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LARISSA RODRIGUES

MULHERES COM LÚPUS EM IDADE REPRODUTIVA: INTERFACE DAS QUESTÕES PSICOLÓGICAS, GRAVIDEZ E IMAGEM CORPORAL

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Tese apresentada ao Programa de Pós-Graduação em Tocoginecologia da Faculdade de Ciências Médicas, da Universidade Estadual de Campinas – UNICAMP, para obtenção do título de doutora em Ciências Médicas na área de concentração Saúde Materna e Perinatal.

Doctoral Thesis presented to the Obstetrics and Gynecology, Graduate Program the School of Medical Sciences, University of Campinas to obtain the title of Doctor of Health Sciences, concentration area Maternal and Perinatal Health.

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“Ando devagar porque já tive pressa e levo esse sorriso porque já chorei demais. Cada um de nós compõe a sua história e cada ser, em si, carrega o dom de ser capaz e ser feliz...”

Trecho da música Tocando em frente de Renato Teixeira e Almir Sater gravada pela primeira vez por Maria Bethânea 1990. Disponível em: https://www.youtube.com/watch?v=_knSdynXLy8

RESUMO

Objetivo: Compreender a experiência de mulheres grávidas com lúpus sobre significados atribuídos à gravidez e ao cotidiano com a doença e entender a relação destas com o lúpus, com foco nas questões psicossociais, na história reprodutiva, na imagem corporal e no autoconceito.

Métodos: Nesta tese, aplicaram-se métodos mistos: 1- Clínico-qualitativo, utilizando-se de técnica de entrevista com roteiro semidirigido de perguntas abertas como instrumento, realizando fechamento da amostra por exaustão e análise dos dados em sete passos da análise clínico-qualitativa e software NVIVO 11 para organização do material. 2- Quantitativo descritivo, com questionário WHOQOL-bref como instrumento, considerando variáveis categóricas, com valores de frequência absoluta (n) e percentual (%) e estatística descritiva (escores das 26 questões do WHOQOL-bref), utilizando-se do programa Sistema de Análise Estatística 9.2. Os estudos primários tiveram o ambulatório de Pré-Natal Especializado do Hospital da Mulher Prof. Dr. José Aristodemo Pinotti - CAISM / UNICAMP como cenário. 3- Desenvolveram-se duas revisões sistemáticas com coleta de dados nas principais bases eletrônicas em saúde: na primeira, buscou-se por questões psicossociais das mulheres com lúpus e, na segunda, pesquisou-se sobre autoconceito e imagem corporal dessas mulheres.

Resultados: Cinco artigos foram construídos: Artigo 1: Revisão sistemática: encontraram-se 166 artigos, destes, sete foram incluídos, a partir da análise de conteúdo, identificaram-se três temas: 1) Planejamento da gravidez; 2) Gravidez e recém-nascido; 3) Habilidades dos profissionais de saúde em planejamento, pré-natal, pós-parto e atividades educativas. Artigo 2: Estudo qualitativo com coleta entre julho / 2017 e julho / 2018 (n = 26). Durante a análise do material (entrevistas transcritas e diário de campo), construíram-se quatro categorias: 1) Gravidez não planejada e não uso de contraceptivos; 2) Sentir-se saudável, apesar do médico ter alertado que a doença pode piorar com a gravidez; 3) Alegria presente, associada à gravidez e ao medo do futuro pelas complicações possíveis; 4) Autopercepção e percepção dos outros. Artigo 3: Aprofundamento metodológico do estudo qualitativo, com parte dos dados brutos. Artigo 4: Análise descritiva acerca da qualidade de vida das mulheres abordadas em campo (n = 50), constatando-se escores mais baixos no domínio físico, quando comparado aos domínios psicológico, social e ambiente. Artigo 5: Revisão sistemática, em que se encontraram 647 artigos, destes, incluíram-se 22, por meio da análise de conteúdo, geraram-se três categorias: 1) Depressão e ansiedade causadas por mudanças corporais (queda de cabelo, ganho de peso); 2) Imagem corporal refletindo a doença; e 3) Intervenções para promover a aceitação e adaptação à nova imagem.

Conclusão: Mulheres com lúpus podem ser vulneráveis emocionalmente com relação aos aspectos reprodutivos: planejamento, gravidez e pós-parto. Evidenciou-se ambiguidade no relato das mulheres participantes, com expressão de potencial desejo por experimentar a maternidade e, ao mesmo tempo, com muitas preocupações relacionadas à segurança para concretizar este anseio. As participantes deste estudo apresentaram percepção de melhor qualidade de vida geral do que mulheres em outras localidades do país acompanhadas em pré-natal de alto risco. O aprofundamento em dimensões de autoconceito e imagem corporal faz entender como a mulher se relaciona com a doença.

Palavras-chave: Lúpus Eritematoso Sistêmico; Gravidez; Saúde Reprodutiva; Puerpério; Aspectos psicossociais; Qualidade de Vida; Autoconceito; Imagem Corporal; Revisão Sistemática; Pesquisa Qualitativa.

ABSTRACT

Objective: To understand the experience of pregnant women with lupus on the meanings attributed to pregnancy and daily life with the disease, and to understand their relationship with lupus, focusing on psychosocial issues, reproductive history, body image, and self-concept.

Methods: Mixed methods were applied: 1) Clinical qualitative; interview technique with a semi-directed script of open questions was used as an instrument, sample closure by exhaustion was performed, and the data were analyzed in seven steps of the clinical qualitative; materials were organized with NVivo 11. 2) Descriptive quantitative, the WHOQOL-BREF questionnaire was used as an instrument, categorical variables were considered with absolute frequencies (n) and percentages (%) and descriptive statistics (scores of the 26 questions in the WHOQOL-BREF) using Statistical Analysis System 9.2. The primary studies used the Specialized Prenatal Outpatient Clinic of Hospital da Mulher Prof. Dr. José Aristodemo Pinotti, CAISM, UNICAMP, as a setting. 3) Two systematic reviews were performed, involving data collection from the main electronic health databases: first, we searched for the psychosocial issues of women with lupus; second, we researched the self-concept and body image of these women.

Results: Five articles were drafted: Article 1: Systematic review: 166 articles were retrieved online, of which seven were included. Content analysis identified three themes: 1) Pregnancy planning, 2) Pregnancy and newborn, 3) Health professionals' skills in planning, prenatal, postpartum, and educational activities. Article 2: Qualitative study; data were collected between July 2017 and July 2018 (n = 26). During analysis of the material (transcribed interviews and field diary), four categories were constructed: 1) Unplanned pregnancy and no contraceptive use, 2) Feeling healthy although the doctor warned that the disease may worsen with pregnancy, 3) Feeling joy associated with pregnancy, and fear of the future due to possible complications, 4) Self-perception and perception of others. Article 3: Methodological deepening of the qualitative study with a part of the raw data. Article 4: Descriptive analysis of the quality of life of women approached in the field (n = 50), with lower scores in the physical domain when compared to the psychological, social, and environment domains. Article 5: Systematic review, where 647 articles were retrieved, of which 22 were included. Content analysis generated three categories: 1) Depression and anxiety caused by body changes (hair loss, weight gain), 2) Body image reflecting the disease, and 3) Interventions for promoting acceptance and adaptation to the new image.

Conclusion: Women with lupus can be emotionally vulnerable regarding aspects of reproduction, i.e., planning, pregnancy, and postpartum. There was ambiguity in the reports of the participating women: they expressed the desire to experience motherhood; at the same time, there were many concerns related to security to fulfill this desire. The participants in this study perceived a better overall quality of life than women in other parts of the country followed-up in high-risk prenatal care. The deepening in the dimensions of self-concept and body image allows us to understand how women relate to the disease.

Key words: Systemic Lupus Erythematosus; Pregnancy; Reproductive Health; Puerperium; Psychosocial aspects; Quality of life; Self-concept; Body image; Systematic review; Qualitative research.

LISTA DE SIGLAS E ABREVIATURAS

ACR – *American College of Reumatology*
ANA- *Antinuclear Antibody*
CAAE – Certificado de Apresentação para Apreciação Ética
CAISM - Hospital da Mulher Prof. Dr. José Aristodemo Pinotti
EUA- Estados Unidos da América
EULAR - *European League Against Rheumatism*
FEBRASGO - Federação Brasileira das Associações de Ginecologia e Obstetrícia
FCM – Faculdade de Ciências Médicas
LES – Lúpus Eritematoso Sistêmico
MAC – Método Anticoncepcional
OMS- Organização Mundial da Saúde
PNA- Pré-Natal de Adolescentes
PNAR- Pré-Natal de Alto Risco
PNE - Pré-Natal Especializado
PRISMA- *Preferred Reporting Items for Systematic Reviews and Meta-Analyses*
PROSPERO- *International Prospective Register of Systematic Reviews*
SARHAS – Saúde Reprodutiva e Hábitos Saudáveis
SAS - *Statistical Analysis System*
SLICC - *Systemic Lupus International Collaborating Clinics*
SUS – Sistema Único de Saúde UNICAMP – Universidade Estadual de Campinas
UV- Ultravioleta

SUMÁRIO

INTRODUÇÃO

Lúpus Eritematoso Sistêmico

No início do século passado, Paul Erlich, em 1940,[1] admitiu a impossibilidade de sistema imunológico para reconhecer elementos autoconstituintes e, então, conceituou o "*horror autotoxicus*"(1). Dois autores contemporâneos identificaram fatores séricos com autorreatividade: o fator reumatóide(2) e o fenômeno da célula LE(3), e abriram o campo das pesquisas sobre um grupo de doenças denominadas autoimunes, assim como os respectivos impactos nos processos de saúde-doença(4).

O progresso constante na demonstração de uma série de autoanticorpos clinicamente relevantes trouxe o sistema de classificação para essas doenças (5-7) e o Lúpus Eritematoso Sistêmico (LES) está entre elas.

Lúpus Eritematoso Sistêmico pode se apresentar de diferentes formas e uma pessoa com LES pode sofrer grande impacto no estilo de vida, enquanto outras apresentarão pouca ou nenhuma interferência nessa perspectiva, o que pode interferir no diagnóstico, tratamento e prognóstico individual(8, 9).

De forma geral, LES é uma doença autoimune multissistêmica que pode afetar qualquer órgão ou sistema, incluindo pele, coração, pulmão, articulações, rins sistema nervoso e membranas serosas. Há entre 9 a 241 para 100.000 pessoas(10), com grande variabilidade da ocorrência da doença mesmo dentro de um país ou região(11) com proporção entre mulheres e homens de 9: 1 e prevalência entre mulheres em idade reprodutiva(8, 9).

A etiologia do LES não é totalmente esclarecida, porém existem algumas associações com a incidência da doença: fatores genéticos(10,12) e fatores

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[1] Erlich P. Gesammelte Arbeiten über Immnitätsforschung. Berlim, A. Hirschwald 1940 apud (1).

ambientais, como exposição à sílica, tabagismo, contraceptivos orais e terapia hormonal na pós-menopausa. Outros fatores são apontados, ainda que mais estudos sejam necessários para confirmação: exposição à poluição do ar, luz ultravioleta (UV), solventes, pesticidas e metais pesados(13).

Há relatos da doença em todos os continentes, e pesquisas têm mostrado diferentes características da doença (incidência e gravidade) entre as diferentes populações (afro-americanos, hispânicos, europeus e asiáticos)(10).

A definição do diagnóstico do LES é complexa e os critérios que definem a atividade da doença estão em constante avaliação, embora alguns sinais e sintomas sejam comuns às classificações existentes.

Nas últimas décadas, observa-se desenvolvimento de critérios de classificação propostos pelo *American College of Reumatology* (ACR)(6), em 1982, revisados em 1997(14); proposta de critérios de classificação, em 2012, pelas *Systemic Lupus International Collaborating Clinics* (SLICC)(15), na tentativa de suprir fragilidades inerentes aos critérios de classificação do ACR; e, em 2019, desenvolvimento de novos critérios de classificação pela *European League Against Rheumatism* (EULAR), junto às *Systemic Lupus International Collaborating Clinics* (SLICC)(16).

O tratamento medicamentoso nos casos mais graves de LES envolve equilíbrio entre suprimir os sinais e sintomas da doença e controlar toxicidades dos medicamentos utilizados. Com o tratamento, pode-se observar melhores índices de atividade da doença, no entanto, em algum momento a pessoa pode ter percepção de piora, em virtude dos efeitos adversos das medicações(17, 18).

Como, talvez, haja relação entre exposição à luz UV e exacerbações do LES (19), e também pela fotossensibilidade que a doença acarreta a orientação às pessoas com LES sobre quanto evitar excessos de exposição ao sol, aplicação adequada de filtro solar com cobertura de amplo espectro e, também, ao uso de vestuário que possam promover essa proteção, as quais constituem medidas educacionais pertinentes(20).

Muitas pessoas com LES têm baixos níveis séricos de 25-hidroxivitamina D, deficiências mais graves foram associadas à presença de doença renal e à fotossensibilidade. A necessidade de estudos que mostrem os resultados na prevenção de episódios de ativação da doença ou no tratamento do LES é apontada(21).

Em revisão de literatura que examinou 11 estudos de intervenção alimentar em pessoas com LES, apontou que a suplementação com ômega-3 mostrou redução de inflamação, atividade da doença, disfunção endotelial e estresse oxidativo; a suplementação de vitamina D aumentou níveis séricos e reduziu inflamação; a suplementação de açafrão reduziu proteinúria, hematúria e pressão arterial sistólica; e uma dieta com baixo índice glicêmico promoveu diminuição de peso, o que contribui para minimizar a fadiga(22).

O tabagismo foi significativamente associado a danos crônicos e à morbidade em pessoas com LES(23, 24). E, por ser fator potencialmente modificável, pessoas com LES precisam ser desencorajadas ao hábito(23).

Algumas terapias complementares à terapia medicamentosa também são citadas como promissoras na literatura em relação ao controle dos sintomas, quais sejam: psicoterapia(25, 26), terapias psicoeducacionais(27), exercícios físicos(28) (fadiga, ansiedade, depressão, qualidade de vida), relaxamento e acupuntura(29) (dor).

Em outra revisão de literatura sobre 15 estudos realizados com essas intervenções(30), há discussão sobre a tendência de bons resultados no controle dos sintomas, no entanto, as intervenções foram realizadas para alcançar objetivos de pesquisa, havendo, assim, necessidade de observar essas práticas no cotidiano das pessoas com LES.

Gravidez e lúpus

Como a maior incidência é observada em mulheres em idade reprodutiva, a gravidez é uma possibilidade para esse grupo, considerando o desenvolvimento de tratamento e preocupação com a qualidade de vida das mulheres com o diagnóstico. No entanto, mulheres com LES têm, durante a gravidez e puerpério, risco aumentado de complicações materno-fetais(8).

As condições mais comuns observadas durante a gravidez incluem hipertensão, nefropatia e presença de autoanticorpos, podendo afetar o binômio materno-fetal(31, 32). Com a presença de complicações, os desfechos relatados englobam: maior incidência de parto prematuro, parto cesáreo e pré-eclâmpsia (33), prognóstico fetal, ainda, prejudicado por situações comuns, como aborto e restrição de crescimento fetal, da mesma forma se observam maiores taxas de mortalidade materna(9, 34). Ainda, pode-se observar mortalidade materna 20 vezes maior nas mulheres com LES, em comparação com as mulheres sadias, embora o índice de mortalidade materna geral tenha caído drasticamente nos últimos 50 anos(34).

A atividade de doença, durante a gravidez, traz desafios, no que diz respeito à distinção de alterações fisiológicas relacionadas à gravidez e às manifestações relacionadas à doença(35).

A recomendação é que a concepção ocorra após período de inatividade da doença de, pelo menos, seis meses, no entanto, mesmo diante desse controle, a presença de complicações foi observada em 30%-60% dos casos, porém a magnitude dessas complicações foram leves e ocorreram, predominantemente, no segundo trimestre da gravidez e no período pós-parto, considerando que, no terceiro trimentre, as alterações hormonais acentuadas podem estar relacionadas a não ocorrência de complicações(36).

Diante do potencial de complicações e morbidades dessas mulheres grávidas com LES, é necessário preconizar acompanhamento por equipe multidisciplinar, com planejamento da gravidez e adequado seguimento pré-natal, com objetivo de alcançar melhor prognóstico materno-fetal. A terapia medicamentosa deve ser mantida e ajustada preferencialmente antes da concepção para o uso de medicação compatível com o período da gestação,observando as particularidades de cada mulher grávida, assim como os outros cuidados citados relacionados ao controle da doença(31). O monitoramento do desenvolvimento e da vitalidade fetal são essenciais e a periodicidade deve ser avaliada em cada caso (32, 36).

A preocupação com a possibilidade de gravidez para essas mulheres passou a ser alvo de estudos, encontrou-se amplo estudo de coorte em pacientes com LES inativo ou doença leve/moderada estável no momento da concepção, cujos resultados mostraram gestação descomplicada em 81% dos casos, sendo que 5% terminaram com óbito fetal ou neonatal e 3% com acometimentos maternos graves(37).

A avaliação obstétrica e clínica da mulher e os processos de doença, durante a gravidez ou anteriores a ela, motivam a reflexão de que, na presença de condição na qual a vida ou a saúde da mãe e/ou do feto e/ou do recém-nascido têm maiores chances de serem atingidas que as da média da população considerada, deve-se referenciar a mulher para o pré-natal de alto risco(38) e, da mesma forma, a classificação deve ser considerada nas maternidades para pré-parto, parto e pós-parto(39).

Nesse cenário, a mulher grávida com LES tem classificação de gravidez de alto risco e necessita de acompanhamento pré-natal especializado.

Experiência e significados atribuídos à gravidez

Além dos aspectos fisiológicos e clínicos, grandes transformações físicas, psíquicas e emocionais são inerentes ao processo gravídico, e as expectativas, de forma geral, vão em direção ao nascimento do bebê e de viver com o filho no cotidiano, nutrindo, cuidando e educando. Desta forma, como será a percepção dessa mulher em relação a essa promessa de nova vida e à gravidade ameaçadora do LES? E como ela percebe a vida diária com a gestação e a doença, além disso, como pode representar a própria qualidade de vida?

A experiência desse processo de gravidez e doença concomitantes, portanto, trarão transformações que alterarão a vida cotidiana das mulheres, fazendo aproximação com a palavra experiência, em sentido subjetivo do que resta de aprendido, a partir de várias ocorrências, no decorrer da própria vida(40).

E, da mesma forma, a partir da leitura de Merleau-Ponty(41-43), entende-se, aqui, experiência como fato inconsciente que fundamenta saber e ação, que produz significados e esses significados permitem ter acesso ao real (consciente), no entanto, considerando que há sempre mais na experiência vivida do que no significado construído e a ela atribuído.

Os significados atribuídos às experiências de vida influenciarão na forma como serão desenvolvidas as relações e se enfrentarão as mais diversas situações(43). Assim, a saúde mental dessas das mulheres grávidas com LES terá grande impacto dos significados que elas construirão, considerando o entendimento sobre gravidade da doença com a gravidez em curso e ocorrências de problemas relacionados à situação de vida. Esse processo será levado para o desfecho da história de puerpério dessas mulheres e, consequentemente, para o processo de vida da mãe e do bebê, ao longo do tempo.

Qualidade de vida, aspectos psicossociais e imagem corporal

A qualidade de vida das pessoas com LES é uma preocupação, tanto pela própria doença quanto por efeitos do tratamento medicamentoso(17). Dessa forma, os profissionais reconhecem a qualidade de vida para essas mulheres em atendimento pré-natal, especialmente por essa percepção poder estar associada à disposição para autocuidado e tratamento(44).

O termo qualidade de vida foi definido pela Organização Mundial da Saúde como “a percepção do indivíduo de sua posição na vida, no contexto da cultura e sistema de valores nos quais ele vive e em relação aos seus objetivos, expectativas, padrões e preocupações”(45:551).

Os aspectos psicossociais influenciam a vida desta mulher grávida com lúpus, podendo interferir na forma como ela vivencia a gravidez e a doença, como percebe a qualidade de vida e como será seu desenvolvimento nos papéis de mulher e mãe, especialmente se o estiver olhar voltado para os aspectos reprodutivos: saúde reprodutiva, planejamento da gravidez, gravidez, parto e pós-parto.

Aspectos entendidos como condições de vida no contexto de variáveis sociodemográficas (ter filhos, conjugalidade, renda, escolaridade, religião, cor da pele) e do impacto desses aspectos no adoecer (isolamento social, ansiedade e depressão), com base nos conceitos da psicologia médica e da psicanálise. Fatores psicossociais são associados ao adoecer e são relevantes no processo saúde-doença(46).

Da mesma forma, alguns pontos importantes sobre a percepção da mulher sobre si e da forma como ela entende que os outros a percebem, grávida e com lúpus, também permeiam e influenciam a vida desta mulher(47).

Dois conceitos interessantes exemplificam esses pontos:

1.a imagem corporal que mostra representação interna da aparência e as percepções de comportamento e atitudes mantidas por um indivíduo(48, 49). As dimensões atitudinais da imagem corporal, que incluem as crenças e os valores de um indivíduo(48), podem ser exploradas em diversas perspectivas. As dimensões perceptivas da imagem corporal estão focadas nos julgamentos precisos de um indivíduo em relação a seu tamanho, peso e forma corporal(48).

2.o autoconceito que difere da imagem corporal, ela reflete a aparência externa e é separada do autoconceito, que se refere à visão de um indivíduo de si como pessoa. Entre as pessoas com LES, o autoconceito pode permanecer positivo, mesmo quando a imagem corporal é negativa(49, 50).

Diante das considerações sobre os pilares que fundamentam o problema de pesquisa e da justificativa para empenhar pesquisas nesse âmbito, sendo a gravidez um dos temas prioritários em pesquisa dentro da grande área saúde da mulher, segundo a Agência Nacional de Prioridades de Pesquisa em Saúde, 2018(51).

E com vistas a preencher lacuna sobre aspectos de saúde mental, no período perinatal, em âmbito internacional(52), procurou-se acessar essas nuances da mulher com LES durante a gravidez e conhecer os significados atribuídos à gravidez na presença do LES, bem como avaliar a qualidade de vida dessa mulher. E, desta forma, trazer reflexões importantes em direção a um atendimento em saúde de maior qualidade.

OBJETIVOS

Geral

Compreender a experiência de mulheres com lúpus sobre significados atribuídos à gravidez e ao cotidiano com a doença e entender a relação destas com o lúpus, com foco nas questões psicossociais, na história reprodutiva, na imagem corporal e no autoconceito.

Específicos

1. Revisar a literatura sobre os aspectos psicossociais das mulheres com LES, em suas questões reprodutivas;
2. Compreender as percepções e os significados atribuídos pelas mulheres com LES à gravidez, em um serviço de pré-natal especializado;
3. Disponibilizar detalhes do desenvolvimento do trabalho qualitativo desta pesquisa para estimular a construção de novas questões de pesquisa, em cenários diversos;
4. Investigar a qualidade de vida das mulheres com LES, no terceiro trimestre de gestação, em um serviço de pré-natal especializado;
5. Explorar a literatura sobre questões relacionadas à imagem corporal e ao autoconceito das mulheres com LES.

MÉTODOS

Esta pesquisa foi desenhada em um método misto que trouxe dois tipos de estudos em campo: clínico-qualitativo e quantitativo descritivo. Além destes, o método de revisão sistemática de literatura foi utilizado para construir outros dois estudos relacionados ao tema. Finalmente, elaborou-se um estudo metodológico que explorou os detalhes de desenvolvimento do trabalho qualitativo e alguns dados brutos. A Figura 1 mostra a relação entre os estudos.

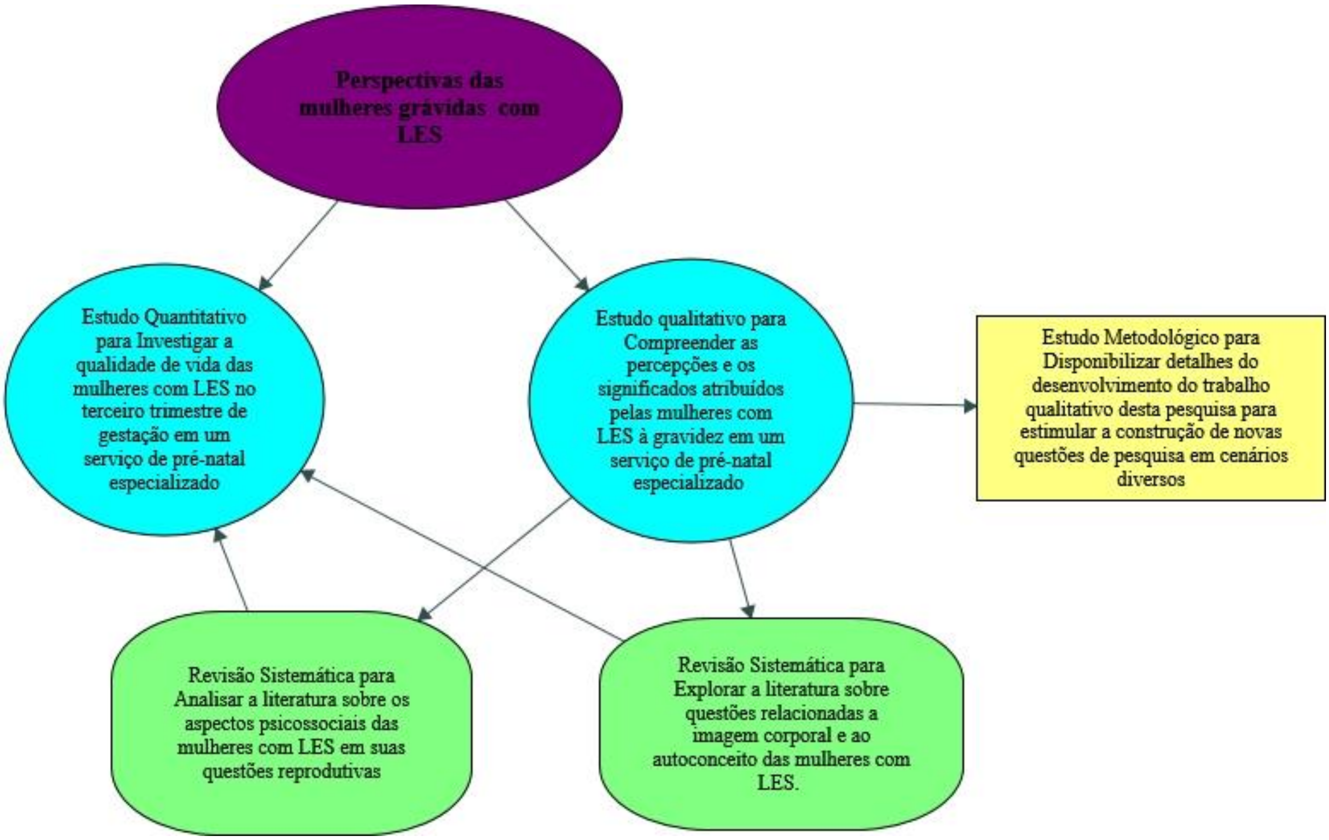

Figura 1. Diferentes métodos para compor o trabalho

Método 1- Qualitativo

O método clínico-qualitativo(53, 54) tem sua origem nos conceitos da pesquisa qualitativa, que se ocupa do estudo dos fenômenos onde eles ocorrem naturalmente. O desenho clínico-qualitativo, utilizado nesta tese, traz refinamento para aplicação nos *settings* dos cuidados com a saúde com algumas particularidades, como atitude existencialista, com valorização dos elementos angústia e ansiedade, presentes na existencialidade do sujeito a ser estudado; atitude clínica da acolhida dos sofrimentos emocionais da pessoa participante, oferecendo-lhe a escuta e o olhar; e, por fim, atitude psicanalítica, do uso das concepções vindas da dinâmica do inconsciente do indivíduo(54).

Ambientação

A ambientação da pesquisadora é relevante no contexto da pesquisa qualitativa (55, 56). Assim, durante o desenvolvimento deste estudo, a pesquisadora esteve no PNE desde fevereiro de 2017, quando se registraram observações sobre as funções e relações no serviço, seguindo um roteiro (Anexo 4) que permitiu desenvolver e manter o comportamento necessário para o relacionamento com as participantes. Além disso, o guia permitiu ampla visualização e entendimento da organização e os fatores ambientais necessários durante o desenvolvimento das entrevistas, incluindo o melhor momento para se reunir com cada participante e o método ideal para manter um ambiente privativo, protegido de interrupções.

Seleção das participantes

A seleção das participantes para o estudo qualitativo ocorreu por intencionalidade, o fechamento da amostra aconteceu por exaustão, no período de tempo de um ano (julho de 2017 e julho de 2018).

Instrumento para coleta dos dados

A coleta de dados foi realizada por técnica de entrevista face-face, por meio de roteiro semidirigido, composto por questões abertas (Anexo 3). Este instrumento possibilitou o aprofundamento do tema pela entrevistada quase que livremente, cuja função foi auxiliar a entrevistadora a guiar-se para o aprofundamento das questões de relevância para a pesquisa, sem a tentativa de indução às respostas e deixando claro o interesse pela experiência de cada entrevistada, de modo que se enfatizou não haver acertos ou erros nas respostas, podendo a pesquisadora, durante a única entrevista com cada participante, voltar às questões do mesmo instrumento. Nenhuma questão fechada foi utilizada nesse momento.

Procedimento de coleta, processamento e análise dos dados

Anteriormente a cada entrevista, estabeleceu-se relação com a entrevistada, utilizando-se de algumas estratégias:

- Estabelecimento do *rapport*(57): momento em que a pesquisadora e a entrevistada criam um sentimento de empatia, confiança e responsividade mútuas;

- Assinatura do Termo de Consentimento Livre Esclarecido: empreendido após esclarecimentos acerca do tema e dos objetivos da pesquisa, assim como sobre os direitos e deveres das partes envolvidas;

- Coleta de dados: realizada a partir da identificação dos entrevistados e da solicitação de permissão para o uso de gravador;

- Aplicação da entrevista semidirigida: composta por questões abertas, observando-se aspectos comportamentais dos entrevistados, que serão registrados no diário de campo.

Os conceitos da psicologia médica foram trazidos para análise de dados. Para descrever mais adequadamente como se executou o processo de análise, expõem-se os sete passos da análise de dados clínico-qualitativa (58-60). Destaca-se que, como o método foi construído nas bases gerais da pesquisa qualitativa, consideraram-se: relevância implícita em cada discurso e recorrência das unidades de sentido(61, 62) para construção dos resultados:

1.Edição de texto: transcrição das entrevistas gravadas e notas de diário de campo. A gravação em áudio foi realizada com o aplicativo *Super Voice Recorder*[2] e, nas transcrições, mantiveram-se os traços originais da fala coloquial dos participantes, com correções gramático-normativas apenas para facilitar a compreensão do conteúdo, respeitando individualidade de cada entrevistada;

2.Escuta e releitura das transcrições utilizando-se da leitura flutuante;

3.Comentários e impressões registradas frente a essa releitura, escrevendo-as na margem direita do texto transcrito;

4.Categorização e subcategorização para promover o agrupamento das unidades de sentido e pontos altos significantes do discurso no texto para o presente estudo;

5.Apresentação e discussão do material aos pares (coautores nos artigos derivados da tese e membros qualificados para discussão do tema e método em grupo de pesquisa);

6.Definição das categorias como fruto do refinamento exaustivo do material; e

7.Validação dos dados pelos pares (coautores dos artigos, orientadora, coorientadora e membros dos grupos de pesquisa nos quais os pesquisadores participam)(60).

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[2] Disponível para download em: http://m.aptoide.com/app/com.enlightment.voicerecorder/voice.recorder¿=pt_BR, baixado em 30 de janeiro de 2016.

Validação dos dados

A validação em pesquisa qualitativa precisa ser garantida de forma interna e externa ao pesquisador e está ligada às habilidades desenvolvidas para lidar com o tipo de estudo e a respectiva proposta.

A validação interna é a potencialidade de conduzir o trabalho com acuidade e sensibilidade desenvolvidas por meio de experiências prévias do pesquisador na clínica e na pesquisa, garantindo apreensão das vivências dos participantes. Para isso, deve-se considerar elementos como formação, atuação e conhecimento do profissional(54).

Diante disso, reitera-se que esta pesquisadora possui formação em enfermagem, especialização em terapia intensiva e em enfermagem obstétrica, tendo passado por anos de experiência assistencial convivendo com pacientes críticos, familiares, acompanhantes e toda equipe multiprofissional de uma UTI geral, acumulando, assim, habilidades comunicacionais e de escuta qualificada, bem como em acompanhamento pré-parto, parto e pós-parto, em que tomada de decisão e manejo de relações são habilidades essenciais que foram também desenvolvidas pela pesquisadora.

Durante a graduação e mestrado, para construir o trabalho de conclusão de curso e dissertação, respectivamente, a pesquisadora teve também experiências com entrevistas e roteiros semidirigidos, o que colaborou para aprendizagem na aplicação da técnica de entrevista na presente pesquisa.

Assim, seguindo para o planejamento do método, das técnicas e dos procedimentos acessados na literatura consagrada, há relevante validação interna dos dados e, portanto, dos resultados desta pesquisa.

E, quanto à validação externa ao pesquisador, pesquisadores qualitativistas buscam convergência e estratégias de investigação que permitem rigor metodológico e garantem validade dos achados e das considerações de pesquisa(54).

Além da participação do pesquisador, o envolvimento dos pares acadêmicos, em achados relacionados à pesquisa, garante a validação externa, que se consolida com a interação entre pesquisador e pares acadêmicos, em momentos nos quais o primeiro apresenta os resultados e se dispõe a receber críticas e apontamentos, na intenção de eliminar possíveis distorções ou vieses oriundos apenas da apreensão sobre o tema. Compreende-se como pares acadêmicos: orientadora e coorientadora, grupos de pesquisa, eventos científicos e semelhantes(54).

Assim, a validação externa ocorreu no Grupo de Pesquisa Saúde Reprodutiva e Hábitos Saudáveis (SARHAS), liderado pela orientadora deste trabalho, com participação de pesquisadores seniores, alunos de pós-doutorado, doutorado, mestrado, iniciação científica e residência, bem como foi apresentado em eventos científicos nacionais e internacionais (11º Congresso Internacional de Autoimunidade- Lisboa, 2018; FIGO XXII World Congress- Rio de Janeiro, 2018; Colóquio Luso-Brasileiro sobre saúde, educação e representações sociais- Évora, 2018; IV Seminário de Obstetrícia da Universidade de Évora- Évora, 2019; XXIII Congresso Paulista de Obstetrícia e Ginecologia- São Paulo, 2018; 58º Congresso Brasileiro de Ginecologia e Obstetrícia- Porto Alegre, 2019).

Método 2- Quantitativo

Paralelamente, houve o desenvolvimento do estudo quantitativo, com análise descritiva que exige do investigador uma série de informações sobre o que deseja pesquisar e tem como finalidade observar, descrever e documentar os aspectos de determinada situação (63, 64).

Os estudos descritivos têm por meta determinar a distribuição de doenças ou condições relacionadas à saúde, segundo o tempo, o lugar e/ou as características dos indivíduos. Este estudo contou com análise de dados primários coletados em campo.

Tamanho amostral

Para o estudo descritivo, obteve-se amostra por conveniência composta por 50 grávidas com LES, no terceiro trimestre de gestação, sendo acompanhadas no PNE. O tamanho da amostra foi calculado pelo profissional estatístico local, utilizando textos com grupos e instrumentos semelhantes(65, 66).

O procedimento utilizado foi o de cálculo de tamanho de amostra para estimar uma média, cuja equação matemática é $n = \left(\frac{z\sigma}{d}\right)^2$. Onde, n é o tamanho amostral estimado, z é o percentil da distribuição normal para um nível de significância de 5%, z = 1,96, σ é o desvio padrão extraído dos estudos usados como referência e d é o erro absoluto considerado máximo permitido.

O programa computacional utilizado para o cálculo foi o *Microsoft Excel*®, versão 2013.

Instrumento para coleta de dados

Quanto ao instrumento para coleta de dados quantitativos, a observação da crescente importância da avaliação da qualidade de vida e o desfecho em diferentes áreas da saúde estimularam o desenvolvimento de um instrumento específico de avaliação de qualidade de vida, com 100 questões, reconhecido pela Organização Mundial da Saúde (OMS) (WHOQOL-100)(45). A partir dele, foi criado e traduzido para o português o WHOQOL-Bref(67) que consiste em um instrumento de 26 questões sobre qualidade de vida, sendo este o escolhido para empenhar o braço quantitativo desta pesquisa.

O WHOqol-Bref está dividido em quatro domínios: físico, psicológico, relações sociais e meio-ambiente(67) e pode ser observado na íntegra no Anexo 5 desta tese. Esse questionário foi aplicado anteriormente em ensaio clínico, nesse mesmo *setting* de pesquisa, com intervenção de exercícios físicos (30). A escolha deste instrumento se deu por avaliar a qualidade de vida de pessoas de forma geral, existem instrumentos específicos para pessoas com diagnóstico de LES, como: LupusPRO(68) e LupusQOL(69), mas não na ocorrência da gravidez.

Para aplicação do questionário WHOQOL-Bref, houve também o *rapport*(57) com cada participante, por parte da pesquisadora e, em alguns casos, por parte do aluno de Iniciação Científica que esteve envolvido em parte da coleta de dados quantitativos desta pesquisa de doutorado.

Processamento e análise dos dados

Para descrever o perfil da amostra, segundo as variáveis estudadas, elaboraram-se tabelas de frequência das variáveis categóricas (itens do questionário de qualidade de vida), com valores de frequência absoluta (n) e percentual (%), e estatísticas descritivas das variáveis numéricas (escores do questionário de qualidade de vida), com valores de média, desvio padrão, valores mínimo e máximo, mediana e quartis. Utilizou-se do seguinte programa computacional: *The SAS System for Windows (Statistical Analysis System*), versão 9.2. SAS Institute Inc, 2002-2008, Cary, NC, USA.

Setting da pesquisa - estudos de campo

O Hospital da Mulher Prof. Dr. José Aristodemo Pinotti (CAISM/ UNICAMP)[3] foi o *setting* dos estudos primários descritos. Inaugurado em março de 1986, o CAISM é referência nacional na assistência à saúde da mulher e do recém-nascido, sendo o atendimento na instituição realizado exclusivamente por meio do Sistema Único de Saúde (SUS) e com equipe multiprofissional e interdisciplinar responsável, também, por promover o ensino, a pesquisa e a

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[3] Centro de Atenção Integral à Saúde da Mulher (CAISM). Site institucional [Internet]. Disponível em: http://www.caism.unicamp.br/. Acesso em: 25 fev. 2017.

extensão, fortalecendo o diálogo entre as comunidades e o conhecimento produzido no ensino universitário.

O CAISM atende mais de 100 municípios, atingindo 82.000 consultas ambulatoriais por ano. No Corpo Clínico, há aproximadamente 95 médicos, 530 profissionais de enfermagem e 33 residentes, além de 49 docentes.

Dentro de um quadro de pessoal com cerca de 1.200 funcionários, a instituição possui 136 leitos de internação para mulheres.

O hospital possui três ambulatórios de atendimento pré-natal: o Pré-Natal de Alto Risco (PNAR), que atende a gestantes referendadas por alguma condição clínica ou obstétrica de risco, o Pré-Natal de Adolescentes (PNA) que atende gestantes até 18 anos e o Pré-Natal Especializado (PNE) que atende gestantes com complexidade maior, após a triagem inicial do PNAR. O PNE atende ambulatórios específicos de medicina fetal, infecções na gestação, endocrinopatias, doenças psiquiátricas, cardiopatias, hipertensão arterial, doenças reumáticas, doenças hematológicas e oncológicas e complicações obstétricas. As mulheres com essas doenças são divididas em cinco ambulatórios durante a semana. O presente estudo foi desenvolvido, especificamente, no Ambulatório que ocorre às quartas-feiras, onde são atendidas gestantes com hipertensão, doenças reumáticas, renais, hematológicas e oncológicas. Os atendimentos são realizados pelos médicos residentes do segundo, terceiro e quarto anos de residência em ginecologia e obstetrícia, em quatro salas de atendimento, e a supervisão é feita por três docentes da área de obstetrícia. Existe uma equipe multidisciplinar no ambulatório, composta por enfermeiros, nutricionistas, assistente social e psicólogo.

As mulheres grávidas com LES, atendidas nesse ambulatório entre 2012 e 2018 (N=102), tiveram os prontuários revisados e apresentaram alguns desfechos peculiares, já apresentados na literatura como taxa de aborto relativamente baixa, no entanto, deve-se considerar que essas mulheres iniciaram o pré-natal em atenção primária e PNAR e, posteriormente, foram referenciadas para o PNE e isso dificultou explicar abortos precoces dentro da amostra. Além disso, taxa de mortalidade neonatal baixa, apesar da considerável taxa de prematuridade observada, uma das principais condições associados a resultados desfavoráveis nesses recém-nascidos. Em relação às mortes fetais relatadas, uma mulher foi diagnosticada com a tetralogia de Fallot, com presença de lúpus grave no segundo trimestre(70).

Critérios de elegibilidade – estudos de campo

Critérios para inclusão: ter diagnóstico de LES (em quaisquer classificações de atividade ou gravidade); estar em atendimento no Ambulatório de Pré-Natal Especializado do CAISM; ter condições emocionais e cognitivas para fornecer dados à pesquisa, falando sobre a própria experiência.

Critérios de exclusão: analfabetismo; doenças psiquiátricas que impossibilitem responder às questões; privação da liberdade; participantes que não aceitassem ter as entrevistas gravadas.

Aspectos éticos

Este estudo respeitou a Resolução do Conselho Nacional de Saúde nº 466, de 2012(71), sobre pesquisas em saúde com seres humanos.

Todas as participantes foram conscientizadas sobre o Termo de Consentimento Livre e Esclarecido TCLE para questionário WHOQOL (Anexo 1) e ou TCLE (para entrevista semidirigida, Anexo 2), que discorre sobre a liberdade de participação e desistência em qualquer tempo da pesquisa, também sobre a manutenção do anonimato, o objetivo de estudo e a voluntariedade da participação, assim como o não ressarcimento de quaisquer valores. Concluído este contato e sanadas as dúvidas eventuais, duas vias do TCLE foram assinadas por cada participante e pela pesquisadora.

As entrevistas foram realizadas em sala privativa previamente preparada, com duas cadeiras de frente uma para outra, sem mesas ou objetos, como pranchetas, separando entrevistada e entrevistadora. Isso foi pensado com a intenção de garantir a horizontalidade da relação e descartar qualquer existência de relações de poderes que pudessem inibir a entrevistada a falar livremente. A confidencialidade da relação foi garantida e cada entrevistada recebeu um número para identificação das entrevistas.

O projeto foi aprovado na comissão de pesquisa do CAISM e na Plataforma Brasil, recebendo parecer CAAE: 68143817.0.0000.5404 (Anexo 6).

Método 3- Revisão Sistemática

O estudos de revisão sistemática podem ser definidos como uma síntese de pesquisa conduzida por grupos que propõem identificar e recuperar evidências internacionais relevantes para responder perguntas de pesquisa e avaliar estudos com resultados para relatar melhores práticas, políticas ou ainda novos estudos, informando lacunas na literatura(72) ou identificando tendências atuais para direcionar futuras investigações(73).

Revisões sistemáticas seguem um processo estruturado e pré-definido que requer rigor, com a intenção de gerar resultados confiáveis e significativos para fornecer base às decisões de cuidados em saúde baseados em evidências(74).

De acordo com essas premissas e seguindo as recomendações do PRISMA *check-list*(75), as duas revisões sistemáticas foram devidamente registradas e construídas com as seguintes questões de pesquisa, respectivamente: 1. Quais as possíveis repercussões psicossociais para mulheres com LES em seus aspectos reprodutivos, durante o planejamento, a gravidez ou o pós-parto? Nesta, encontraram-se 114 artigos, dos quais, incluíram-se quatro para análise, sendo dois estudos coorte e dois qualitativos; e 2. Quais as percepções sobre autoconceito e imagem corporal de mulheres vivendo com lúpus? Nesta, encontraram-se 647 artigos e incluíram-se 22 para análise, sendo 10 qualitativos e 12 quantitativos.

Coleta e processamento de dados

As duas revisões desenvolvidas tiveram coleta de dados realizada por dois autores, nas seguintes bases eletrônicas: *US National Library of Medicine - National Institutes of Health (PubMed), Cumulative Index to Nursing and Allied Health Literature (CINAHL), Excerpta Medica* **(***Embase), SCOPUS, the Web of Science, Medline, Medline Complete, and Academic Search Premier*.

Utilizando-se dos seguintes descritores, respectivamente: *medical subheading* (MeSH) *"lupus erythematosus, systemic" AND "psychology" OR "psychosocial" OR "psychological aspects" AND "pregnancy" OR "pregnant woman" OR "postpartum period" OR "gravidity."; medical subheading (MeSH) "Systemic Lupus Erythematosus" AND "Self-Concept" OR "Body Image" AND Woman.*

A busca pelos artigos, o processo de exclusão e a análise foram realizados por dois autores separadamente e, sempre que necessário, um terceiro ou quarto autor do grupo foi consultado.

Os dois projetos de revisão sistemática foram registrados em *International Prospective Register of Systematic Reviews* PROPERO: 1. *Psychosocial aspects of women at reproductive age, pregnant or postpartum period living with lupus: a systematic review,* sob código CRD42018079456 (Anexo 7) e 2. *Self concept and body imagem of women living with lupus: a systematic review,* sob código CRD42019126613 (Anexo 8).

RESULTADOS

Os resultados desta tese estão apresentados, a seguir, no formato de artigos científicos.

1. *Reproductive aspects of women with lupus in family planning, pregnancy or postpartum period: a systematic review*. Larissa Rodrigues, Vera Lucia Pereira Alves, Débora Bicudo Faria-Shützer, Maria Margarida Fialho Sim-Sim, Fernanda Garanhani Surita, submetido a *Nursing for Women's Health*.

2. *Perceptions of women with systemic lupus erythematosus undergoing high-risk prenatal care: a qualitative study*. Larissa Rodrigues, Vera Lucia Pereira Alves, Maria Margarida Fialho Sim-Sim, Fernanda Garanhani Surita, publicado em *Midwifery*;

3. *Qualitative data regarding the experiences of pregnant women with lupus in Brazil*. Larissa Rodrigues, Vera Lucia Pereira Alves, Maria Margarida Fialho Sim-Sim, Fernanda Garanhani Surita, publicado em *Data in Brief*;

4. *Quality of life among pregnant women with lupus*. Larissa Rodrigues, Maria Laura Costa, Maria Margarida Fialho Sim-Sim, Fernanda Garanhani Surita, submetido a *Revista Brasileira de Ginecologia e Obstetrícia*.

5. *Self-concept and body image of people living with lupus: a systematic review*. Larissa Rodrigues, Maria Margarida Fialho Sim-Sim, Luis Sousa, Débora Bicudo Faria-Shützer, Fernanda Garanhani Surita, submetido a *International Journal of Rheumatic Disease.*.

ARTIGO 1

Reproductive aspects of women with lupus in family planning, pregnancy or postpartum period: a systematic review

Larissa Rodrigues, Vera Lucia Pereira Alves, Débora Bicudo Faria-Shützer,
Maria Margarida Fialho Sim-Sim, Fernanda Garanhani Surita

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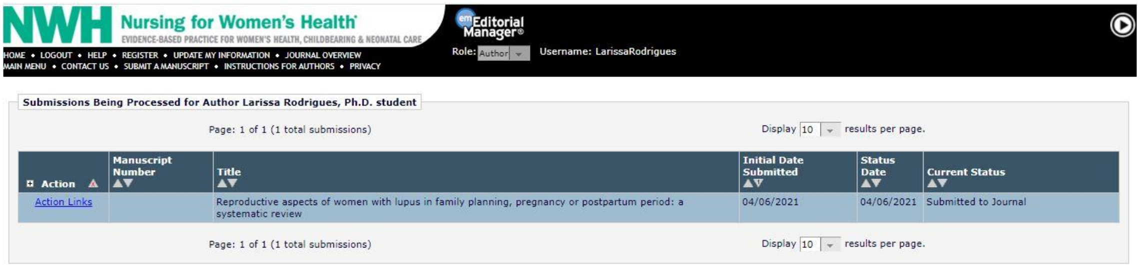

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Action	Manuscript Number	Title	Initial Date Submitted	Status Date	Current Status
Action Links		Reproductive aspects of women with lupus in family planning, pregnancy or postpartum period: a systematic review	04/06/2021	04/06/2021	Submitted to Journal

Page: 1 of 1 (1 total submissions)

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REPRODUCTIVE ASPECTS OF WOMEN WITH LUPUS IN FAMILY PLANNING, PREGNANCY OR POSTPARTUM PERIOD: A SYSTEMATIC REVIEW

Précis statement. Women with Lupus need help in making decisions and being prepared to face choices related to gestational outcomes.

ABSTRACT

Objective: to elucidate how the scientific literature describes the psychosocial repercussions of women with lupus during the pregnancy-postpartum cycle.

Data Sources: A bibliographic search was performed in the health databases We conducted a literature search in March 2021 of the following electronic databases: PubMed, CINAHL, Embase, PsycINFO, SCOPUS, and the Web of Science. We reviewed the lists of bibliographic references of the relevant articles to identify additional studies, with descriptors about psychosocial issues of women with lupus in the pregnancy-postpartum cycle.

Study Selection: We included all original articles that explored the psychosocial repercussions of women with SLE relative to reproductive aspects and excluded all literature reviews and secondary studies. We did not apply any restrictions to the period of publication or the original language of the indexed articles. The search resulted in 166 articles, 7 were included in this review.

Data Extraction: Two authors independently performed the literature search on March 2021. Primary articles were considered, including interventional or observational studies), whereas reviews and case reports were excluded. Two authors independently screened all titles and study abstracts to identify. The full texts of all potentially eligible studies were retrieved and independently assessed for eligibility by two review team members. All disagreements regarding the eligibility of any specific study were discussed by the two authors who performed the research and a third author until we reached a consensus.

Data Synthesis:We used a thematic analysis. We explore the following themes: pregnancy planning; pregnancy and newborn; and skills needed by health professionals to support women.

Conclusions: The psychosocial issues related to the planning stages of pregnancy, the actual pregnancy, and the postpartum period require additional study to guide professionals in the management of these issues among women with lupus.

Key words: Systemic lupus erythematosus; Family planning, Pregnancy; Postpartum period; Psychologic issues; Systematic review

Introduction

Systemic lupus erythematosus (SLE) is a multisystemic disease that can affect many organs and vital systems, such as the joints, kidneys, and serous membranes. The incidence ranges between 9 and 241cases per 100,000 people (Gergianaki, Bortoluzzi, & Bertsias, 2018), and the female:male SLE incidence is 9:1, typically presenting between the ages of 15 and 45 years (Pastore, Costa, Parpinelli, & Surita, 2018). Women with SLE can have experience significant treatment complications, which can lead to emotional challenges.

Women with SLE often experience a high degree of psychological symptoms, including anxiety and depression (Beckerman, Auerbach, & Blanco, 2011). The incorporation of a psychosocial approach is not routine in the majority of health service offerings targeted at those with high-risk diseases and is not significantly discussed by authors in the academic literature. However, this approach can have great relevance for the lives of these women, who must consider various factors associated with their reproductive health, including the ideal times to consider pregnancy.

During pregnancy and the postpartum period, women with SLE have a higher incidence of unfavorable outcomes, such as preeclampsia, fetal loss, fetal growth restriction, and preterm birth, compared with their healthy counterparts (Borella et al., 2014). Particularly among women with moderate-to-severe SLE, a marked decrease in live births has been reported, with almost one-quarter of these pregnancies resulting in fetal loss.

Currently, advances in treatment options have resulted in a relatively good quality of life among patients with SLE, resulting in the possibility of improved maternal and fetal outcomes (Silva & Amadei, 2016; Rúa-Figueroa et al., 2015).

To obtain better results during the perinatal period, current recommendations suggest that pregnancy should be planned when the disease has been inactive for at least six months, in the absence of kidney failure or any heart and lung complications (Pastore, Costa, Parpinelli, & Surita, 2018). More broadly, pregnancy in women with SLE demands a systematic and preventive discussion between the women and their health care professionals because this process also involves relevant psychosocial aspects.

The planning of pregnancy, the pregnancy itself, and the puerperal period place the woman in an intimate relationship with her family, her community, and with health services. These relationships can have large impacts on the lives of women with SLE, causing the women to feel either encouraged and confident or anxious, frightened, and insecure.

Although the scientific literature does not directly address the psychosocial aspects, some studies have addressed aspects that involve psychosocial repercussions. Thus, we aimed to elucidate how the scientific literature describes the potential psychosocial repercussions that affect women with SLE in terms of various reproductive aspects, such as family planning, pregnancy, or the postpartum period.

Methods

Protocol and registration

First, confirm that you have the correct template for your paper size. This template has been tailored for output on the custom paper size (21 cm * 28.5 cm). We registered this review in the PROSPERO international prospective register of systematic reviews (no. CRD42018079456). We also adhered to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines during the conduct of this review (Moher, Liberati, Tetzlaff, & Altman, 2009).

Eligibility criteria

Our guiding question for this systematic review was: "What are the possible psychosocial repercussions experienced by women with SLE with regard to reproductive aspects, including family planning, pregnancy, or the postpartum period?" We included all original articles that explored the psychosocial repercussions of women with SLE relative to reproductive aspects and excluded all literature reviews and secondary studies. We did not apply any restrictions to the period of publication or the original language of the idexed articles.

Information sources

We conducted a literature search in March 2021 of the following electronic databases: US National Library of Medicine National Institutes of Health (PubMed), Cumulative Index to Nursing and Allied Health Literature (CINAHL), Excerpta Medica ***(***Embase), PsycINFO, SCOPUS, and the Web of Science. We reviewed the lists of bibliographic references of the relevant articles to identify additional studies.

Search Strategy

We choose medical subheading (MeSH) terms to simultaneously contemplate the disease, the psychosocial aspects, and events associated with pregnancy. The MeSH terms used were: "lupus erythematosus, systemic" AND "psychology" OR "psychosocial" OR "psychological aspects" AND "pregnancy" OR "pregnant woman" OR "postpartum period" OR "gravidity."

Study selection and selection process

Two authors independently performed the literature search (LR and VLPA), and a process validation was performed by the study site librarian (PPR). Primary articles were considered, including interventional or observational studies (e.g., randomized controlled trials, cohort studies, transversal studies, and qualitative research), whereas reviews and case reports were excluded. After the electronic database review, the records were transferred into the EndNote software program (Clarivate Analytics, Philadelphia, PA, USA), and duplicated articles were removed.

Two authors (LR and VLPA) independently screened all titles and study abstracts to identify studies that potentially met the inclusion criteria described above. The full texts of all potentially eligible studies were retrieved and independently assessed for eligibility by two review team members (LR and VLPA).

All disagreements regarding the eligibility of any specific study were discussed by the two authors who performed the research and a third author (FGS) until we reached a consensus. Finally, we used the NVIVO 11 program (QSR International, Melbourne, Australia) to validate the data according to categories established by the authors of the present study.

Data collection process

We extract data from each manuscript using a standardized data extraction form that was agreed upon by all authors. After reading the full texts, we extracted data from those articles that met the inclusion criteria. The methodological details of each text were tabulated, and the findings were summarized according to the discussion and considerations expressed by the authors.

Data Itens

The process followed the Problem/Patient/Population, Intervention/Indicator, Comparison, and Outcome (PICO) strategy. The study participants were all women with SLE of reproductive age, and the following stages were explored: pre-conception, pregnancy, and the postpartum period. Interventions included the evaluation of psychosocial aspects such as feelings, emotions, socioeconomic status, family, health care, meanings, beliefs, and fantasies. The results included any descriptions of psychosocial issues, such as meanings, beliefs, and fantasies. All studies were conducted among women with SLE who were pregnant or who expressed a desire for pregnancy during the pre-conception period. The study designs were qualitative and observational.

Risk of bias in individual studies

We assessed the risk of bias in the included studies, considering the criteria established by the Strengthening of Observational Epidemiology Study Reports (Von Elm et al., 2008), Consolidated Criteria for Qualitative Research Reports (Tong, Sainsbury, & Craig, 2007), and Consolidated Standards of Reporting Trials (CONSORT) for clinical trials (Moher et al., 2010) checklists by two authors independently (LR and VLPA).

All disagreements regarding the risk of bias in any article were resolved with the involvement of the third author (FGS).

In this review, we did not consider the publication year, although the included articles were all published during the last 16 years. The oldest study was performed in 2004, and the newest was performed in 2020.

We observed that the criteria used to write and publish studies changed over the years. This evolution became especially clear based on the observed differences encountered during the evaluation of the risk for bias. This point is particularly important because newer studies describe more details regarding the research that was conducted, and this change was especially noticeable for qualitative studies.

Summary measures

We consider the following references to be representative of the psychosocial repercussions associated with the reproductive aspects of women with SLE: negative emotional disorders (Buyon et al., 2015; Monk, Leight, & Fang, 2008) emotional experiences, interpersonal relationships, social support, stressful life events, and familiar conflict (Alves, Carniel, Costallat, & Turato, 2015).

The full text of each article included in this review was read exhaustively and independently by two authors (LR and VLPA). We used a thematic analysis to identify those themes with the most relevance. These themes were used to construct the categories that were explored, presented, and discussed. We used the NVIVO 11 program (QSR International, Melbourne, Australia) to validate the data according to the categories that were established for this study.

Findings

Our main review question was considered in the context of authors who explored the psychosocial issues of women with SLE during the pregnancy planning and the pregnancy–postpartum cycle.

In this review, no studies were identified that directly examined any psychosocial measures or dimensions, such as anxiety, depression, and body image, during the pregnancy planning and pregnancy–postpartum cycle of women with SLE.

In our search, we identified authors who discussed the psychosocial dimensions of patients with SLE in-depth (Beckerman, Auerbach, & Blanco, 2011; Auerbach & Beckerman, 2011; Zembylas & Bekerman, 2011), but they did not consider the specific periods associated with pregnancy planning and the pregnancy–postpartum cycle, which represent such significant events in the lives of women with SLE.

The authors of the articles selected in this review did address some of the issues associated with the feelings of women of a reproductive age coping with SLE. We present the identified results according to category. Those studies that encountered the psychological themes of lupus in women who wish to become pregnant or during the pregnancy–postpartum cycle were selected for inclusion, shown in the study flowchart found in Figure 1, which presents the article selection process used in this systematic review.

In 1 of the 7 included studies, the authors explored some psychological problems that were closely associated with psychosocial problems. Among a sample of 40 couples, in which the women were diagnosed with SLE, the authors presented the following problems: Concerns about the disease in 17 (43%) couples, pregnancy anxiety in 18 (45%) couples, problems with children in 10 (25 %) couples, SLE and associated limitation in 9 (23%) couples, and the need for psychological help in 10 (25%) couples (Neri et al., 2004).

Figure 1. Flow diagram of the article selection process according to the PRISMA 2009 guidelines

The articles included in this review are summarized in Table 1, which also includes the main characteristics of each of the included articles. The four included articles addressed more than 1,600 participants.

Table 1. Characteristics of the included studies

Based on the risk of bias assessments (Neri et al., 2004), we first observed that the quality of the published studies increased over time. Periodically, the scientific community develops new criteria for ensuring good methodological rigor and the quality of writing in scientific texts. Based on these standards of measurement, we can say that older texts are most likely to be of lower quality.

In a qualitative study, the authors should describe not only the setting of the research but also the inclusion and exclusion criteria applied to the participants, the technique(s) used to perform data collection, and the methods used for data analysis.

No description of the inclusion and exclusion criteria was provided by the authors of one article, which can introduce bias. In the same text, the authors also did not describe either the data collection technique or the data analysis technique, suggesting the potential for bias. In addition, no full description of the outcomes was presented, which further supports the likelihood of bias (Schulz, Chalmers, Hayes, & Altman, 1995).

Following a content analysis of the articles, three themes were identified:

1) Pregnancy planning and generating the need for active participation in decision-making for reproductive planning.

2) Pregnancy and the newborn and the commitment that women with SLE demonstrate when facing the risks associated with pregnancy.

3) A discussion of the health professional skills that are necessary for appropriate family planning, prenatal care, postpartum care, and health education.

These themes were gleaned from the exhaustive reading of the full texts. Figure 2 presents further information.

Figure 2. Comprehensiveness of the reporting in the included studies.

Pregnancy planning

In the results found, the authors showed that attempts to become pregnant were marked by the high occurrence of gestational loss among women with SLE; these women typically have fewer children than those without the disease (Clowse et al., 2012; Kim et al., 2016). This fact worries them and influences their decision not to become pregnant. However, numerous other concerns also contribute to these decisions, including physical limitations, such as fatigue and pain, discomfort caused by the effects of medications, routines imposed by the disease, such as frequent doctor’s appointments, the genetic risks of disease transmission to offspring, and other risks to the health of the child or the required care necessary to monitoring the development of children (Clowse et al., 2012; Kim et al., 2016).

Although both mild and severe forms of the disease can be defined and differentiated by clinical criteria and specific test results, the authors do not indicate any significant differences between women with various disease severity related to the decision or attempt to have children or the psychosocial aspects of pregnancy (Kim et al., 2016).

One important consideration in the decision to conceive is the understanding of the possible risks associated with fetal development. According to the authors, this knowledge should be developed before gestation to promote greater confidence and understanding regarding the inherent risks associated with pregnancy in the presence of SLE. However, this information does not appear to be well-known to women before pregnancy (Clowse et al., 2012; Tingström et al., 2010).

In some studies, the authors indicated that the women reported not receiving any information from their physician regarding the impacts that SLE may have on the development of serious fetal diseases (Clowse et al., 2012), such as heart block (Tingström et al., 2010), and they relate this lack of information to the fact that they were diagnosed with SLE when they were not yet able to conceive because they were younger than reproductive age; therefore, it was unnecessary or not ideal for the health professional to raise this subject.

Some women with SLE indicated that because they did not plan for pregnancy, the prenatal follow-up time remained the only opportunity to talk about such risks (Tingström et al., 2010). They completed their reflection by concluding that the discussion of these problems during prenatal care is insufficient because the available time to prepare for the consequences of these risks is short (Tingström et al., 2010).

Most of the women who were diagnosed with SLE before experiencing their first pregnancy reported having fewer children than they expected (Clowse et al., 2012; Tingström et al., 2010). They felt the need to elaborate and redirect their desires regarding family planning due to their disease.

In one of the studies, women with lupus expressed the desire to have children and the great challenge associated with reproductive planning through the use of adequate and effective contraception (Rodrigues, Alves, Sim-Simc, & Surita, 2020). In this text, most women stated that they did not plan their pregnancy and mentioned not using contraceptives (Rodrigues, Alves, Sim-Simc, & Surita, 2020).

Unplanned pregnancies also occurred at a significantly higher rate among the group of women with SLE compared with those in groups of women with rheumatoid arthritis or no chronic disease (Galappatthy et al., 2017). Similarly, the non-use of an effective contraceptive method was significantly higher in women with SLE than in women without chronic disease (Galappatthy et al., 2017).

Pregnancy and the newborn

After the planning phase of pregnancy or the occurrence of an unplanned pregnancy, a woman faces inherent risks associated with pregnancy, and during this time, her family and professionals should act as her support network.

However, the authors note that many women desire pregnancy despite a diagnosis of SLE (Clowse et al., 2012; Rodrigues, Alves, Sim-Simc, & Surita, 2020) and show a great commitment to getting pregnant despite the risks. However, women with SLE often feel impotent and without autonomy due to the great need for medical follow-up to control their disease. However, the various examinations required also comfort the pregnant woman and put her in better communication with doctors, although she is sometimes the mediator of this communication (Tingström et al., 2010).

The occurrence of premature births, assisted births, and low birth weight were all significantly more frequently associated with pregnancies after a diagnosis of SLE, compared with those before a diagnosis of SLE. These outcomes also affect significantly more patients with SLE than patients with rheumatoid arthritis (RA) and patients without chronic disease. The occurrence of pregnancy-induced hypertension was significantly higher in the presence of SLE (53%) compared with RA (2%) or no chronic disease (Galappatthy et al., 2017).

In SLE patients with antiphospholipid antibody syndrome (aPL), whites, African-Americans, and Hispanics had significantly higher risks of adverse pregnancy outcomes compared with white SLE patients without aPL (Kaplowitz et al., 2018).

Tingström et al. (2010) reported that

> [Women] who became aware of the risk of heart block and its consequences for their pregnancy could not prepare themselves for the risks involved [and that they] expressed the feeling of being subjected to an unyielding fact, [describing] the situation as overwhelming and disconcerting (p. 218).

This commitment is also marked by increased medical follow-up, including an increase in the numbers of consultations and examinations requested and enhanced follow-up with more than one medical specialist.

Women with SLE express a fear of not being able to provide effective childcare (Clowse et al., 2012), which can largely only be alleviated by good management of the disease during gestation, which can help calm these fears (Clowse et al., 2012).

Perceptions about health services

Reproductive planning care

Those who provide assistance to any woman with SLE should advocate for these women to help them meet their pregnancy goals with proper guidance and autonomy. The health care team should present and discuss the underlying causes related to SLE that promote infertility and gestational losses (Clowse et al., 2012).

However, the desire to become pregnant can be detected in the speech of women and most pregnancies after SLE are unplanned among both women with lupus in southeastern

Brazil (Rodrigues, Alves, Sim-Simc, & Surita, 2020) and among those in Sri Lanka (Galappatthy et al., 2017).

A careful evaluation of the physical and psychological aspects should be performed for women with SLE as a component of counseling, before pregnancy, during the prenatal follow-up, and when monitoring the development of their children after childbirth (Clowse et al., 2012). The strength of a continuous bond between these women and their health care providers is, therefore, important, and the health care providers should take the professional initiative of presenting these questions in family planning scenarios.

Prenatal care

The authors indicate that one reported issue occurs when fetal problems are diagnosed, resulting in women with SLE becoming conflicted between accepting the child's problem and denying their own symptoms, making efforts to appear healthy, and minimize the anxiety of the whole family (Schulz, Chalmers, Hayes, & Altman, 1995).

Because they are generally treated by several medical specialties during prenatal care (e.g., gynecologist and obstetrician, rheumatologist, and nephrologist, among others), women with SLE report that the obstetrician is not always the main informant (Rodrigues, Alves, Sim-Simc, & Surita, 2020).

In cases that required the need for several fetal echocardiographs, the women felt comforted by the good results of the examinations reported by the cardiologist, adopting this specialist as a noteworthy reference in their specific situation (Rodrigues, Alves, Sim-Simc, & Surita, 2020).

During prenatal examinations, the women reported feeling anxiety about what might happen to the child but also indicated feeling very safe when they came to the clinic regularly for tests, initially because they received consistent information about the fetus that was confirmed during imaging examinations but especially because they felt free to contact the team if they wanted or needed to (Rodrigues, Alves, Sim-Simc, & Surita, 2020).

However, these women sometimes felt as if they were the messengers of their case information between the professionals of the various specialties responsible for their prenatal care and often felt that the specialists did not want to interfere with the care and instructions provided by other specialists, resulting in a feeling of fragmented care. These women perceived divergent behaviors among the specialists, which introduced doubts to the areas of their drug treatment and general care.

The women also expressed that their needs for professional psychological support were not adequately met. Although they reported that they felt stressed and vulnerable, none of them were attended to by psychologists or social workers to discuss their situation in terms of high-risk pregnancy or SLE (Rodrigues, Alves, Sim-Simc, & Surita, 2020).

Discussion

The authors of the studies analyzed indicated that women with SLE require assistance and indicated that the existing links between health services and the woman and her family do not appear to be sufficiently strong to provide the necessary understanding of the factors that can affect the timing of pregnancy.

The controversies cited by the authors indicate a lack of effective measures for addressing the increased risks associated with SLE and a lack of consensus among health care professionals regarding how best to provide knowledge of the risks to both the woman and her child in the context of SLE.

The authors report that when some women received early information about the severity of the disease, they made decisions based on this information, whereas those who obtained this information during prenatal care often lacked the emotional resources to deal with their feelings regarding the imminent risks (Schulz, Chalmers, Hayes, & Altman, 1995; Clowse et al., 2012; Kim et al., 2016; Tingström et al., 2010).

A degree of ambiguity was evident in terms of the decision to become pregnant; therefore, the psychosocial care of women with SLE remains necessary to help them make decisions regarding whether or not to have children. The woman and her family should be adequately prepared to face the choices related to pregnancy planning and gestational evolution.

The pathological, physiological predictors and treatment do not represent a single point to be discussed on a case-by-case basis (Pastore, Costa, Parpinelli, & Surita, 2018).

When the woman becomes pregnant, she often describes conflicting feelings: she feels good about the pregnancy and simultaneously experiences anxiety about the possible outcomes (Rodrigues, Alves, Sim-Simc, & Surita, 2020).

The psychosocial nuances and the health service provided to the woman can help her acquire autonomy and develop increased knowledge and experience pertaining to the decision to become pregnant.

Reflecting on the psychological aspects combined with increased discussion of better drug and therapeutic control of the disease appears to be the optimal approach to the situation.

The severity of the disease was not explored by the authors as a factor affecting the decision of the woman; only one of the included studies refers to more severe or less serious variants of SLE (Kim et al., 2016).

A general understanding exists that women with moderate or severe SLE experience a higher risk of poor outcomes compared with women with mild SLE, and the management of pregnancy and the perinatal period is less critical for cases of disease associated with minor complications (Pastore, Costa, Parpinelli, & Surita, 2018; Borella et al., 2014).

However, a disconnect appears to exist between the severity of the physical and physiological complications of moderate-to-severe SLE and the psychological and emotional states of these women. Understanding how these women and their relatives experience and perceive the risks associated with pregnancy during SLE is urgent for providing effective psychosocial support (Martínez, Sánchez, Martínez, & Miró, 2016).

In the present study, we sought to explore some of the psychosocial issues that affect pregnancy planning and the pregnancy–postpartum cycle. We were particularly interested in whether psychosocial differences exist among women with SLE during important and distinct reproductive stages, whether these differences were reflected by the needs and psychosocial problems of their families, and whether they were adequately addressed by health services. During this review, we also identified gaps in the literature regarding the measures and psychological dimensions among women of reproductive age with SLE during pregnancy planning and the pregnancy–postpartum cycle.

Limitations and Strengths

In this review, we intended to collect the main psychosocial aspects experienced among women with SLE during their reproductive stages, as described by authors in the scientific literature. However, we instead discussed the feelings of these women relative to the planning of pregnancy and the pregnancy–postpartum cycle because adequate measurements of these aspects have not yet been published. However, this review contributes to understanding these women's feelings in terms of pregnancy planning, perinatal anxiety, and the challenges faced when interacting with health services and health professionals.

Our research included the most indexed databases, but we encountered only a small number of relevant articles in the small final sample and suggest that future research might consider including gray literature or regional databases.

We also emphasize that the family circumstances, including the role of the women within their families, economic conditions, problems with parental relationships, and other historical aspects, were not considered in the evaluation of the identified.

Conclusions

In the internal movement carried out by the woman, situations associated with increased emotional and psychological vulnerability can arise; however, we found little material published to date discussing the psychosocial aspects and tools for the practice of attending to these women. The relationship between health care professionals and women with SLE during postpartum care was not addressed by any of the included studies, and the professional performance of health education specific to these women was also not a focus of the studies. In the day-to-day practice of health services, comprehensive care for psychosocial needs remains largely inadequate, and the literature that discusses these issues has not yet been solidly constructed. Therefore, a further need exists for the theoretical and practical development of this approach to comprehensive care for women with SLE. The psychosocial issues related to the planning stages of pregnancy, the actual pregnancy, and the postpartum period require additional study to guide professionals in the management of these issues among women with SLE.

Clinical Implication

. The decision-making process of women with SLE and their families with regards to pregnancy requires additional support for family planning and the provision of health services.

. Having a referral professional brings greater security and peace of mind to women with SLE who are looking to become pregnant or who are pregnant.

. Supportive strategies offered by health services can help these women to better understand the risks inherent to their decision to become pregnant and prepare them for the management of events that might occur during pregnancy, childbirth, and the puerperium period.

. Health services should consider their existing knowledge regarding the family and social situations of these women, the emotional and psychological state of the women, and the social resources available through the family and community to ensure the continuity of care for both mother and child. This level of support can help women with SLE overcome the difficulties associated with the symptoms of pain and discomfort during daily life.

.Women who experience a good relationship with health services feel strengthened by this support. Having a referral professional brings greater security and peace of mind to women with SLE who are looking to become pregnant or who are pregnant.

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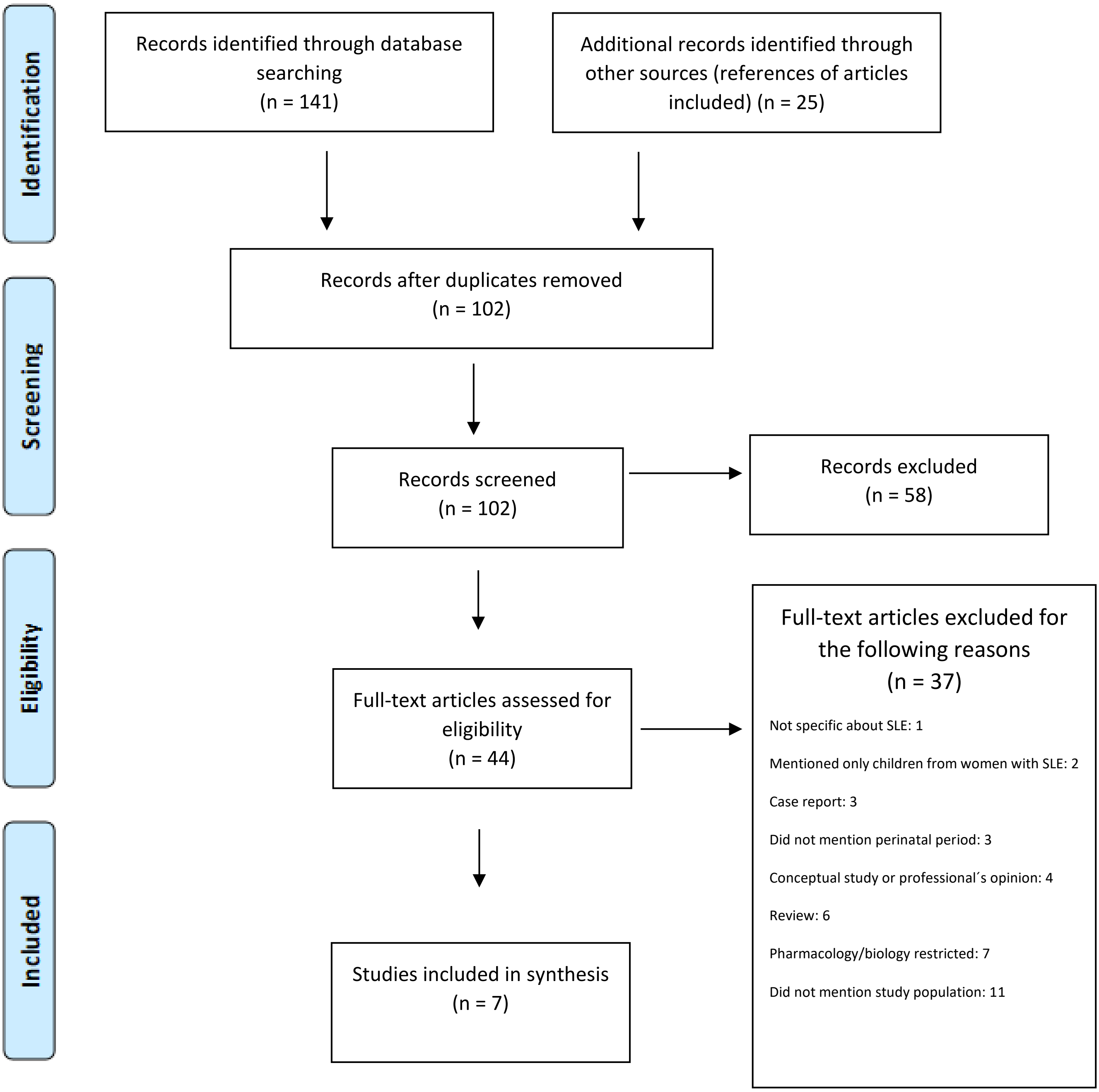

Figure 1. Flow diagram of articles selection according to the PRISMA 2009 guideline. Adapted of the Moher, D., Liberati, A., Tetzlaff, J., & Altman, D. G. (2009). Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. *PLoS Med*, *6*(7), e1000097. doi:10.1371/journal.pmed.1000097

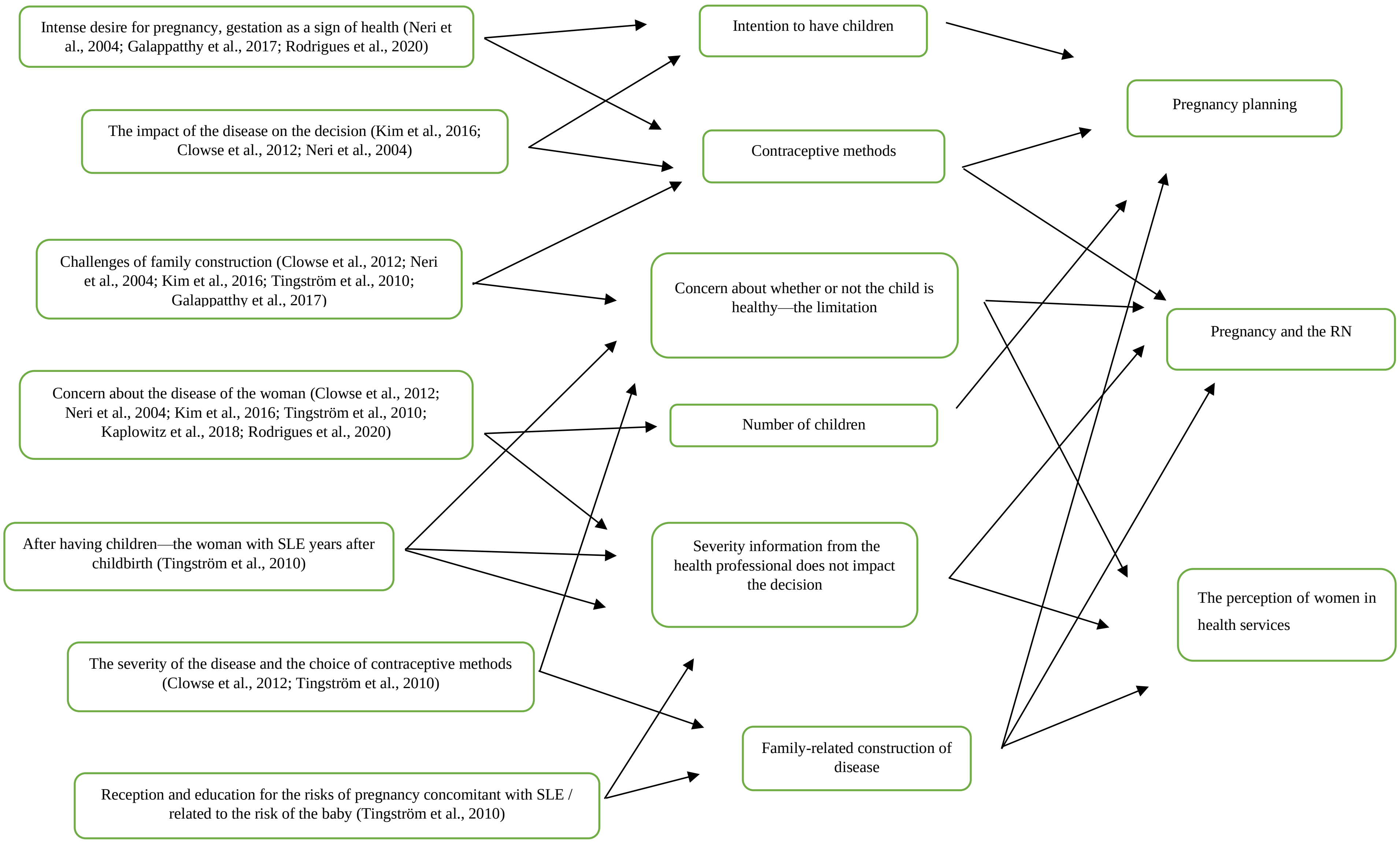

Figure 2. Comprehensiveness of the reporting in the included

Table 1. Characteristics of included studies

Author, year /Country	Study method	Objective	Collection	Analysis	N	Average Age	Average period since diagnosis	Main participants/experiences explored	Main results
Neri et al., 2004, Italy	Qualitative/descriptive	Consider the disease aspects at the familiar planning.	Interview. A neuropsychiatrist, expert in the diagnosis and therapy of couples, performed interviews with the volunteer patients and their partners.	Descriptive analysis on sociodemographic characteristics.	40 parent couples	33	12	Women affected by SLE attending the rheumatology and clinical immunology unit (Brescia Hospital) that delivered live births in the last 20 years, as well as the neuropsychological and, more directly, psychical aspects of their children.	Mentioned experience about the intention of building a family and whether the SLE influences at that planning.
Tingström et al., 2010 Sweden	Qualitative/interpretive	Explore how SSA/Ro-positive women experience their pregnancy.	Individual semi structured interview. The questions were open-ended in order to let the women describe feelings and situations they had experienced during their pregnancy	Qualitative framework for content analysis and interpretative description. The coding results from two authors were compared and discussed until a consensus was reached. Data Pertained to three levels (codes, categories, themes)	T=14 7 SLE, 7 ss e ra	-	-	Women with SSA/Ro autoantibodies that had undergone serial ultrasound/Doppler echocardiography examinations between 18- and 24-weeks' gestation.	Previous pregnancy experiences described by women who had undergone serial Doppler echography during gestation with the risk of fetal heart diseases for having anti RO+
Clowse et al., 2011, EUA	Cohort study	To determine if young women with SLE had fewer pregnancies and children than women diagnosed later in life, and the causes for these differences.	Reproductive health Questionnaire. Patients were asked if they had used physician-assisted reproductive methods to get pregnant and which types (oral or injectable medications, in vitro fertilization, or other).	A chi-squared test and Student's *t*-test were used. Linear regression was used to assess the impact of independent predictors of pregnancy and live birth rates.	T = 966 114 SLE 852 RA	35	13	1,017 female participants in the NDB. Each woman had indicated that she would be interested in completing an additional questionnaire about her reproductive health history. Each woman had been diagnosed by her physician with either RA (n _ 852) or SLE (n _ 165) and had previously completed a recent NDB six-month questionnaire.	Considerations of how different the SLE families are compared to two other family groups: healthy women and other critically diseased women.
Kim et al., 2016, Korea	Cohort study	To investigate the influence of personal decisions on the family size of Korean patients with SLE and factors that affect the decisions.	Sociodemographic and clinical data regarding SLE disease history and laboratory data were collected through a survey using a standardized questionnaire and medical record review.	Shapiro–Wilk test, chi-squared test, Kruskal–Wallis test and Student's *t*-test or Man–Whitney test.	T= 227 112 SLE 135 control	36	6	Criteria were between 18 and 45 years of age who are/were married or living with a partner. 112 patients were recruited and 135 age-matched healthy women who visited the participating hospital for routine obstetric checkup were recruited as controls.	Considerations of how different the SLE families are as compared with two other family groups: healthy women and other critically diseased women.

Galappatthy et al., 2017, Sri Lanka	Comparative study	To compare the pregnancy outcomes and contraceptive practices in systemic lupus erythematosus (SLE), rheumatoid arthritis (RA) and women with no chronic illness (WNCI) in a tertiary care referral center in Colombo, Sri Lanka.	Data were collected using an interviewer-administered pre-tested questionnaire and past clinical and obstetric records were obtained after taking informed, written consent.	Statistical analysis was carried out using the Statistical Package for Social Sciences for Windows (SPSS), Version 15.0. Chi-square (v2) and continuous variable were analyzed using t-test to compare betweengroups. Statistical significance was set at a two-sided Pvalue of < 0.05.	T= - SLE= 71 RA= - WNCI= -	Between 15 and 49	8	Patients with SLE satisfying American College of Rheumatology criteria for diagnosis and history of pregnancies were recruited from university lupus clinic, National Hospital of Sri Lanka (NHSL). Age-matched women with history of pregnancy and RA were recruited from the rheumatology clinic, NHSL and WNCI from a surgical clinic.	Pregnancies occurring after diagnosis were significantly higher in SLE compared to RA. Contraceptive usage was lower in patients with SLE and RAcompared to WNCI. Unplanned pregnancies and adverse pregnancy outcomes need to be addressed more in SLE than in RA or in WNCI.
Kaplowitz et al., 2018, EUA	Clinical trials	We examined rates of APO by race/ethnicity among women with SLE, with and without aPL, and hether SES accounted for differences.	The screening visit included medical history, physical examination, and laboratory tests, including aPL. Patients were followed monthly during the pregnancy. Laboratory tests were repeated during 20–23 weeks of gestation 32–35 weeks of gestation) of pregnancy and at 3 months postpartum.	Logistic regression analyses were conducted to determine odds of APO for each racial/ethnic group, controlling first for age and clinical variables, and then for SES.	T= 402 340 SLE without aPL and 62 SLE with aPL	29-32	-	From PROMISSE study, This analyses included 340 patients with SLE without aPL, and 62 patients with SLE with aPL. Womenself-identifying as Asian/Pacific Islander comprised 12.1%, Hispanic 16.9%, African American 20.0%, American Indian/Alaska Native 1%, other 1.5%, and white 50.3%.	African American women with SLE without aPL, SES factors are key contributors to disparities in APO, despite monthly care from experts, whereas other factors contribute to disparities in SLE with aPL.
Rodrigues et al., 2020, Brazil	Qualitative study	To understand the meanings attributed to pregnancy by women with SLE	Study data were collected via 1 in- terview with each participant. with six open-ended questions de- signed to explore the following themes: feelings about being an SLE carrier, experience with carrying this disease while being preg- nant, pregnancy monitoring, sexual behaviors after finding out about the illness and pregnancy, and daily life.	Data collection: seven steps of content analysis were performed. These were: 1 Text editing 2 Listening to and re-reading of the material by two authors 3 Documenting impressions 4 Organizing categories and subcategories 5 Debating disagreements that arose between the 6 Establishment of categories- authors' interpretation and 7 Data validation by peers and NVivo 11 (QSR International, Melbourne, Australia).	26 SLE	29	9,5	The selection of participants was intentional. All women had in common the experience of pregnancy and SLE diagnosis and were under care at the clinic in question. All participants were in the third trimester of pregnancy. Finally, all women visiting the clinic from July 2017 to July 2018.	Four categories were identified: (1) unplanned pregnancy and nonuse of contraception, (2) feeling healthy despite a doctor's warning of the disease worsening because of pregnancy, (3) joy coupled with fear of the future and pregnancy, and (4) self-perception and straight perception. The experiences of pregnant women with SLE are permeated by ambiguous feelings.

SSA/RO (antibodies found in 30% of the SLE patients that showed neonatal lupus, skin lupus, and antiphospholipid antibody syndrome, Open Code text analysis program (Umeå University, Sweden), SS (Sjögren's syndrome), RA (Rheumatoid arthritis), RO (core and cytoplasmatic protein linked to RNA), NBD (National Data Bank for Rheumatic Diseases), APO (adverse pregnancy outcomes), ApL (antiphospholipid antibodies), SES (socioeconomic status).

ARTIGO 2

Perceptions of women with systemic lupus erythematosus undergoing high-risk prenatal care: a qualitative study

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Perceptions of women with systemic lupus erythematosus undergoing high-risk prenatal care: A qualitative study

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ABSTRACT

Background: Systemic lupus erythematosus (SLE) is a multisystem autoimmune disease that often leads to situations of harm to the mother-fetus binomial. Given the potential for complications and morbidities in these pregnant women, it is essential that a multidisciplinary team be involved in pregnancy planning, as well as monitoring the course of the pregnancy and the postpartum period. Owing to the imminent risks of disease worsening along with consequent disabilities, these women may experience psychological and psychosocial impacts conflicting with the psychological demands of pregnancy.

Objective: To understand the meanings attributed to pregnancy by women with SLE.

Design: A qualitative design with face-to-face interview following a semi-structured script of open-ended questions.

Setting: A specialized outpatient clinic where during prenatal care, women with stable disease undergo scheduled appointments.

Participants: The sample was intentionally composed of women visiting a specialized outpatient clinic from July 2017 to July 2018. The participants ($N = 26$) were interviewed in depth, with no refusal. Thematic analysis according to the 7 steps of qualitative analysis was conducted using NVivo 11.

Findings: Four categories were identified: (1) unplanned pregnancy and nonuse of contraception, (2) feeling healthy despite a doctor's warning of the disease worsening because of pregnancy, (3) joy coupled with fear of the future and pregnancy, and (4) self-perception and straight perception.

Conclusions: The experiences of pregnant women with SLE are permeated by ambiguous feelings. These women feel healthy because they can bear a child despite the chronic disease diagnosis and, at the same time, experience fear and insecurity owing to the imminent possibility of disease-related disabilities and limitations. They especially wish to experience motherhood, and they strive for safety and support.

Implications for practice: Health teams must be structured to welcome and advise these women in planning relationships and pregnancy, as well as choosing the best contraceptive methods and making optimal reproductive decisions. The development of strategies to deal with changes in the perinatal period may be helpful, as these women are willing to take care of themselves.

Introduction

Systemic lupus erythematosus (SLE) is a multisystem autoimmune disease that can affect the skin, joints, kidneys, heart, lungs, and serous membranes, among others, with a prevalence of 40 to 200 cases per 100,000 individuals and a female to male incidence

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ratio of 9:1 (Borella et al., 2014; Pastore et al., 2018; Petri et al., 2012; Fortuna & Brennan, 2013). Owing to its high prevalence among women of childbearing age (15–45 years), amid pregnant women, the SLE incidence ranges from 1:660 to 1:2.952 and the condition is associated with an increased risk of maternal and fetal complications (Lateef & Petri, 2017; Shaikh, Jordan, & D'Cruz, 2017).

Many common conditions, including hypertension, nephropathy, and the presence of autoantibodies, can affect the maternal–fetal binomial (Lateef & Petri, 2017; Shaikh et al., 2017). As results, situations such as preterm birth, cesarean delivery, and preeclampsia have been reported (Harris, Eudy, & Clowse, 2019) Despite advances in clinical follow-up, the fetal prognosis may still be impaired by common situations such as miscarriage, growth restriction, and prematurity as well as increased maternal mortality rates (Buyon et al., 2015; Pastore et al., 2018)

In such scenarios, challenges exist both related to the management of the disease and pregnancy and in making the distinction between expected physiological changes and manifestations of the disease (Harris et al., 2019).

The ideal time for pregnancy in a woman affected by SLE is when the disease has been in remission for at least six months, when the medication regimen is compatible with pregnancy, and in the absence of disabilities such as heart or pulmonary failure; therefore, it is strongly advised that pregnancy be planned for in advance (Andreoli et al., 2017; Borella et al., 2014; Pastore et al., 2019). Given the potential complications and morbidities that may present in pregnant women with the abovementioned conditions, it is essential to follow the pregnancy and puerperium management plan formulated by the multidisciplinary team in question (Knight & Nelson-Piercy, 2017; Surita et al., 2007).

In addition, there are major physical, psychic, and emotional transformations inherent in the pregnancy process (Bjelica, Cetkovic, Trninic-Pjevic, & Mladenovic-Segedi, 2018). Usually, women's expectations revolve around bearing a healthy child and beginning the experience of motherhood.

Throughout pregnancy, psychic movements cause a transformation, priming the woman to welcome her child; thus, her identity as a mother is built on past experiences gained to this point (Falcone et al., 2005). In the context of SLE, with the imminent risk of a worsening condition and the onset of disabilities, women may experience unique psychological and psychosocial impacts (Neri et al., 2004; Tingström et al., 2010), conflicting with the psychological demands of pregnancy.

In such a situation, how women perceive the disparity between the promise of a new life and the threat of more severe SLE? In an attempt to answer this question, this study aims to understand the meanings attributed to pregnancy by pregnant women with SLE during prenatal care.

Methods

Study design

The study design used was based on the qualitative method (Turato, 2011; Fontanella, Campos & Turato, 2006) which is constructed via three pillars: (1) a clinical attitude that values listening and contact between the health care professional and patient; (2) an existentialist attitude that values the problems experienced by a participant; (3) and a psychoanalytic attitude that accepts the existence of the unconscious psychic instance that lies between the lines of the discourses and the behavior of the participants.

Research setting

The study setting was a single specialized outpatient clinic where, during prenatal care, women with stable disease undergo scheduled appointments. On a weekly basis, about 40 pregnant women diagnosed with high blood pressure, sickle cell anemia, cancer, and autoimmune diseases are treated at this clinic, and the average annual number of pregnant women patients treated with SLE is 25.

Sampling

The selection of participants was intentional. All women had in common the experience of pregnancy and SLE diagnosis and were under care at the clinic in question. All participants were in the third trimester of pregnancy, near 30 weeks of gestation. Finally, all women visiting the clinic from July 2017 to July 2018 were invited to participate and all those who were invited agreed to be part of the present study.

Approaching the participants

The first author (L. R.) established the field setting between November 2016 and July 2017. Study data were collected via 1 interview with each participant. Prior to each interview, a rapport was established by creating an atmosphere of empathy, trust, and responsiveness. Participants were provided with an explanation of the research topic, study aims, and rights of the parties involved, with sociodemographic data were collected thereafter. Written permission to use a tape recorder was sought.

Subsequently, the first author (L. R.) conducted the interviews using a semi-structured script with six open-ended questions designed to explore the following themes: feelings about being an SLE carrier, experience with carrying this disease while being pregnant, pregnancy monitoring, sexual behaviors after finding out about the illness and pregnancy, and daily life.

The question script was created to guide the interviewer during the data collection process but was flexible to account for the interviewee's speech flow, with no need to ask the questions in a certain sequence. Behavioral and intervening aspects were recorded in a field diary.

The interviews took place on the same day that the patients underwent prenatal consultations and were held in a private room previously prepared to receive each participant after acceptance. This room had two chairs facing each other (interviewee and interviewer) without tables or clipboards or any materials that would distance the two people or indicate any power.

Data analysis and validation

Following data collection, seven steps of content analysis (Faria-Schützer, et al., 2018) were performed. These were:

1 Text editing for transcription of the recorded interviews and field diary notes organized by the first author (L.R.); the interviews were transcribed verbatim by the first author (L.R.) and later had grammar corrected grammar to facilitate the reader's understanding
2 Listening to and re-reading of the material by two independent authors (L. R. and F. G. S.)
3 Documenting impressions of the re-reading by registering emerging and meaningful themes in the right margin of the transcribed text
4 Organizing all generated content under categories and subcategories to identify patterns of meaningful units and main features of the text, carried out while taking into account the relevance implicit in each interview as well as the frequency (Bardin, 2011; Berelson, 1984) of the appearance of a theme
5 Debating disagreements that arose between the two authors (L. R. and F. G. S.) with the other authors until a consensus was

reached (V.L.P.A.), followed by presentations in research groups and congresses to attain validation of the material

6. Establishment of categories based on the authors' interpretation and discussions
7. Data validation by peers (all authors) and members of the research group

Here, NVivo 11 (QSR International, Melbourne, Australia) was used for material organization beginning with the first step. The COREQ checklist (Tong et al., 2007) was used to promote good qualitative rigor of the study.

Ethical aspects

This study complies with National Health Council Resolution No. 466 (Brazil, 2012) on health research with human beings. It was authorized by the local ethics committee under no. 68143817.0.0000.5404. All content gathered from the interviews was treated confidentially. The first author (L.R.) read and explained the free and informed consent form to the participants, who signed the document after the necessary clarifications were made. One copy of the document remained with the researcher and the other copy was given to the participant.

Results

Our sample included 26 participants interviewed in depth, with the per-interview average (standard deviation) length of time being 29.14 (14.22) minutes. The average age of the study population was 28.80 (4.30) years and the average time since SLE diagnosis was 9.5 (6.50) years. All participants reported experiencing previous disease activity but stability during the current pregnancy. Seven patients had previously experienced miscarriages, 14 had other living children, and five were in their first pregnancy. Most reported having a partner and some religiosity, and half of them were white. The participants' characteristics are described in Table 1.

Table 1. Participants' Characteristics

During data analysis, four categories were identified as follows: (1) unplanned pregnancy and nonuse of contraception, (2) feeling healthy despite a doctor's warning of the disease worsening because of pregnancy, (3) joy coupled with fear of the future and pregnancy, and (4) self-perception and straight perception.

The following categories reflect the meta-aggregation of the collected data. The process of elaborating these structures is illustrated in Figure 1.

1. Unplanned pregnancy and nonuse of contraception

This theme represents the ambiguous domain between planning failure and the veiled desire to get pregnant. Participants seemed to deny the obstetric risk associated with their condition or the possibility of conceiving. Pregnancy appeared to be a challenge, with success seeming to empower the participants and give them a sense of having overcome the disability caused by the disease. Many of these disabilities were imagined.

> **E23**. It was a surprise. I did not use contraception because, despite being sexually active, I never got pregnant and, thus, believed it wouldn't happen. I thought the medications I used to take for lupus had destroyed my womb and that I wouldn't ever get pregnant. That was my gut feeling. However, I got pregnant.

Reasons for continuing with this pregnancy

Association between the partner's desire to have a child appears as in the women's speech, they face the risks of pregnancy in the presence of the disease to satisfy the partner.

> **E25**. While the reason for this pregnancy was a desire to strengthen our bond, I have decided [that] this is the last time. I won't put myself at risk again.

The impossibility of using effective contraceptive methods available due to the disease is present in the speech of women.

> **E24**. I was not planning on getting pregnant, especially because I was unemployed. It was an accident. We used only condoms because of the hormone issues associated with lupus.

Table 1
Characteristics of women with lupus in prenatal care

Interview	Age (years)	Skin color	Religious	Partner	Paid work	Schooling	Number of pregnancies	Gestational losses	Years of diagnosis	Planned pregnancy	Use of CM*
1	29	Mix	Evangelical	Yes	Yes	HS**	1	0	9	No	No
2	25	Black	Evangelical	Yes	Yes	HS	1	0	2	No	No
3	27	White	Catholic	Yes	Yes	HS	1	0	4	No	No
4	28	Mix	Catholic	Yes	Yes	HS	3	0	3	No	No
5	24	White	Catholic	No	No	HS	1	0	3	No	No
6	23	White	Catholic	Yes	Yes	TE***	1	0	2	No	No
7	23	Mix	Believes in God	Yes	No	ES#	1	0	5	No	No
8	22	White	Catholic	No	Yes	UE##	1	0	12	No	No
9	30	Mix	Not religious	Yes	Yes	HS	1	0	9	No	No
10	28	White	Believes in God	No	No	ES	3	0	23	No	Yes
11	33	White	Catholic	Yes	Yes	HS	3	1	5	Yes	Yes
12	32	Mix	Evangelical	No	Yes	HS	4	2	3	No	No
13	34	White	Believes in God	Yes	Yes	UE	5	0	6	No	No
14	28	Mix	Evangelical	Yes	Yes	HS	2	0	18	No	Yes
15	34	White	Evangelical	Yes	Yes	HS	2	0	7	Yes	No
16	29	White	Catholic	Yes	Yes	HS	2	0	4	No	Yes
17	28	Mix	Catholic	Yes	Yes	HS	3	0	17	No	No
18	33	Mix	Evangelical	Yes	Yes	HS	3	1	6	No	Yes
19	19	White	Christian	Yes	Yes	HS	1	0	12	No	No
20	26	White	Catholic	Yes	Yes	HS	3	2	13	Yes	No
21	30	Black	Catholic	Yes	Yes	UE	3	0	13	No	No
22	33	White	Catholic	Yes	No	UE	1	0	13	Yes	No
23	31	Black	Non confessional	Yes	No	HS	3	0	7	No	No
24	30	White	Non confessional	Yes	No	UE	2	1	23	Yes	No
25	35	White	Sei-Sho-No-Ie	Yes	No	HS	2	1	21	No	Yes
26	35	White	Evangelical	Yes	Yes	HS	4	2	7	No	No

*CM - Contraception Methods, **HS - High School, ***TE - Technical Education, #ES - Elementary School, ##UE - University Education

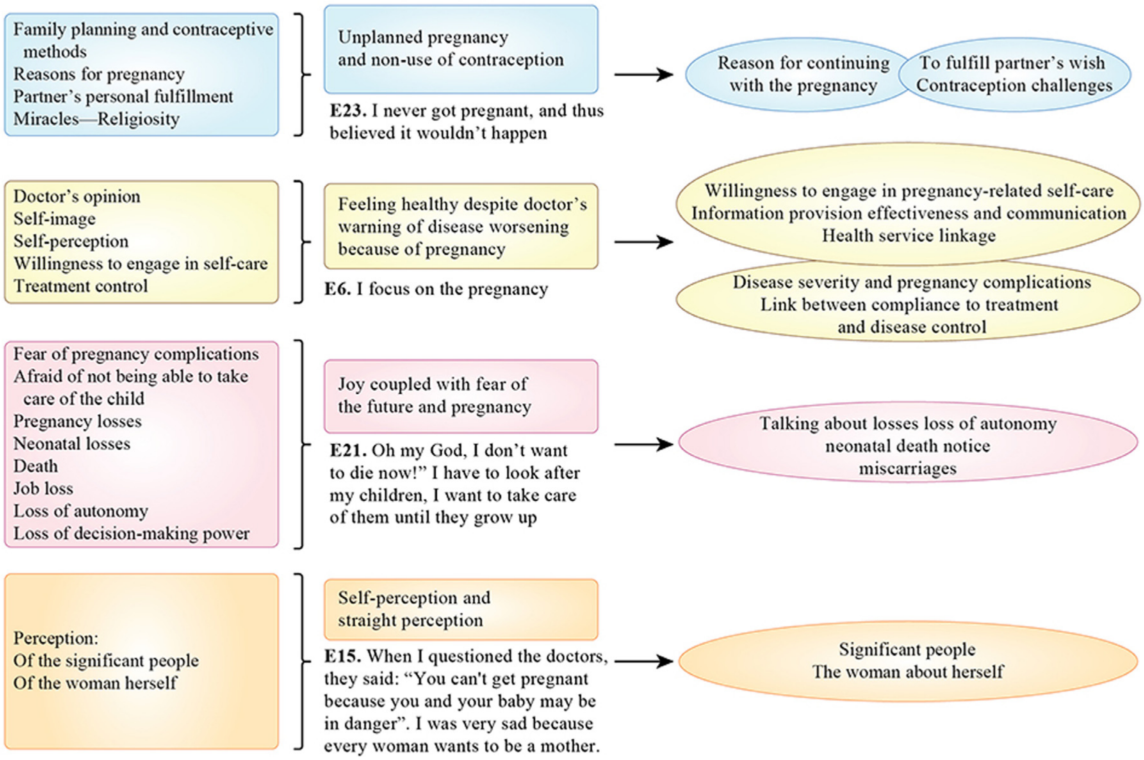

Figure 1. Comprehending interview reports and the category construction process.

There were also reports of women who underwent proper pregnancy planning.

> **E15**. [It]s been nine years [of waiting] for this to happen [pregnancy]. Then, the day of my appointment arrived and I said to the doctor, "look, I can't have a child" and so on. On that occasion, she said: "It's a great time for you to have a child." So when she said that...Wow! Because, every time I asked [previously], [the answer was] "No! No! No." I would leave sad [and] devastated. And, on that day, she said yes. So, I was very happy and thought "wow! I am fine." And I was at ease.

2. Feeling healthy despite doctor's warning of disease worsening because of pregnancy

This category reflects the interplay between having a disease and the choice to feel sick or healthy. In this specific situation, it seems that the idea of "bringing forth life" is a kind of cure because it leaves no space for disease in the pregnancy experience.

> **E6**. I take the medication but I tend to forget that I have lupus. Sometimes there is a reddening of the skin and I have to put on some sunscreen, a habit I didn't previously have. These things serve as a reminder [of the disease] but they become inconsequential as I focus on the pregnancy.

Feeling sick because of medication use

The participants expressed displeasure with the side effects of their medication. Since the disease would eventually go into remission, they attributed all discomfort and symptoms to the prescribed medications. That connects then with a professional relationship.

> **E20**. I stopped taking hydroxychloroquine on my own. I even told the doctor that I wasn't going to take it anymore because it was causing major hair loss and because I felt it was bad for me… I feel so well that taking medication is just an obligation. Doctors know what we have to do. But, if it were up to me, I wouldn't take it because I feel fine. My body is fine, you know?

Willingness to pursue self-care related to SLE in pregnancy

The participants wished to engage in self-care and comply with the treatment proposals for the benefit of the pregnancy and the baby.

> **E07**. Earlier, I didn't care about going to the doctor but [this is] not [true] nowadays (with the pregnancy). Now, I don't think only about myself; I think of the baby [and] I think about the life to come. Because I never imagined being pregnant, I didn't think I had what it takes. But, I think it happened for the better...

Information provision and the effectiveness of communication with health care providers

The relationship of the woman with the health professional will mark the woman's life. This mark can be positive or negative depending upon the quality of communication. This subcategory highlights the importance of assertive communication between health professionals and women with SLE.

> **E19**. We are not kept informed of all relevant matters. Even when I started treatment with a high-risk doctor, I wasn't told about the risks of pregnancy. Another professional I visited gave me a huge scare by saying that the risk was very great and that, in most cases, either the child or the mother dies. I think [the resulting] anxiety worsened my condition and, at present, the lupus bothers me a lot.

Disease severity and pregnancy complications

This subcategory reflects the brush with reality; the possibility of complications and negative outcomes for oneself and the fetus. It reflects the very real presence of SLE.

> **E26**. Sometimes we have to insist that they pass information on to us; otherwise, they don't tell us, and we end up uninformed... Sometimes we feel something, go to a medical appointment, and they say: "how are you?" But, when I don't even know what the disease entails, how am I going to talk about it?

Link between compliance with treatment and disease control

This subcategory reflects women's perception of the need for SLE monitoring and treatment.

> **E24**. I do not think I need it [all the treatment prescribed during pregnancy].

> **E26**. I told the doctor that I intended to get pregnant. I was young but I had wanted to have a child since before I knew I had lupus. He said, "look, you can get pregnant, but it will be a high-risk pregnancy."

3. Joy coupled with fear of the future and pregnancy

This category reflects a fear of death and of the possible disabilities associated with SLE. This is further correlated with the possibility of not being able to take care of the child. Therefore, the interviewed women reported lifestyle changes related to the desire to be in good health so as to live with the baby and experience motherhood.

> **E21** I feel fearful because this disease has no cure, only treatment, so sometimes one gets psychologically distressed. Overwhelmed by sadness, anguish, and fear, I say, "oh my God, I don't want to die now!" I have to look after my children, I want to take care of them until they grow up.

> **E17**. How am I going to take care of a baby if I can't even take care of myself properly? It has to be bathed, taken care of... A baby needs all sorts of care, so I ask myself "how are you going to do this? On days you are in pain, how are you going to handle it? On days that you are sick, with whom will you leave the baby [with] so you can go to the hospital?"

The participants reported that they do not share their concerns for fear of increasing everyone's suffering and try to appear strong.

> **E18**. Regarding family members: spare them. When you expose your suffering, they suffer harder. My mother started to cry. I said, "don't cry, because you have to be stronger than me."

Talking about losses

Women talked about the loss of autonomy during pregnancy with lupus.

> **E18**. I needed to be hospitalized and the doctor said, "then, do you accept the hospitalization?" I [responded] "there is no way of not accepting it, doctor." Imagine if I don't accept it and I have thrombosis at home because of the lack of treatment and I lose my baby.

There was the consideration of gestational and neonatal losses in the participants' statements.

> **E26**. When I found out [about my pregnancy], I was happy and worried at the same time. The worry came from the fact that I was taking a lot of medication for lupus, which I was afraid would affect the fetus. My husband and my son, too; we all wanted that child. So, we wanted it. When I found out it was there, that lifeless child, I couldn't accept it. That loss was hard for me. I cried a lot.

> **E12**. I hate answering phone calls at night. The ringing of the phone at that time instills in me a horrible fear of receiving news of death.

4. Self-perception and straight perception

This category suggests the women's self-image: sick and pregnant. It also reflects how the participants imagined they were perceived by significant people such as family members, friends, and even strangers.

The women reflected on themselves that their lives and desires evolve over time but everything remains shaped by lupus because the disease does not pass.

> **E15**. I started treatment when I was single, then I got married. And then, at some point, you want to have a child, right? And, when I questioned the doctors, they said, "you can't get pregnant because you and your baby may be in danger." I was very sad because every woman wants to be a mother.

Among significant people, the woman perceives a constant concern exists about her health and even a strangeness that a woman sick with lupus is pregnant.

> **E17**. Everybody in my family was happy [about pregnancy] but they had concerns about my health. Once you speak about lupus and pregnancy, everyone gets scared.

> **E22**. People see the limitation. I don't. It can even be funny. Everyone worries a lot. Many people told me they were worried, that they even thought I could not get pregnant. Sometimes it's because they don't know much about the disease.

Discussion

Our results allow us to gain an understanding of the perceptions of pregnant women with SLE. Ambiguous aspects were clarified through organization into themes such as (1) unplanned pregnancy and nonuse of contraception, (2) feeling healthy despite a doctor's warning of the disease worsening because of pregnancy, (3) joy coupled with fear of the future and pregnancy, and (4) self-perception and straight perception.

The average duration since diagnosis with this chronic disease was seven years. Considering the imminent possibility of the disease worsening and perinatal complications, pregnancy planning and the very desire to get pregnant are topics that health care professionals should discuss with women diagnosed with SLE. This would engender the possibility of choosing an effective contraceptive method (CM) and the best time for pregnancy.

The World Health Organization (WHO) publishes and updates the best contraception practices for medical conditions, as well as large-scale family planning models (national level) (WHO, 2018). Moreover, a study on contraception best practices (Fox et al., 2018) suggests that women prefer to use the services of qualified counselors who empower them to make their own decisions about CMs and who prioritize their autonomy and respect their preferences.

The majority of women in this sample reported either no contraceptive use or the misuse of CM. Thus, in the context of women with SLE, selecting adequate contraception may be a challenge for health care teams.

Another issue that warrants attention in this population is that these women do not want to think about their disease; they would rather focus on the pregnancy. This reveals a great motivation because they feel healthy and attribute it to the fact that they are pregnant. However, this is associated with an increased risk of nonadherence to prescribed medications. Psychologically, this may be an act of denial of the disease and its consequences can include inefficacy or the complete discontinuation of treatment.

Another rationale for discontinuing medication is the associated feelings of sickness. These findings are consistent with the literature (Haag et al., 2018); further, patients' understanding of their treatment has a profound effect on their perceptions, compliance, and withdrawal. Sometimes, women seem to believe that the impact of SLE is not severe enough to justify the use of such strong medications, possibly because they are in remission when the disease is not actively manifested.

However, participants also displayed an increased willingness to pursue self-care and compliance with SLE treatment during pregnancy, reporting commitment to changing their habits to offer the pregnancy and the baby the best possible chance of flourishing. Therefore, the pregnancy may represent a great opportunity for discussion and intervention by health professionals. This complements the literature on prenatal health interventions that emphasizes this as an opportunity for good short-term outcomes (Solhi et al., 2019; Miller, 2016; Shorey & Ng, 2019; Rasouli et al., 2019).

The side effects of medications used for controlling SLE can also lead to changes in self-concept and body image, which may cause a woman not to identify with herself. This engenders psychological and social impacts activated by the visibility of the disease. Participants reported experiencing social isolation, sadness, and hopelessness because of their disease-related self-image. In this sense, our findings corroborate prior literature (Rutter & Kiemle, 2015; Jolly et al., 2012) correlating self-image disorders with treatment manifestations and disease symptoms. The available literature largely mentions also about women's experiences during the perinatal period regarding the complexity of body image (Fuller-Tyszkiewicz, Skouteris, Watson, & Hill, 2013; B. Watson, Fuller-Tyszkiewicz, Broadbent, & Skouteris, 2015). Thus, we emphasize the difficulty in attributing the perceptions related to self-concept and body image solely to the pregnancy or to the lupus. As such, we limit ourselves only to highlighting the observation in our findings.

Disease activity may lead women with SLE to experience temporary or permanent disabilities, and participants expressed fear in this regard. Even if they do not actually experience a disability, there is a constant feeling of imminent risk, leading to anxiety. In this sense, it seems that the guarantee of a support system that helps the mother to care for both herself and the newborn would contribute to increasing her sense of security.

The participants frequently mentioned gestational and neonatal losses; past losses instilled anxiety and fear about the possibility of future losses. Therefore, it is essential that the services offered to pregnant women with SLE include the discussion of ways to accept their losses while also supporting them in their grief. This reflection corroborates the literature that observes the need for adequate support in situations of loss (Watson et al., 2019). Especially in the event of a new pregnancy, support offered using appropriate strategies can reduce anxiety and improve maternal attachment to the new baby (Lamb, 2002).

The women of this study reported that, at times, their relationships with other people were influenced by ignorance, prejudice, and discrimination. SLE causes various difficulties in daily life, especially in the context of how people view the associated changes in the patient's physical appearance. The women related this to the manifestation of the disease as well as to the consequences and adverse effects of treatment, and a similar situation can be seen in cases of other discriminatory or stigmatizing factors (Mascayano et al., 2015; Faria-Schützer, et al., 2018).

This perception of prejudice and discrimination may be another factor related to the development of mental health problems. Our participants reported experiencing a realistic level of fear regarding what the disease might cause or bring on in the future. The existence of SLE, which has both psychological and psychosocial dimensions, demands a commitment to ensuring mental health and calls for cooperation among health care professionals to meet the needs of these women (Nowicka-Sauer et al., 2018).

The women interviewed also revealed a desire to feel active and unrestrained. This indicates that working can promote a sense of wellness. In this respect, our study is in agreement with other literature on work as a health intervention (Booth et al., 2018; Gordon et al., 2013).

Finally, participants referred to the active stage of disease as a moment of disturbance. However, the literature highlights the role of stressful social factors contributing to the progression of SLE and correlates lower family income with greater damage caused by the disease (Chae et al., 2015).

Given the above, we can infer some particularities of women with lupus while in prenatal care. Most of our participants did not plan on becoming pregnant but many of them demonstrated a veiled desire for pregnancy, finding nonphysiological justifications for the occurrence of their pregnancy. Their perceptions prompt us to consider the health care gaps that contribute to the occurrence of unplanned pregnancies.

Limitations and strengths

This research contributes to the existing pool of literature on SLE, detailing how women perceive their disease in the context of pregnancy. Based on the results, when women with SLE visit the doctor, they can and should be armed with information that goes beyond epidemiological data, enabling better communication. In addition, this study highlights the need for broad mindsets that go beyond simply the clinical context.

These data emphasize the importance of empowering pregnant and sick women without ignoring their need for constant and solid support. However, the study has some limitations as well. As the participants belonged to a specific region of a country with great diversity, attempts to generalize the results must be conducted with caution. Further research involving other groups of women is required with the intention of showing differences and similarities between groups with different characteristics.

Conclusions

Women with lupus who became pregnant and were treated at a high-risk prenatal clinic had experiences permeated by ambiguous feelings. These women felt healthy because they found that they could have a child despite being diagnosed with a chronic disease; at the same time, they experienced fear and insecurity because of the imminent possibility of disease-related disabilities and limitations. Further, they had a strong desire to experience motherhood but concerns regarding safety and support, owing to the possibility of limitations related to the disease interfering in adverse ways.

The understanding of these women's experiences afforded by this study can lead to and support improvements in clinical management and approaches. Thus, this study seeks to offer health professionals relevant information about the greater scope of service required when caring for pregnant women with SLE. Health teams can be structured to accommodate and advise these women when planning for relationships and pregnancy and how to choose the best CMs and make optimal reproductive decisions. It can also aid in the development of strategies to facilitate behavioral changes in the perinatal period since these women are willing to take care of themselves. Thus, this period can be used to prepare women for managing their disease and their reproductive lives more diligently.

Ethical Approval

This study complies with National Health Council Resolution No. 466 (BRAZIL. Ministry of Health. National Health Council, 2012) on health research with human beings. It was authorized by the local ethics committee under CAAE no. 68143817.0.0000.5404.

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Declaration of Competing Interest

None declared

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ARTIGO 3

Qualitative data regarding the experiences of pregnant women with lupus in Brazil

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Data Article

Qualitative data regarding the experiences of pregnant women with lupus in Brazil

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ABSTRACT

A qualitative design was performed as individual face-to-face interviews with each participant, following a semi-structured script based on open questions. Participants were interviewed at a specialized clinic, where, during prenatal care, women with stable systemic lupus erythematosus disease were received scheduled consultations. The sample was intentionally composed of women who attended a specialized high-risk clinic, from July 2017 to July 2018. Participants ($N = 26$) were interviewed in-depth, without refusal. A thematic analysis, according to the 7 steps of the qualitative analysis, was performed. Before conducting interviews, the researcher went through a period of environmental adaptation to the clinic, following a service observation script and maturing the open consultation script questions, to deepen the themes derived from these women's perceptions during the individual interview. Two authors analyzed the material, which was recorded as audio and transcribed in full; later, the material that was organized in the NVIVO 11 software was validated.

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Specifications Table

Subject	Obstetrics, Gynecology and Women's Health
Specific subject area	Women's health in high-risk, outpatient prenatal care
Type of data	Tables and Figures Interview script Observation script Maps
How data were acquired	The interviews were performed face-to-face, among 26 pregnant women with lupus. Interviews were recorded by Super Voice recorder and transcribed into text manually. (App Super Voice recorder available at https://play.google.com/store/apps/details?id=com.meihillman.audiorecorder&hl=en_US&pli=1)
Data format	Raw data. The complete raw data are only for peer-review and in Portuguese. However, a summary of the participants' statements divided into the questions used in the interview script is made publicly available (Table 3) The analyzed data gave rise to categories of results and are presented in an article published in the Journal of Midwifery (Elsevier) DOI: https://doi.org/10.1016/j.midw.2020.102715.
Parameters for data collection	The interviews occurred on the same day that the patients received prenatal consultations and were conducted in a private room, which was prepared to receive each participant after acceptance. This room contained two chairs facing each other (interviewee and interviewer), without tables, clipboards, or any material that kept the two people away or indicated power.
Description of data collection	The first author (L. R.) collected data by performing 1 interview with each participant, using a flexible guide and 6 open-ended questions. Before each interview, a relationship was established, creating an atmosphere of empathy, trust, and responsiveness. Participants received an explanation of the research topic, a description of the study objectives, and the rights of the parties involved, with sociodemographic data being collected from then on. Written permission was requested to use a recorder. Behavioral and intervening aspects were recorded in a field diary.
Data source location	The University of Campinas- Center for Integral Attention to Women's Health (CAISM)Campinas/State of Sao Paulo/Country: Brazil. Latitude: −22.9064, Longitude: −47.0616 22° 54′ 23″ south 47° 3′ 42″ west
Data accessibility	With the article
Related research article	Rodrigues L, Alves VLP, Sim-Simc MMF, Surita FG. Perceptions of women with systemic lupus erythematosus undergoing high-risk prenatal care: A qualitative study. Midwifery. 2020 May 13;87:102,715. https://doi.org/10.1016/j.midw.2020.102715. Epub ahead of print.

Value of the Data

- The perspectives held by women with lupus, regarding pregnancy, is little explored [1–3].
- Health professionals can benefit from this data, by developing roadmaps for issues that can enhance the perspective of the women they care.
- Health professionals can use an observational script model in research or assistance fields.
- The replication of this method, using other populations, with different or similar characteristics in other settings, can facilitate the understanding of their experiences.
- Knowing these data can lead the health professional to reflect on the non-adherence to medication or contraceptive treatments, by women with lupus.
- The data provided knowledge regarding the characteristics associated with the participants at the research location, and health professionals can identify similarities among women treated by other services, to perform a naturalistic generalization of the research results.

1. Data Description

Table 1 - Characteristics of the participants [3].

Table 2
Raw data for various participant characteristics.

Interview	Occupation/work	Gestational age (weeks + days)	Disease manifestation
1	cashier	29	pseudotumor in the eyelid joint pain, swelling
2	caregiver for the elderly	33 + 3	skin rash
3	manager	36 + 6	skin rash
4	call-center operator	32 + 4	idiopathic thrombocytopenic purpura renal insufficiency
5	unemployed	30	uveitis
6	saleswoman in a furniture store	32 + 5	idiopathic thrombocytopenia purpura skin rash
7	housewife	26 + 6	ulcer on the palate recurrent fever face rash
8	salesperson in a clothing store	30	skin rash (story of 2 young sisters who suffered strokes) anti-nuclear and anti-Ro factor antibody positive
9	hospital receptionist	31	glomerulonephritis (required peritoneal dialysis) and osteopenia
10	worked with handicrafts, now unemployed	30 + 4	early childhood pain crises
11	waitress	28 + 3	joint pain
12	cold-storage assistant	30 + 6	deep vein thrombosis
13	nurse	34	depression
14	retired due to disease	30	stroke
15	supervisor of children	29 + 4	thrombocytopenia, diffuse bleeding
16	industrial production-line worker	24 + 6	erythema on the skin (whole body) focal rash on the face
17	retired due to disease	26	nephritis joint pain
18	manicurist	30	nephritis and thrombocytopenia, deep vein thrombosis
19	dental assistant	29 + 1	head and face lesions
20	accounting clerk	30	anti-phospholipid antibody syndrome brain stroke
21	clerk	28 + 6	skin rash, joint pain
22	nutritionist	35	joint pain swelling
23	cleaning lady	27 + 3	recurrent fever skin rash
24	unemployed engineer	28	skin rash
25	housewife	27 + 5	recurring pain meningitis fever
26	self-employed (sales)	27	pain in arms, swelling, Raynaud's phenomenon, and systemic arterial hypertension

A description of the study participants' sociodemographic characteristics can be viewed in Table 1 from the article "Perceptions of women with systemic lupus erythematosus undergoing high-risk prenatal care: a qualitative study", available at https://www.sciencedirect.com/science/article/abs/pii/S0266613820300887?dgcid=rss_sd_all.

Table 2 - Raw data for various participant characteristics.

This table shows some raw data about the characteristics of the participants.

Table 3 – Raw data of the speeches of the participants' responses.

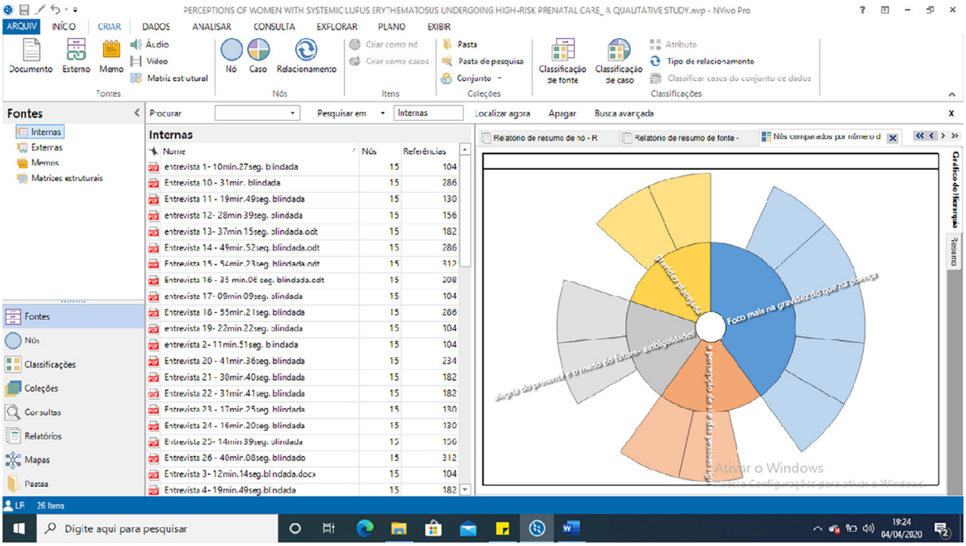
Table 3
Raw data from the participants' responses.

Interviewed	Speech
	1) Tell me how you feel about having an autoimmune disease and 2) Tell me about the experience of being pregnant with this disease:
I18 55 minutes 21 seconds	She needed to be hospitalized, and the doctor said, "So, do you accept?" I said, "There is no way not to accept it, doctor." Imagine me not accepting and having a thrombosis inside my house without being treated, and I lose my son. How will my conscience look afterwards? Just because I was proud to not want to be hospitalized?
I2 11 minutes 51 seconds	And after a while, I found out that I was pregnant. At first, I was scared because my fiancé, who really wanted to be a father…because I will be very sincere, I was not preventing myself [from pregnancy] because the doctor said it would not be good for me to take contraceptives…he told me it was better to avoid…and this contraceptive could make the disease worse.
I13 37 minutes 15 seconds	In the beginning, it was an impact because the hematologist always told me not to get pregnant because lupus affects, attacks the fetus, and aborts. And I cannot take any type of contraceptive or hormone because I am predisposed to having APS. Because I have that positive antibody…Then, he said that if I happened to ovulate, get pregnant, and everything, I wouldn't even find out about the pregnancy because I was going to abort before…And then I got pregnant. So, it was a surprise. It was a surprise. It was not planned at all. But God knows what he does.
I16 35 minutes 06 seconds	Look, you have one more complication. So, I think you're scared. Having it again, there will be complications. At first, it was difficult for me to accept. Wow, it took me about two months to accept the pregnancy. But today I am very happy. Now that I'm going to have a child.
I23 17 minutes 25 seconds	It wasn't planned; it was a surprise. I did not use any contraceptives because, in my other relationship, I had relationships normally, did not avoid, and did not gain a child. And then, I believed that I was not coming. For me, the drugs I take for lupus had wiped out my uterus. I thought I was not pregnant anymore. That's what I put in my head. And I trusted that. Then, in the new relationship, came the pregnancy.
I25 14 minutes 39 seconds	I didn't understand much about gravity. But I'm taking the pregnancy peacefully.
I26 40 minutes 08 seconds	The doctor who attended me when I checked in to do the curettage [for the previous abortion] said that I was crazy about getting pregnant because I have lupus. I couldn't put my life at risk…He spoke to the other doctors, "Ah, this one, she lost [referring to the abortion], but she wants to get pregnant." You know? That I was aware of the problem I had, but I still wanted to try. He wanted to rule my life. I was there suffering; because it is a loss, a pregnancy that you want, and the person treats you that way. I even complained about him here.
	3) Tell me about your follow-up during pregnancy:
I5 22 minutes 34 seconds	Because I thought I was going to get there [at the clinic for consultation] and I wasn't going to listen to the heart, I was already prepared to hear that it hadn't worked out.
I6 38 minutes 27 seconds	My concern is this: being born perfect. The drugs I take harm him. Because I think this is the concern of people who are mothers: doing harm to the baby, reaching something. So, sometimes, listening to what women say [about the healthy children of lupus mothers] more relieved and the doctor said that lupus sleeps, but there are times when he wakes up, understand? So, each case is different.
I6 38 minutes 27 seconds	For me, I have only the pregnancy, and that's it. Because if we don't go crazy, because if you go online and search, "can women with lupus get pregnant?" you see everything. So I prefer not to see it. If it's a phase, let's go, it will pass, and that's it…the only major concern is with the baby…if it will be perfect, if…that's why all the ultrasounds that I do, I ask the doctors, "Is everything ok?" You can talk, right, because…pregnancy…there are people who are healthy, the child comes with a problem.
I8 22 minutes 42 seconds	So, I don't know why. Sometimes I think it's a lot [care in the health service] because with the results of these exams today, I may not have anything, but tomorrow I may have. But at the same time, I think that is too much. I know it is necessary, you know? So, I don't know…[PAUSE].
I10 31 minutes	He's chubby. He'll be born big. I was a little afraid because it took a long time to do an ultrasound. I asked if I could see the brain. They said that I couldn't see it anymore [because I was at an advanced gestational age]. Then I just cry out to God and ask him to come with good health. Counting on the grace of God.
I13 37 minutes 15 seconds	And with pregnancy came even more health. Thank God. Because when I got pregnant…Some of my tests were changed. After I got pregnant, all of my exams became normal. And the FAN was inactive after the pregnancy. So, I think that for me, it was God who sent this son because my health has improved a lot, my heart.

(*continued on next page*)

Table 3 (*continued*)

Interviewed	Speech
I14 49 minutes 52 seconds	Now, I don't even feel like I have lupus. It looks like I don't have lupus [in pregnancy] Because everything the doctor said I couldn't do, I do it. Do not speak [to the doctors]. He was talking to me about the sun, which was meant to be protective. I don't pass anything. He said it might come out. There was no stain. I don't feel any pain.
I24 16 minutes 20 seconds	I don't think I need to [undergo all of the treatments received during pregnancy].
	4) Tell me about your relationships since you discovered the disease and pregnancy:
I14 49 minutes 52 seconds	My mother treats me like a patient. She is always worried about me. My husband doesn't anymore. He treats me like a normal person. To walk, he wants to pull me because he wants me to walk fast. When we are like this [relaxed], he comes and jumps on my lap, and sometimes my leg hurts. My mom gets angry but doesn't speak to him. Then she gets mad and comes to talk to me. And then I talk to him. But because he treats me like that, I feel normal, and it's better than feeling sick.
I25 14 minutes 39 seconds	This pregnancy was to strengthen our union, only now I decided that it is the last one. That I'm not taking any more chances because I know it's dangerous.
I26 40 minutes 08 seconds	My husband, at the beginning, did not accept [the pregnancy]. He was unsure. I wanted to tell him [about the pregnancy] things, and he would say, "I don't know what you want to tell it for. You don't even know if you're going to carry this pregnancy forward." So he was looking forward to the abortions, which had already happened twice. He didn't want to get attached. But at first, it was difficult. I really felt his contempt in that part. But I understand, it is for fear of having that suffering again.
	5) Tell me about your life today:
I7 49 minutes 59 seconds	There's that wall, like, I can't go from there. But you can get there, right? So, like a normal person, right? But you don't have to keep saying, "Ah, but you can't." Like, instead of helping you, that you're capable, [some people] keep putting you down.
I12 28 minutes 39 seconds	I hate taking phone calls at night. The ringing of the phone. That feeling comes. There comes that horrible feeling of receiving news of death.
I25 14 minutes 39 seconds	The disease is visible. Because I was skinny, and suddenly I was swollen, very fat. They played games at school too. They asked if I was pregnant at the time. It upset me a lot. But then I started taking it normal. Nowadays, I already have another thought. I think if you want to be with me, you will live my way, not me in her way.
	6) Is there something else you want to talk about?
I6 38 minutes 27 seconds	When I was about 19 years old, the doctor said that to have a child, I would have to have a treatment, so much that I never took contraceptives. I never took them. So, when I found out I was pregnant, I said, "my God is a miracle," because I never took it, never used a condom, and never got pregnant. So, for me, it was a miracle, a very good feeling…at first I didn't believe it. I only believed it when I saw the ultrasound, that I saw that little thing there.
I25 14 minutes 39 seconds	People asked how I was, and I said, "I'm fine, I have nothing." But it is difficult because lupus is not very popularly known. People did not know what lupus was. There, they were afraid. I already lost a lot of friendship because they thought it was contagious. Because it was a total change, mainly of the body.
I25 14 minutes 39 seconds	I once stopped the medications. When I lost my mom. I was disgusted. But then, I realized later that it's no use. My luck was that lupus did not activate. But then I came back. So, I just abandoned the medication, but the doctor did not.
I2 11 minutes 51 seconds	Work takes away my peace. With the pregnancy, the relationship with the company worsened even more.
I7 49 minutes 59 seconds	No, I don't work now. I quit because I started to feel really bad, and as I was working in a refrigerator. When I started the treatment of lupus, I worked in a very closed place and got very sick; got everything. It was flu, pain, you know? Fever, almost every day, and then I walked away. Then, the doctor discharged me. I filed a lawsuit because there was no way I could go back there because the place was closed, and they didn't want to move me to a more open place, you know? But then I went to work in the refrigerator. It got worse.
I23 17 minutes 25 seconds	With work, it is horrible because, in a farm, I am homely. My friends are doing my job because I can't do it. I can't do it. We need the money to survive because my husband is unemployed.



Internas

Nome	Nós	Referências
entrevista 1- 10min.27seg. blindada	15	104
Entrevista 10 - 31min. blindada	15	286
Entrevista 11 - 19min.49seg. blindada	15	130
entrevista 12- 28min 39seg. blindada	15	156
entrevista 13- 37min 15seg. blindada.odt	15	182
Entrevista 14 - 49min.52seg. blindada.odt	15	286
Entrevista 15 - 54min.23seg. blindada.odt	15	312
Entrevista 16 - 35 min.06 seg. blindada.odt	15	208
entrevista 17- 09min 09seg. blindada	15	104
Entrevista 18 - 55min.21seg. blindada	15	286
entrevista 19- 22min 22seg. blindada	15	104
entrevista 2- 11min.51seg. blindada	15	104
Entrevista 20 - 41min.36seg. blindada	15	234
Entrevista 21 - 30min.40seg. blindada	15	182
Entrevista 22 - 31min.41seg. blindada	15	182
Entrevista 23 - 17min.25seg. blindada	15	130
Entrevista 24 - 16min.20seg. blindada	15	130
Entrevista 25- 14min 39seg. blindada	15	156
Entrevista 26 - 40min.08seg. blindado	15	312
Entrevista 3- 12min.14seg.blindada.docx	15	104
Entrevista 4- 19min.49seg.blindada	15	182

Fig. 2. Image of the generation of codes and graphics for the NVIVO 11 categories.

Fig. 3. Word cloud formulated through NVIVO software.

This table shows a summary of the participants' responses divided by the questions in the script used, previously the construction of categories in the data analysis process.

A figure demonstrating the interview reports and the category construction process can be found as Fig. 1, in the article "Perceptions of women with systemic lupus erythematosus undergoing high-risk prenatal care: a qualitative study" [3], available at https://www.sciencedirect.com/science/article/abs/pii/S0266613820300887?dgcid=rss_sd_all.

Fig. 2 represents a photograph of the data processed using the NVIVO11 software, after being manually analyzed by two researchers, as units of meaning that will be used as nodes. The transcribed and recorded materials of the interviews were coded by the software, showing that the references to speech vignettes chosen for each category were included and coded by the software. NVIVO identified references from all interviews, for all generated nodes and subnodes, as shown in Fig. 2.

This figure shows that the bigger the word appears in the figure, the greater its frequency of appearance in the participants' speeches.

Supplementary material.

Appendix 1- The service coverage map

A geographical and political perspective of the survey location, including a map of the country, a map of the state, and a map of the regional metropolis.

Appendix 2- Guide for the observation of setting during environmental adaptation

The guide used to observe the activities during field research.

Appendix 3 - Semi-structured script, with six open questions

The guide used to conduct interviews.

2. Experimental Design, Materials and Methods

A detailed description of the experimental design, materials, and methods can be found in the article “Perceptions of women with systemic lupus erythematosus undergoing high-risk prenatal care: a qualitative study” [3], available at https://www.sciencedirect.com/science/article/abs/pii/S0266613820300887?dgcid=rss_sd_all.

2.1. Study design

The primary study was designed using the qualitative method, specifically for a clinical setting, where the practice of patient care is routine [4, 5]. The foundation of the method includes three pillars that represent three attitudes of the researcher. The first represents the clinical attitude of valuing active listening and contact between health professionals and patients, who are women with lupus receiving prenatal care, in this study. The second is an existentialist attitude that represents the validation of the problems experienced by each participant. The third attitude is psychoanalytic, manifested as the acceptance and consideration of the unconscious existence, manifest as the psychic expressions between the lines of speech and expressed in the behavior of participants, which requires careful evaluation to be perceived by researchers [3, 4].

2.2. Research setting

The research setting was a specialized outpatient clinic, where women with stable diseases attended scheduled appointments for prenatal care [3]. At this specific clinic, approximately 40 pregnant women, who were diagnosed with high blood pressure, sickle cell anemia, cancer, or autoimmune diseases, are treated weekly, and an average of 25 pregnant women with systemic lupus erythematosusare treated annually [3].

This clinic is located in the City of Campinas, associated with the University of Campinas, where medical residents, nursing students, and students studying nutrition and physiotherapy participate in services provided by the Women’s Hospital "Professor Doutor José Aristodemo Pinotti" - Center for Integral Attention to Women’s Health (CAISM). The Women’s Hospital is the second-largest unit at the University of Campinas, with 1200 employees, provides services in over 60 subspecialties, encompassing the complex array of teaching and research activities that exist in the field of health care for women and newborns, and offers diagnostic and therapeutic services, especially in the areas of Gynecology, Obstetrics, Neonatology, and Oncology. The Women’s Hospital is maintained using budgetary resources from the University and the public health system in Brazil (SUS). (https://www.unicamp.br/unicamp/saude), and is a reference service center for a region that covers 42 cities (http://www.saude.sp.gov.br/ses/institucional/departamentos-regionais-de-saude/drs-vii-campinas).

The metropolitan region of Campinas is the second-largest metropolitan region in the country, with more than 3.2 million inhabitants [Brazilian Institute of Geography and Statistics (IBGE)], and generated 8.75% of the state’s Gross Domestic Product (GDP) in 2016.

The service coverage map can be viewed in Appendix 1.

2.3. Environmental adaptation

The researcher's environment is relevant within the context of qualitative research [6,7]. Thus, during the development of our primary study, the first author had been situated in the setting since February 2017, when the observations regarding the functions and relationships within the service were recorded, according to a script, which is available in full in Appendix 2. This script allowed the researcher to undertake and maintain the behavior necessary to develop a rapport with the participants. In addition, the script allowed ample visualization and understanding of the necessary organization and environmental factors during the development of interviews, including the best time to meet with each participant and the best method for maintaining a private environment, protected from interruptions.

2.4. Sampling

The sample of participants considered for the primary study was intentionally selected. Our participants had common questions, which covered the pregnancy experience and the diagnosis of lupus, which resulted in their referral and receipt of treatment from the clinic. In addition, we chose to interview the participants during the third trimester of pregnancy, increasing the likelihood that experiences would accumulate during the first two quarters, which appeared to enriched the speeches of the participants, although no studies describing or exploring the perceptions of pregnant SLE patients during earlier periods of pregnancy exist for comparison.

To better highlight the characteristics and particularities of these women, we built a table describing the relevant sociodemographic data, which can be found in "Table 1. Characteristics of the participants" in the article "Perceptions of women with systemic lupus erythematosus undergoing high-risk prenatal care: a qualitative study" [3], available at https://www.sciencedirect.com/science/article/abs/pii/S0266613820300887?dgcid=rss_sd_all5.

2.5. Approaching the participants

Data collection was performed through one interview with each participant, between July 2017 to July 2018. The first author established relationships with the interviewees prior to the interview, to create rapport [8], and increase the atmosphere of empathy, trust, and openness for the interview, which can increase the comfort of the participants to respond more freely.

Subsequently, all interviews were conducted by the first author, using a semi-structured script consisting of six open questions, which can be found, in full, in Appendix 3.

The following considerations were applied to the question roadmap:

- The script was created during the research project and received necessary modifications during the environmental adaptation period.
- The objective was to guide the interviewer during the data collection process, but the researcher remained flexible, allowing the free flow of speech with the women being interviewed.
- As a guide, the script was used, as necessary, by the interviewer, who sometimes realized that there was no need to obey the sequence of questions or to ask them all because the interviewee's speech often provided answers without having to pose the questions.

In addition to the interviewees' speeches, we recorded a field diary, containing behavioral and intervening aspects observed during data collection.

A private room was prepared for each interview, containing two chairs facing each other (for the interviewee and interviewer), without tables or utensils that could physically separate the two people or that could indicate any power in this relationship, to provide a relationship without hierarchies and allowing the woman to freely talk about her experience as she saw fit.

The women were invited to participate in the interview on the same day that they had an antenatal medical appointment, to avoid the necessity of additional visits to the clinic.

3. Data Analysis

The content analysis was performed in 7 different stages [9], as follows:

1. The notes in the field diary were organized, and the recorded audio of the interviews was literally transcribed by the first author. These notes and transcriptions formed a text that we call the corpus. To present the results, in the text of the primary article, grammatical corrections were made to sections of the chosen discourses, to facilitate the reader's understanding.
2. During this stage, two authors (first author LR and her PhD supervisor FGS) listened to the interviews and read the corpus.
3. The authors registered their impressions on the emerging and significant themes in the right margins of the transcribed text during reading and rereading.
4. During this step, all perceived content (themes and emerging meanings) was organized into categories and subcategories, with the intention of identifying patterns representing significant units and relevant characteristics within the text, considering two important issues: the relevance of the content in each interview, and the frequency [10] with which a given topic appears across all interviews.
5. During the independent analyses performed by two authors, disagreements were identified and discussed with the other authors, until a consensus was reached. In addition to this discussion, this material was presented at meetings for a research group, called Reproductive Health and Healthy Habits (SARHAS), at the University of Campinas, in the same hospital where the care for women with prenatal lupus occurred. Posters and presentations at national and international congresses were also performed, with the intention to discuss and validate this material.
6. The finalization of the screen and the structure of the categories and subcategories, including the construction of a figure that illustrates the thought process of the authors and the discussions between them. This is titled "Figure 1. Comprehending interview reports and the category construction process" and can be found in the article "Perceptions of women with systemic lupus erythematosus undergoing high-risk prenatal care: a qualitative study" [3], available at:
   https://www.sciencedirect.com/science/article/abs/pii/S0266613820300887?dgcid=rss_sd_all
7. All material was validated by peers and members of the SARHAS research group, and NVivo 11 software (QSR International, Melbourne, Australia) was used to organize all material from the beginning of data collection until the end of the study.

In addition, to write the primary article, the consolidated criteria for reporting qualitative research (COREQ) checklist [11] was used, to guarantee the necessary rigor for this type of study.

4. Data Validation

Data validation is necessary for qualitative studies to guarantee accuracy [12]. This rigor is understood and must be presented in two ways:

- Internal validation ensures that researchers have the skills to perform the data collection, to establish the necessary relationships with research participants, to understand the eminent meanings in the speeches of the participants, and to analyze the observations made in the field.
- External validation requires that the data, which was analyzed in pairs, be exposed to those with expertise in the theme, through presentations to research groups and scientific events.

For internal validation, we made some necessary reflections and we emphasize the following points:

The first author, who conducted all of the interviews, is a nurse and has experience in hospital care practice and primary care, with a focus on family health, and has accumulated professional experience in relationships with patients and family members in critical situations, such as hospitalizations in a nursing unit or intensive care; situations of social vulnerability, such as hospitalizations in psychiatry and psychosocial care; and situations in which rapid decision-making is required, such as care at a normal birth center.

This experience has allowed her to develop skills in relationships with different hierarchies and to understand how power relationships can be neutralized during different meetings. She (LR) has professional experience as a teacher, accompanying students in theory and care practice, which has helped her to develop the necessary skills to exercise and teach confidentiality and ethics in relationships.

She (LR) has experience with face-to-face interviews, during graduation with nursing academics, facing death and during a master's degree program with parents who experienced the loss of their child in a neonatal intensive care unit, she which made them develop the skills to use semi-structured scripts, dealing with the necessary flexibility to use these instruments and the development of qualitative research on subjects with dense content that may affect the interviewee's feelings and emotions.

However, the interviewee's feelings were welcomed by the research advisor supervisor (F. G. S.) and members of the research group (V. L. P. A. and M. S. S.) during the development of all the work.

For external validation, we have presented our research to the SARHAS group and The 11th international autoimmunity congress, 23th Congress of Gynecology and Obstetrics of Sao Paulo, 2018.

Ethical Approval

The primary study complies with National Health Council Resolution No. 466 [13] on health research with human beings. It was authorized by the local ethics committee under CAAE no. 68143817.0.0000.5404 [3]. Informed consent of all participants has been obtained in writing.

CRediT_author_statement

Larissa Rodrigues: Conceptualization, Methodology, Data colection, Data analysis, Writing- Original draft preparation, Writing- Reviewing and Editing. **Fernanda Garanhani Surita**: Conceptualization, Methodology, Writing- Original draft preparation, Reviewing and Supervision. **Vera Lucia Pereira Alves:** Data analysis,Visualization, Validation. **Maria Margarida Fialho Sim-Sim:** Data analysis,Visualization, Validation.

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Declaration of Competing Interest

All authors declare that there are no known financial interests or interests that may influence or work on this document.

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Supplementary Materials

Supplementary material associated with this article can be found in the online version at doi:10.1016/j.dib.2020.106606.

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ARTIGO 4

Quality of life among pregnant women with lupus

Larissa Rodrigues, Maria Laura Costa do Nascimento, Maria Margarida Fialho Sim-Sim, Fernanda Garanhani Surita

Submetido

20-Jan-2021

Dear Dr. Surita:

Your manuscript entitled "QUALITY OF LIFE AMONG PREGNANT WOMEN WITH LUPUS" has been successfully submitted online and is presently being given full consideration for publication in the Revista Brasileira de Ginecologia e Obstetrícia.

Your manuscript ID is RBGO-2021-0020.

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QUALITY OF LIFE AMONG PREGNANT WOMEN WITH LUPUS

QUALIDADE DE VIDA ENTRE MULHERES GRÁVIDAS COM LÚPUS

ABSTRACT

Objective: This study aimed to investigate the quality of life among pregnant women with lupus, who are being treated at a high-risk, prenatal outpatient clinic, during the third trimester of gestation. **Methods**: The World Health Organization Quality of Life (WHOQOL)-BREF questionnaire was used, comprised of 26 questions, divided into four domains (physical, psychological, social, and environment). **Results**: Fifty pregnant women who were diagnosed with systemic lupus erythematosus (SLE) were interviewed. The average age of participants was 30 years [standard deviation (SD) = 14.85] and the average time since lupus diagnosis was 9.06 years (SD = 15.55). Most participants had a partner, did not plan their pregnancy (76%), and did not use contraception prior to pregnancy (80%). Each of the domains can be scored between 0 (worst score) and 100(better score). Our participants presented mean (SD) scores for the following domains: physical, 52.21 (18.44); psychological, 64.17 (18.56); social 66.33 (27.09), environment, 64.56 (18.53); general quality of life (QOL), 70.50 (24.06); and health-related QOL, 70.00 (30.72). **Conclusions**: The physical domain presented the lowest scores compared with the psychological, social, and environmental domains. Pregnant women with SLE reported general QOL scores higher than other women, and their health-related QOL scores were also relatively high.

Key-words: pregnancy; systemic lupus erythematosus; quality of life

RESUMO

Objetivo: Este estudo teve como objetivo investigar a qualidade de vida de gestantes com lúpus, em acompanhamento ambulatorial pré-natal de alto risco, durante o terceiro trimestre de gestação. **Método**: Foi utilizado o questionário da Organização Mundial da Saúde de Qualidade de Vida (WHOQOL) -BREF, composto por 26 questões, divididas em quatro domínios (físico, psicológico, social e meio ambiente). **Resultados**: Foram entrevistadas 50 gestantes com diagnóstico de lúpus eritematoso sistêmico (LES). A idade média dos participantes foi de 30 anos [desvio padrão (DP) = 14,85] e o tempo médio desde o diagnóstico de lúpus foi de 9,06 anos (DP = 15,55). A maioria das participantes tinha companheiro, não planejava a gravidez (76%) e não fazia uso de anticoncepcional antes da gravidez (80%). Cada um dos domínios pode ser pontuado entre 0 (pior pontuação) e 100 (melhor pontuação). Nossos participantes apresentaram escores médios (DP) para os seguintes domínios: físico, 52,21 (18,44); psicológico, 64,17 (18,56); social 66,33 (27,09), meio ambiente, 64,56 (18,53); qualidade de vida geral (QV), 70,50 (24,06); e QV relacionada à saúde, 70,00 (30,72). **Conclusões**: O domínio físico apresentou os menores escores em comparação com os domínios psicológico, social e ambiental. Mulheres grávidas com LES relataram escores gerais de QV mais altos do que outras mulheres, e seus escores de QV relacionados à saúde também foram relativamente altos.

Palavras-chave: gravidez; lupus eritematoso sistêmico; qualidade de vida

INTRODUCTION

Systemic lupus erythematosus (SLE) is an autoimmune, multisystem disease that can cause damage to the skin, kidneys, heart, lungs, and other organs. SLE is more prevalent among women of reproductive age and has been associated with a high risk of adverse maternal and perinatal outcomes.(1,2)

The most common conditions observed during pregnancy include hypertension, nephropathy, and the presence of autoantibodies, which can affect the maternal-fetal binomial.(3,4) The management of SLE during pregnancy can become challenging, both due to difficulties distinguishing disease manifestations from the physiological changes associated with pregnancy and due to the increased need for therapeutic control and surveillance.(5) Therefore, pregnancy may affect the quality of life (QOL) among women with SLE.

QOL is defined by the World Health Organization (WHO) as how people perceive their position in life, how they view their goals, their expectations, and their concerns, and how they relate to the culture and values of the place where they live.(6) QOL can be measured with validated instruments, such as the WHOQOL-BREF questionnaire.(7)

The WHOQOL has previously been used to measure general QOL and has previously been validated in Portuguese, making this an appropriate tool for use in Brazil.(7) The WHOQOL is not specific to the functional aspects associated with health during pregnancy or among women with lupus. Although the WHOQOL has been used in Brazil for the assessment of other pregnant women receiving both usual-risk(8-10) and high-risk antenatal care(8,11,12) this study represents the first time that this instrument was used in women with two health conditions: pregnancy and lupus.

Using another questionnaire, the SF-36, low QOL scores were verified among individuals diagnosed with lupus for items related to emotional function, physical function, and mental health [13]. The SF-36 is a self-administered questionnaire containing 36 items that takes approximately five minutes to complete and was validated in 1992.(14)

A review of QOL among individuals with lupus, not during pregnancy, using the SF-36 also showed compromised QOL in aspects of general health, vitality, and physical and emotional functions.(15)

The QOL among pregnant women with lupus has been discussed, previously, and their perceptions of pregnancy in the context of the disease appear to be ambiguous. Some reports have described a sense of well-being and satisfaction accompanying pregnancy, in addition to fears and uncertainties regarding the limitations that the disease may impose on maternal-fetal health.(16) Women with lupus desire the experience of maternity; however, to fulfill this desire, they require adequate support.(16)

In Brazil, and worldwide, the healthcare strategies during pregnancy aim to achieve specific good practices during prenatal care, childbirth, and the puerperium, strengthening the bond between women and health services(17,18), based on global recommendations for positive antenatal care experiences.(19,20)

Therefore, this study aimed to investigate QOL among women with lupus during the third trimester of pregnancy while being treated at a specialized antenatal care unit.

METHODS

Study design

A descriptive quantitative study was performed.

Setting

The research setting was a specialized outpatient clinic that performs multidisciplinary follow-up of pregnant women with underlying diagnoses of lupus and other complications. Approximately 40 pregnant women, diagnosed with hypertension, sickle cell disease, cancer, and autoimmune diseases, are treated at this location each week, including an average of 25 lupus patients, annually.

Participants

Pregnant women with diagnosis of lupus were eligible if they were in the 3rd trimester of pregnancy and receiving antenatal care follow-up care.

Participants received an explanation of the study topic, the study objectives, and the rights of the parties involved, after which, the sociodemographic data were collected (age, time since lupus diagnosis, parity, miscarriage or fetal death, planned pregnancy, prior contraception, education level, paid work, with a partner). The questionnaire was applied in the form of an interview, which took an average of 15 minutes to administer. Participants were approached on the same day that they participated in a medical consultation for antenatal care. The interviewees were guaranteed confidentiality. Permission was requested to use a recording device. The interviewer read and explained the Informed Consent Form to the participants, and interviews were only performed after patients indicated their understanding and signed the document.

Sample size

The sample size was calculated for 50 participants, based on previous studies performed for similar groups and instruments.(11,21)

The procedure used was the calculation of a sample size to estimate a mean, using the mathematical equation $n = \left(\frac{z\sigma}{d}\right)^2$, where n is the estimated sample size, z is the percentile of the normal distribution for a significance level of 5%, z = 1.96, σ is the standard deviation extracted from the studies used as references, and d is the maximum absolute error allowed = 5 e 6.

Microsoft Excel®, version 2013, was used to perform this calculation.

Instrument

The instrument for analyzing QOL measurements was the WHOQOL-BREF.(7) The questionnaire presents 26 items regarding QOL, divided into 4 domains: physical, psychological, social relationships, and environment. These 26 items are presented in a Likert scale format, with scores from 1 to 5. Lower scores represent worse perceptions of QOL. For the proper interpretation of results, the questions Q3, Q4, and Q26 have reversed scores, with 5 representing the worst score and 1 representing the best score for these questions, requiring inversions when indicated.(22)

The results of the domains show values between 0 and 100; therefore, we consider the worst scores to be those closer to 0, whereas the best scores were closer to 100. Research defining cutoff points for women and pregnant women has not yet been reported. We found only one study that discussed cutoff points for the perception of QOL in the elderly population.(23)

Statistical analysis

To describe the profile of the sample according to the studied variables, frequency tables were made for categorical variables (items from the QOL questionnaire according to the physical, psychological, social, environmental, general QOL, and health-related QOL domains), reporting values for absolute frequency (n) and percentage (%), and descriptive statistics are reported for all numerical variables (scores from the QOL questionnaire for each of the 26 questions), with mean values, standard deviations, minimum and maximum values, medians, and quartiles. SAS System for Windows (Statistical Analysis System), version 9.2 (SAS Institute Inc., 2002-2008, Cary, NC, USA) was used to perform statistical analyses.

Ethical aspects

This study was performed in accordance with the Resolution of the National Health Council Law no. 466(24) on health research with human beings and received authorization from the local Ethics Committee, under the number #68143817.0.0000.5404.

RESULTS

All women who were treated at the considered outpatient clinic between July 2017 and July 2019 were invited to participate in this study, with no cases of refusal.

A total of 50 pregnant women with lupus participated in this study, with an average age of 30 years [standard deviation (SD) = 14.85] and an average time since lupus diagnosis of 9.06 years (SD = 15.55). Most participants had a partner, did not plan their pregnancies, and did not use contraception. The sociodemographic characteristics are shown in Table 1.

Table 1: Characteristics of women with Lupus in prenatal care (n=50)

Participants women (n=50)		**N (%)**
Variable	**Categories**	
Age	Up to 30 years old	27 (54%)
	> 30 years old	23 (46%)
Lupus diagnosis time	Up to 5 years	23 (46%)
	> 5 years	27 (54%)
Parity	Primiparous	18 (36%)
	Multiparous	32 (64%)
Abortion or fetal death	Yes	11(22%)
	No	39 (78%)
Planned pregnancy	Yes	12 (24%)
	No	38 (76%)
Prior contraception	Yes	10 (20%)
	No	40 (80%)
Education level	High school	30 (60%)
	Elementary School	8 (16%)
	College	8 (16%)
	No schooling	3 (6%)
	Technical education	1 (2%)
Paid activity	Yes	30 (60%)
	No	20 (40%)
With partner	Yes	35 (70%)
	No	15 (30%)

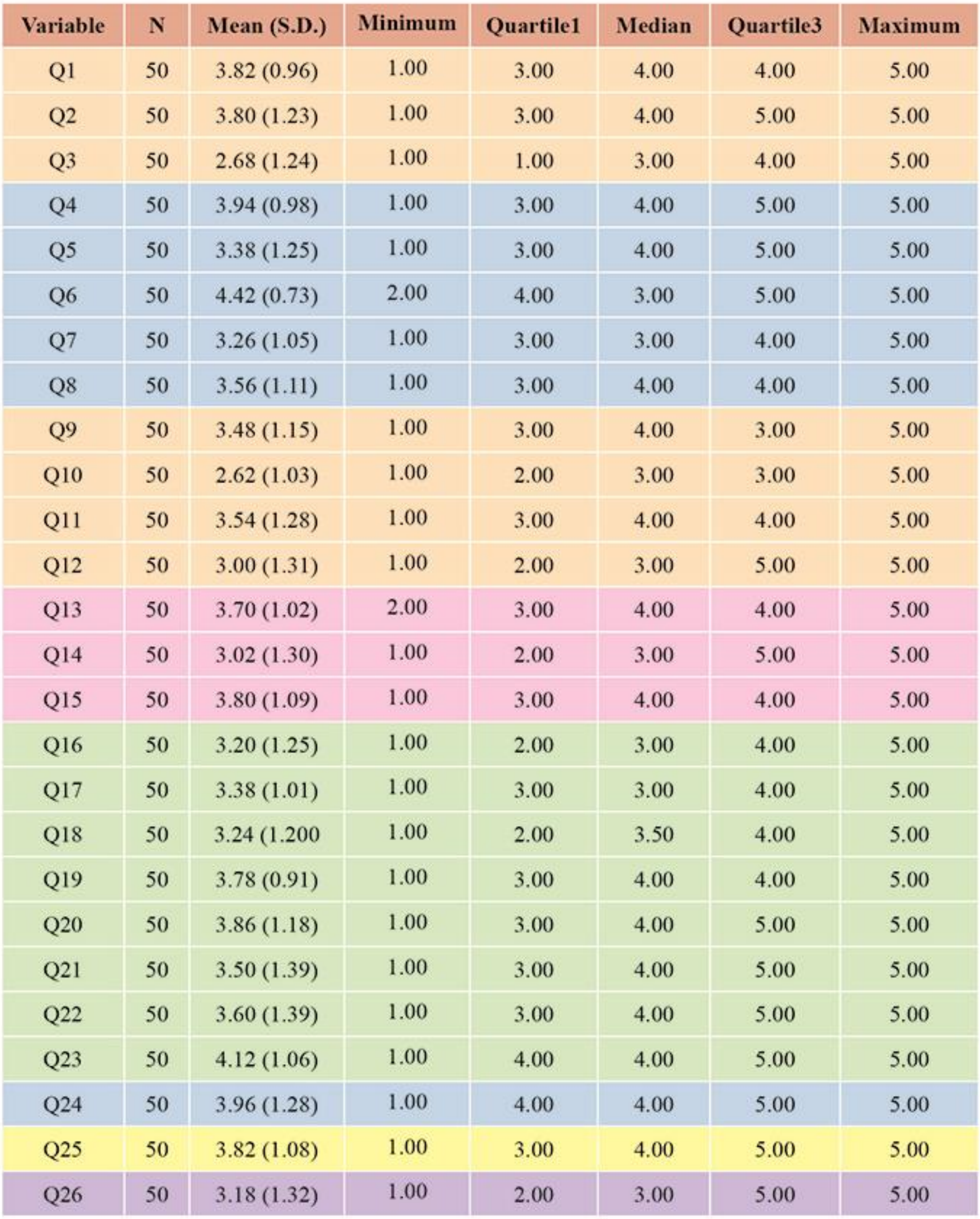
According to the domains of the WHOQOL-BREF questionnaire, our participants presented mean (SD) scores for each of the following domains: physical, 52.21 (18.44); psychological, 64.17 (18.56); social, 66.33 (27.09); environment, 64.56 (18.53); general QOL, 70.50 (24.06); and health-related QOL, 70.00 (30.72). Table 2 shows the scores for each domain.

Table 2. Descriptive analysis by domains WHOQOL-bref (n=50)

Domains	N	Mean (S.D.)	Minimum	Quartile1	Median	Quartile3	Maximum
Physical	50	52.21(18.44)	14.29	39.29	53.57	67.86	85.71
Psychological	50	64.17(18.56)	20.83	54.17	66.67	75.00	100.00
Social	50	66.33(27.09)	8.33	50.00	66.67	91.67	100.00
Environment	50	64.56(18.53)	12.50	50.00	65.63	81.25	100.00
General QOL	50	70.50(24.06)	0.00	50.00	75.00	75.00	100.00
Health-related QOL	50	70.00(30.72)	0.00	50.00	75.00	100.00	100.00

When we examined each question of the WHOQOL-BREF instrument, the lowest average score of 2.68 (1.24) was found for question 3, which referred to sleep and rest within the physical domain, whereas the highest average score was 4.42 (0.73) for question 6, which referred to the sense of life within the psychological domain. Table 3 describes the scores for each of the 26 questions contained in the instrument.

Table 3. Descriptive analysis of numerical variables (n = 50)



Variable	N	Mean (S.D.)	Minimum	Quartile1	Median	Quartile3	Maximum
Q1	50	3.82 (0.96)	1.00	3.00	4.00	4.00	5.00
Q2	50	3.80 (1.23)	1.00	3.00	4.00	5.00	5.00
Q3	50	2.68 (1.24)	1.00	1.00	3.00	4.00	5.00
Q4	50	3.94 (0.98)	1.00	3.00	4.00	5.00	5.00
Q5	50	3.38 (1.25)	1.00	3.00	4.00	5.00	5.00
Q6	50	4.42 (0.73)	2.00	4.00	3.00	5.00	5.00
Q7	50	3.26 (1.05)	1.00	3.00	3.00	4.00	5.00
Q8	50	3.56 (1.11)	1.00	3.00	4.00	4.00	5.00
Q9	50	3.48 (1.15)	1.00	3.00	4.00	3.00	5.00
Q10	50	2.62 (1.03)	1.00	2.00	3.00	3.00	5.00
Q11	50	3.54 (1.28)	1.00	3.00	4.00	4.00	5.00
Q12	50	3.00 (1.31)	1.00	2.00	3.00	5.00	5.00
Q13	50	3.70 (1.02)	2.00	3.00	4.00	4.00	5.00
Q14	50	3.02 (1.30)	1.00	2.00	3.00	5.00	5.00
Q15	50	3.80 (1.09)	1.00	3.00	4.00	4.00	5.00
Q16	50	3.20 (1.25)	1.00	2.00	3.00	4.00	5.00
Q17	50	3.38 (1.01)	1.00	3.00	3.00	4.00	5.00
Q18	50	3.24 (1.200	1.00	2.00	3.50	4.00	5.00
Q19	50	3.78 (0.91)	1.00	3.00	4.00	4.00	5.00
Q20	50	3.86 (1.18)	1.00	3.00	4.00	5.00	5.00
Q21	50	3.50 (1.39)	1.00	3.00	4.00	5.00	5.00
Q22	50	3.60 (1.39)	1.00	3.00	4.00	5.00	5.00
Q23	50	4.12 (1.06)	1.00	4.00	4.00	5.00	5.00
Q24	50	3.96 (1.28)	1.00	4.00	4.00	5.00	5.00
Q25	50	3.82 (1.08)	1.00	3.00	4.00	5.00	5.00
Q26	50	3.18 (1.32)	1.00	2.00	3.00	5.00	5.00

🟧 Physical Domain; 🟦 Psychological Domain; 🟥 Social relationships; 🟩 Environment;
🟨 General QOL; 🟪 QOL health

DISCUSSION

When using the WHOQOL-BREF to evaluate QOL among women with high-risk pregnancies, complicated by lupus, the lowest scores were identified in the physical domain, with the lowest mean score reported for a question referring to activities of daily life. The scores in the present study were similar to those reported by other studies of pregnant women receiving high-risk prenatal care.(8,25)

In our study, among the four domains evaluated by the WHOQOL-BEF (physical, psychological, social, and environmental), the physical domain was found to have the lowest score, of 52.21 (18.44). In another Brazilian study, which also evaluated pregnant women receiving high-risk prenatal care, the physical domain was the domain with the lowest reported scores of 47.8 (15.9)(8), and a similar finding was reported by a study performed in Greece(25); however, a different result was reported by a study in Poland, where the lowest score was observed for the social domain.(26)

Within the physical domain, the question regarding pain and discomfort among the participants resulted in an average score of 3.82, which may be associated with the control of pain issues related to lupus, either through medication or alternative therapies, which is consistent with the literature.(27,28)

For the question on energy and fatigue, participants responded with an average score of 3.80, which indicated that these symptoms have been endured, which may be related to the control of the disease and its symptoms and are similar to studies performed among non-pregnant women with lupus.(27,28)

The participants reported an average score of 2.68 for the question regarding sleep and rest. Poor sleep quality among women with lupus, whether objective or subjective, has also been reported in a previous study.(29) Similarly, pregnant women, even without lupus, are known to have difficulties achieving good quality sleep and rest and report symptoms of sleep disorders at significant rates(30) Sleep disorders have also been shown to be associated with depressive symptoms.(31,32)

With regard to mobility, the participants had an average score of 3.48, which indicated a decrease in their ability to move, which may impact the autonomy of women, their safety, and their abilities to participate in activities, as described in a recent study of the importance of mobility when caring for individuals with lupus.(33)

In response to the question regarding activities of daily living, the women reported an average score of 2.62, which was the lowest score for this domain. This response suggested that women with SLE feel less capable of performing commonplace activities, and which may represent the synthesis of the discomfort indicated by the other items.

With regard to dependence on medication or treatment, our subjects reported an average score of 3.54, possibly due to a sense of dependence on treatments for the illness and the need to monitor the pregnancy. However, from a more subjective perspective, these women have indicated that the use of some medications make them feel bad and that they would prefer to focus on the pregnancy, instead of the disease.(16)

Analyzing the ambiguity among these reports has resulted in increased attention being paid to the possibility that women may wish to engage in the discontinuation of treatment or be more inclined toward improved self-care while pregnant.(16)

For the question that referenced work capacity, participants reported an average score of 3.0, indicating that they feel less able to perform their professional activities or engage in work at home. A similar finding was reported by another study regarding the difficulties encountered in relation to work after being diagnosed with lupus and the need to maintain a different routine due to the monitoring required and the limitations imposed by the disease.(34)

The psychological score of 64.17 (18.56) and the environmental score of 64.56 (18.53) were higher than the scores for the other domains. In the psychological domain, a connection appears to exist between feeling healthy and being pregnant, despite the underlying presence of the disease.(16) A desire for pregnancy may also be associated with a sense of fulfillment, resulting in the sensation of psychological satisfaction.

The scores for the environmental domain are associated with the study setting coinciding with the most economically and culturally developed region of the country, which is similar to the findings of other studies that have indicated that qualified insertion and good remuneration in the labor market, transportation, leisure possibilities, and security are aspects that affect the social capital of people.(35,36)

The social domain score of 66.33 (27.09) was the highest score among the domains examined in this study; however, the literature has indicated that lupus tends to interfere with the social aspects of affected individuals.(34)

General QOL is assessed by a specific question, separate from the other domains, for which the participants had a mean score of 70.50 (24.06), which is higher than the average score reported among women with lupus in other locations in the country, and other high-risk pregnant women were reported to have an average score of 62.8 (13.8).(8)

The assessment of health-related QOL, which is also separate from the other domains, the score was high, at 70 (30.72), but we did not find comparative values reported in other studies. This discrepancy may be associated with the access to specialized health services for the monitoring of pregnancy and childbirth among our population, as access to health services has been previously indicated and discussed as a factor that is associated with a better QOL perception.(35,36)

The manifestations of lupus during pregnancy.(1,3) may annoy women more than usual and stand out more strongly when women refer to QOL, even when the disease is under control. Pregnancy involves major physical changes(37), which may also be associated with the lower scores expressed by our patients in the physical domains.

In other countries, the QOL of pregnant women receiving high-risk prenatal care has been assessed using the same instrument, among women diagnosed with diabetes in Thessaloniki, Greece(25) and Lublin, Poland.(26) This instrument was also used to assess

QOL before and after the implementation of a physical exercise intervention in Brazil (in a hospital environment), and in Szczecin and Warsaw, Poland (in an exercise club environment).(38). This instrument has also been used to assess changes in QOL and among women with lupus during pregnancy and puerperium, in Providence, in the United States of America.(39)

QOL among pregnant women, in general, has been poorly explored in the literature, which has hindered the accurate assessment and setting of adequate parameters for this population.(40)

Some characteristics of our participants may be related to their perceptions of QOL. For example, 38 of the 50 participating women have completed high school or complete graduation, which can be characterized as more than 10 years of school attendance. The literature has indicated that more schooling may be associated with better perceptions of QOL.(41). Similarly, 35 of them have a partner, which may be associated with the perception of social satisfaction, which also reinforces the reported literature.(41)

Another characteristic observed among our participants is the counterpoint between the 38 women who did not plan the pregnancy and the 40 women who used any contraceptive method, a practically inverse relationship with the 12 who planned the pregnancy and the 10 who used a contraceptive method, which may be associated with a veiled desire for pregnancy.(16)

Strengths and limitations

The QOL among women diagnosed with lupus during the third trimester of pregnancy has been poorly investigated, and we have not identified any other studies examining this issue. This study is limited to the assessment of QOL perceptions among women in a specific area of one country and cannot be generalized. Future studies can contribute to the development of associations between QOL perceptions and sociodemographic characteristics of women in this area or with other characteristics of pregnant women with lupus in other locations. Another limitation of this study is that no group of women without the disease, treated by the same service, was recruited for comparison with women with lupus.

CONCLUSION

Among women with lupus who were treated at a specialized, high-risk, prenatal care center, the physical domain of QOL received the lowest scores compared with the psychological, social, and environmental domains. The women in this study had higher general QOL scores than women in other parts of the country, and the health-related QOL scores were also relatively high among this population.

CONFLICT OF INTEREST

The authors have no disclosures of interests to make.

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ARTIGO 5

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

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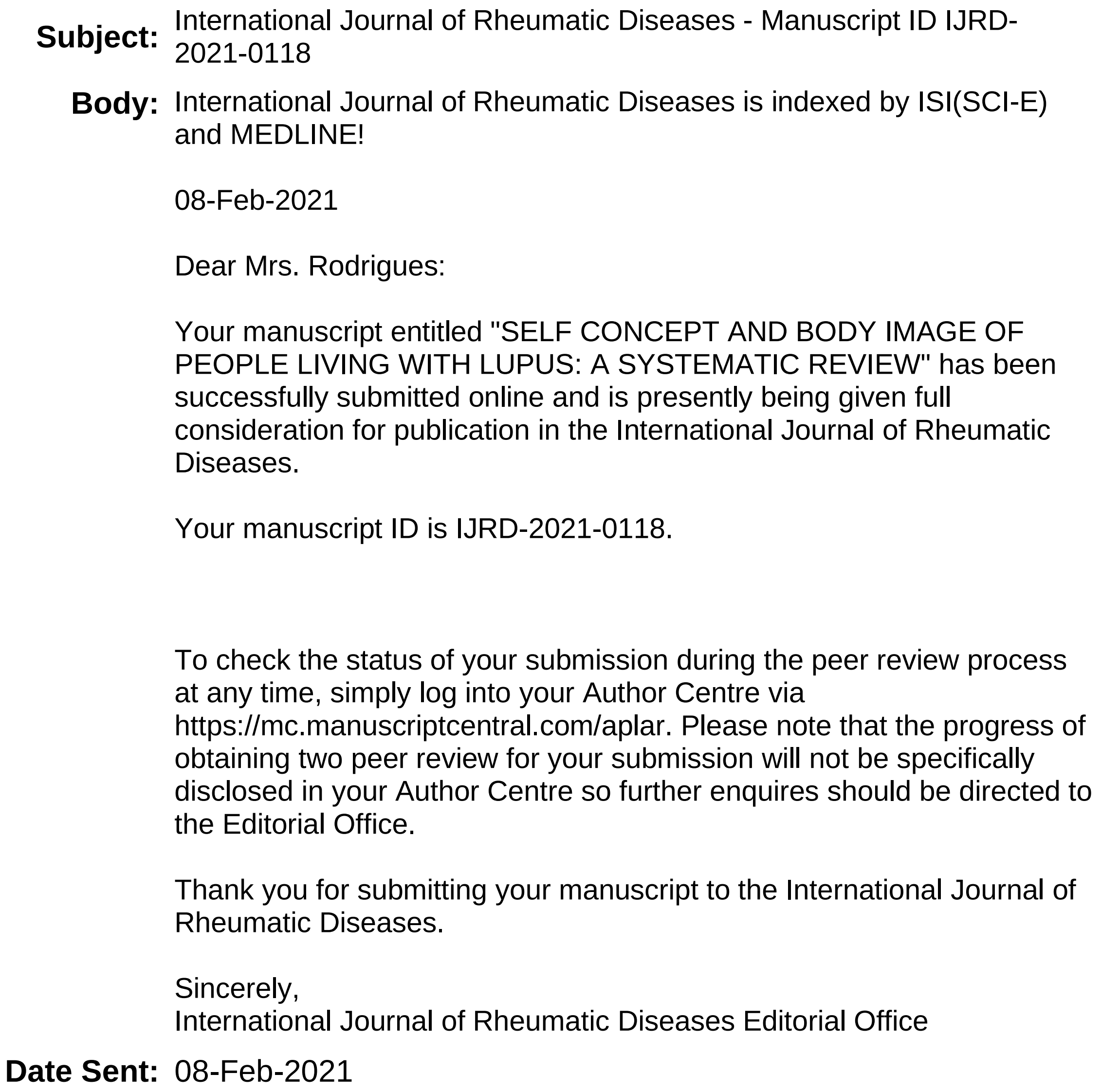

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SELF-CONCEPT AND BODY IMAGE OF PEOPLE LIVING WITH LUPUS: A SYSTEMATIC REVIEW

Abstract

Aim: To summarize existing evidence regarding body image in patients with SLE, with the following considerations: 1) the perceptions patients have of their body image; 2) how patients cope with changes in their body image; 3) and what their perceptions are of body changes. **Method:** A systematic review of literature integrating quantitative and qualitative studies. We searched databases (PubMed, CINAHL, Embase, SCOPUS, the Web of Science, Medline, Medline Complete, and Academic Search Premier) and publications from 2010 to 2020 with “Systemic Lupus Erythematosus” AND “Self-Concept” OR “Body Image” AND Woman as medical subheading terms. The studies included were subjected to a thematic content analysis, which allowed subjective interpretation of data through a systematic classification process for coding themes or patterns.

Results: We identified 647 studies, of which 22 were analyzed in this study. Our results indicate that changes in the body image of people with lupus are conditions that must be treated as characteristics of the disease; therefore, they need to receive the same attention as that given to physical disabilities and pain. The analysis identified three thematic categories: 1) depression and anxiety caused by body changes (hair loss, weight gain); 2) body image reflecting the disease; and 3) confrontations and interventions to promote the acceptance of and adaptation to the new image.

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

Keywords: Systemic lupus erythematosus; self-concept; body image; body dissatisfaction; systematic review

1. INTRODUCTION

Body image(BI) refers to the internal representation and perceptions of appearance and behavior and attitudes held by an individual.[1,2]. The attitudinal dimensions of BI, which include the beliefs and values of the individual[1,3], can be explored from many perspectives. The perceptual dimensions of BI are focused on the individual's precise judgments of their size, weight, and body shape.[1]. Some aspects of BI are associated with efforts made to control or change the appearance, adopt behaviors to avoid being judged by others(1), and achieve a desired or idealized body.[1,4] BI disorders can take many forms, including extreme dissatisfaction with appearance and compulsory checking and fear of judgment of appearance.[2]. These disorders have been consistently associated with psychological consequences[5], including depressive symptoms[6] and impaired self-esteem[7]. Body image disturbance (BID) is defined as the distortion of perceptions or cognition related to body weight or shape[8]. BID plays an important role in anxiety/depression and reduces quality of life (QoL).[9,10]

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

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

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

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

2. METHODS

2.1 Protocol and registration

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

2.2 Inclusion criteria

2.2.1 Types of patients and conditions

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

2.2.2 Types of outcomes

Outcomes are reported for the participants' experience or perception of the influence of SLE on their own persons: the patient's perception of her/his body; how their interprets and copes with their BI; what kind of symptoms are associated with how the patient feels; and how she/he sees or conceptualizes his/her self.

2.2.3 Types of studies

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

2.3 Search strategy

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

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

2.4 Study records

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

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

2.5 Bias assessment

Assessments of the quality of articles were based on checklists developed by Joanna Briggs Institute (JBI) for quasi-experimental, cross-sectional, and qualitative research[18], available at The System for the Unified Management, Assessment and Review of Information (SUMMARI). Two authors (LR and MSS) performed the assessments. Disagreements were managed to reach consensus through analysis and discussion with a third author (LMS). The level of evidence provided by the studies was evaluated according to the JBI Model of Evidence Based Healthcare.[19]

2.6 Data analysis

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

3 RESULTS

3.1 Search results

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

3.2 Description of studies

Of the 22 studies, 15 were cross-sectional. Twelve studies had a quantitative approach, and one of them had a quasi-experimental design. The remaining 10 had a qualitative design. Figure 2 presents the main topics of the articles. These topics were always related to BI, either as a domain or as a question in a questionnaire or as an emerging theme in comments made by study participants. The results are for a total of 3.394 participants. A large variation in sample size was observed, ranging between 6 and 1.259 participants.

For the quantitative studies, the alpha coefficients of the applied instruments were 0.96 for the Body Image Quality of Life Inventory (BIQLI)[22], 0.91 for the depression sub-scale of the Systemic Lupus Erythematosus Needs Questionnaire (SLENQ)[23,24], 0.73 for an adapted version of the Body Image Questionnaire[10], and 0.93 for the Pain & Vitality domain and 0.94 for the BI domain of the LupusPRO questionnaire.[25] In studies that did not calculate Cronbach's alpha, evaluations from previous studies were reported.[26-28,30,31]

Quantitative studies carried out bivariate analyses using the following statistical tests: a) chi-squared test[24,27-30] b) Student's *t*-test[10,26,29,31]; c) one-way analysis of variance

(ANOVA)[23, 24]; d) Mann–Whitney *U* test[27, 28]; and e) correlations.[28, 31] When indicated, non-parametric tests were applied.[28,29, 30, 32] Some studies also performed multivariate analyses.[10,24-27,31]

Qualitative studies examining the singularity of living experiences, the emerging cascading process, and the revelations of the participants[33] included four phenomenological studies[11, 34-36], three conceptual analysis studies based on focus groups[37-39], and a content analysis of individual discourse in three studies[40-42]. The data interpretation process was supported by Dedoose software[43] in one case[38] and NVIVO software[44] in two cases[40,42], whereas seven cases did not clarify whether data were analyzed manually or with software.

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

3.3 Critical appraisal

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

3.4 Thematic categories

Two articles used specific terms for exploring the results of their studies[11,34]. Through interpretive analyses of the interviewees, they conceptualized “self-concept,” which they distinguished from BI. Self-concept was defined as a psychological entity, referring to how an individual felt about himself or herself or the type of person the individual believed himself or herself to be.[11] These articles assumed the study participants’ defined BI as something external, which referred to their external physical appearance.[11]

Self-concept represents a BI image that has been adjusted to the environment in which the person lives, which extends to clothing, to meet their needs and to situate the individual in their own world.[34] The authors interpreted BI as intentional and closely associated with being healthy and living a healthy life, which is related to the concepts of beauty and youth. Not meeting these patterns may lead to feelings of rejection, fear, and shame.

Three thematic categories were created to organize and present the meta-aggregation[20,21] performed during the analysis of the articles: 1) depression and anxiety caused by body changes (hair loss, weight gain); 2) body image reflecting the disease; and 3) confrontations and interventions to promote acceptance and adaptation to the new image.

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

3.4.1 Depression and anxiety caused by body changes (hair loss, weight gain)

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

Body image, self-concept, and the use of SLE medications

SLE is commonly associated with hair loss and changes in appearance[23,40], as well as psychosocial needs[37] and symptoms related to vasoconstriction.[26] Emotional and sexual life is disturbed.[10, 30], and QoL suffers as a result of the disease.[22,24] In addition, problems with facial appearance and weight have a strong correlation with BI.[27,40].

Qol related to BI mediates the relationship between pain and depressive symptoms.[25]

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

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

Visibility of disease and the judgment of others

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

SLE patiensts felt that they did not recognize themselves when looking in the mirror because they felt that the skin and hair damage altered their appearance, making the disease visible, and, therefore, making the situation more serious.[34]

There is dissatisfaction related to body image due to the visibility of skin changes, such as scars, alopecia and depigmentation and weight gain (due to the use of steroids).[38]

3.5.2 Body image reflecting the disease

Appearance does not reflect who the people with lupus nephritis are.[29,30] Ethnicity and other individual factors have an impact on the prevalence and severity of the disease, and may generate different feelings about BI in each person.[32] Many people with SLE use cosmetics to help their self-image[29], a time-consuming and expensive process.[30]

Pain and swelling in the joints are common for these people, making them unable to participate in activities, which causes insecurity by altering their self-concept.[35] Pregnant women in the third trimester feel strange in their own bodies, often experiencing social isolation, sadness, and hopelessness related to this perception of their BI.[42]

People expressed a desire to have the body they had before the onset of lupus symptoms.[38]

3.5.3 Confrontations and interventions to promote acceptance of and adaptation to the new body image

Women with SLE experience greater BID, which has a significant relationship with age but not with disease duration.[28] Confrontation with the new BI appears to be relevant for the majority of SLE patients, and many change their lifestyles and attitudes to adapt to the disease and to their changing body.[32]

Attitudes of acceptance and surrender

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

Loving/sexual relationships and acceptance of the changed body

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

Unattractiveness is a major feeling reported by women with SLE, compared to those with other chronic diseases.[31] However, their emotions and feeling of coherence could explain the participants' perception of attractiveness.[31] Impaired sexual function, related to distress and deficiencies in the patient's social life, suggests a link between physical function and psychological function, which can contribute to sexual health and overall QoL.[10]

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

4 DISCUSSION

4.1 Considerations of study design and population representativeness

We acknowledge that the BI theme has already been explored, especially linked to other themes, which shows the importance of it being highlighted for people with lupus. However, in order to establish protocols/interventions to manage issues of BI and self-concept of people with lupus, it is necessary to think of study designs that establish interventions, such as clinical trials, aimed at coping with changes in BI of people with lupus.

The results of this review are representative in terms of the SLE population. The 3.394 participants in the studies came from five continents: Asia (Taiwan and China), Africa (South Africa), North and South America (United States and Brazil), Europe (Denmark, United Kingdom, Austria, Netherlands), and Oceania (New Zealand). Given the assessment of such a diverse population, it makes sense that BI, a burning problem among people with lupus, should be explored in different cultures.

4.2. Considerations of measures of self-image

All instruments used in the studies included in this review are validated and widely used in research. However, we emphasize that while some instruments focused on BI[10,22,27,29,32], others did not. Instead, they concentrated on issues such as QoL[18,25,27,28,30], psychosocial needs[23,24], quality of sleep, and sexual disfunction[26,31], but used BI as a questionnaire domain to measure these factors; therefore, they provide information on BI for discussion, even if indirectly.

4.3. Synthesis of research findings

In this systematic review, we identified three thematic categories: 1) depression and anxiety caused by body changes (hair loss and weight gain); 2) body image reflecting SLE, demonstrating the person's perception that their body does not portray who they are; and 3) confrontation and interventions for acceptance of and adaptation to the new BI, indicating attitudes that can facilitate the women's acceptance of body transformations.

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

The condition of individuals with lupus is like that of chronic patients, and the limitations imposed can cause suffering, anguish, uncertainty, loss, and pain[41]. Despite having the same disease, with the same symptoms and even the same treatments (medication and dosage), each patient's experience of SLE is unique[41]; therefore, BI and self-concept can be altered by the conditions imposed by the disease, which may have an impact on sexual behavior[27] and personal relationships.[11]

Having and maintaining a positive attitude under disease conditions can be an actively difficult pursuit, and individuals with SLE must preserve their self-image despite the changes caused by the disease. Therefore, people with lupus report the use of "symbolic masks" to hide, such as keeping a smile on their face or appearing to be strong and cheerful, to meet the expectations of others, even if they are experiencing deep sadness[11] as a result of loss of identity[34], which must be reconstructed.

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

4.4 Limitations of primary studies

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

4.5 Strengths of the systematic review

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

4.6 Implications for research

We argue that the effects of the psychosocial issues related to BI are essential considerations for health professionals when treating people with SLE. The use of scales such as the SLENQ to identify psychosocial problems, a mental health inventory to predict depression and anxiety, and questionnaires such as LupusPRO to predict QoL is recommended.

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

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

4.7 Implications for clinical practice

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

Support groups can also be a good way of encouraging positive mental health. Setting goals and discussing with patients their changes in appearance, concerns, attempts at social isolation, and relationship problems can be a good strategy for dealing with changes in BI and related mental health problems.

Knowledge and presentation of therapeutic options can prevent or limit adverse effects and ameliorate the negative impacts of BI on QoL. These options include a) the use of sunscreen; b) early referral, screening, and treatment of active disease, thereby limiting organ involvement and preventing impairment[21,28]; c) training in the use of suitable cosmetics[29]; d) early diagnosis, referral, and treatment of depression[22,23,25]; and e) coping and self-esteem exercises.[29, 34]

4.8. Recommendations

We summarize three key recommendations for health practitioners: 1) the need to recognize the importance of changes in BI and self-concept of people with lupus, as well as recognizing their experience of pain and physical limitations; 2) the need to consider psychosocial problems and the use of questionnaires for early screening of symptoms of illness due to depression, anxiety, and relationship problems (e.g., social isolation and helplessness) linked to BI; and 3) the need to offer products, such as cosmetics, that can assist in coping with changes in BI.

5. CONCLUSION

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

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

STATEMENT REGARDING INFORMED CONSENT

Formal consent is not required for this type of study.

STATEMENT REGARDING ETHICAL APPROVAL

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

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Table 1. Comprised included atudies

	Sample	Objective	Study design/ Evidence level/Collection/Measures	Main results
Auerback and Beckerman, 2011[23] **USA**	N= 378, 357 female; 13 male Age: 21-60 years	- To identify and to clarify the unique psychosocial challenges for those living with SLE	Cross-sectional- Descriptive & Observational study- Level 4b - SLENQ – Psychosocial needs and beliefs. Considering three subscales: Depression, Anxiety, Social Economic Coping (SEC); - MHLOC – Multidimensional Health Locus of Control Scale: two subscales: Chance and Internal	- Changes in the body have been associated with depression, as well as limitations with SLE and the side effects of treatment - Changes in appearance were also associated with anxiety, as well as the feeling of injustice for being affected by the disease, anger because of SLE, perception of an uncertain future, side effects from treatment
Beckerman et al., 2011[24] **USA**	N=378, 357 female; 13 male Age: 20-67 years	- To identify psychosocial experiences; - To identify what ethnicities may be at risk for which psychosocial stressors	Cross-sectional - Approach: Quantitative Study - Level 4b - SLENQ – Psychosocial needs and beliefs. Considering three subscales: Depression, Anxiety, Social Economic Coping (SEC); - MHLOC – Multidimensional Health Locus of Control Scale: two subscales: Chance and Internal - Side effects of medication	-There were the following associations with changes in body image: - changes in the body with depression; - changes in appearance with the perception of the side effect of the medication (greater with the use of hydroxychloroquine and corticosteroids) - hair loss with a higher degree of depression; - weight gain with greater need for psychosocial care (for Hispanics); -hair loss and muscle pain with feelings of depression and anxiety; - hair loss with higher levels of anxiety
Beckermam, 2011[37] **USA**	N=32, 29 female; 3 male Age: Under 35 years old = 19; Over 35 years old= 13	- The purpose was the further identification and clarification of unique psychosocial challenges for those living with SLE	Qualitative Study- Meaningfulness for qualitative studies- Level 3- Focus group - to explore, in an open way, how this disease affected women's lives, in a safe environment to talk about their shared and unique experiences - Thematic content analysis was used	- Body image, self-concept and the inability to function as before were related to feelings of depression. The reports are that the participants ceased to be who they were before the beginning of the SLE.
Chiang et al., 2019[26] **Taiwan**	N= 75, 67 female; 8 male Mean age 23.0 (range:9.6-37.2)	- Explore prevalence of symptoms perceived by SLE patients; - Develop groups of symptoms; - Examine the association of the load of each group of symptoms with sleep quality and depression	Descriptive correlational study- Level 4b - SSC - The SLE Symptom Checklist - PSQI – The Pittsburgh sleep quality - BDI – The Beck Depression inventory II - Demographic (treatment information; the Medical Impact; - SFQ Scale of the Sexual Functioning Questionnaire - B-IPQ Brief Illness Perception Questionnaire	- Five groups of symptoms prevailed: - symptoms related to body image and circulatory problems: white fingers in the cold, hair loss and sensitivity to sunlight;- symptoms related to weight gain: cheeks / face, more appetite and nightmares; - symptoms related to pain and itching: aching joints, aching muscles, headache and itching;- symptoms related to bruises and stomach complaints: spontaneous hematomas and stomach complaints;- symptoms related to fatigue: fatigue, mood swings, loss of concentration, disturbed memory and skin vulnerability
Cordeiro and Andrade, 2012[34] **Brazil**	N= 10 female= 100% Age= >18 years old	- Understand the meaning attributed by women to the fact that they have a diagnosis of lupus	Qualitative Study with Phenomenology Meaningfulness for qualitative studies- Level 3- Face-to-face Interview, with the following question: How do you feel, as a woman, to have a diagnosis of lupus?	- Self-image has changes imposed by lupus, participants feel it in the relationship with family and in the development of activities daily - Participants need care with clinical manifestations and psychological aspects of this pathology, helping the to develop a positive self-image, guiding them self-care, control and revention of possible complications
Daleboudt__ et al., 2013[31] **The Netherlands** **The New Zealand**	N= 106 participants female= 94.3%; male=5.7% Mean age = 43.34 years (SD=14.96)	- Access the influence of SLE on sexual function; - Investigate the association between sexuality and perception of the disease and sociodemographic aspects; - Compare sexual functions of patients with SLE and other chronic diseases	Cross-sectional- - Approach: Quantitative Study - Level 4b - PDSBE Physical Disability and Sexual and Body Esteem scale - SFQ Medical Impact Scale of the Sexual Functioning Questionnaire - B-IPQ Brief Illness Perception Questionnaire	- The perception of changes in the body image of patients was to experience negative effects of SLE on their sexual functioning, especially on their sexual and body esteem - The perception of the disease was a more important predictor than the sociodemographic and clinical characteristics of sexual functioning - The influence of SLE on sexual functioning appears to be disease-specific, unlike other chronic diseases
Gholizadeh et al., 2019[25] **USA**	N= 135 Female 92.6% Male 7,4% Mean age: 48.54 (13.9)	- examined whether body image (specifically, body image-related quality of life) serves as a mediator of the relationship between pain and depressive symptoms among patients with SLE	Cross-sectional- - Approach: Quantitative Study - Level 4b - LupusPRO Pain and vitality - LupusPRO-Body Image - HADS Hospital anxiety and depression scale	- Body image related quality of life was a significant mediator in the relationship between pain and depressive symptoms

Hale et al., 2015[11] **USA**	N=15 female= 14 (94%); male= 1 (6%) Ages ranged: 22 to 57 years	- To understand experiences within a group of patients diagnosed with SLE	Cross-sectional- Approach: Qualitative Study Meaningfulness for qualitative studies- Level 3- Qualitative mode of enquiry using semi-structured interviews with audio-records: (Q1: what body image and self-image meant to patients; Q2: how they cope about their medication's effects)	- Women often refer to the appearance of women and compare themselves to other women. matter with skin, weight or functional problems - Participants felt that, when more confident, they were less concerned with the external appearance, emphasizing their self-image- - Participants feel more prepared to address other people's comments or opinions when they receive interventions on psychosocial issues, such as social skills training.
Jolly et al., 2010[28] **USA**	N= 185 patients female= 174 (94%); male= 11 (6%) Mean age: 42.2 ± 14.5 years	- To characterized US patient regarding demographic and LupusQol-US	Cross-sectional- Approach: Quantitative Study- Level 4b- LupusQoL-US domains: Physical health (PH), Pain (PN), Planning (PL), Intimate Relationships (IR), Burden to others (BU), Emotional health (EH), Body image (BI), and Fatigue (FA)	- Alopecia correlated with body-image, intimate relationships and pain - Age was associated to Body-image domain - Skin damage was associated with the Body image domain in LupusQol
Jolly et al., 2012[22] **USA**	N= 165 participants Control group: 78 healthy (47.27%) Experimental group: 87 SLE (52.72%) Age: 42.4±13.1 for SLE and 38.7± 13.2 years for non-SLE subjects	- To compare Body-image-related QOL (healthy and SLE patients); - To determine associations: BIQLI and disease features, comorbid conditions and health related QOL; - To determine the amount of variation in HRQOL explained by disease activity, damage and BI	Cross-sectional- Approach: Quantitative Study Level 4 b- BMI Body Mass Index - BIQLI Body Image Quality of Life Inventory - HRQOL Health-related quality of life - SF-6D (functional status index; a variant of SF-36) - EQ-5D (health status index)	- Poor body image is a realistic problem that patients with SLE frequently face, and this needs to be addressed through focused on cutaneous disease activity, damage and depression -Patients with SLE have significantly worse BI-related QOL than 1) age-matched non-SLE controls- Considering SLE patients, the BI-related QoL has negative correlation with alopecia, irreversible cutaneous damage, depression; Considering SLE patients, the BI-related QoL has positive
Jolly et al., 2014[29] **USA**	N= 15 Intervention group: 10 Control group:5 Mean age= Intervention group 43.2 (12.2) Control group 44.4 (8.7)	- Determine the feasibility and effectiveness of a novel body image intervention in improving body image - Determine health outcomes among women	Quasi-Experimental study- Approach: Quantitative Study- Level 2 c - BILS Body-image measures: (Body Image in Lupus Scale ; MBSRQ The Multidimensional Body Self-relations Questionnaire; Appearance Scale) - Psychological Health Measures: (CES-D Center for Epidemiological Studies Depression; STAI State Trait Anxiety Index) - Quality of Life : (LUPUSPRO)	- Major improvements in body image were seen after body image interventions - body image was modified in patients with SLE, improving psychological well-being and quality of life, maintaining this improvement over time
Jolly et al., 2018[32] **USA**	N: 1259 patients with lupus nephritis (LN) Median age: 41.7(13.5)	- Describe HRQOL(lupus symptoms and medication; cognition; procreation; physical and emotional health; pain vitality; body image) and non-HRQOL (desire goals; social support; satisfaction care	Cross-sectional- Approach: Quantitative Study- Level 4 b - BILS Body-image measures: (Body Image in Lupus Scale ; MBSRQ The Multidimensional Body Self-relations Questionnaire; Appearance Scale) - Psychological Health Measures: (CES-D Center for Epidemiological Studies Depression; STAI State Trait Anxiety Index) -Quality of Life : (LUPUSPRO)	- Patients with LN was younger had worst HRQOL and nonHRQOL - Specific domains of HRQOL adversely affected include Lupus symptoms, medications, procreation, emotional health, body image and desires-goals - Among patients with LN and active LN, lupus medications and procreation HRQOL are significantly adversely impacted, independent of their age, gender, ethnicity and country
Larsen et al., 2018[35] **Denmark**	N= 15 women Mean age= 45,6	- To explore the experience of being diagnosed with SLE as an existential phenomenon	Cross-sectional- Approach: Qualitative Study Meaningfulness for qualitative studies- Level 3- Semi-structured interview Van Manen's phenomenology of practice	- About self-concept, receiving the diagnosis of lupus is an experience that suspends life, increasing uncertainties in the present and in the future, is to find yourself in a whirlwind of events, is to step on uneven ground and be at an inflection point with yourself and with others
Ogunsanya, 2018[38] **USA**	N= 19 Famale =18 (94,7%); Male= 1 Mean age: 49 ± 14	- To explore patients' views on how cutaneous lupus has affected their lives and the unmet needs with regard to CLE treatment and care.	Qualitative Study - Meaningfulness for qualitative studies- Level 3- Focus group discussion guide based on the themes: Understanding the impact of SLE on patients' lives; Unmet needs in relation to treatment and care for SLE	- Changes in appearance extrapolated the image and patients used several coping mechanisms, both positive and negative, to mitigate the effects of cutaneous lupus - Several themes captured the burden of cutaneous lupus in patients; these ranged from disease sequelae and social effects to functioning
Phuti et al., 2019[40] **South Africa**	N= 25 women Mean age: 30.9 years (range: 22–45)	- to explore living experiences, perceptions and unmet needs of South African patients with SLE	Qualitative Study -Meaningfulness for qualitative studies: Level 3-individual in-depth interviews exploring their physical concerns, emotional health, sexual well-being and fertility	- Changes in self-image have been associated with physical disfigurements resulting from lupus as alopecia, skin rashes and weight fluctuations induced by corticosteroids were a major concern. These changes were also associated with the affected libido, leading to strained personal relationships

Rodrigues et al., 2020[42] **Brazil**	N= 26 pregnant women Mean age:30 (SD 14,85)	- to understand the meanings attributed to pregnancy by pregnant women with SLE during prenatal care	Qualitative Study- Meaningfulness for qualitative studies- Level 3- face-to-face interview with semi-structured script with open-ended questions with the following themes: feelings about being an SLE carrier, experience with carrying this disease while being preg- nant, pregnancy monitoring, sexual behaviors after finding out about the illness and pregnancy, and daily life	- Changes in self-concept and body image are associated with disease and the side effects of drugs used to control lupus, which can prevent pregnant women with lupus from identifying with themselves. - This engenders psychological and social impacts activated by the visibility of the disease. Participants reported experiencing social isolation, sad- ness, and hopelessness because of their disease-related self-image
Rodriguez-Rivera et al., 2016[30] **USA**	N=98 patients disadvantaged= 40; private care= 58 Female=94(95.9%); Male=4(4.1%) Mean Age=44.9(SD 12)	- To determine patient-reported outcomes measures - To compare outcomes between public sector patients and private sector patients	Cross-sectional- Approach: Quantitative Study Level 4 b – LUPUSPRO - HRQOL (8 domains; BI is 8th domain) - Non HRQOL (4 domains)	- No significant differences were observed for the domains of body image - Patients from the public sector reported better coping than the private group
Rutter and Kiemle 2014[36] **UK**	N=6 Female 100% Mean age= 42(28-47)	- To describe interpersonal experiences considering their ethnicity and cultural influences	Cross-sectional- Approach: Qualitative Study Meaningfulness for qualitative studies- Level 3-Phenomenological Interpretative Analysis with semi-structured questions: a) SLE diagnosis, physical effects, social function, sense of self, relationships, intimacy and the future	- Body image and changes in the appearance of SLE medications were related to the feeling of helplessness. 5 themes arise: a) SLE: Complexities and Ironies; b) The power of the SLE; c) A Sense of Personal Responsibility; d) Essential relationships: qualities and consequences; e) Fighting in the public's view.
Shen et al., 2015[10] **China**	N=352 participants (26 missing) 156 patients (SLE experimental group) 210 healthy (control group) Female= 142 patients (91%); 176 healthy(89.8%); Male= 14(9%); 20 healthy(10.2%) Mean age= 32.9 (±10.2) patients; 35.0 (±11.4) healthy	- To examine the association between BID and sexual function	Cross-sectional - Approach: Quantitative Study Level 4 b - BID Body Image Disturbance [7 subscale] - SAS The Revised Self-Rating Anxiety Scale - SDS The Revised Self-Rating Depression Scale - SF-36 Quality of Life	- In patients' group (BID, generally, has significant correlations with partner relationship; also BID, generally, has significant correlations with sexual function . -Patients has higher risk for anxiety then healthy group - There were significant differences in sexual relationship impairment between patients and healthy, sexual partner relationships were disturbed by appearance-related concerns
Stamm et al., 2014[39] **Austria,**	N=229 patients (21 with SLE) Female=20 (95.%) Male=1 (5%) Age= 21-38 years	- To compare and contrast the concepts of functioning in daily life in patients with different rheumatological conditions (multicentric 8 countries)	Cross-sectional- Approach: Qualitative Study Meaningfulness for qualitative studies- Level 3- Focus group [3-8 people with SLE] Interviews (6 open questions) supported by the WHO International Classification of Functioning, Disability and Health (ICF) (Body functions and structures; Activities and participation; Environmental and personal factors)	- Patients report: Body image and appearance: 1) changes in the body as a whole, but also specific parts [skin; guy; weight loss] and Attitudes of others [based on appearance]: 1) positive attitudes recognized by family members, colleagues; 2) negative attitudes recognized by strangers, employers and society in general;
Xavier et al., 2013[41] **Brazil**	N= 9 Female patients (100%) Age= 21-38 years old	- To understand the conceptions attributed to the disease process	Cross-sectional- Approach: Qualitative Study Meaningfulness for qualitative studies- Level 3- Semi-structured Interviews (13 questions script- Life course from getting sick to the moment; Patient perspective about treatment; How describes the relationship with their doctor; How patient defines her pathology; How patient defines the association between her illness and the specific events in their life	- Body image and lupus as a unknown body: a) negative feelings [strangeness, horror, anguish, shame]; b) the brand of a new image permanently/ chronically sick - Emerges 5 themes: a) The onset of the disease; b) Body and lupus; c) The treatment; d) Lupus and its causes; e) Medical Speech the lupus.
Zhao, et al., 2018[27] **China**	N=256 participants; 109 patients (experimental group) 128 healthy (control group)- Missing 19 (9 patients; 10 healthy Female= 101 patients(92.7%); 114 healthy(89.1%); Male= 8 patients(7.3%); 14 healthy(10.9%), Mean age= 33 (SD 17) patients; 36.5 (SD 16.8) healthy	- To investigate the relationship among psychological status, quality of life, self-esteem, social support, BID - To explore risks factors of BID	Cross-sectional- Approach: Quantitative Study Level 4b- IDB Body Image Disruption [5 scales; IDB> .30 = disturbance] - HADS Hospital Anxiety and Depression Scale - Rosenberg self-esteem - SSRS social support rating scale - HRQOL and LupusQol	- BDI higher in patients then in healthy ($p<.05$ in all 7 dimensions) - LupusQoL in patients: Body image the best score - BID association with: Personal health insurance, diabetes complication, appearance of new rash, depression, anxiety, self-esteem - Risk factors for BID: appearance of new rash, high anxiety

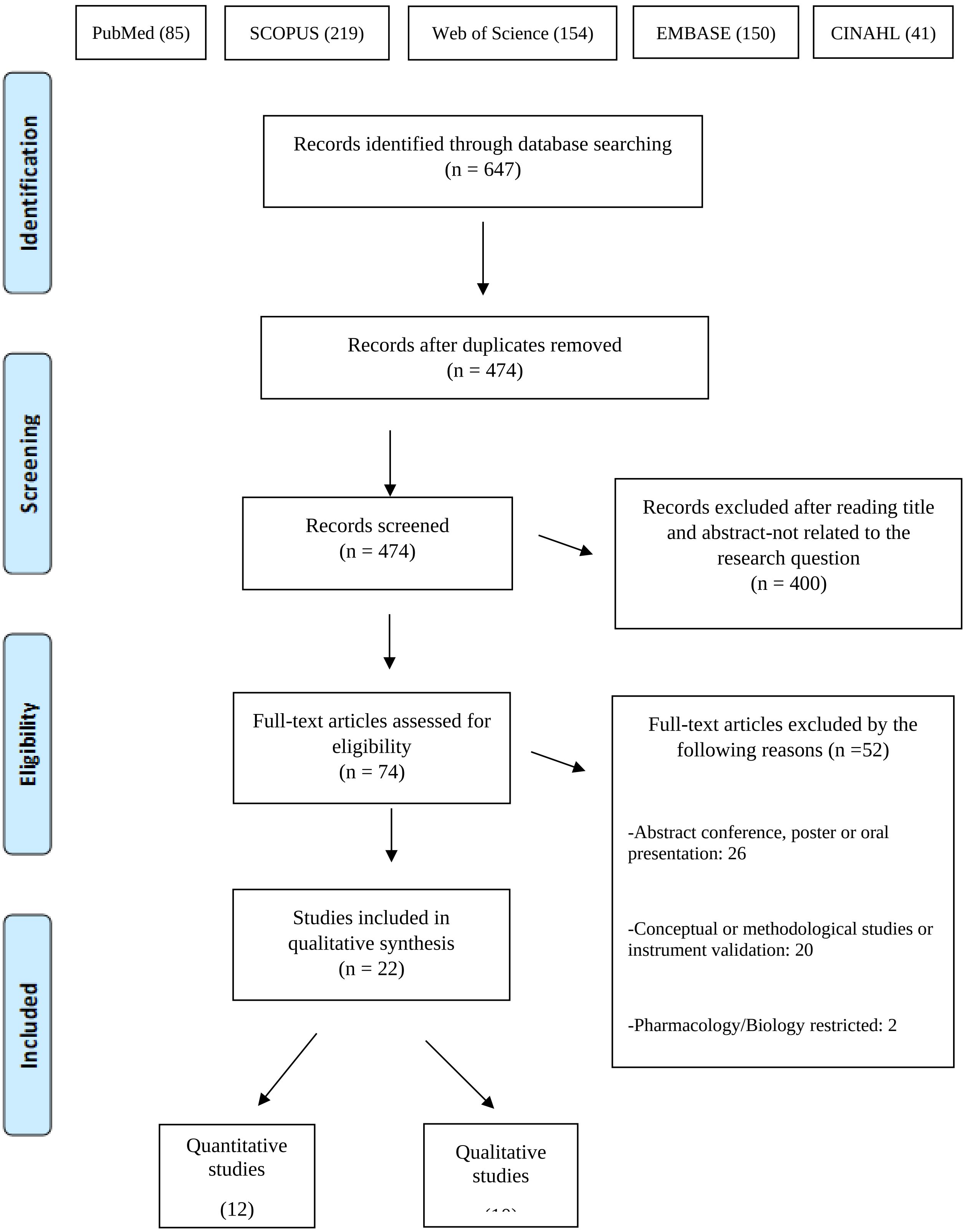
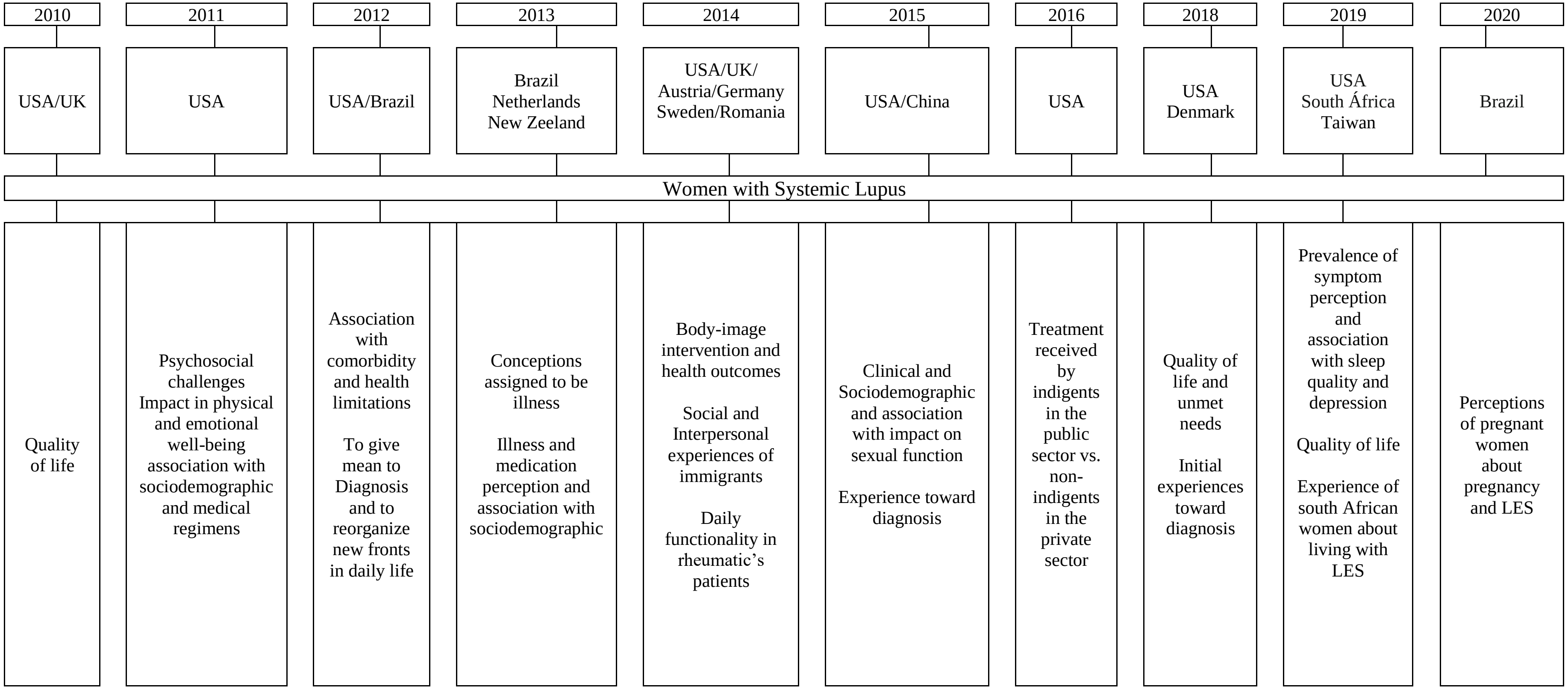


Figure 1. Study search flow diagram



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

Figure 2. Publications over last ten years

	Hale 2015	Larsen 2018	Rutter 2015	Stam 2014	Xavier 2013	Ogunsanya2 018	Cordeiro 2013	Beckerman 2011	Rodrigues 2020	Puthi 2019
1 Is there congruity between the stated philosophical perspective and the research methodology?	🟢	🟢	🟢	🟢	🟢	🟢	🟢	🟢	🟢	🟢
2.Is there congruity between the research methodology and the research question or objectives?	🟢	🟢	🟢	🟢	🟢	🟢	🟢	🟢	🟢	🟢
3.Is there congruity between the research methodology and the methods used to collect data?	🟢	🟢	🟢	🟢	🟢	🟢	🟢	🟢	🟢	🟢
4.Is there congruity between the research methodology and the representation and analysis of data?	🟢	🟢	🟢	🟢	🟢	🟢	🟢	🟢	🟢	🟢
5.Is there congruity between the research methodology and the interpretation of results?	🟢	🟢	🟢	🟢	🟢	🟢	🟢	🟢	🟢	🟢
6.Is there a statement locating the researcher culturally or theoretically?	🟢	🟢	🟡	🟡	🟡	🟢	🟡	🔴	🟢	🟢
7 Is the influence of the researcher on the research, and vice- versa, addressed?	🟡	🟢	🟡	🟢	🟡	🟢	🟡	🟢	🟢	🟢
8.Are participants, and their voices, adequately represented?	🟢	🟢	🟢	🟢	🟢	🟢	🟢	🟢	🟢	🟢
9.Is the research ethical according to current criteria or, for recent studies, and is there evidence of ethical approval by an appropriate body?	🟢	🟢	🟢	🟢	🟢	🟢	🟢	🟢	🟢	🟢
10.Do the conclusions drawn in the research report flow from the analysis, or interpretation, of the data?	🟢	🟢	🟢	🟢	🟢	🟢	🟢	🟢	🟢	🟢
Total	9/10	10/10	9/10	9/10	8/10	10/10	8/10	9/10	10/10	10/10
%	90	100	90	90	80	100	80	90	100	100

Qualitative Critical Appraisal

	Auerbach 2011	Beckerman 2011	Chiang 2019	Daleboudt 2013	Gholizade 2019	Jolly 2010	Jolly 2012	Jolly 2018	Rodriguez-Rivera 2016	Shen 2015	Zhao 2018
1.Inclusion criteria are defined	🔴	🔴	🟢	🟢	🟢	🔴	🟢	🔴	🟢	🟢	🔴
2.Subjects and context detailled	🟢	🟢	🟢	🟢	🟢	🟢	🟢	🟢	🟢	🟢	🟢
3. Exposition measured in a valid and reliable way	🟢	🟢	🟢	🟢	🟢	🟢	🟢	🟢	🟢	🟢	🟢
4. Objective and standardized criteria used	🟢	🟢	🟢	🟢	🟢	🟢	🟢	🟢	🟢	🟢	🟢
5. Confounding factors identified	🔴	🟢	🔴	🟢	🔴	🔴	🟢	🟢	🔴	🟢	🟢
6. Strategies declared to deal with confounding factors	⚫	🟢	⚫	🟢	⚫	⚫	🟢	🟢	⚫	🟢	🟢
7. Results evaluated in a valid and reliable way	🟢	🟢	🟢	🟢	🟢	🟢	🟢	🟢	🟢	🟢	🟢
8. Appropriate statistics texts	🟢	🟢	🟢	🟢	🟢	🟢	🟢	🟢	🟢	🟢	🟢
Total	5/7	7/8	6/7	8/8	6/7	5/7	8/8	7/8	6/7	8/8	7/8
%	71,4	87.5	85,7	100	85,7	71,4	100	87.5	85,7	100	87.5

Cross-sectional Critical Apraisal

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

Quasi-experimental critical appraisal

● NA ● No ● Yes ● Unclear

Figure 3. Quality appraisal of the included studies

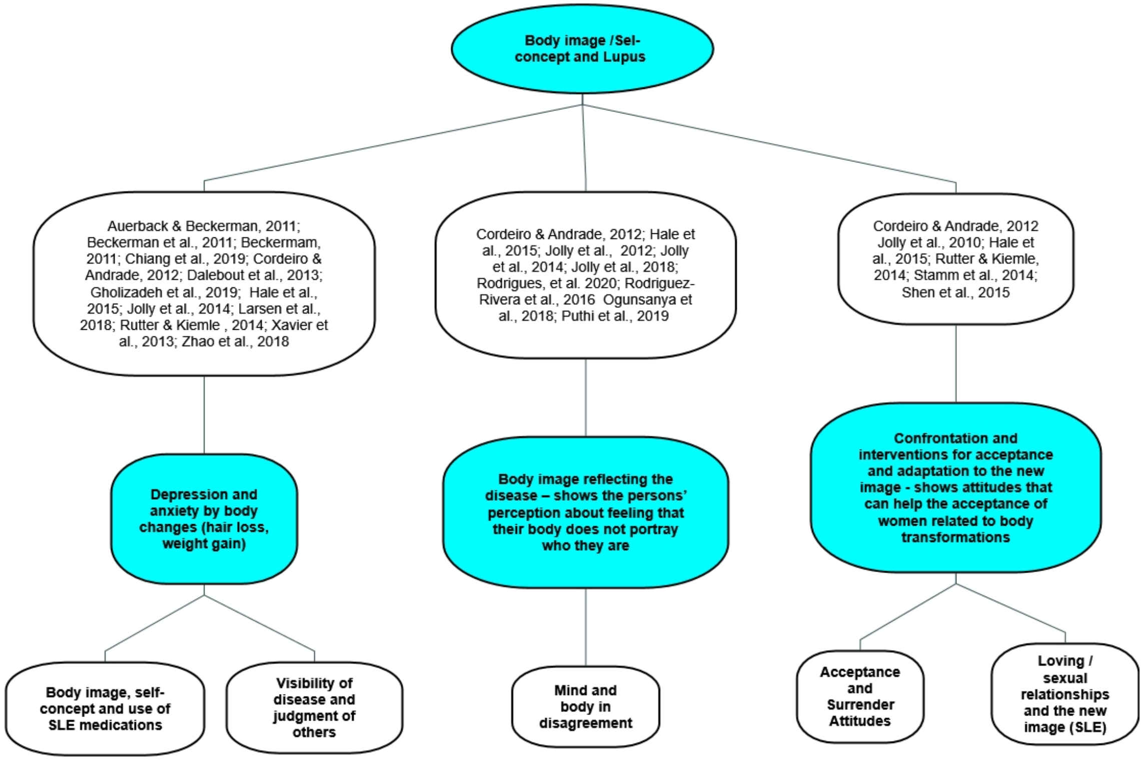


Figure 4. Comprehensiveness of reporting the included studies

DISCUSSÃO

“Demorou uns quinze dias para diagnosticar e, depois desse tempo, falaram que era lúpus mesmo. O eritematoso sistêmico...E, então, começou a jornada...”

Entrevistada 18

A partir deste relato, tão simples e tão amplo, de uma das entrevistadas deste estudo, começou-se a pensar nos desfechos deste trabalho e o que ele traz de entendimento das perspectivas das mulheres e, com isso, o que pode acrescentar à literatura científica com o registro do olhar para discursos tão profundos, carregados de conhecimento sobre dor, medo e satisfação.

Os significados atribuídos a essa experiência da mulher de ter um diagnóstico de lúpus, ameaçador, coloca-a em uma outra jornada, uma caminhada que contém agora as regras da doença. E, junto a isso, a mulher apresenta o significado de poder, no mais genuíno sentido da palavra, quando, ao ter o diagnóstico da gravidez, ela quebra as regras da doença e expressa esse poder, quando diz sobre se sentir grávida e saudável.

Para significar esse sentimento, contido na experiência, essas mulheres trazem relatos de que grávida, elas estão em outra história, uma história de bem-estar e de contentamento, como se, na estrada da jornada do lúpus, um atalho lhes fosse permitido para momentos sublimes, de leveza.

E, durante essas reflexões, no aprofundamento dos discursos, associando as ideias livremente, essas mulheres apresentam um local íntimo, onde está o lúpus e a gravidez com seu concepto, como estivesse à beira do rio, na fábula de La Fontaine, recontada por Monteiro Lobato, mostrando O *lobo e o cordeiro* dentro de si, falando sobre o lúpus e o filho e o medo que ela sente de que o lúpus destrua a gravidez e o filho, e complique toda a leveza e a satisfação sentidas. Desta forma, essa mulher mostra, no olhar, o sentimento de fragilidade e angustiada, refém dessa relação com o lúpus, parece admitir a soberania da doença.

Em uma visão psicanalítica, a relação da mãe para com o filho passa, de forma inexorável, por uma renúncia às próprias necessidades, isso para reconhecer as necessidades do filho, só ela pode identificar essas necessidades e somente dentro desta situação, planejando estar e estando grávida, ou cuidando do filho após o nascimento, isso requer grandes esforços psíquicos por parte da mulher e nenhuma outra pessoa estabelecerá essa relação com o filho(76). Inerente à maternidade, ainda que seja na ausência de qualquer condição de doença, esses esforços podem interferir no equilíbrio emocional da mulher.

Na presença do lúpus, as questões psicossociais associadas a essa relação da mulher com a gravidez e as necessidades que serão apresentadas pelo filho, foram objeto de investigação para entender a mulher nesta situação, isso provocou a construção da primeira revisão sistemática e permitiu alcançar o primeiro objetivo específico do presente trabalho.

E com a criação de três categorias após análise de conteúdo: 1) Planejamento da gravidez, gerando a necessidade de participação ativa na tomada de decisões para o planejamento familiar; 2) Gravidez e recém-nascido e o compromisso que as mulheres com LES demonstram diante dos riscos associados à gravidez; 3) Discussão das habilidades dos profissionais de saúde necessárias em relação ao planejamento familiar, pré-natal, pós-parto e educação em saúde, compreendeu-se que essas questões não estão solidamente discutidas na literatura.

No movimento interno realizado pela mulher com relação aos aspectos reprodutivos: planejamento da gravidez, gravidez e pós-parto, podem surgir situações de vulnerabilidade emocional, especialmente por perceber que as possíveis complicações maternas podem gerar limitações que a tornem incapaz de identificar e suprir as necessidades do filho, seja durante a gravidez ou após.

Quando algumas mulheres receberam informações sobre a gravidade da doença precocemente, essa foi a base para a decisão, enquanto outras obtiveram essas informações durante o pré-natal e careceram de recursos emocionais para lidar com sentimentos sobre riscos iminentes (77-80).

A ambiguidade é evidente em relação à decisão de engravidar; portanto, é necessário atendimento psicossocial às mulheres com LES, para que elas tomem a decisão de ter ou não ter filhos. Desta forma, a mulher e respectiva família devem estar adequadamente preparadas para enfrentar as escolhas relacionadas ao planejamento, à evolução da gravidez e aos desfechos.

Paralelamente a esse entendimento, desenvolveu-se a pesquisa qualitativa (54, 81, 82), em seu paradigma de valorização da compreensão dos fenômenos no local onde eles naturalmente ocorrem, sem controles para o ambiente onde as relações do ser humano com as coisas do mundo se desenvolvem.

E, nesse paradigma de vertente fenomenológica (81,82) e, mais restritamente, clínico-qualitativa(54), desvelaram-se as perspectivas dessas mulheres sobre a experiência e os significados atribuídos à gravidez na presença do lúpus, o que permitiu alcançar o segundo objetivo específico deste trabalho de doutorado.

Os resultados deste estudo mostraram que mulheres grávidas com LES, em atendimento pré-natal de alto risco, tiveram experiências permeadas por sentimentos ambíguos organizados em quatro categorias: 1) gravidez não planejada e não uso de contracepção; 2) sensação de saúde, apesar do alerta médico sobre o agravamento da doença durante a gravidez; 3) alegria presente, associada à gravidez e ao medo do futuro; e 4) autopercepção e percepção dos outros.

Considerando a possibilidade iminente de agravamento da doença e complicações perinatais, o planejamento da gravidez e o próprio desejo de engravidar são tópicos que os profissionais de saúde devem discutir com as mulheres diagnosticadas com LES. Isso pode gerar possibilidade de escolher um Método Anticoncepcional (MAC) eficaz e o melhor momento para a gravidez (83, 84), isso pode representar um desafio para equipe de saúde.

Outra questão que merece atenção nessa população é que essas mulheres não querem pensar na doença, elas preferem se concentrar na gravidez. Isso revela uma grande motivação, porque se sentem saudáveis e atribuem isso ao fato de estarem grávidas. No entanto, isso talvez possa se associar a um risco aumentado de não adesão aos medicamentos prescritos. Psicologicamente, isso pode ser um ato de negação da doença e as consequências desta podem incluir ineficácia ou descontinuação completa do tratamento. Outra justificativa para interromper a medicação são os sentimentos associados de doença. Esses achados são consistentes com a literatura(85).

No entanto, as participantes também demonstraram maior disposição em buscar o autocuidado e a adesão ao tratamento do LES durante a gravidez, relatando compromisso em mudar os hábitos para oferecer à gravidez e ao bebê a melhor chance possível.

A atividade de doença pode levar as mulheres com LES a sofrerem incapacidades temporárias ou permanentes, assim, as participantes expressaram medo a esse respeito. Mesmo se elas não experimentam uma deficiência real, há um sentimento constante de risco iminente, resultando em ansiedade. Neste sentido, parece que a garantia de um sistema de apoio que ajude a mãe a cuidar de si e do recém-nascido contribuiria para aumentar a sensação de segurança.

As participantes mencionaram, frequentemente, perdas gestacionais e neonatais; as perdas passadas incutiram ansiedade e medo sobre a possibilidade de perdas futuras. Portanto, é essencial que os serviços oferecidos às mulheres grávidas com LES incluam a discussão sobre estratégias para aceitar as perdas e, ao mesmo tempo, apoiá-las quanto ao luto. Essa reflexão ratifica a literatura que observa a necessidade de suporte adequado em situações de perda (86, 87). Especialmente no caso de uma nova gravidez, o apoio oferecido, usando estratégias apropriadas pode reduzir a ansiedade e favorecer o apego materno ao novo bebê(88).

Diante dos bastidores tão detalhados do método qualitativo e da relação do pesquisador com os dados, em que não se tentou negar a subjetividade inerente à interpretação humana, mas contar com essa subjetividade alicerçada na bagagem teórica e prática dos pesquisadores envolvidos no estudo para acurada análise e apresentação dos dados, empenhou-se no desafio de mostrar o percurso metodológico e os dados brutos do trabalho em artigo de dados.

O convite para construir este artigo veio da editora que publicou o artigo de resultados qualitativos, sendo a tarefa foi inovadora, pois mostrar o trabalho neste formato não é tão comum entre os pares acadêmicos. Mas, preparou-se todo material, um processo longo de diálogo com os editores para compreender corretamente a proposta da revista e, assim, ter essa aprendizagem e o artigo publicado, ampliando a comunicação sobre o trabalho desenvolvido.

E, por meio desta disponibilização dos dados, acredita-se que outros pesquisadores possam replicar estudos semelhantes em outras realidades e, com isso, ampliar o conhecimento científico, assim como abrir portas para novas colaborações e clarificar a forma de trabalho. Desta forma, alcançou-se o terceiro objetivo específico deste estudo.

Os esforços psíquicos, os temores de viver com lúpus, a satisfação de estar grávida (como se ganhasse uma batalha sobre a doença), a ameaça de complicações à gravidez e a vida cotidiana de atividades dentro e fora de casa (com inúmeras consultas e exames agendados, outros filhos para cuidar e organizar a rotina, outras perdas para superar) e os impactos de viver onde vivem (Região Sudeste, Brasil, América Latina, questões políticas, ambientais, entre outras) trouxeram a necessidade de saber acerca da percepção sobre a qualidade de vida dessas mulheres e, com uso do WHOqol-bref, alcançou-se o quarto objetivo deste trabalho.

Ao observar os domínios descritos na divisão do questionário, o domínio físico que se refere à dor, ao desconforto, à energia, à fadiga, à mobilidade, às atividades da vida diária, à dependência de medicação ou tratamento e à capacidade de trabalho, foi o que apresentou os escores mais baixos, quando comparado aos domínios psicológico, social e ambiente.

Piores escores foram observados no domínio físico 52.21(18.44) que, de qualquer forma, foram mais altos que o mesmo domínio em outras localidades do Brasil, 47,8 (15,9) em Minas Gerais(89), bem como em localidades da Grécia 25.5 (5.1)(90) e, diferente da Polônia, cujos menores escores foram observados no domínio social(91).

A investigação dos fenômenos concretos ou imaginários das relações da humanidade com as coisas, neste estudo, ocorreu no campo de pesquisa no Brasil, no entanto, a possibilidade de conhecer outros pesquisadores e o manejo do cuidado à mulher com lúpus, em outra cultura, ampliou o olhar da pesquisadora deste estudo.

Isso foi possível durante o doutorado sanduíche em Portugal, quando, durante a estada na Universidade de Évora como pesquisadora colaboradora, discutindo dados da pesquisa de campo e estudando a literatura sobre lúpus e gravidez, percebeu-se a necessidade de saber sobre o autoconceito da mulher com lúpus e a imagem corporal e, então, empenhou-se a produzir a segunda revisão de literatura que permitiu alcançar o quinto objetivo deste trabalho.

As dimensões do autoconceito e da imagem corporal trazidas pela literatura permitem entender que são essenciais para avaliar a qualidade de vida de pessoas com lúpus, pois esses aspectos podem revelar a relação da pessoa com a doença e auxiliar na compreensão de como o lúpus afeta negativamente o autoconceito e a imagem corporal, além de atingir a vida, de forma geral, e os relacionamentos, principalmente se essas questões não forem abordadas ativamente pela equipe de saúde.

Com a identificação de três categorias:

1. Depressão e ansiedade causadas por alterações corporais (queda de cabelo, ganho de peso): aspectos que podem levar ao agravamento da doença e reduzir a qualidade de vida e o relacionamento dos pacientes (imagem corporal, autoconceito e uso de medicamentos para o LES e visibilidade da doença e julgamento de outras pessoas).

2. Imagem corporal que reflete a doença: a doença não pode ser mantida em segredo, dentro do corpo da pessoa. Assim, a pessoa perde privacidade e autonomia sobre esses problemas e fica exposta pela imagem corporal (mente e corpo em desacordo).

3. Confronto e intervenções para promover a aceitação e adaptação à nova imagem corporal: aspectos que geram a necessidade de recursos emocionais e

tratamento para se adaptar a uma nova vida com LES (atitudes de aceitação e entrega, relações amorosas / sexuais e a nova imagem).

Os dados desta revisão mostraram que os sentimentos mais relatados associados às alterações da imagem corporal foram depressão, ansiedade, isolamento social, exaustão, incompreensão, desânimo, desamparo, descrença, angústia e fracasso. Além disso, foram relatados sentimento de perda e falta de funcionalidade relacionados à cronicidade da doença(92).

Esses sentimentos podem caracterizar ou predispor as pessoas a transtornos mentais, agravando a situação de saúde dos indivíduos com LES.

Os profissionais de saúde devem entender a relação entre as pessoas com LES e a imagem corporal, considerando, também, as intervenções que podem contribuir para melhores compromissos com o tratamento e o bem-estar geral, isso não se restringe a uma atitude prescritiva(49).

As condições dos indivíduos com lúpus são semelhantes às circunstâncias das pessoas com outras doenças crônicas, em que as limitações impostas pela condição podem causar sofrimento, em um processo repleto de angústia, incerteza, perda e dor(92). Apesar de compartilhar a mesma doença, com os mesmos sintomas e até os mesmos tratamentos (medicação, dosagem), cada paciente experimenta o LES exclusivamente(92); portanto, a imagem corporal e o autoconceito podem ser alterados pelas condições impostas pela doença, que podem impactar a sexualidade(93) e as relações pessoais(49).

Ter e manter atitudes positivas em condições de doença pode ser um trabalho ativamente difícil, e esses indivíduos precisam construir um novo eu.

Após a realização do trabalho de doutorado e avançando na compreensão das perspectivas das mulheres com LES, percebeu-se a necessidade de estratégias de apoio oferecidas pelos serviços de saúde, a fim de auxiliar essas mulheres a entender os riscos inerentes à decisão de engravidar e a se preparar para o gerenciamento de eventos durante a gravidez, parto e pós-parto.

As equipes de saúde podem ser estruturadas para acomodar e aconselhar essas mulheres ao planejar os relacionamentos e a gravidez e a fazer as melhores escolhas de MAC para tomar decisões reprodutivas seguras.

Estratégias para facilitar mudanças de comportamento no período perinatal, também, são relevantes, uma vez que essas mulheres estão dispostas a cuidar de si. Assim, esse período pode ser uma oportunidade para auxiliar as mulheres a se prepararem para lidar com a doença e a vida reprodutiva, complementando a literatura sobre intervenções de saúde pré-natal que enfatiza este momento como oportunidade para bons resultados a curto prazo(94-97).

CONCLUSÕES

1.As necessidades psicossociais ainda não recebem atendimento adequado e a literatura que discute essas questões ainda não se encontra solidamente construída. A mulher pode estar vulnerável emocionalmente com relação aos aspectos reprodutivos: planejamento da gravidez, gravidez e pós-parto.

2.Mulheres grávidas com LES tiveram experiências permeadas por sentimentos ambíguos: se sentiram saudáveis porque descobriram que poderiam ter um filho, apesar de serem diagnosticadas com uma doença crônica, ao mesmo tempo, experimentaram medo e insegurança, devido à possibilidade iminente de deficiências e limitações relacionadas à doença.

3.Mostrar o percurso metodológico do estudo qualitativo, de forma mais detalhada, e expor os roteiros de entrevista e observação, pode proporcionar a possibilidade de replicação do método em outras realidades e, desta forma, trazer ampliação do conhecimento científico.

4.A qualidade de vida das mulheres com LES obteve, no domínio físico, apresentação de escores mais baixos, quando comparado aos domínios psicológico, social e ambiente. Com relação à qualidade de vida geral, as mulheres atendidas na região pesquisada apresentaram maiores scores do que mulheres em outras localidades do país, em que os escores de qualidade de vida relacionados à saúde foram altos.

5.As alterações mais comuns relacionadas à imagem corporal das mulheres com LES foram: ganho de peso e alterações na pele, cabelos e articulações, que afetam a imagem e, também, a funcionalidade do corpo. O entendimento das dimensões autoconceito e imagem corporal fez perceber como a mulher se relaciona com a doença.

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ANEXOS

Anexo 1: Termo de Consentimento Livre Esclarecido- WHOqol

TERMO DE CONSENTIMENTO LIVRE E ESCLARECIDO

GESTAÇÃO E LÚPUS ERITEMATOSO SISTÊMICO: ESTUDO QUALIQUANTI SOBRE AS PERSPECTIVAS DAS MULHERES EM UM SERVIÇO DE PRÉ-NATAL ESPECIALIZADO

Doutoranda Larissa Rodrigues

Orientadora: Professora Livre Docente Dra. Fernanda Garanhani de Castro Surita

Você está sendo convidado a participar como voluntário de uma pesquisa. Este documento, chamado Termo de Consentimento Livre e Esclarecido, visa assegurar seus direitos como participante e é elaborado em duas vias, sendo que após assinada, uma deverá ficar com você e outra com a pesquisadora. Por favor, leia com atenção e calma, aproveitando para esclarecer suas dúvidas. Se houver perguntas antes ou mesmo depois de assiná-lo, você poderá esclarecê-las com a pesquisadora. Se preferir, pode levar este Termo para casa e consultar seus familiares ou outras pessoas antes de decidir participar. Se você não quiser participar ou retirar sua autorização, a qualquer momento, não haverá nenhum tipo de penalização ou prejuízo.

Justificativa:

Nosso estudo quer falar sobre seus sentimentos nos meses finais da gestação, isso trará maior compreensão sobre essa situação e poderemos desenvolver melhores cuidados.

Objetivos:

Compreender como você se sente, sendo mulher com Lúpus e estando no período gestacional sendo atendida em um serviço de pré-natal especializado.

Procedimentos:

Participando do estudo você está sendo convidado a: responder um questionário denominado Whoqol, elaborado para medir a qualidade de vida, que será realizado em um só encontro que terá duração aproximada de 20 minutos e será registrado em papel para posterior interpretação. Esse encontro será realizado em local privativo, (sala do Ambulatório de Pré Natal Especializado do CAISM) antes ou após sua consulta médica aconclusão da pesquisa esse material será armazenado em arquivo digital por 5 anos, esse arquivo ficará em poder da pesquisadora principal, após esse período será descartado.

Desconfortos e riscos:

Você pode se emocionar ao responder um questionário sobre sua vida.

Acompanhamento e assistência: No caso de desconforto emocional por conta da entrevista, se for necessário, teremos a equipe que atende no ambulatório de pré-natal especializado: médicos, residentes de medicina, enfermeiras, psicóloga e assistente social para nos auxiliar.

Sigilo e privacidade: Você tem a garantia de que sua identidade será mantida em sigilo e nenhuma informação será dada a outras pessoas que não seja a pesquisadora responsável, mesmo a orientadora da pesquisa e os membros dos grupos de pesquisa que a responsável frequenta (Núcleo de pesquisa e estudos qualitativos em saúde e Laboratório de pesquisa clínico-qualitativa), conhecerão somente os pseudônimos (nomes fantasia). Na divulgação dos resultados desse estudo, seu nome não será citado.

Benefícios: Não haverá benefício direto, somente o fato de que será ouvido (a) sobre sua vivência no presente momento. Além disso, é esperado que o estudo sirva de base para novas pesquisas e desenvolvimento da assistência em saúde, podendo haver benefícios futuros. Sua participação é voluntária, não haverá nenhum pagamento por ela.

Ressarcimento:

O encontro para responder ao questionário (Whoqol brief) será realizada antes ou após seu atendimento no ambulatório de pré-natal especializado com horário agendado previamente, portanto você já estará no CAISM, não havendo ressarcimento de despesas com deslocamento.

Ressaltamos que você tem direitos a indenização, previstos no código civil , por parte do pesquisador, patrocinador e das instituições envolvidas em virtude de quaisquer danos decorrentes da pesquisa .Em caso de dúvidas sobre o estudo, você poderá entrar em contato com os pesquisadores Larissa Rodrigues, Rua: Tessália Vieira de Camargo, 126; CEP 13083-887 Campinas – SP enfermeira, aluna do Programa de Pós Graduação em Tocoginecologia da faculdade de Ciências Médicas, Telefone: (19) 3521-8852, (11) 9 9529-7797 e mail: rodrigues-larissa@uol.com.br . Em caso de denúncias ou reclamações sobre sua participação e sobre questões éticas do estudo, você pode entrar em contato com a secretaria do Comitê de Ética em Pesquisa (CEP) da UNICAMP das 08:30hs às 13:30hs e das 13:00hs as 17:00hs na Rua: Tessália Vieira de Camargo, 126; CEP 13083-887 Campinas – SP; telefone (19) 3521-8936; fax (19) 3521-7187; email: cep@fcm.unicamp.br

Consentimento livre e esclarecido:

Após ter recebido esclarecimentos sobre a natureza da pesquisa, seus objetivos, métodos, benefícios previstos, potenciais riscos e o incômodo que esta possa acarretar, aceito participar: Nome do(a) participante:

____

Data: ____/_____/______.

____

(Assinatura do participante)

Responsabilidade do Pesquisador:

Asseguro ter cumprido as exigências da resolução 466/2012 CNS/MS e complementares na elaboração do protocolo e na obtenção deste Termo de Consentimento Livre e Esclarecido. Asseguro, também, ter explicado e fornecido uma via deste documento ao participante. Informo que o estudo foi aprovado pelo CEP perante o qual o projeto foi apresentado. Comprometo-me a utilizar o material e os dados obtidos nesta pesquisa exclusivamente para as finalidades previstas neste documento ou conforme o consentimento dado pelo participante.

Data: ____/_____/______.

____

(Assinatura do Pesquisador)

Anexo 2: Termo de Consentimento Livre Esclarecido- Entrevista

TERMO DE CONSENTIMENTO LIVRE E ESCLARECIDO

GESTAÇÃO E LÚPUS ERITEMATOSO SISTÊMICO: ESTUDO QUALIQUANTI SOBRE AS PERSPECTIVAS DAS MULHERES EM UM SERVIÇO DE PRÉ-NATAL ESPECIALIZADO

Doutoranda Larissa Rodrigues

Orientadora: Professora Dra. Fernanda Garanhani de Castro Surita

Você está sendo convidado a participar como voluntário de uma pesquisa. Este documento, chamado Termo de Consentimento Livre e Esclarecido, visa assegurar seus direitos como participante e é elaborado em duas vias, sendo que após assinada, uma deverá ficar com você e outra com a pesquisadora. Por favor, leia com atenção e calma, aproveitando para esclarecer suas dúvidas. Se houver perguntas antes ou mesmo depois de assiná-lo, você poderá esclarecê-las com a pesquisadora. Se preferir, pode levar este Termo para casa e consultar seus familiares ou outras pessoas antes de decidir participar. Se você não quiser participar ou retirar sua autorização, a qualquer momento, não haverá nenhum tipo de penalização ou prejuízo.

Justificativa:

Nosso estudo quer falar sobre seus sentimentos nos meses finais da gestação, isso trará maior compreensão sobre essa situação e poderemos desenvolver melhores cuidados.

Objetivos:

Compreender como você se sente, sendo mulher com Lúpus e estando no período gestacional sendo atendida em um serviço de pré-natal especializado.

Procedimentos: Participando do estudo você está sendo convidada a: responder um roteiro de perguntas abertas sobre estar grávida e ter Lúpus, como isso interfere ou não em sua vida. Você responderá na forma verbal (falando), será realizado um único encontro para uma só entrevista que terá duração aproximada de uma hora (60 minutos) e será gravada em áudio para posterior transcrição e interpretação.

Essa entrevista será realizada em local privativo, (sala do Ambulatório de Pré Natal Especializado do CAISM) antes ou após sua consulta médica agendada, além disso, vale ressaltar que em todos os casos a entrevista será sempre realizada pela pesquisadora responsável.

Após a conclusão da pesquisa esse material será armazenado em arquivo digital por 5 anos, esse arquivo ficará em poder da pesquisadora principal, após esse período será descartado.

Quanto a gravação da entrevista, peço que coloque sua rubrica no espaço entre parênteses correspondente à sua decisão:

( ) autorizo a gravação de minha entrevista em áudio

( ) não autorizo a gravação de minha entrevista em áudio.

Desconfortos e riscos:

Você pode se emocionar ao responder um questionário sobre sua vida.

Acompanhamento e assistência: No caso de desconforto emocional por conta da entrevista, se for necessário, teremos a equipe que atende no ambulatório de pré-natal especializado: médicos, residentes de medicina, enfermeiras, psicóloga e assistente social para nos auxiliar.

Sigilo e privacidade: Você tem a garantia de que sua identidade será mantida em sigilo e nenhuma informação será dada a outras pessoas que não seja a pesquisadora responsável, mesmo a orientadora da pesquisa e os membros dos grupos de pesquisa que a responsável frequenta (Núcleo de pesquisa e estudos qualitativos em saúde e Laboratório de pesquisa clínico-qualitativa), conhecerão somente os pseudônimos (nomes fantasia). Na divulgação dos resultados desse estudo, seu nome não será citado.

Benefícios: Não haverá benefício direto, somente o fato de que será ouvido (a) sobre sua vivência no presente momento. Além disso, é esperado que o estudo sirva de base para novas pesquisas e desenvolvimento da assistência em saúde, podendo haver benefícios futuros. Sua participação é voluntária, não haverá nenhum pagamento por ela.

Ressarcimento: A entrevista será realizada antes ou após seu atendimento no ambulatório de pré-natal especializado com horário agendado previamente, portanto você já estará no CAISM, não havendo ressarcimento de despesas com deslocamento. Ressaltamos que você tem direitos a indenização, previstos no código civil, por parte do pesquisador, patrocinador e das instituições envolvidas em virtude de quaisquer danos decorrentes da pesquisa.

Em caso de dúvidas sobre o estudo, você poderá entrar em contato com os pesquisadores Larissa Rodrigues, Rua: Tessália Vieira de Camargo, 126; CEP 13083-887 Campinas – SP enfermeira, aluna do Programa de Pós Graduação em Tocoginecologia da faculdade de Ciências Médicas, Telefone: (19) 3521-8852, (11) 9 9529-7797 e mail: rodrigues-larissa@uol.com.br . Em caso de denúncias ou reclamações sobre sua participação e sobre questões éticas do estudo, você pode entrar em contato com a secretaria do Comitê de Ética em Pesquisa (CEP) da UNICAMP das 08:30hs às 13:30hs e das 13:00hs as 17:00hs na Rua: Tessália Vieira de Camargo, 126; CEP 13083-887 Campinas – SP; telefone (19) 3521-8936; fax (19) 3521-7187; email: cep@fcm.unicamp.br

Consentimento livre e esclarecido:

Após ter recebido esclarecimentos sobre a natureza da pesquisa, seus objetivos, métodos, benefícios previstos, potenciais riscos e o incômodo que esta possa acarretar, aceito participar:

Nome do(a) participante:

____

Data: ____/_____/______.

____

(Assinatura do participante)

Responsabilidade do Pesquisador:

Asseguro ter cumprido as exigências da resolução 466/2012 CNS/MS e complementares na elaboração do protocolo e na obtenção deste Termo de Consentimento Livre e Esclarecido. Asseguro, também, ter explicado e fornecido uma via deste documento ao participante. Informo que o estudo foi aprovado pelo CEP perante o qual o projeto foi apresentado. Comprometo-me a utilizar o material e os dados obtidos nesta pesquisa exclusivamente para as finalidades previstas neste documento ou conforme o consentimento dado pelo participante.

Data: ____/_____/______.

____

(Assinatura do Pesquisador)

Rubrica do pesquisador:_______________ Rubrica do participante:_______________

Anexo 3: Roteiro de entrevista semidirigida

Entrevista nº _____

Local (Instituição):____

Cidade e data_____________________________e_,_____/_____/_______________

Início:______:_____h. Término:______:_______h. Duração em min.:____________

Entrevistador:_______________________________Assinatura________________

Identificação Pessoal do Entrevistado:

Nome Completo:____

Endereço p/ contato:____

Data de Nascimento:_____/_____/_____ Idade:_______ anos.

Profissão/Ocupação:____

Naturalidade: ____

Estado civil/ Situação conjugal atual/ Há quanto tempo:______________________

Com quem mora____

Filhos._______ Idades:____

Religião (prática religiosa):____

1) Conte-me como se sente em relação à ser portadora de doença auto imune:
2) Conte-me a experiência de estar gestante com essa doença:
3) Conte-me sobre seu acompanhamento na gestação:
4) Conte-me sobre suas relações desde que descobriu a doença e a gestação:
5) Conte-me sobre sua vida atualmente:
6) Há algo mais que queira falar:

Anexo 4: Roteiro de Observação durante ambientação

Roteiro de observação durante o período de adaptação do pesquisador no serviço

1) Relacionamentos na sala de espera:

2) Consulta médica:

Tempo

relação

discussões de casos com supervisores

3) Consulta à enfermagem:

Tempo

relacionamentos

4) Movimento de mulheres dentro do serviço:

Salas de exames:

Salas de procedimentos:

Anexo 5: WHOQOL – Bref

Instruções

Este questionário é sobre como você se sente a respeito de sua qualidade de vida, saúde e outras áreas de sua vida. Por favor responda a todas as questões. Se você não tem certeza sobre que resposta dar em uma questão, por favor, escolha entre as alternativas a que lhe parece mais apropriada. Esta, muitas vezes, poderá ser sua primeira escolha.

Por favor, tenha em mente seus valores, aspirações, prazeres e preocupações. Nós estamos perguntando o que você acha de sua vida, tomando como como referência as **duas últimas semanas**. Por exemplo, pensando nas últimas duas semanas, uma questão poderia ser:

	nada	Muito pouco	Médio	Muito	completamente
Você recebe dos outros o apoio de que necessita?	1	2	3	4	5

Você deve circular o número que melhor corresponde ao quanto você recebe dos outros o apoio de que necessita nestas últimas duas semanas. Portanto, você deve circular o número 4 se você recebeu "muito" apoio como abaixo.

	nada	Muito pouco	Médio	Muito	completamente
Você recebe dos outros o apoio de que necessita?	1	2	3	–	5

Você deve circular o número 1 se você não recebeu "nada" de apoio.

Por favor, leia cada questão, veja o que você acha e circule no número e lhe parece a melhor resposta.

		muito ruim	Ruim	nem ruim nem boa	boa	muito boa
1	Como você avaliaria sua qualidade de vida?	1	2	3	4	5

		muito insatisfeito	Insatisfeito	nem satisfeito nem insatisfeito	satisfeito	muito satisfeito
2	Quão satisfeito(a) você está com a sua saúde?	1	2	3	4	5

As questões seguintes são sobre **o quanto** você tem sentido algumas coisas nas últimas duas semanas.

		nada	muito pouco	mais ou meno	bastante	extremamente
3	Em que medida você acha que sua dor (física) impede você de fazer o que você precisa?	1	2	3	4	5
4	O quanto você precisa de algum tratamento médico para levar sua vida diária?	1	2	3	4	5
5	O quanto você aproveita a vida?	1	2	3	4	5
6	Em que medida você acha que a sua vida tem sentido?	1	2	3	4	5
7	O quanto você consegue se concentrar?	1	2	3	4	5
8	Quão seguro(a) você se sente em sua vida diária?	1	2	3	4	5
9	Quão saudável é o seu ambiente físico (clima, barulho, poluição, atrativos)?	1	2	3	4	5

As questões seguintes perguntam sobre **quão completamente** você tem sentido ou é capaz de fazer certas coisas nestas últimas duas semanas.

		nada	muito pouco	médio	muito	completamente
10	Você tem energia suficiente para seu dia-a- dia?	1	2	3	4	5
11	Você é capaz de aceitar sua aparência física?	1	2	3	4	5
12	Você tem dinheiro suficiente para satisfazer suas necessidades?	1	2	3	4	5
13	Quão disponíveis para você estão as informações que precisa no seu dia-a-dia?	1	2	3	4	5
14	Em que medida você tem oportunidades de atividade de lazer?	1	2	3	4	5

As questões seguintes perguntam sobre **quão bem ou satisfeito** você se sentiu a respeito de vários aspectos de sua vida nas últimas duas semanas.

		muito ruim	Ruim	nem ruim nem bom	bom	muito bom
15	Quão bem você é capaz de se locomover?	1	2	3	4	5
		muito insatisfeito	Insatisfeito	nem satisfeito nem insatisfeito	satisfeito	Muito satisfeito
16	Quão satisfeito(a) você está com o seu sono?	1	2	3	4	5
17	Quão satisfeito(a) você está com sua capacidade de desempenhar as atividades do seu dia-a-dia?	1	2	3	4	5

18	Quão satisfeito(a) você está com sua capacidade para o trabalho?	1	2	3	4	5
19	Quão satisfeito(a) você está consigo mesmo?	1	2	3	4	5
20	Quão satisfeito(a) você está com suas relações pessoais (amigos, parentes, conhecidos, colegas)?	1	2	3	4	5
21	Quão satisfeito(a) você está com sua vida sexual?	1	2	3	4	5
22	Quão satisfeito(a) você está com o apoio que você recebe de seus amigos?	1	2	3	4	5
23	Quão satisfeito(a) você está com as condições do local onde mora?	1	2	3	4	5
24	Quão satisfeito(a) você está com o seu acesso aos serviços de saúde?	1	2	3	4	5
25	Quão satisfeito(a) você está com o seu meio de transporte?	1	2	3	4	5

As questões seguintes referem-se a **com que freqüência** você sentiu ou experimentou certas coisas nas últimas duas semanas.

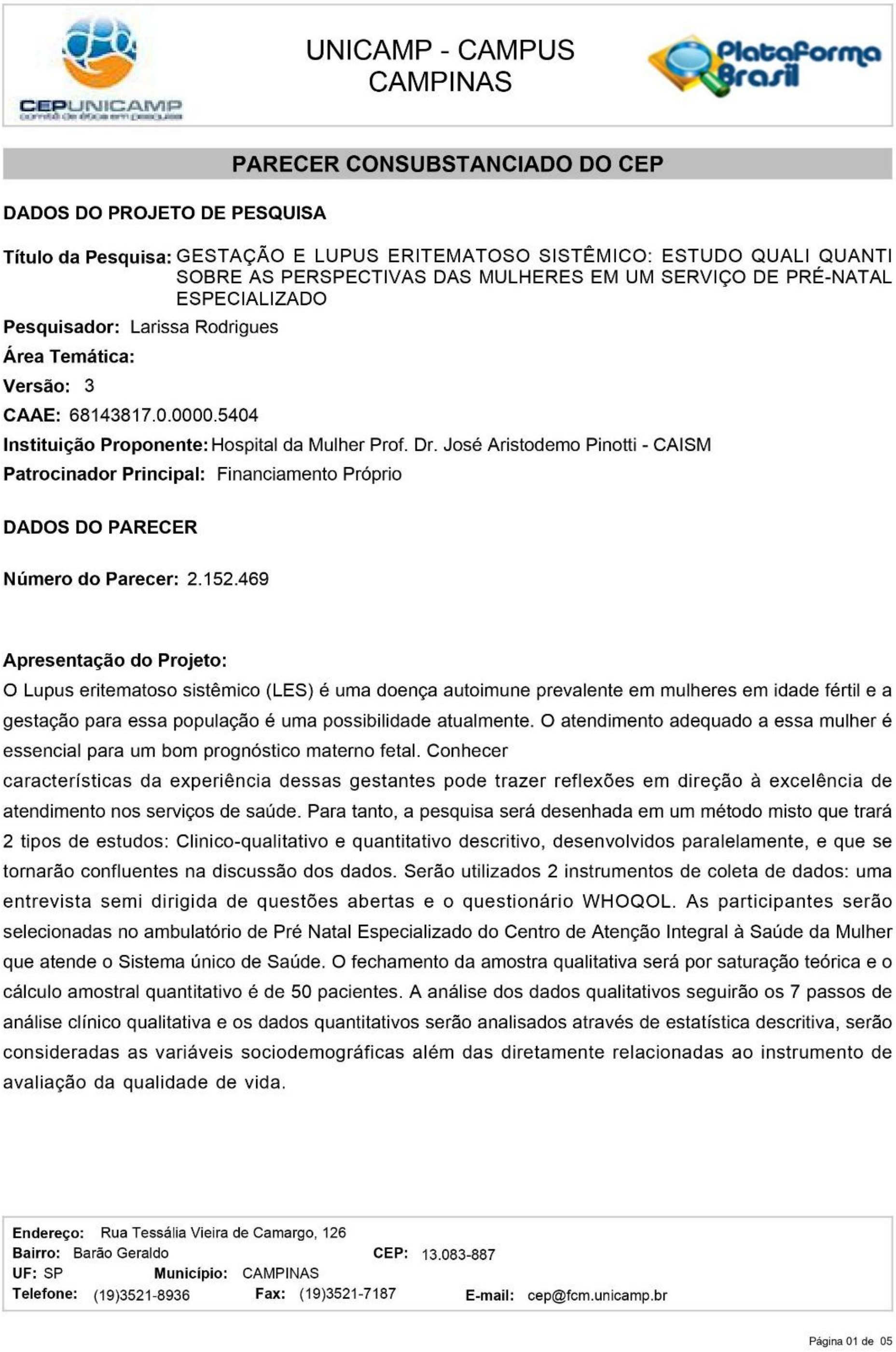
		nunca	Algumas vezes	freqüentemente	muito freqüentemente	sempre
26	Com que frequência você tem sentimentos negativos tais como mau humor, desespero	1	2	3	4	5

Alguém lhe ajudou a preencher este questionário? ....

Quanto tempo você levou para preencher este questionário?

....

Anexo 6: Parecer Consubstanciado Plataforma Brasil



UNICAMP - CAMPUS
CAMPINAS

PARECER CONSUBSTANCIADO DO CEP

DADOS DO PROJETO DE PESQUISA

Título da Pesquisa: GESTAÇÃO E LUPUS ERITEMATOSO SISTÊMICO: ESTUDO QUALI QUANTI SOBRE AS PERSPECTIVAS DAS MULHERES EM UM SERVIÇO DE PRÉ-NATAL ESPECIALIZADO

Pesquisador: Larissa Rodrigues

Área Temática:

Versão: 3

CAAE: 68143817.0.0000.5404

Instituição Proponente: Hospital da Mulher Prof. Dr. José Aristodemo Pinotti - CAISM

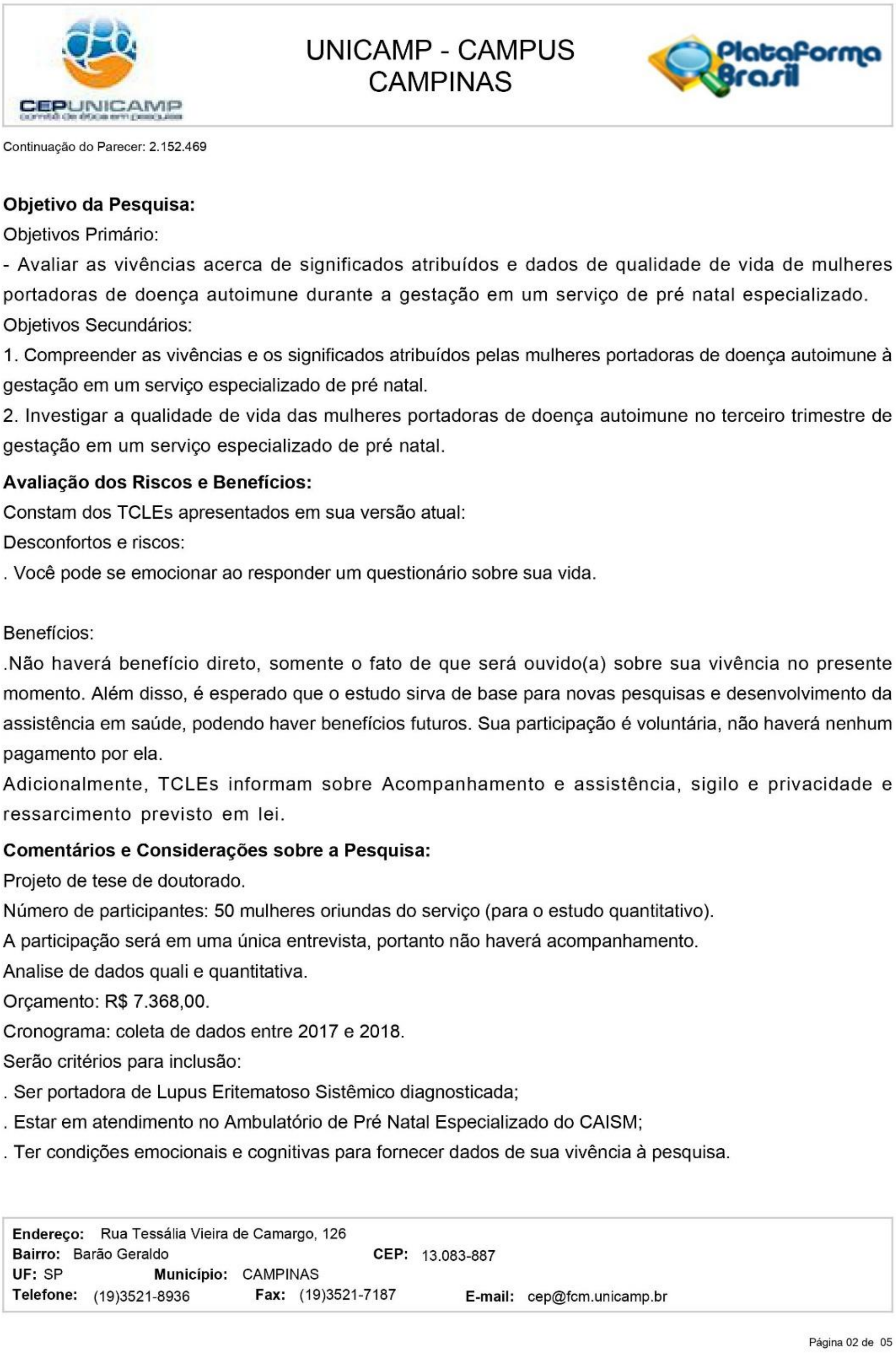
Patrocinador Principal: Financiamento Próprio

DADOS DO PARECER

Número do Parecer: 2.152.469

Apresentação do Projeto:

O Lupus eritematoso sistêmico (LES) é uma doença autoimune prevalente em mulheres em idade fértil e a gestação para essa população é uma possibilidade atualmente. O atendimento adequado a essa mulher é essencial para um bom prognóstico materno fetal. Conhecer
características da experiência dessas gestantes pode trazer reflexões em direção à excelência de atendimento nos serviços de saúde. Para tanto, a pesquisa será desenhada em um método misto que trará 2 tipos de estudos: Clinico-qualitativo e quantitativo descritivo, desenvolvidos paralelamente, e que se tornarão confluentes na discussão dos dados. Serão utilizados 2 instrumentos de coleta de dados: uma entrevista semi dirigida de questões abertas e o questionário WHOQOL. As participantes serão selecionadas no ambulatório de Pré Natal Especializado do Centro de Atenção Integral à Saúde da Mulher que atende o Sistema único de Saúde. O fechamento da amostra qualitativa será por saturação teórica e o cálculo amostral quantitativo é de 50 pacientes. A análise dos dados qualitativos seguirão os 7 passos de análise clínico qualitativa e os dados quantitativos serão analisados através de estatística descritiva, serão consideradas as variáveis sociodemográficas além das diretamente relacionadas ao instrumento de avaliação da qualidade de vida.



Continuação do Parecer: 2.152.469

Objetivo da Pesquisa:

Objetivos Primário:

- Avaliar as vivências acerca de significados atribuídos e dados de qualidade de vida de mulheres portadoras de doença autoimune durante a gestação em um serviço de pré natal especializado.

Objetivos Secundários:

1. Compreender as vivências e os significados atribuídos pelas mulheres portadoras de doença autoimune à gestação em um serviço especializado de pré natal.
2. Investigar a qualidade de vida das mulheres portadoras de doença autoimune no terceiro trimestre de gestação em um serviço especializado de pré natal.

Avaliação dos Riscos e Benefícios:

Constam dos TCLEs apresentados em sua versão atual:

Desconfortos e riscos:

. Você pode se emocionar ao responder um questionário sobre sua vida.

Benefícios:

.Não haverá benefício direto, somente o fato de que será ouvido(a) sobre sua vivência no presente momento. Além disso, é esperado que o estudo sirva de base para novas pesquisas e desenvolvimento da assistência em saúde, podendo haver benefícios futuros. Sua participação é voluntária, não haverá nenhum pagamento por ela.

Adicionalmente, TCLEs informam sobre Acompanhamento e assistência, sigilo e privacidade e ressarcimento previsto em lei.

Comentários e Considerações sobre a Pesquisa:

Projeto de tese de doutorado.

Número de participantes: 50 mulheres oriundas do serviço (para o estudo quantitativo).

A participação será em uma única entrevista, portanto não haverá acompanhamento.

Analise de dados quali e quantitativa.

Orçamento: R$ 7.368,00.

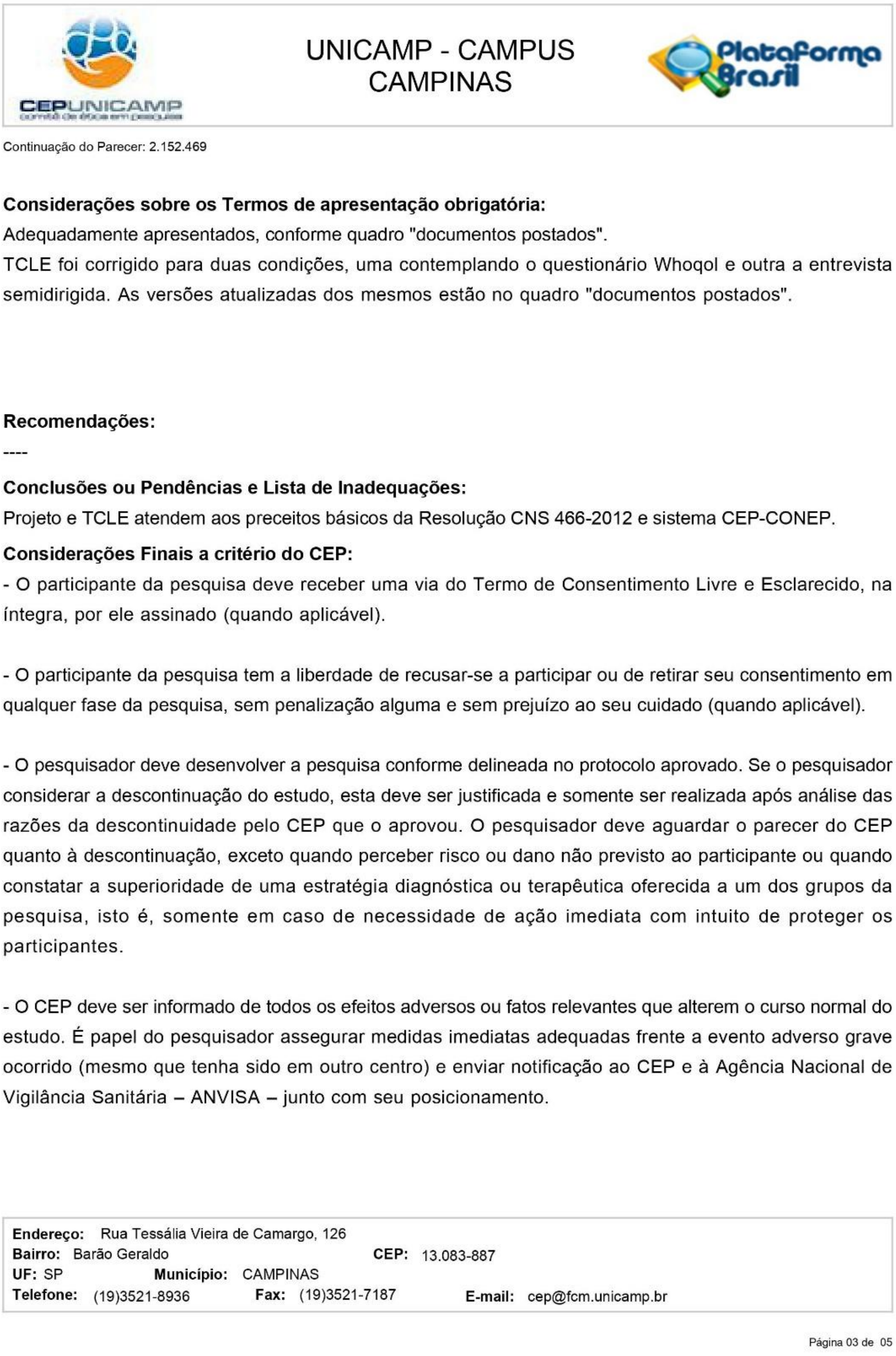
Cronograma: coleta de dados entre 2017 e 2018.

Serão critérios para inclusão:

. Ser portadora de Lupus Eritematoso Sistêmico diagnosticada;

. Estar em atendimento no Ambulatório de Pré Natal Especializado do CAISM;

. Ter condições emocionais e cognitivas para fornecer dados de sua vivência à pesquisa.



Continuação do Parecer: 2.152.469

Considerações sobre os Termos de apresentação obrigatória:

Adequadamente apresentados, conforme quadro "documentos postados".

TCLE foi corrigido para duas condições, uma contemplando o questionário Whoqol e outra a entrevista semidirigida. As versões atualizadas dos mesmos estão no quadro "documentos postados".

Recomendações:

Conclusões ou Pendências e Lista de Inadequações:

Projeto e TCLE atendem aos preceitos básicos da Resolução CNS 466-2012 e sistema CEP-CONEP.

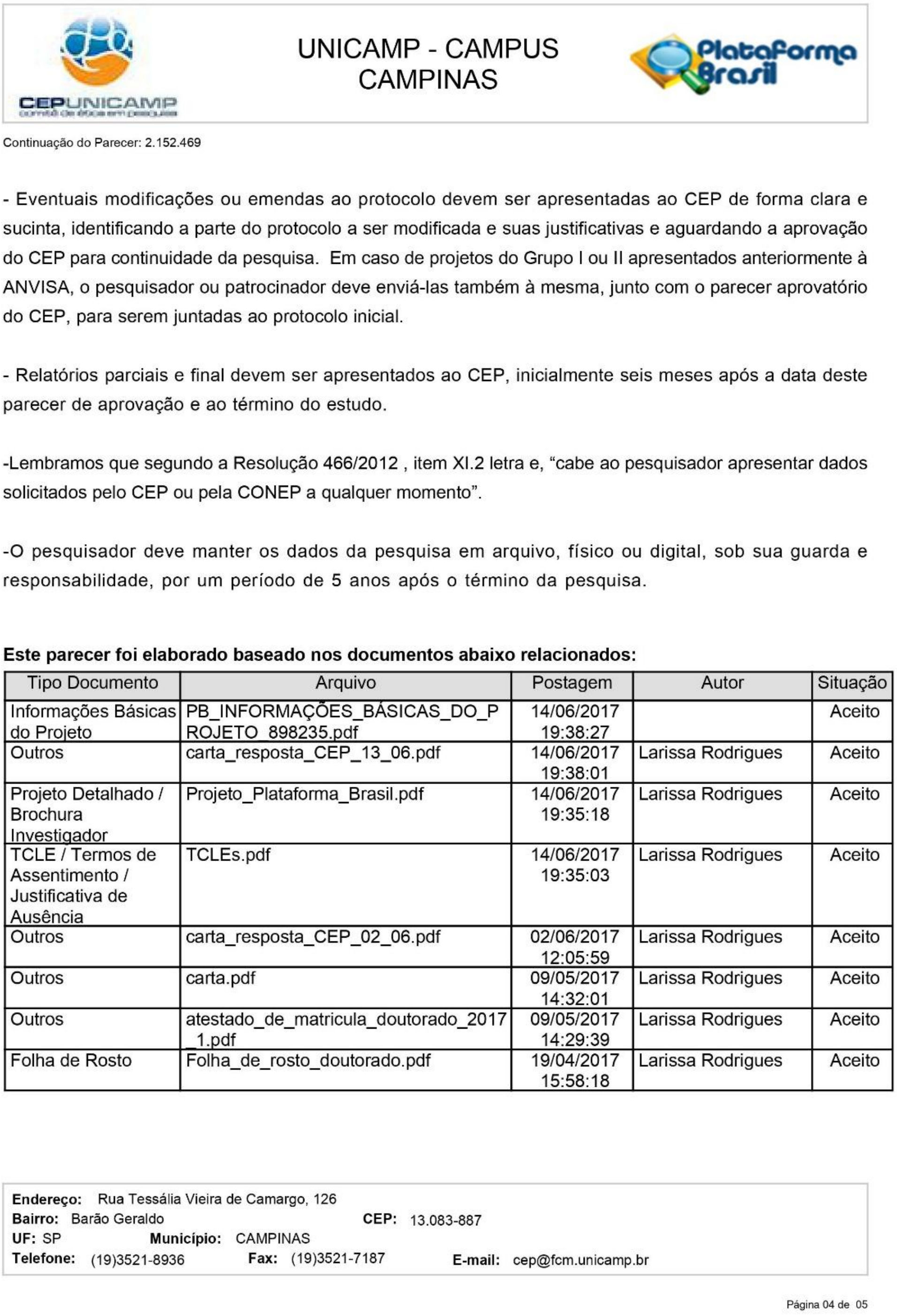
Considerações Finais a critério do CEP:

- O participante da pesquisa deve receber uma via do Termo de Consentimento Livre e Esclarecido, na íntegra, por ele assinado (quando aplicável).

- O participante da pesquisa tem a liberdade de recusar-se a participar ou de retirar seu consentimento em qualquer fase da pesquisa, sem penalização alguma e sem prejuízo ao seu cuidado (quando aplicável).

- O pesquisador deve desenvolver a pesquisa conforme delineada no protocolo aprovado. Se o pesquisador considerar a descontinuação do estudo, esta deve ser justificada e somente ser realizada após análise das razões da descontinuidade pelo CEP que o aprovou. O pesquisador deve aguardar o parecer do CEP quanto à descontinuação, exceto quando perceber risco ou dano não previsto ao participante ou quando constatar a superioridade de uma estratégia diagnóstica ou terapêutica oferecida a um dos grupos da pesquisa, isto é, somente em caso de necessidade de ação imediata com intuito de proteger os participantes.

- O CEP deve ser informado de todos os efeitos adversos ou fatos relevantes que alterem o curso normal do estudo. É papel do pesquisador assegurar medidas imediatas adequadas frente a evento adverso grave ocorrido (mesmo que tenha sido em outro centro) e enviar notificação ao CEP e à Agência Nacional de Vigilância Sanitária – ANVISA – junto com seu posicionamento.



- Eventuais modificações ou emendas ao protocolo devem ser apresentadas ao CEP de forma clara e sucinta, identificando a parte do protocolo a ser modificada e suas justificativas e aguardando a aprovação do CEP para continuidade da pesquisa. Em caso de projetos do Grupo I ou II apresentados anteriormente à ANVISA, o pesquisador ou patrocinador deve enviá-las também à mesma, junto com o parecer aprovatório do CEP, para serem juntadas ao protocolo inicial.

- Relatórios parciais e final devem ser apresentados ao CEP, inicialmente seis meses após a data deste parecer de aprovação e ao término do estudo.

-Lembramos que segundo a Resolução 466/2012 , item XI.2 letra e, “cabe ao pesquisador apresentar dados solicitados pelo CEP ou pela CONEP a qualquer momento”.

-O pesquisador deve manter os dados da pesquisa em arquivo, físico ou digital, sob sua guarda e responsabilidade, por um período de 5 anos após o término da pesquisa.

Este parecer foi elaborado baseado nos documentos abaixo relacionados:

Tipo Documento	Arquivo	Postagem	Autor	Situação
Informações Básicas do Projeto	PB_INFORMAÇÕES_BÁSICAS_DO_PROJETO_898235.pdf	14/06/2017 19:38:27		Aceito
Outros	carta_resposta_CEP_13_06.pdf	14/06/2017 19:38:01	Larissa Rodrigues	Aceito
Projeto Detalhado / Brochura Investigador	Projeto_Plataforma_Brasil.pdf	14/06/2017 19:35:18	Larissa Rodrigues	Aceito
TCLE / Termos de Assentimento / Justificativa de Ausência	TCLEs.pdf	14/06/2017 19:35:03	Larissa Rodrigues	Aceito
Outros	carta_resposta_CEP_02_06.pdf	02/06/2017 12:05:59	Larissa Rodrigues	Aceito
Outros	carta.pdf	09/05/2017 14:32:01	Larissa Rodrigues	Aceito
Outros	atestado_de_matricula_doutorado_2017_1.pdf	09/05/2017 14:29:39	Larissa Rodrigues	Aceito
Folha de Rosto	Folha_de_rosto_doutorado.pdf	19/04/2017 15:58:18	Larissa Rodrigues	Aceito

Continuação do Parecer: 2.152.469

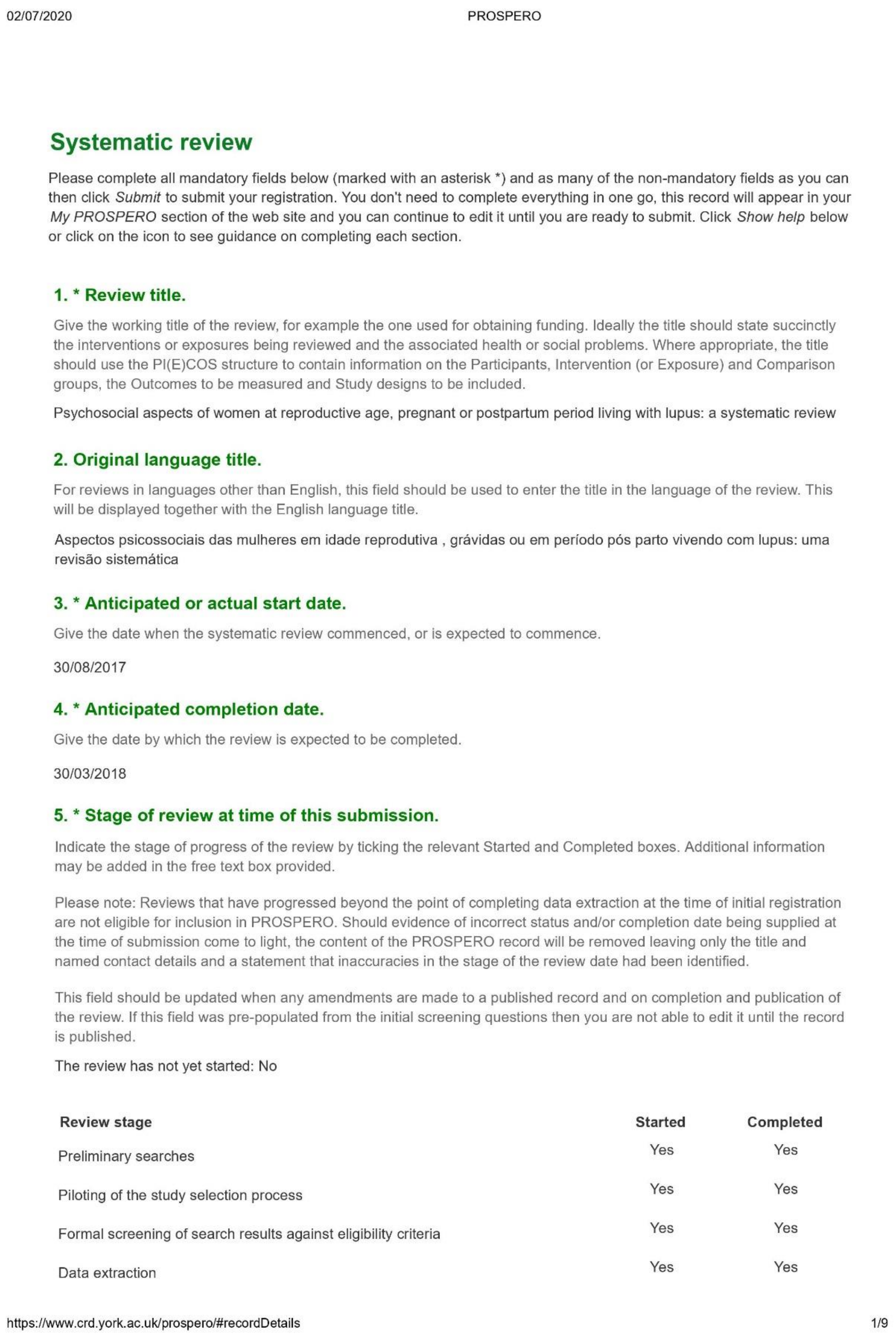
Situação do Parecer:
Aprovado

Necessita Apreciação da CONEP:
Não

CAMPINAS, 03 de Julho de 2017

Assinado por:
Renata Maria dos Santos Celeghini
(Coordenador)

Anexo 7: PROSPERO- Registro da Revisão Sistemática 1



Systematic review

Please complete all mandatory fields below (marked with an asterisk *) and as many of the non-mandatory fields as you can then click *Submit* to submit your registration. You don't need to complete everything in one go, this record will appear in your *My PROSPERO* section of the web site and you can continue to edit it until you are ready to submit. Click *Show help* below or click on the icon to see guidance on completing each section.

1. * Review title.

Give the working title of the review, for example the one used for obtaining funding. Ideally the title should state succinctly the interventions or exposures being reviewed and the associated health or social problems. Where appropriate, the title should use the PI(E)COS structure to contain information on the Participants, Intervention (or Exposure) and Comparison groups, the Outcomes to be measured and Study designs to be included.

Psychosocial aspects of women at reproductive age, pregnant or postpartum period living with lupus: a systematic review

2. Original language title.

For reviews in languages other than English, this field should be used to enter the title in the language of the review. This will be displayed together with the English language title.

Aspectos psicossociais das mulheres em idade reprodutiva , grávidas ou em período pós parto vivendo com lupus: uma revisão sistemática

3. * Anticipated or actual start date.

Give the date when the systematic review commenced, or is expected to commence.

30/08/2017

4. * Anticipated completion date.

Give the date by which the review is expected to be completed.

30/03/2018

5. * Stage of review at time of this submission.

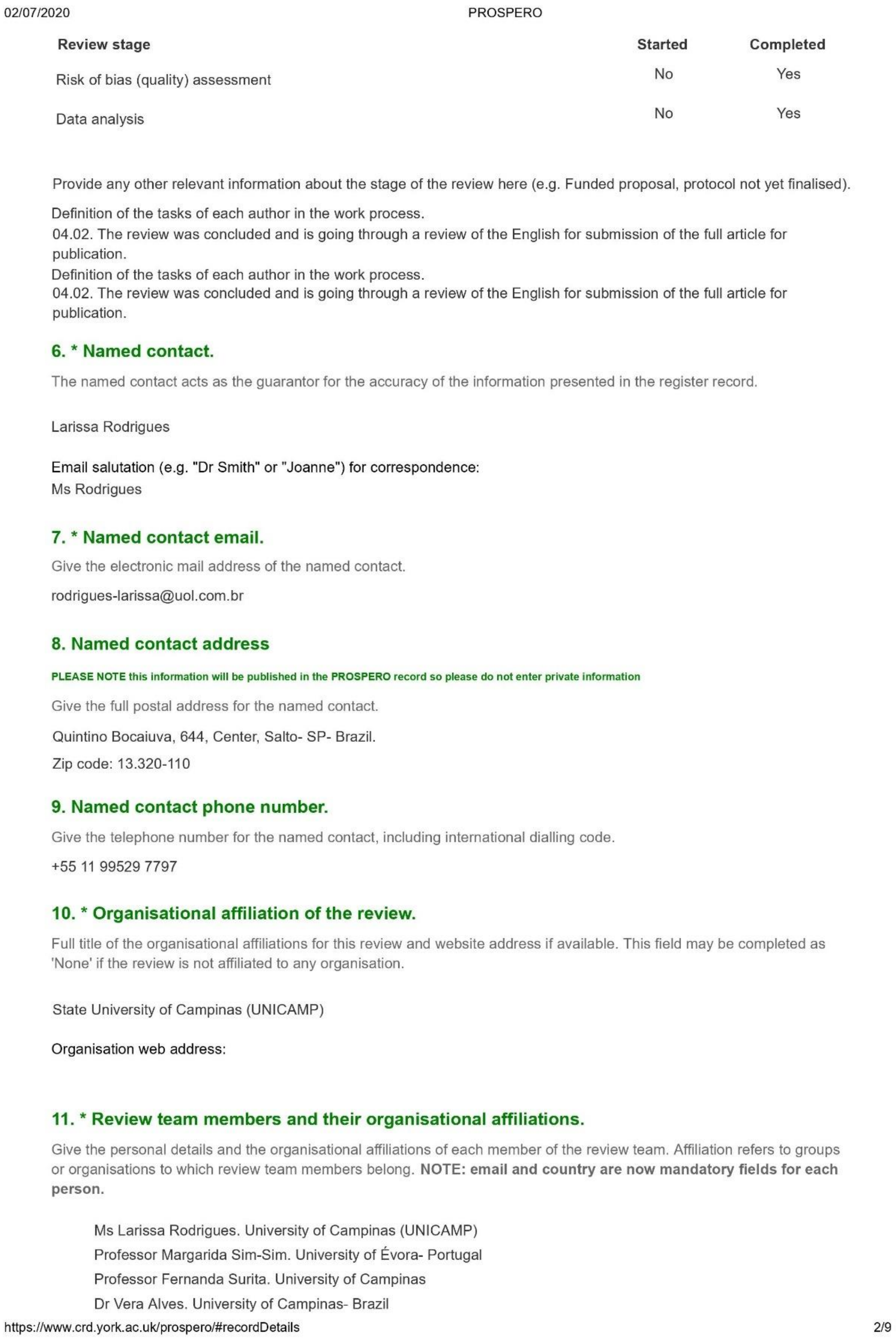
Indicate the stage of progress of the review by ticking the relevant Started and Completed boxes. Additional information may be added in the free text box provided.

Please note: Reviews that have progressed beyond the point of completing data extraction at the time of initial registration are not eligible for inclusion in PROSPERO. Should evidence of incorrect status and/or completion date being supplied at the time of submission come to light, the content of the PROSPERO record will be removed leaving only the title and named contact details and a statement that inaccuracies in the stage of the review date had been identified.

This field should be updated when any amendments are made to a published record and on completion and publication of the review. If this field was pre-populated from the initial screening questions then you are not able to edit it until the record is published.

The review has not yet started: No

Review stage	Started	Completed
Preliminary searches	Yes	Yes
Piloting of the study selection process	Yes	Yes
Formal screening of search results against eligibility criteria	Yes	Yes
Data extraction	Yes	Yes



Review stage	Started	Completed
Risk of bias (quality) assessment	No	Yes
Data analysis	No	Yes

Provide any other relevant information about the stage of the review here (e.g. Funded proposal, protocol not yet finalised).

Definition of the tasks of each author in the work process.
04.02. The review was concluded and is going through a review of the English for submission of the full article for publication.

Definition of the tasks of each author in the work process.
04.02. The review was concluded and is going through a review of the English for submission of the full article for publication.

6. * Named contact.

The named contact acts as the guarantor for the accuracy of the information presented in the register record.

Larissa Rodrigues

Email salutation (e.g. "Dr Smith" or "Joanne") for correspondence:
Ms Rodrigues

7. * Named contact email.

Give the electronic mail address of the named contact.

rodrigues-larissa@uol.com.br

8. Named contact address

PLEASE NOTE this information will be published in the PROSPERO record so please do not enter private information

Give the full postal address for the named contact.

Quintino Bocaiuva, 644, Center, Salto- SP- Brazil.
Zip code: 13.320-110

9. Named contact phone number.

Give the telephone number for the named contact, including international dialling code.

+55 11 99529 7797

10. * Organisational affiliation of the review.

Full title of the organisational affiliations for this review and website address if available. This field may be completed as 'None' if the review is not affiliated to any organisation.

State University of Campinas (UNICAMP)

Organisation web address:

11. * Review team members and their organisational affiliations.

Give the personal details and the organisational affiliations of each member of the review team. Affiliation refers to groups or organisations to which review team members belong. **NOTE: email and country are now mandatory fields for each person.**

Ms Larissa Rodrigues. University of Campinas (UNICAMP)
Professor Margarida Sim-Sim. University of Évora- Portugal
Professor Fernanda Surita. University of Campinas
Dr Vera Alves. University of Campinas- Brazil

12. * Funding sources/sponsors.

Give details of the individuals, organizations, groups or other legal entities who take responsibility for initiating, managing, sponsoring and/or financing the review. Include any unique identification numbers assigned to the review by the individuals or bodies listed.

Larissa Rodrigues: Nurse. Professor of the technical college of campinas (UNICAMP), master in health sciences by (UNICAMP) and PHD student in Todoginecology by (FCM/UNICAMP) ID: orcid.org/0000-0001-8714-7010. Curriculum lattes: http://lattes.cnpq.br/8955530249690108

Vera Lucia Pereira Alves : Psychologist and Psychotherapist, Post-Doctorate in Medical Sciences LPCQ/DPMP - FCM - UNICAMP, PhD in Education - UNICAMP. ID: orcid.org/0000-0003-4293-1439, Currículum lattes http://lattes.cnpq.br/7646994628891216.

Maria Margarida Fialho Sim-Sim: Professor-Coordinator. (Department of Nursing) University of Evora Portugal. ID: orcid.org/0000-0002-0028-2664. Portal de Gois: http://www.degois.pt/visualizador/curriculum.jsp?key=1250318196407443

Fernanda Garanhani de Castro Surita: Professor of Obstetrics, Department of Tocoginecology (FCM / UNICAMP). Chair of the Research Committee of (CAISM / UNICAMP) and coordinator of the outpatient clinics of the Center for Integral Attention to Women's Health (CAISM / UNICAMP). ID: orcid.org/0000-0003-4335-0337, Curriculum lattes: http://lattes.cnpq.br/1955463916442636

Grant number(s)

13. * Conflicts of interest.

List any conditions that could lead to actual or perceived undue influence on judgements concerning the main topic investigated in the review.

None

14. Collaborators.

Give the name and affiliation of any individuals or organisations who are working on the review but who are not listed as review team members. **NOTE: email and country are now mandatory fields for each person.**

15. * Review question.

State the question(s) to be addressed by the review, clearly and precisely. Review questions may be specific or broad. It may be appropriate to break very broad questions down into a series of related more specific questions. Questions may be framed or refined using PI(E)COS where relevant.

How are the psychosocial aspects of pregnant women with lupus described in the literature?

16. * Searches.

State the sources that will be searched. Give the search dates, and any restrictions (e.g. language or publication period). Do NOT enter the full search strategy (it may be provided as a link or attachment.)

The search will be in CINAHL, Embase, PsycINFO, Scopus, Cochrane Library and Web of Science, with the descriptors: "Lupus Erythematosus, Systemic"; Psychology; Pregnancy; "Pregnant woman"; "Postpartum period"; "Breast-feeding"; Lactation. With Boolean operators "and" between the first 3 descriptors and "or" at the intersections between the others. There will be no language restrictions and no publication period restrictions.

17. URL to search strategy.

Give a link to a published pdf/word document detailing either the search strategy or an example of a search strategy for a specific database if available (including the keywords that will be used in the search strategies), or upload your search strategy.

Do NOT provide links to your search results.

Yes I give permission for this file to be made publicly available

18. * Condition or domain being studied.

Give a short description of the disease, condition or healthcare domain being studied. This could include health and wellbeing outcomes.

In general, systemic lupus erythematosus (SLE) is a multisystemic autoimmune disease that can affect any organ or system including skin, joints, kidneys and serous membranes. There are between 20 and 50 cases for 100,000 people, with a ratio between women and men of 9: 1 and prevalence between 15 and 45 years. Higher incidence was observed in women of childbearing age. Pregnancy is a possibility for this group, considering the evolution of treatment and quality of life of patients with the disease over time. However, women with SLE have, during pregnancy and puerperium, an increased risk of maternal-fetal complications, such as fetal loss, growth restriction and premature birth. The perception and emotions of these women at maternal and child risk are little explored. Then there remains the interest in understanding the psychosocial aspects involved in this experience to think about extended and appropriate care for these women.

19. * Participants/population.

Give summary criteria for the participants or populations being studied by the review. The preferred format includes details of both inclusion and exclusion criteria.

We will include studies examining adults women with lupus at gestational age planning pregnancy, pregnant, in postpartum period or breastfeeding.

20. * Intervention(s), exposure(s).

Give full and clear descriptions or definitions of the nature of the interventions or the exposures to be reviewed.

Psychosocial aspects as: feelings, emotions, situation of life (economic), family, health assistance.

21. * Comparator(s)/control.

Where relevant, give details of the alternatives against which the main subject/topic of the review will be compared (e.g. another intervention or a non-exposed control group). The preferred format includes details of both inclusion and exclusion criteria.

We will consider articles with people with lupus who did not necessarily experience gestation and pregnant women not suffering from lupus as control group for researches where applicable (RCT or cohort studies).

22. * Types of study to be included.

Give details of the types of study (study designs) eligible for inclusion in the review. If there are no restrictions on the types of study design eligible for inclusion, or certain study types are excluded, this should be stated. The preferred format includes details of both inclusion and exclusion criteria.

Primary articles will be considered, including interventional or observational studies (randomized controlled trials (RCT), cohort studies, transversal studies and qualitative research).

Reviews or case reports will be excluded.

23. Context.

Give summary details of the setting and other relevant characteristics which help define the inclusion or exclusion criteria.

By the few articles published about psychosocial aspects of pregnant or puerperal women with lupus, we do not restrict time or language.
There is an ongoing qualitative study on the meanings attributed by women with lupus to gestation in a specialized prenatal service of which the authors of this review are part, therefore the exclusion and inclusion criteria were related to the same type of population and situation experienced.

24. * Main outcome(s).

Give the pre-specified main (most important) outcomes of the review, including details of how the outcome is defined and measured and when these measurement are made, if these are part of the review inclusion criteria.

We will consider psychosocial aspects described for women pregnant with lupus. These aspects are described as following: negative emotional disorders (e.g. depression and anxiety), emotional experiences, interpersonal relationships, social support, stressful life events.

* Measures of effect

25. * Additional outcome(s).

List the pre-specified additional outcomes of the review, with a similar level of detail to that required for main outcomes. Where there are no additional outcomes please state 'None' or 'Not applicable' as appropriate to the review

We will consider factors related to psychosocial aspects such as family and professional relationships.

* Measures of effect

26. * Data extraction (selection and coding).

Describe how studies will be selected for inclusion. State what data will be extracted or obtained. State how this will be done and recorded.

After electronic searching, the records will be moved to EndNote software and the duplicated articles will be excluded automatically and we will remove manually as well. Titles and abstracts of studies retrieved will be screened independently by two review authors to identify studies that potentially meet the inclusion criteria outlined above. The full text of these potentially eligible studies will be retrieved and independently assessed for eligibility by four review team members. Any disagreement between them over the eligibility of particular studies will be discussed you reach consensus and software NVIVO will be used for data validation. A flow diagram will be used to summarize the study selection processes.

27. * Risk of bias (quality) assessment.

Describe the method of assessing risk of bias or quality assessment. State which characteristics of the studies will be assessed and any formal risk of bias tools that will be used.

Two review authors will independently assess the risk of bias in included studies by considering 60% of the criteria set by the following checklists: Consolidated Standards of Reporting Trials (CONSORT), Strengthening the Reporting of Observational studies in Epidemiology (STROBE), Consensus-based Clinical Case Reporting Guideline Development (CARE) and Consolidated Criteria for Reporting Qualitative Research (COREQ).
Disagreements between the review authors over the risk of bias in some articles will be resolved by discussion, with involvement of a third and fourth review author.

28. * Strategy for data synthesis.

Provide details of the planned synthesis including a rationale for the methods selected. This **must not be generic text** but should be **specific to your review** and describe how the proposed analysis will be applied to your data.

A standardized, pre-piloted form will be used to extract data from the included studies for assessment of study quality and evidence synthesis. Two review authors will extract data independently, discrepancies will be identified and resolved through discussion . Missing data will be requested from study authors. Extracted information will include:

1) Characteristics of the study: the country where data were collected, study design, setting, objectives, sample size, and duration of follow-up when applicable;

2) Publication details: journal and year of publication, language, and publication status;

3) Information of domain and population: marital status, number of pregnancy, socioeconomic status, and religion;

4) Information of determinants/control group: kind of control group, and psychosocial aspects studied;

5) Information of outcome: main results following the psychosocial aspects criteria.

29. * Analysis of subgroups or subsets.

State any planned investigation of 'subgroups'. Be clear and specific about which type of study or participant will be included in each group or covariate investigated. State the planned analytic approach.

Quantitative studies are separated by qualitative studies for analysis more pertinent to each type.

30. * Type and method of review.

Select the type of review and the review method from the lists below. Select the health area(s) of interest for your review.

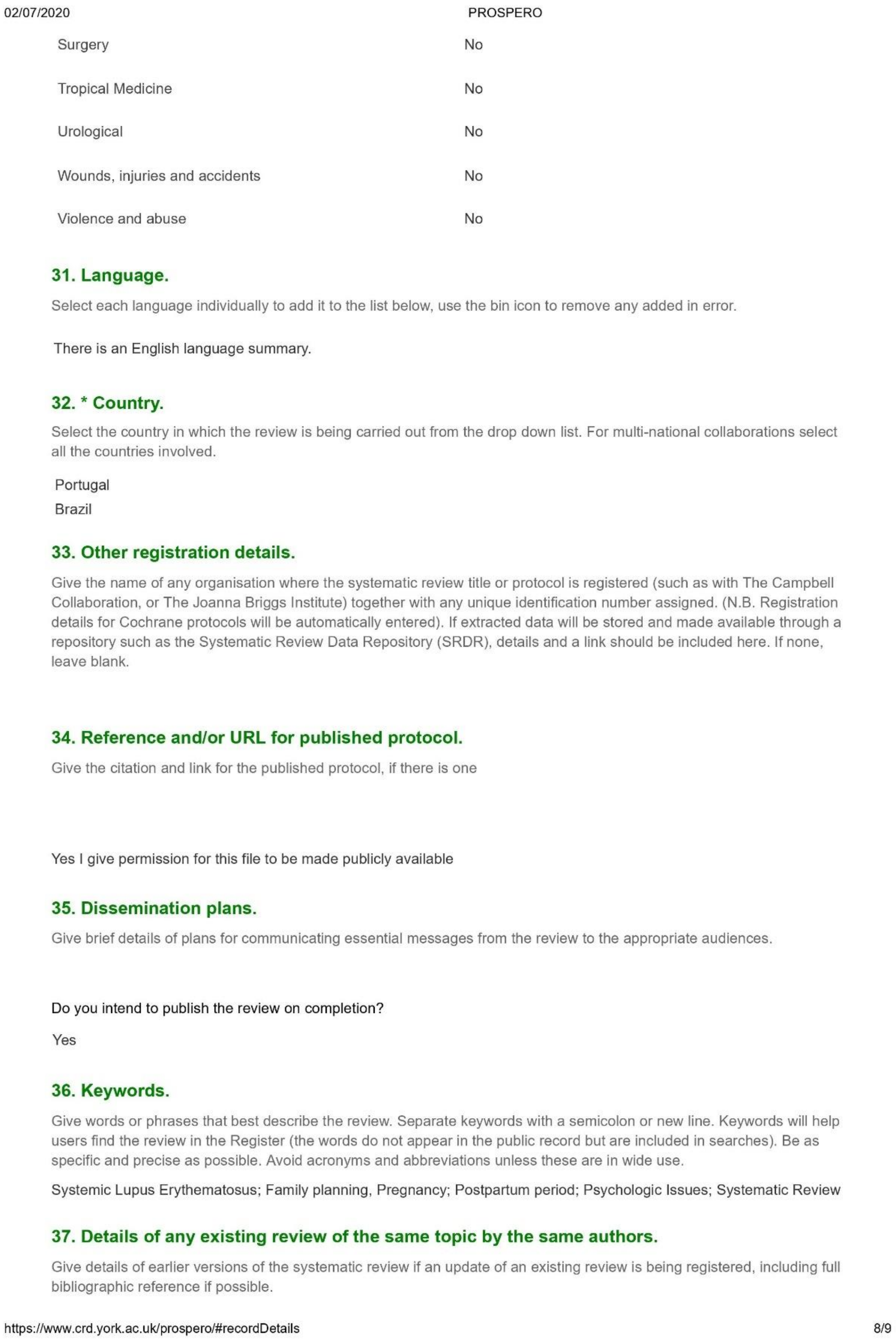
Type of review

Cost effectiveness	No
Diagnostic	No
Epidemiologic	No
Individual patient data (IPD) meta-analysis	No
Intervention	No
Meta-analysis	No
Methodology	No
Narrative synthesis	No
Network meta-analysis	No
Pre-clinical	No
Prevention	No
Prognostic	No
Prospective meta-analysis (PMA)	No
Review of reviews	No
Service delivery	No
Synthesis of qualitative studies	No
Systematic review	Yes
Other	No

Health area of the review

Alcohol/substance misuse/abuse	No
Blood and immune system	Yes
Cancer	No
Cardiovascular	No
Care of the elderly	No
Child health	No
Complementary therapies	No

COVID-19	No
Crime and justice	No
Dental	No
Digestive system	No
Ear, nose and throat	No
Education	No
Endocrine and metabolic disorders	No
Eye disorders	No
General interest	No
Genetics	No
Health inequalities/health equity	No
Infections and infestations	No
International development	No
Mental health and behavioural conditions	No
Musculoskeletal	No
Neurological	No
Nursing	No
Obstetrics and gynaecology	Yes
Oral health	No
Palliative care	No
Perioperative care	No
Physiotherapy	No
Pregnancy and childbirth	Yes
Public health (including social determinants of health)	No
Rehabilitation	No
Respiratory disorders	No
Service delivery	No
Skin disorders	No
Social care	Yes



Surgery	No
Tropical Medicine	No
Urological	No
Wounds, injuries and accidents	No
Violence and abuse	No

31. Language.

Select each language individually to add it to the list below, use the bin icon to remove any added in error.

There is an English language summary.

32. * Country.

Select the country in which the review is being carried out from the drop down list. For multi-national collaborations select all the countries involved.

Portugal
Brazil

33. Other registration details.

Give the name of any organisation where the systematic review title or protocol is registered (such as with The Campbell Collaboration, or The Joanna Briggs Institute) together with any unique identification number assigned. (N.B. Registration details for Cochrane protocols will be automatically entered). If extracted data will be stored and made available through a repository such as the Systematic Review Data Repository (SRDR), details and a link should be included here. If none, leave blank.

34. Reference and/or URL for published protocol.

Give the citation and link for the published protocol, if there is one

Yes I give permission for this file to be made publicly available

35. Dissemination plans.

Give brief details of plans for communicating essential messages from the review to the appropriate audiences.

Do you intend to publish the review on completion?

Yes

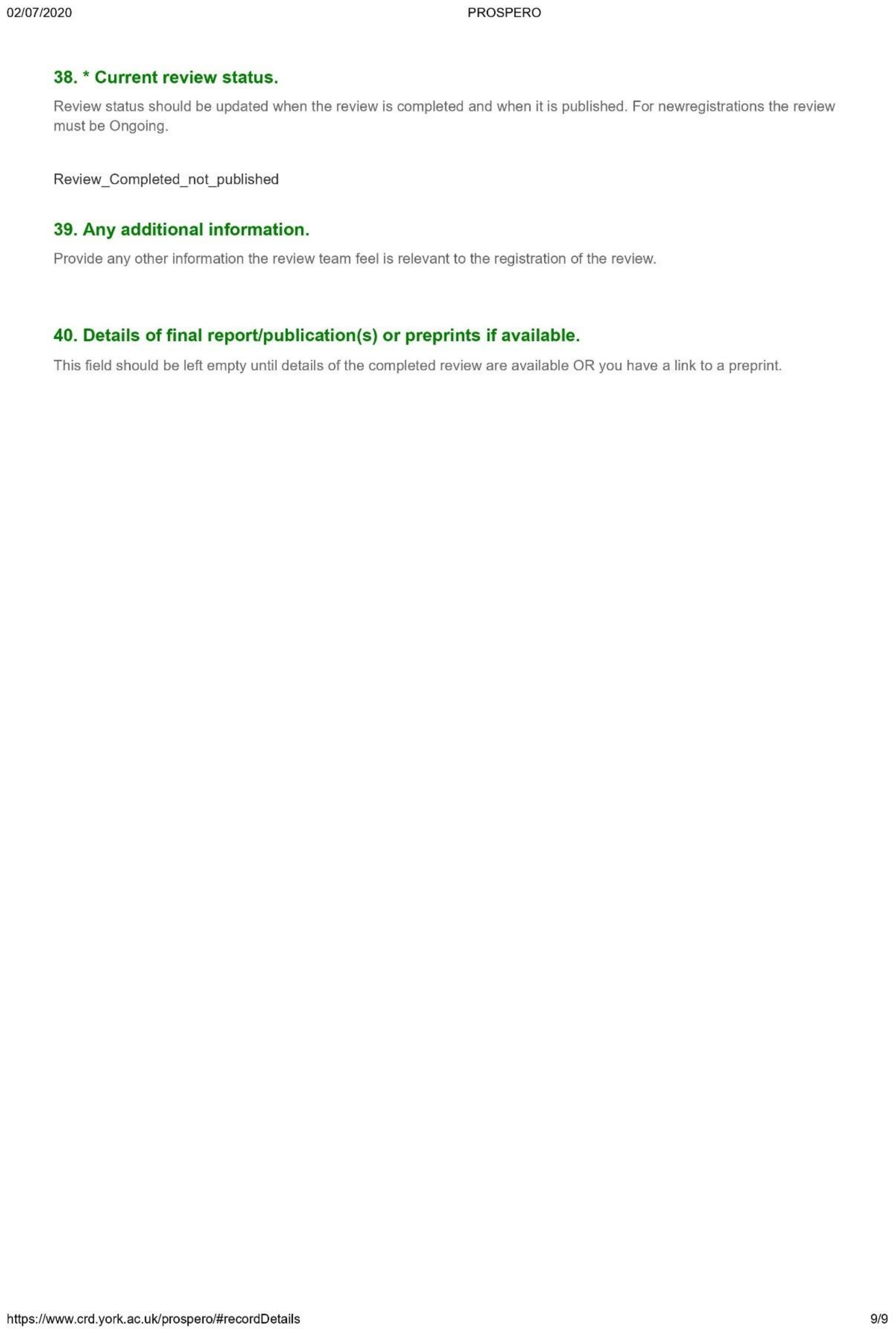
36. Keywords.

Give words or phrases that best describe the review. Separate keywords with a semicolon or new line. Keywords will help users find the review in the Register (the words do not appear in the public record but are included in searches). Be as specific and precise as possible. Avoid acronyms and abbreviations unless these are in wide use.

Systemic Lupus Erythematosus; Family planning, Pregnancy; Postpartum period; Psychologic Issues; Systematic Review

37. Details of any existing review of the same topic by the same authors.

Give details of earlier versions of the systematic review if an update of an existing review is being registered, including full bibliographic reference if possible.



38. * Current review status.

Review status should be updated when the review is completed and when it is published. For newregistrations the review must be Ongoing.

Review_Completed_not_published

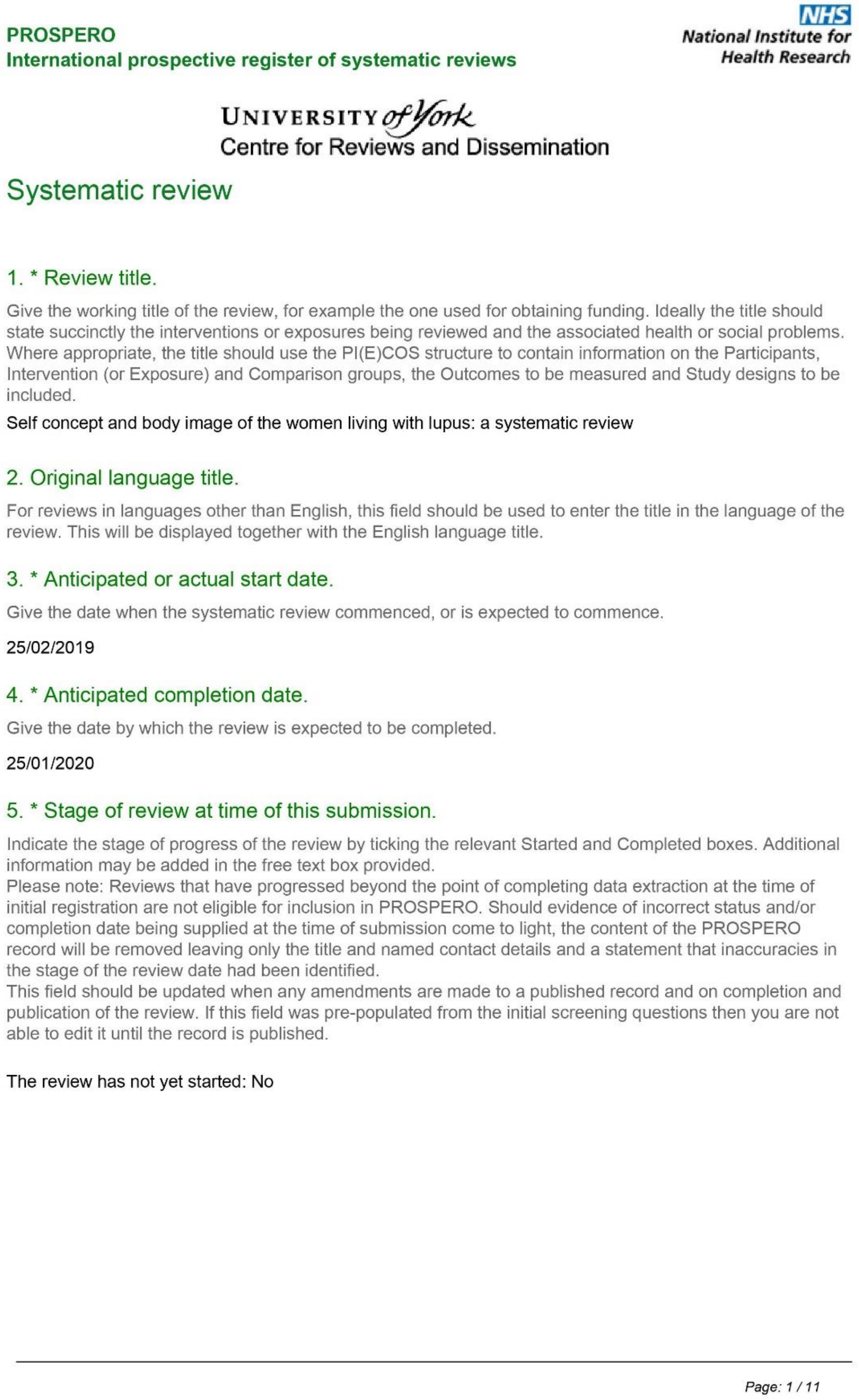
39. Any additional information.

Provide any other information the review team feel is relevant to the registration of the review.

40. Details of final report/publication(s) or preprints if available.

This field should be left empty until details of the completed review are available OR you have a link to a preprint.

Anexo 8: PROSPERO- Registro da Revisão Sistemática 2



PROSPERO
International prospective register of systematic reviews

NHS
National Institute for Health Research

UNIVERSITY of York
Centre for Reviews and Dissemination

Systematic review

1. * Review title.

Give the working title of the review, for example the one used for obtaining funding. Ideally the title should state succinctly the interventions or exposures being reviewed and the associated health or social problems. Where appropriate, the title should use the PI(E)COS structure to contain information on the Participants, Intervention (or Exposure) and Comparison groups, the Outcomes to be measured and Study designs to be included.

Self concept and body image of the women living with lupus: a systematic review

2. Original language title.

For reviews in languages other than English, this field should be used to enter the title in the language of the review. This will be displayed together with the English language title.

3. * Anticipated or actual start date.

Give the date when the systematic review commenced, or is expected to commence.

25/02/2019

4. * Anticipated completion date.

Give the date by which the review is expected to be completed.

25/01/2020

5. * Stage of review at time of this submission.

Indicate the stage of progress of the review by ticking the relevant Started and Completed boxes. Additional information may be added in the free text box provided.
Please note: Reviews that have progressed beyond the point of completing data extraction at the time of initial registration are not eligible for inclusion in PROSPERO. Should evidence of incorrect status and/or completion date being supplied at the time of submission come to light, the content of the PROSPERO record will be removed leaving only the title and named contact details and a statement that inaccuracies in the stage of the review date had been identified.
This field should be updated when any amendments are made to a published record and on completion and publication of the review. If this field was pre-populated from the initial screening questions then you are not able to edit it until the record is published.

The review has not yet started: No

Review stage	**Started**	**Completed**
Preliminary searches	Yes	No
Piloting of the study selection process	Yes	Yes
Formal screening of search results against eligibility criteria	No	No
Data extraction	No	No
Risk of bias (quality) assessment	No	No
Data analysis	No	No

Provide any other relevant information about the stage of the review here (e.g. Funded proposal, protocol not yet finalised).

6. * Named contact.

The named contact acts as the guarantor for the accuracy of the information presented in the register record.

Larissa Rodrigues

Email salutation (e.g. "Dr Smith" or "Joanne") for correspondence:

Miss Rodrigues

7. * Named contact email.

Give the electronic mail address of the named contact.

rodrigues-larissa@uol.com.br

8. Named contact address

Give the full postal address for the named contact.

Rua Quintino Bocaiuva, 644, Centro Salto, SP

9. Named contact phone number.

Give the telephone number for the named contact, including international dialling code.

5511995297797

10. * Organisational affiliation of the review.

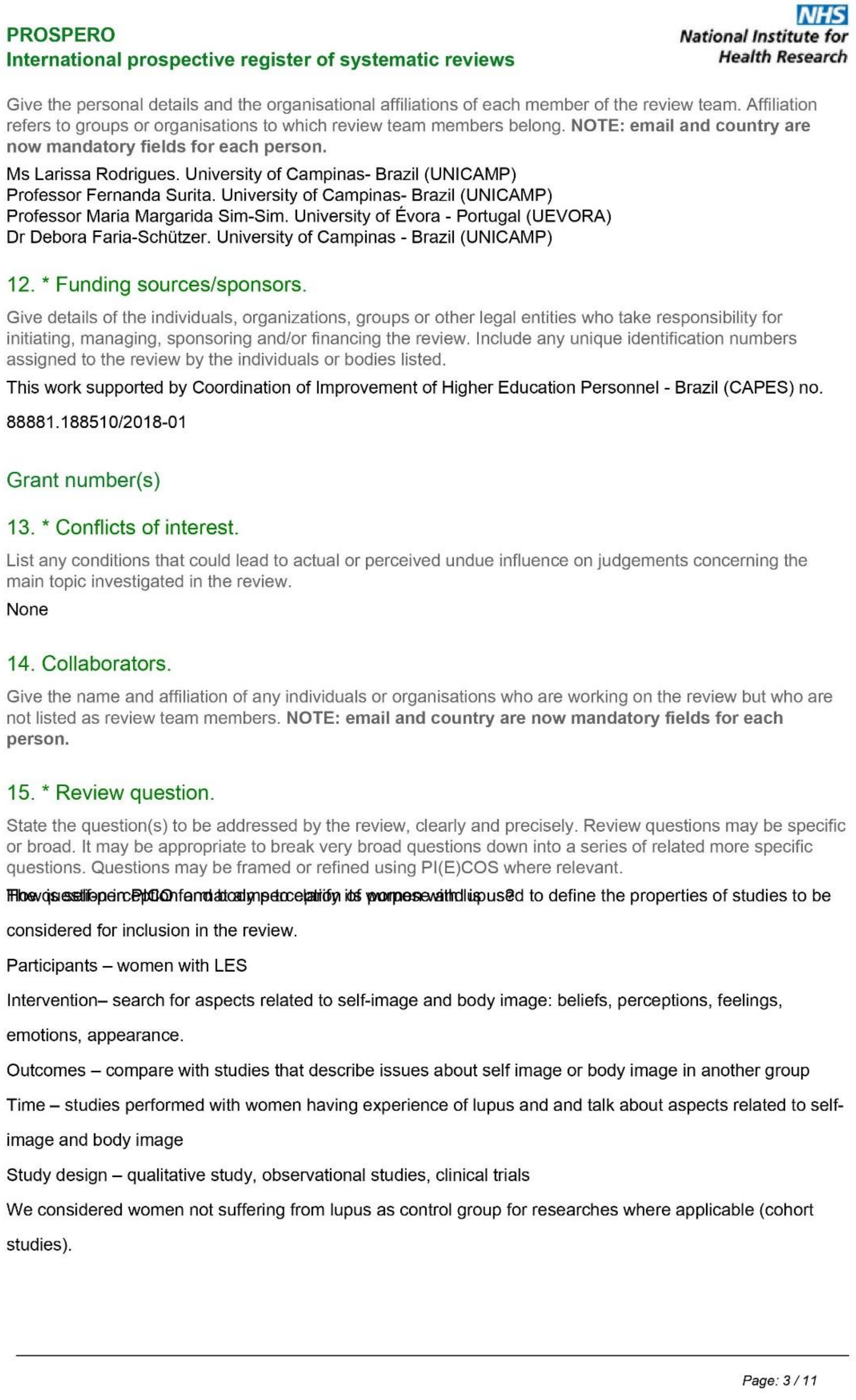
Full title of the organisational affiliations for this review and website address if available. This field may be completed as 'None' if the review is not affiliated to any organisation.

University of Campinas- Brazil (UNICAMP)

Organisation web address:

www.unicamp.br

11. * Review team members and their organisational affiliations.



Give the personal details and the organisational affiliations of each member of the review team. Affiliation refers to groups or organisations to which review team members belong. **NOTE: email and country are now mandatory fields for each person.**

Ms Larissa Rodrigues. University of Campinas- Brazil (UNICAMP)
Professor Fernanda Surita. University of Campinas- Brazil (UNICAMP)
Professor Maria Margarida Sim-Sim. University of Évora - Portugal (UEVORA)
Dr Debora Faria-Schützer. University of Campinas - Brazil (UNICAMP)

12. * Funding sources/sponsors.

Give details of the individuals, organizations, groups or other legal entities who take responsibility for initiating, managing, sponsoring and/or financing the review. Include any unique identification numbers assigned to the review by the individuals or bodies listed.

This work supported by Coordination of Improvement of Higher Education Personnel - Brazil (CAPES) no.

88881.188510/2018-01

Grant number(s)

13. * Conflicts of interest.

List any conditions that could lead to actual or perceived undue influence on judgements concerning the main topic investigated in the review.

None

14. Collaborators.

Give the name and affiliation of any individuals or organisations who are working on the review but who are not listed as review team members. **NOTE: email and country are now mandatory fields for each person.**

15. * Review question.

State the question(s) to be addressed by the review, clearly and precisely. Review questions may be specific or broad. It may be appropriate to break very broad questions down into a series of related more specific questions. Questions may be framed or refined using PI(E)COS where relevant.

How is self-perception and body perception of women with lupus?

The question PICO format to clarify its purpose and is used to define the properties of studies to be considered for inclusion in the review.

Participants – women with LES

Intervention– search for aspects related to self-image and body image: beliefs, perceptions, feelings, emotions, appearance.

Outcomes – compare with studies that describe issues about self image or body image in another group

Time – studies performed with women having experience of lupus and and talk about aspects related to self-image and body image

Study design – qualitative study, observational studies, clinical trials

We considered women not suffering from lupus as control group for researches where applicable (cohort studies).

16. * Searches.

State the sources that will be searched. Give the search dates, and any restrictions (e.g. language or publication period). Do NOT enter the full search strategy (it may be provided as a link or attachment.)

A literature search was performed in March, 2019 in the following electronic databases: US National Library of Medicine National Institutes of Health (PubMed), Cumulative Index to Nursing and Allied Health Literature (CINAHL), Excerpta Medica (Embase), Scopus, and the Web of Science, MEDLINE, MEDLINE Complete, Academic Search Premier. The lists of bibliographic references of the relevant articles identified in March, 2019 were also reviewed to identify additional studies.

Two authors made the search process. A process validation was carried out by the Medical School UNICAMP librarian. The MeSH terms used were: “Lupus Erythematosus, Systemic” AND “Self concept” OR “Body image” AND Woman.

17. URL to search strategy.

Give a link to a published pdf/word document detailing either the search strategy or an example of a search strategy for a specific database if available (including the keywords that will be used in the search strategies), or upload your search strategy.Do NOT provide links to your search results.

Alternatively, upload your search strategy to CRD in pdf format. Please note that by doing so you are consenting to the file being made publicly accessible.

Yes I give permission for this file to be made publicly available

18. * Condition or domain being studied.

Give a short description of the disease, condition or healthcare domain being studied. This could include health and wellbeing outcomes.

Systemic lupus erythematosus is an autoimmune, multisystemic disease that can bring various organic manifestations. It has a higher incidence among women 9:1 and its appearance prevails between 15 and 45 years (1) Women with lupus may have visible manifestations caused by disease or treatment, as well as: rashes, joint changes, gait and posture, weight gain, swelling and alopecia (2). The self concept and body image of the patient are affected by these manifestations, causing psychosocial impacts (3-5) and being a risk factor for other diseases such as depression (6).

Self concept is understood as referring to physical body, thought processes and a conscious experience of someone who is unique and different from others, which involves a mental representation of personal staff (7).

Body image is understood by a multidimensional construct that describes the internal representations of body structure and physical appearance in relation to oneself and others (8, 9).

The issue has not been identified in other systematic reviews, so it is relevant to develop this review, given the impact these aspects have for women in various areas of their lives. Self-image-related frustrations can lead to depressions, social isolation, work-related changes, and family roles, thereby generating social and economic impacts on the collective environment.

19. * Participants/population.

Give summary criteria for the participants or populations being studied by the review. The preferred format includes details of both inclusion and exclusion criteria.

The population of interest for the study are women with systemic lupus erythematosus diagnosed.
Will not be considered specific age group, time of diagnosis of disease and severity level of the disease.

20. * Intervention(s), exposure(s).

Give full and clear descriptions or definitions of the nature of the interventions or the exposures to be reviewed.

This review will consider studies that explore aspects related with perceptions of the women about self concept or body image and how theses aspects were related with the disease or it manifestations.

21. * Comparator(s)/control.

Where relevant, give details of the alternatives against which the main subject/topic of the review will be compared (e.g. another intervention or a non-exposed control group). The preferred format includes details of both inclusion and exclusion criteria.

We will consider articles with people without lupus who shows perceptions about self concept and body image.

22. * Types of study to be included.

Give details of the types of study (study designs) eligible for inclusion in the review. If there are no restrictions on the types of study design eligible for inclusion, or certain study types are excluded, this should be stated. The preferred format includes details of both inclusion and exclusion criteria.

Our review considers quantitative studies, qualitative designs studies and mixed method studies.
Quantitative studies are considered epidemiological designs studies such as non-randomized clinical trials, cross-sectional studies, longitudinal observations, retrospective cohorts.

Inclusion criteria: Articles that discuss aspects related with self concept or body image of this women with lupus.

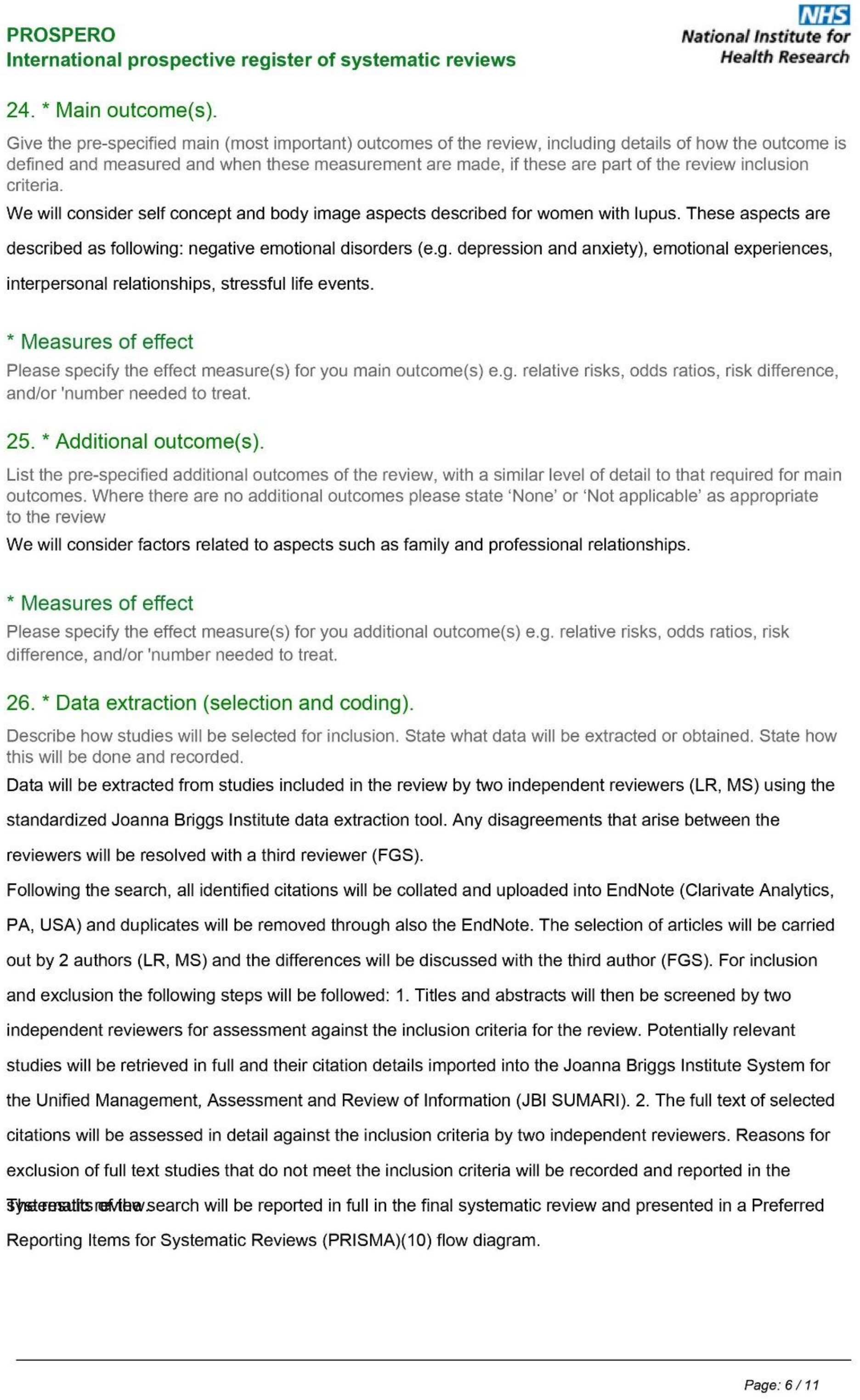
Exclusion criteria: Literature reviews or secondary studies, editorials, opinion articles, abstracts and conference proceedings and articles that do not contribute to the answer of the guiding question not discussing these aspects.

There will be a restriction of the publication period between 2008 & 2018 and will be not restriction original language for the indexed articles.

23. Context.

Give summary details of the setting and other relevant characteristics which help define the inclusion or exclusion criteria.

This review will consider articles that show primary studies about this group, so we consider female gender to inclusion criteria, but we not consider cultural/sub-cultural factors, geographic location, specific racial or based interests or details about the specific setting.



24. * Main outcome(s).

Give the pre-specified main (most important) outcomes of the review, including details of how the outcome is defined and measured and when these measurement are made, if these are part of the review inclusion criteria.

We will consider self concept and body image aspects described for women with lupus. These aspects are described as following: negative emotional disorders (e.g. depression and anxiety), emotional experiences, interpersonal relationships, stressful life events.

* Measures of effect

Please specify the effect measure(s) for you main outcome(s) e.g. relative risks, odds ratios, risk difference, and/or 'number needed to treat.

25. * Additional outcome(s).

List the pre-specified additional outcomes of the review, with a similar level of detail to that required for main outcomes. Where there are no additional outcomes please state 'None' or 'Not applicable' as appropriate to the review

We will consider factors related to aspects such as family and professional relationships.

* Measures of effect

Please specify the effect measure(s) for you additional outcome(s) e.g. relative risks, odds ratios, risk difference, and/or 'number needed to treat.

26. * Data extraction (selection and coding).

Describe how studies will be selected for inclusion. State what data will be extracted or obtained. State how this will be done and recorded.

Data will be extracted from studies included in the review by two independent reviewers (LR, MS) using the standardized Joanna Briggs Institute data extraction tool. Any disagreements that arise between the reviewers will be resolved with a third reviewer (FGS).

Following the search, all identified citations will be collated and uploaded into EndNote (Clarivate Analytics, PA, USA) and duplicates will be removed through also the EndNote. The selection of articles will be carried out by 2 authors (LR, MS) and the differences will be discussed with the third author (FGS). For inclusion and exclusion the following steps will be followed: 1. Titles and abstracts will then be screened by two independent reviewers for assessment against the inclusion criteria for the review. Potentially relevant studies will be retrieved in full and their citation details imported into the Joanna Briggs Institute System for the Unified Management, Assessment and Review of Information (JBI SUMARI). 2. The full text of selected citations will be assessed in detail against the inclusion criteria by two independent reviewers. Reasons for exclusion of full text studies that do not meet the inclusion criteria will be recorded and reported in the Systematic review.

The results of the search will be reported in full in the final systematic review and presented in a Preferred Reporting Items for Systematic Reviews (PRISMA)(10) flow diagram.

27. * Risk of bias (quality) assessment.

Describe the method of assessing risk of bias or quality assessment. State which characteristics of the studies will be assessed and any formal risk of bias tools that will be used.

Eligible studies will be critically appraised by two independent reviewers (LR, MS) for methodological quality using the standard Joanna Briggs Institute Critical Appraisal Checklist according to each type of study design.

Disagreements between the review authors over the risk of bias in some articles will resolve by discussion, with involvement of a third review author (FGS).

The results of critical appraisal will be reported in narrative form and in a table.

All studies, regardless of the results of their methodological quality, will undergo data extraction and synthesis.

28. * Strategy for data synthesis.

Provide details of the planned synthesis including a rationale for the methods selected. This **must not be generic text** but should be **specific to your review** and describe how the proposed analysis will be applied to your data.

Qualitative research findings will, where possible, be pooled using JBI SUMARI with the meta-aggregation approach. This will involve the aggregation or synthesis of findings to generate a set of statements that represent that aggregation, through assembling the findings and categorizing these findings on the basis of similarity in meaning.

These categories will then be subjected to a synthesis in order to produce a single comprehensive set of synthesized findings that can be used as a basis for evidence-based practice. Where textual pooling is not possible the findings will be presented in narrative form.

29. * Analysis of subgroups or subsets.

State any planned investigation of 'subgroups'. Be clear and specific about which type of study or participant will be included in each group or covariate investigated. State the planned analytic approach.

Quantitative studies are separated by qualitative studies for analysis more pertinent to each type.

30. * Type and method of review.

Select the type of review and the review method from the lists below. Select the health area(s) of interest for your review.

Type of review

Cost effectiveness
No

Diagnostic
No

Epidemiologic
No

Individual patient data (IPD) meta-analysis
No

Intervention
No

Meta-analysis

No

Methodology
No

Narrative synthesis
No

Network meta-analysis
No

Pre-clinical
No

Prevention
No

Prognostic
No

Prospective meta-analysis (PMA)
No

Review of reviews
No

Service delivery
No

Synthesis of qualitative studies
No

Systematic review
Yes

Other
No

Health area of the review

Alcohol/substance misuse/abuse
No

Blood and immune system
No

Cancer
No

Cardiovascular
No

Care of the elderly
No

Child health
No

Complementary therapies
No

COVID-19
No

Crime and justice
No

Dental
No

Digestive system
No

Ear, nose and throat

No

Education
No

Endocrine and metabolic disorders
No

Eye disorders
No

General interest
No

Genetics
No

Health inequalities/health equity
No

Infections and infestations
No

International development
No

Mental health and behavioural conditions
Yes

Musculoskeletal
No

Neurological
No

Nursing
No

Obstetrics and gynaecology
No

Oral health
No

Palliative care
No

Perioperative care
No

Physiotherapy
No

Pregnancy and childbirth
No

Public health (including social determinants of health)
No

Rehabilitation
No

Respiratory disorders
No

Service delivery
No

Skin disorders
No

Social care
No

Surgery
No

Tropical Medicine
No

Urological
No

Wounds, injuries and accidents
No

Violence and abuse
No

31. Language.

Select each language individually to add it to the list below, use the bin icon to remove any added in error.
English

There is not an English language summary

32. * Country.

Select the country in which the review is being carried out from the drop down list. For multi-national collaborations select all the countries involved.

Brazil

33. Other registration details.

Give the name of any organisation where the systematic review title or protocol is registered (such as with The Campbell Collaboration, or The Joanna Briggs Institute) together with any unique identification number assigned. (N.B. Registration details for Cochrane protocols will be automatically entered). If extracted data will be stored and made available through a repository such as the Systematic Review Data Repository (SRDR), details and a link should be included here. If none, leave blank.

34. Reference and/or URL for published protocol.

Give the citation and link for the published protocol, if there is one

Give the link to the published protocol.

Alternatively, upload your published protocol to CRD in pdf format. Please note that by doing so you are consenting to the file being made publicly accessible.

Yes I give permission for this file to be made publicly available

Please note that the information required in the PROSPERO registration form must be completed in full even if access to a protocol is given.

35. Dissemination plans.

Give brief details of plans for communicating essential messages from the review to the appropriate audiences.

Do you intend to publish the review on completion?

Yes

36. Keywords.

Give words or phrases that best describe the review. Separate keywords with a semicolon or new line. Keywords will help users find the review in the Register (the words do not appear in the public record but are included in searches). Be as specific and precise as possible. Avoid acronyms and abbreviations unless these are in wide use.

Systemic Lupus Erythematosus; Self Concept; Body Image; Systematic Review; Woman

37. Details of any existing review of the same topic by the same authors.

Give details of earlier versions of the systematic review if an update of an existing review is being registered, including full bibliographic reference if possible.

38. * Current review status.

Review status should be updated when the review is completed and when it is published. For newregistrations the review must be Ongoing.
Please provide anticipated publication date

Review_Ongoing

39. Any additional information.

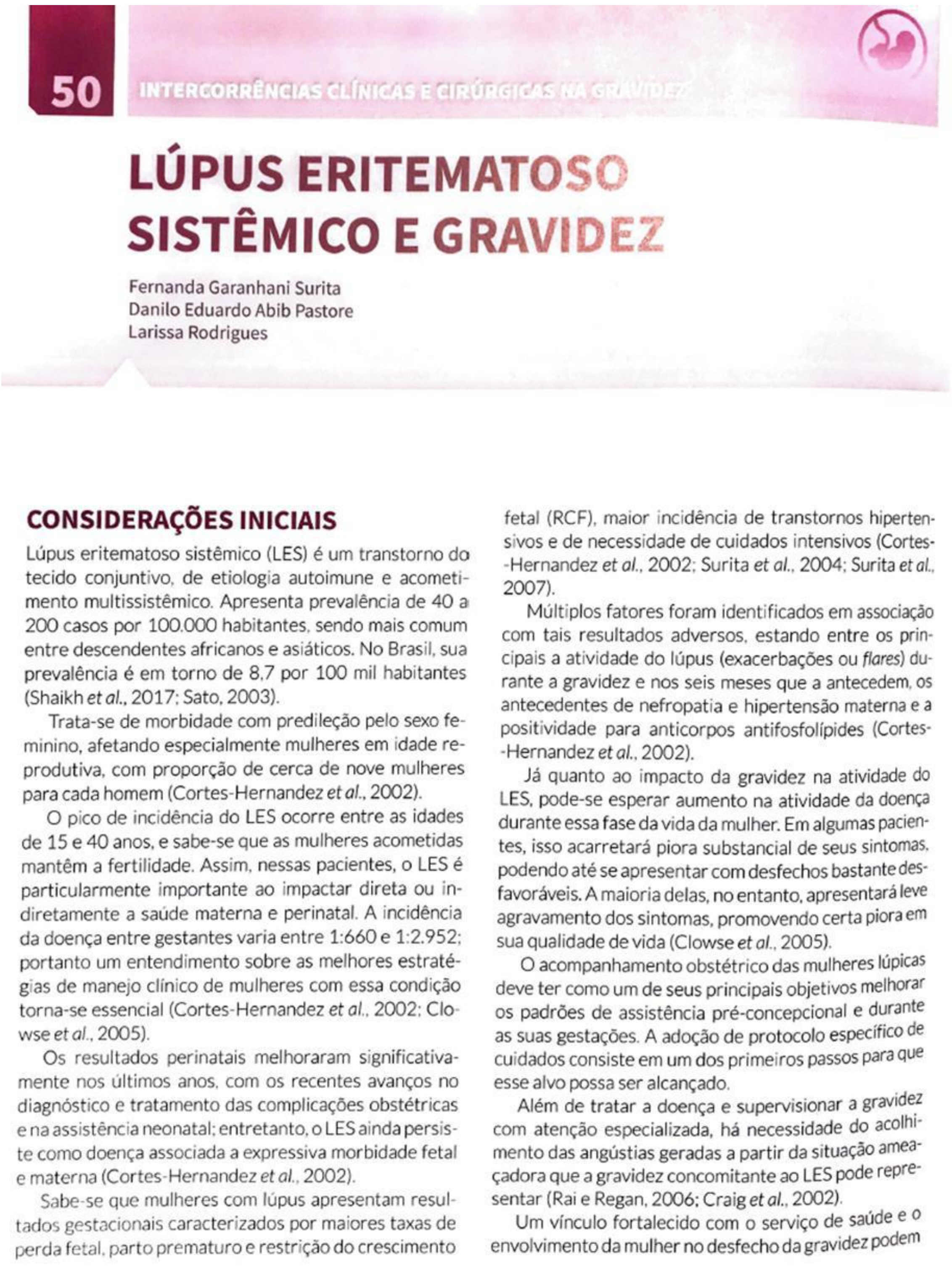
Provide any other information the review team feel is relevant to the registration of the review.

40. Details of final report/publication(s) or preprints if available.

This field should be left empty until details of the completed review are available OR you have a link to a preprint.

Give the link to the published review.

Anexo 9: Capítulo de Livro da Federação Brasileira das Associações de Ginecologia e Obstetrícia FEBRASGO – Coautoria



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INTERCORRÊNCIAS CLÍNICAS E CIRÚRGICAS NA GRAVIDEZ

LÚPUS ERITEMATOSO SISTÊMICO E GRAVIDEZ

Fernanda Garanhani Surita
Danilo Eduardo Abib Pastore
Larissa Rodrigues

CONSIDERAÇÕES INICIAIS

Lúpus eritematoso sistêmico (LES) é um transtorno do tecido conjuntivo, de etiologia autoimune e acometimento multissistêmico. Apresenta prevalência de 40 a 200 casos por 100.000 habitantes, sendo mais comum entre descendentes africanos e asiáticos. No Brasil, sua prevalência é em torno de 8,7 por 100 mil habitantes (Shaikh *et al.*, 2017; Sato, 2003).

Trata-se de morbidade com predileção pelo sexo feminino, afetando especialmente mulheres em idade reprodutiva, com proporção de cerca de nove mulheres para cada homem (Cortes-Hernandez *et al.*, 2002).

O pico de incidência do LES ocorre entre as idades de 15 e 40 anos, e sabe-se que as mulheres acometidas mantêm a fertilidade. Assim, nessas pacientes, o LES é particularmente importante ao impactar direta ou indiretamente a saúde materna e perinatal. A incidência da doença entre gestantes varia entre 1:660 e 1:2.952; portanto um entendimento sobre as melhores estratégias de manejo clínico de mulheres com essa condição torna-se essencial (Cortes-Hernandez *et al.*, 2002; Clowse *et al.*, 2005).

Os resultados perinatais melhoraram significativamente nos últimos anos, com os recentes avanços no diagnóstico e tratamento das complicações obstétricas e na assistência neonatal; entretanto, o LES ainda persiste como doença associada a expressiva morbidade fetal e materna (Cortes-Hernandez *et al.*, 2002).

Sabe-se que mulheres com lúpus apresentam resultados gestacionais caracterizados por maiores taxas de perda fetal, parto prematuro e restrição do crescimento fetal (RCF), maior incidência de transtornos hipertensivos e de necessidade de cuidados intensivos (Cortes-Hernandez *et al.*, 2002; Surita *et al.*, 2004; Surita *et al.*, 2007).

Múltiplos fatores foram identificados em associação com tais resultados adversos, estando entre os principais a atividade do lúpus (exacerbações ou *flares*) durante a gravidez e nos seis meses que a antecedem, os antecedentes de nefropatia e hipertensão materna e a positividade para anticorpos antifosfolípides (Cortes-Hernandez *et al.*, 2002).

Já quanto ao impacto da gravidez na atividade do LES, pode-se esperar aumento na atividade da doença durante essa fase da vida da mulher. Em algumas pacientes, isso acarretará piora substancial de seus sintomas, podendo até se apresentar com desfechos bastante desfavoráveis. A maioria delas, no entanto, apresentará leve agravamento dos sintomas, promovendo certa piora em sua qualidade de vida (Clowse *et al.*, 2005).

O acompanhamento obstétrico das mulheres lúpicas deve ter como um de seus principais objetivos melhorar os padrões de assistência pré-concepcional e durante as suas gestações. A adoção de protocolo específico de cuidados consiste em um dos primeiros passos para que esse alvo possa ser alcançado.

Além de tratar a doença e supervisionar a gravidez com atenção especializada, há necessidade do acolhimento das angústias geradas a partir da situação ameaçadora que a gravidez concomitante ao LES pode representar (Rai e Regan, 2006; Craig *et al.*, 2002).

Um vínculo fortalecido com o serviço de saúde e o envolvimento da mulher no desfecho da gravidez podem