising' and 'coping' among patients, we used a stepwise regression model to reduce the number of variables. Those variables that presented as significant in the UVA, entered this multivariable analysis (MVA) model including clinical and demographic parameters (SF-12 PCS, SF-12 MCS, SLAQ score, VFS, SLICC/ACR DI, number of concomitant diseases, number of lupus-specific drugs, inability to work, degree of disability (%), pain in the last 7 days, impairment in the last 7 days, disease flares during the last 3 months and social participation). Missing values were not imputated. Analysed number of cases may vary due to missing values. In MVA only complete cases were included.



## RESULTS

The LuLa 2009 cohort included 620 patients of whom 173 reported no pain (86,1%) or did not answer the PRSS questionnaire (13,9%). This resulted in 447 cases (94.9% female) with a mean age of 52.0 years (SD 12.5) and mean disease duration of 16.1 years (SD 8.1), which were included in the analyses. The analysis of the PRSS subscales showed a mean catastrophising score of 1.1 (SD 0.8) and a mean coping score of 2.8 (SD 0.9). Details and further results of self-reported disease activity, damage, current treatment, employment status, assessments of general health and physical functioning are listed in table 1.

Table 2 opposes four groups of different catastrophising and coping levels. Higher catastrophising centiles (upper quartile) are associated with higher experienced pain, current lupus activity (SLAQ score), fatigue (VFS score), damage (SLICC/ACR DI scores) and a decrease of HRQoL domains (SF-36-pfi, SF-12 PCS and SF-12 MCS) whereas they present inversely for coping (table 2).

Nine out of the 18 acquired comorbidities showed significant association to the PRSS subscale catastrophising with higher catastrophising means in presence of comorbidities than in absence (table 3).

A relationship between coping and comorbidities was not observed. Three of the nine comorbidities with

**Table 1** Sample description (447 patients)

| | Per cent | Mean±SD | Range | n |
|---|---|---|---|---|
| Age in 2009 (years) | | 52.0±12.5 | 14–86 | 447 |
| Disease duration in 2009 (years) | | 16.1±8.1 | 5–49 | 440 |
| Medication | | | | 447 |
| NSAIDs | 29.3 | | | |
| Cortisone ≤7.5 mg | 53.0 | | | |
| Cortisone >7.5 mg | 16.1 | | | |
| Antimalarials | 41.2 | | | |
| Methotrexate | 9.8 | | | |
| Azathioprine | 18.8 | | | |
| Ciclosporine | 2.2 | | | |
| Cyclophosphamide | 1.1 | | | |
| Mycofenolatmofetil (MMF) | 13.0 | | | |
| Medication groups | | | | 447 |
| NSAIDs or no medication | 14.3 | | | |
| Antimalarials and/or steroids, possible NSAIDs | 40.3 | | | |
| Immunosuppressants, possible NSAIDs, antimalarials, steroids | 45.4 | | | |
| Occupation type | | | | 443 |
| Retired | 50.1 | | | |
| Employees | 29.6 | | | |
| Unemployed | 12.9 | | | |
| Worker | 3.8 | | | |
| Self-employed | 2.9 | | | |
| Pupils/students | 0.7 | | | |
| Physical functioning (0–100) (SF-36-pfi) | | 62.4±27.5 | 0–100 | 447 |
| SF-12 PCS | | 37.9±11.0 | 11.0–62.9 | 414 |
| SF-12 MCS | | 46.1±11.7 | 18.4–69.5 | 414 |
| SLAQ score | | 14.8±7.0 | 0–37 | 446 |
| VFS score | | 26.7±19.2 | 0–70 | 424 |
| SLICC/ACR DI | | 2.8±2.9 | 0–21 | 407 |
| PRSS catastrophising | | 1.1±0.8 | 0–4.1 | 426 |
| PRSS coping | | 2.8±0.9 | 0–4.8 | 431 |

Data are percentages (%), means, SD and ranges.
N, number of cases; NSAIDs, non-steroidal anti-inflammatory drugs; PRSS, Pain-Related Self Statements Scale; SF-12 MCS, SF-12 Mental Component Summary; SF-12 PCS, SF-12 Physical Component Summary; SF-36-pfi, 36-item short-form physical functioning index; SLAQ, Systemic Lupus Activity Questionnaire; SLICC/ACR DI, Systemic Lupus International Collaborating Clinics/American College of Rheumatology Damage Index; VFS, Vanderbilt Fatigue Score.

significant association remained significant after Bonferroni correction (p value <0.003). These three comorbidities 'chronic gastrointestinal disorders' (p value 0.002), 'mental illness' (p value <0.001) and 'scarring changes of skin' (p value <0.001) were included in the MVA but did not show significant association to catastrophising any more.

In total, 52 patients (11.6%) participated in the bowling and dancing activities, whereby 31 (7.0%) participated in dancing, 13 (2.9%) in bowling and 8 (1.8%) in both. This was considered as social participation.

As shown in table 4, coping presented statistical significance for 'social participation' in the UVA (p value 0.001) and the MVA (p value 0.006). Mean coping was significantly higher in participants with social participation than without (mean 3.2 vs 2.8). 'SF-12 MCS' was significant for both PRSS subscales in the UVA (p value catastrophising <0.001; p value coping 0.001) but only significant for catastrophising in the MVA (p<0.001). Catastrophising demonstrated a multitude of significant correlations with different disease parameters and conditions among others SF-12, SLAQ, SLICC/ACR DI and disease flares during last 3 months. The variables 'pain in the last 7 days' (correlation coefficient 0.420), 'impairment in the last 7 days' (correlation coefficient 0.388), fatigue (VFS score) (correlation coefficient 0.367) and disease activity (SLAQ score) (correlation coefficient 0.475) evinced the highest correlation coefficients (table 4).

After Bonferroni correction all significant variables of the UVA were included in the MVA. Four variables reached statistical significance regarding catastrophising ('number of lupus-specific drugs' (p value 0.004), 'pain in the last 7 days' (p value 0.034), 'SF-12 MCS' (p value <0.0001), and 'SLAQ score' (p value 0.042)), and one ('social participation'; p value 0.006) regarding coping.

Parameters for basic, sports and leisure activities, assessed by the FFkA, were also compared with the two PRSS subscales. However, none of the activity parameters or the extent of health related physical activity showed a coherent statistical significance regarding pain coping and catastrophising.

**Table 2** Characteristics of PRSS catastrophising and coping groups split by quartiles

| | PRSS catastrophising | | | | PRSS coping | | | |
|---|---|---|---|---|---|---|---|---|
| | Lower quartile (0–0.4) | 25–50% (0.5–1.0) | 50–75% (1.1–1.7) | Upper quartile (1.8–4.1) | Lower quartile (0–2.3) | 25–50% (2.4–2.9) | 50–75% (3.0–3.4) | Upper quartile (3.5–4.8) |
| n | 113 | 101 | 114 | 98 | 131 | 106 | 102 | 92 |
| Age in 2009 | 50.8 | 53.2 | 51.0 | 52.4 | 51.6 | 52.5 | 51.4 | 51.0 |
| Disease duration in 2009 | 16.0 | 16.4 | 16.0 | 15.8 | 16.6 | 15.9 | 15.6 | 15.7 |
| Coping | 2.8 | 2.9 | 2.9 | 2.7 | 1.6 | 2.6 | 3.2 | 3.9 |
| **Catastrophising** | 0.2 | 0.7 | 1.4 | 2.2 | 1.2 | 1.3 | 1.1 | 0.9 |
| SF-36-pfi | 73.3 | 65.5 | 59.3 | 51.6 | 62.8 | 57.0 | 63.9 | 66.5 |
| SF-12 PCS | 41.6 | 38.8 | 36.0 | 34.9 | 38.8 | 36.5 | 37.6 | 38.6 |
| SF-12 MCS | 52.2 | 49.2 | 43.6 | 40.0 | 44.5 | 43.1 | 48.3 | 49.8 |
| SLAQ score | 10.5 | 13.6 | 17.1 | 18.2 | 14.7 | 16.4 | 14.4 | 13.4 |
| VFS score | 17.9 | 24.2 | 30.6 | 34.4 | 27.9 | 29.1 | 25.9 | 22.0 |
| SLICC/ACR DI | 1.8 | 2.6 | 3.1 | 3.6 | 2.5 | 3.5 | 3.1 | 2.2 |
| Pain (last 7 days) | 2.6 | 3.4 | 4.3 | 5.1 | 3.8 | 4.2 | 3.8 | 3.3 |

Data are means illustrated separately for PRSS catastrophising and PRSS coping. Different levels of catastrophising resp. coping are represented in four quartiles.
n, number of cases; PRSS, Pain-Related Self Statements Scale; SF-12 MCS, SF-12 Mental Component Summary; SF-12 PCS, SF-12 Physical Component Summary; SF-36-pfi, 36-item short-form physical functioning index; SLAQ, Systemic Lupus Activity Questionnaire; SLICC/ACR DI: Systemic Lupus International Collaborating Clinics/American College of Rheumatology Damage Index; VFS, Vanderbilt Fatigue Score.

## DISCUSSION

Despite the numerous recent advances in research and clinical treatment, SLE keeps being an incurable chronic disease with a huge impact on persons' lives by affecting patients' physical and mental functioning. Former studies illustrated that coping capacities help in dealing with the disease and are associated with a better HRQoL.[21]

The PRSS results from our cross-sectional study in SLE depicted significantly worse catastrophising and coping scores than reported from healthy controls.[43] Coping presented worse in our cohort compared with patients with chronic pain but was similar to patients suffering from TMPD.[43] In contrast our cohort presented significantly less catastrophising.[43] As pain related catastrophising differs in younger and older adults[55] these



**Table 3** Univariable analysis: comorbidities (n=447)

| | Catastrophising mean±SD (n) | | |
|---|---|---|---|
| **Comorbidity** | **Comorbidity=yes** | **Comorbidity=no** | **p Value catastrophising** |
| Diabetes | 1.4±0.8 (8) | 1.1±0.8 (375) | 0.034 |
| Chronic respiratory disease | 1.2±0.8 (36) | 1.1±0.8 (349) | 0.031 |
| Chronic liver damage | 1.5±0.9 (10) | 1.1±0.8 (370) | 0.007 |
| Chronic gastrointestinal disorders | 1.3±0.8 (26) | 1.0±0.8 (355) | 0.002 |
| Mental illness | 1.7±0.8 (38) | 1.0±0.7 (342) | <0.001 |
| Arthrosis | 1.2±0.8 (86) | 1.0±0.7 (295) | 0.021 |
| Scarring changes of skin | 1.3±0.8 (47) | 1.0±0.8 (332) | <0.001 |
| Fibromyalgia | 1.4±0.8 (27) | 1.1±0.8 (347) | 0.014 |
| Stroke | 1.9±0.9 (9) | 1.1±0.8 (376) | 0.023 |
| Hypertension | | | NS |
| Myocardial infarction | | | NS |
| Chronic kidney damage | | | NS |
| Cancer | | | NS |
| Hypercholesterolaemia | | | NS |
| Osteoporosis | | | NS |
| Thrombosis | | | NS |
| Miscarriages | | | NS |
| Early menopause | | | NS |

Data are means and SD, n: number of cases. Means are depending on existence of comorbidities (comorbidity=yes, means: comorbidity exists; comorbidity=no, means: comorbidity does not exist). The p values for catastrophising were derived from the Mann–Whitney U test. As there were no significant associations regarding coping, it is not listed in the table.
NS, not significant.

Table 4 Findings of the univariable analysis (UVA) and multivariable analysis (MVA)

| | Catastrophising | | | Coping | | |
|---|---|---|---|---|---|---|
| Variable name | p Value (UVA) | Correlation coefficient | p Value (MVA) | p Value (UVA) | Correlation coefficient | p Value (MVA) |
| SF-12 PCS | <0.001 | −0.250** | | NS | | |
| SF-12 MCS | <0.001 | −0.443** | <0.001 | 0.001 | 0.171** | NS |
| SLAQ score | <0.001 | 0.475* | 0.042 | NS | | NS |
| VFS score | <0.001 | 0.367* | | NS | | |
| SLICC/ACR DI | <0.001 | 0.192* | | NS | | |
| Number of concomitant diseases | <0.001 | 0.202* | | NS | | |
| Number of lupus-specific drugs | <0.001 | 0.204* | 0.004 | NS | | NS |
| Inability to work | 0.001 | 0.213* | | NS | | |
| Degree of disability (%) | 0.003 | 0.169** | | NS | | |
| Pain in the last 7 days | <0.001 | 0.420* | 0.034 | NS | | NS |
| Impairment in the last 7 days | <0.001 | 0.388* | | NS | | |
| Disease flares during last 3 months | <0.001 | 0.280* | | NS | | |
| Social participation | NS$^{x}$ | | NS | 0.001$^{x}$ | | 0.006 |

Data are p values and correlation coefficients. Correlations were carried out by Spearman's (*) and Pearson's (**) correlations. The p values for catastrophising and coping in the UVA were derived from Spearman's and Pearson's correlation or from the Mann–Whitney U test (x). The p values for catastrophising and coping in the MVA were derived from ANOVA (analysis of variance). Only complete cases (n=323) were included in the MVA.
SF-12 MCS, SF-12 Mental Component Summary; SF-12 PCS, SF-12 Physical Component Summary; SLAQ, Systemic Lupus Activity Questionnaire; SLICC/ACR DI, Systemic Lupus International Collaborating Clinics/American College of Rheumatology Damage Index; VFS, Vanderbilt Fatigue Score.

differences may partly be explained by the younger age in Flor's cohort[43] (42.4 years vs 52.1 years). Compared with patients with fibromyalgia[56] our SLE cohort showed lower amount of catastrophising and coping. This might be attributed to a high rate of depression in the fibromyalgia cohort and to the inclusion of patients participating in pain management programmes.[56]

We identified valuable parameters that seem to influence the occurrence of either catastrophising or coping in patients with SLE. Yet it should be noted that cross-sectional studies limit the ability to make causal assumptions between the predictors and outcomes.

First, our results demonstrated that patients with SLE with our above mentioned comorbidities catastrophise more than those without, which emphasises the impact of these specific comorbidities in patients with SLE. Studies from other chronic diseases support our findings.[57 58] Thus it is of importance that 'scarring changes of skin',[59] 'mental illness'[60] and 'gastrointestinal disorders'[61] might also be attributable to lupus and are preventable by an early and optimised lupus therapy.

Second, we found statistically significant associations between the number of lupus-specific drugs, pain, 'SF-12 MCS', damage and catastrophising. In detail the high correlation between the 'experienced pain in the last 7 days' and catastrophising (Table 4) confirms findings from former studies depicting that the experience of pain in rheumatological disorders is closely related to catastrophising.[29 31 62]

The moderate correlation between 'SF-12 MCS' (a proxy for depression and anxiety) and catastrophising presented in our work substantiates the fact that suboptimal mental health is associated with catastrophising, which has already been demonstrated in former studies.[34–37]

Besides, we showed that the 'number of lupus-specific drugs' significantly increases with a higher catastrophising score. Yet, it has not been clarified whether a rising amount of medication leads to increased catastrophising or vice versa. Consequently, physicians should be aware of possible aggravations and ought to apply objective criteria for the choice of medication.

Third, referring to coping, the variable 'social participation' reached statistical significance in the MVA. This is allegeable by the numerous positive effects associated with an existing social network and the provided socioemotional support.[22] An obviously anticipated reciprocal correlation between the amount of pain coping and catastrophising could likewise be shown in our work. This indicates that a sufficient manner of coping (eg, by increasing social participation/activity) might be helpful to reduce catastrophising and consequently improve physical and mental functioning in SLE (Table 2).

In addition, it needs to be considered that catastrophising, pain, disability and mood-emotional functioning might bias the questionnaire's response behaviour. Patients might indicate a poorer health condition than it actually is because of their tendency to catastrophise,

their experienced severity of pain, their physical functioning and/or psychological condition. Our results depicted in table 2 support this hypothesis, as the group of the strongest catastrophiser (upper quartile) showed poorer values for all mentioned variables than the others (lower quartile, 25–50%, 50–75%). A similar observation was published by Mancuso *et al*[63] who detected that patients with asthma with more depressive symptoms reported worse HRQoL than patients with asthma with similar disease activity but fewer depressive symptoms. These findings emphasise that psychological conditions might have an impact on patients' response behaviour.

Most of our identified key factors that interact with pain coping strategies (number of lupus-specific drugs, pain, mental health, disease activity) have been identified as disease aggravating factors in the SLE treat-to-target recommendations published in 2014.[64] They can be modified by an effective therapy which is regularly adjusted to lupus manifestations and individual needs. Furthermore pain and mental health as well as pain coping and catastrophising can effectively be improved by using psychological or psychoeducational interventions,[38 65–68] which among others aim at increasing the self-efficacy of patients.

### Limitations

There are certain limitations to this study. In favour of other items there was no implementation of further questions regarding social participation and social environment in the LuLa study. Our variable 'social participation' was constructed by use of two variables ('dancing' and 'bowling'), not considering other social activities. It should be mentioned though that other solitary activities (eg, 'taking a walk', 'cycling'), which by the way can be performed also in groups and not only alone, as well as the extent of health related physical activity, assessed by parts of the FFkA,[42] did not show statistical significance regarding coping nor regarding catastrophising. For further evaluation future studies should consider other activities in detail as well (eg, membership with active participation in societies or clubs, team sports or regular leisure activities in groups) in order to provide better recommendations for optimal patient care.

As the surveyed participants were all members of the German Lupus Erythematosus Self-Help Organisation, we were not able to evaluate the impact of support groups. A distinction between passive and active members (eg, participants in support group meetings, activities or online discussion groups) could point out further strategies to improve coping and minimise catastrophising.

To our knowledge our sample included predominantly Caucasians and did not include other ethnical groups. In addition we are not able to comment on catastrophising and coping in recently diseased patients. Hence, further studies in an inception cohort are necessary in order to evaluate coping strategies in early disease.

## CONCLUSION

Our work points out that in order to optimise pain coping and catastrophising in the care of patients with SLE and to affect patients' physical and mental functioning, positive factors should be protected and promoted and negative factors need to be prevented. In this context social participation represents an essential positive factor whereas negative ones include disease activity, pain, impairments and an extensive lupus-specific medication. Further studies are necessary to determine which patients benefit most from a psychoeducation and to identify the impact of revised modifiable parameters on coping strategies.

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