

INPLASY PROTOCOL

To cite: Xie et al. Experiences of Patients Living with Systemic Lupus Erythematosus: A Qualitative Meta-synthesis. Inplasy protocol 202210033. doi: 10.37766/inplasy2022.1.0033

Received: 07 January 2022

Published: 08 January 2022

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Support: None.

Review Stage at time of this submission: Preliminary searches.

Conflicts of interest:
None declared.

INTRODUCTION

Review question / Objective: Systemic lupus erythematosus (SLE) is a chronic, immune-mediated disease that major impact patients physical, mental, and social well-being. This paper aimed to synthesize qualitative studies on experiences of patients living with SLE.

Experiences of Patients Living with Systemic Lupus Erythematosus: A Qualitative Meta-synthesis

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Review question / Objective: Systemic lupus erythematosus (SLE) is a chronic, immune-mediated disease that major impact patients physical, mental, and social well-being. This paper aimed to synthesize qualitative studies on experiences of patients living with SLE.

Condition being studied: (a) Research theme was about experience and feelings of patients diagnosed with Systemic lupus erythematosus (SLE) (b) Qualitative methodology was used in studies data needed to be collected via customary qualitative approaches e. g, interview, focus group open-ended survey questions) with sufficient data (i. e, patients' quotations) reported to support the study findings; (c) Focusing on patients who were or more than 18 years old;(d) Published in Chinese and English.

INPLASY registration number: This protocol was registered with the International Platform of Registered Systematic Review and Meta-Analysis Protocols (INPLASY) on 08 January 2022 and was last updated on 08 January 2022 (registration number INPLASY202210033).

Rationale: Systemic lupus erythematosus (SLE) is a chronic, immune-mediated disease characterized by multiple organ damage, and now its pathogenesis isn't very clear. This lifelong disorder commonly occurs in child-bearing period women, which has major impacts on physical, mental, and social well-being and imposes considerable influence on health-related

quality of life(HRQoL). Despite the progress of modern treatments, most SLE patients experience symptoms such as pain, fatigue as well as psychological symptoms such as anxiety, depression, and cognitive dysfunction. The improvement in symptoms and advancement in quality of life are noteworthy, owing to the significance of symptoms and HRQoL to patients and their families. Currently, there is no satisfactory and effective prevention or cure, the top priority is to relieve disease burden on HRQoL. Therefore, it is necessary to explore treatment experiences, feelings, and thoughts from the patient perspective. The majority of previous meta-analysis has been devoted to understanding HRQoL among SLE patients by using quantitative research, which contributed plenty of rigorous and repeatable evidence. Contrary to quantitative measures, qualitative research is more emphasis on drawing the essence of living with SLE from the patient's own experience. There are many small-scale qualitative studies revealing the experience of living with SLE from the patient's aspect but there is a need to aggregative existing evidence to provide further insights. The first thematic synthesis research on experience of SLE published in 2013, nevertheless, the data sources they indexed only until 2012. There is a lack of centralized synthesis gathering related studies on experiences of SLE patients in the past ten years. As noted above, this paper aimed to synthesize qualitative studies on experiences of patients living with SLE. To expand and to integrate current knowledge on patient's emotional experience and practical needs.

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the study findings; (c) Focusing on patients who were or more than 18 years old;(d) Published in Chinese and English.

METHODS

Search strategy: The following is the search strategy used: #1 TS=(systematic lupus erythematosus) OR TS=(lupus) OR TS=(Lupus Erythematosus, Systemic) Timespan: 2010-01-01 to 2020-12-31 (Publication Date) #2 (((((((TS=(illness experience)) OR TS=(experience*)) OR TS=(feeling*)) OR TS=(qualitative research)) OR TS=(grounded theory)) OR TS=(focus group)) OR TS=(participant observation)) OR TS=(phenomenology*)) OR TS=(action research) Timespan: 2010-01-01 to 2020-12-31 (Publication Date) #3 #1 AND #2.

Participant or population: (a) people with Systemic lupus erythematosus (SLE); (b) patients who were or more than 18 years old.

Intervention: Not applicable

Comparator: Not applicable.

Study designs to be included: Qualitative methodology was used in studies, data needed to be collected via customary qualitative approaches (e.g.interview, focus group, open-ended survey questions) with sufficient data (e, patients' quotations) reported to support the study findings.

Eligibility criteria: Inclusion Criteria: (a)research theme was about experience and feelings of patients diagnosed with SLE;(b) Qualitative methodology was used in studies data needed to be collected via customary qualitative approaches (e.g, interview, focus group, open-ended survey questions) with sufficient data (i.e., patients' quotations.) reported to support the study findings;(c) Focusing on patients who were or more than 18 years old; (d) Published in Chinese and English Exclusion

criteria:(e) articles that only discuss the factors of illness experience without involving patient` perspectiveWas exclude. (f) Review, conference paper, studies that adopt mixed methods design were also exclude.(g) Articles did not have full text were excluded owing to lack of resources.

Information sources: A systematic search of relevant articles published from January 2010 to December 2020 was conducted using the following electronic databases: The Cochrane Library, PubMed, Web of Science, Medline, CNKI, VIP, and WANFANG.

Main outcome(s): Not applicable.

Additional outcome(s): Not applicable.

Data management: We use Note Express V3.4 to screen, Excel to conduct data extraction.

Quality assessment / Risk of bias analysis: We evaluated the eligible articles according to the JBI Critical Appraisal Checklist for Qualitative Research. Two reviewers who have been instructed in evidence-based methodology, independently, assessed each study. The disagreements were resolved by discussion or invited a third person to judge. Each evaluation standard is judged as "yes", "no", "unclear", and "not applicable". The evaluation standards are divided into three levels: A, B, and C. Fully meet the criteria as A level, and partial satisfaction as Grade B, all unsatisfied as GradeC.

Strategy of data synthesis: A thematic synthesis approach was used to gather information and identify all themes It is the most appropriate approach for qualitative meta-synthesis. The inductive analysis by Sandelowski and Barroso (Sandelowski Barroso, 2007) was adapted and used 3stages: (1) extraction of findings and coding of findings for each article; (2) grouping of findings (codes) according to their topical similarity to determine whether findings confirm, extend, or refute each

other; and (3) abstraction of findings (analyzing the grouped findings to identify additional patterns, overlaps, comparisons and redundancies to form a set of concise statements that capture the content of findings).

Subgroup analysis: Not applicable.

Sensitivity analysis: Not applicable.

Language: Chinese and English.

Country(ies) involved: China.

Keywords: Meta-synthesis, qualitative research, disease experience; systemic lupus erythematosus.

Contributions of each author:

Author 1- Xie Juan conceived this study constructed the search strategy, ran the searching exported literature, developed eligibility criteria, designed the structure Excel of data extraction conducted initial screening full-text screening and drafted the manuscript.

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Author 2 - Zhao Dan Involved in drafted the manuscript.

Author 3 - Pan Lei involved in screening of search results, data extraction, quality assessment, data synthesis.

Author 4 - Xu Wenfang involved in screening of search results, data extraction, quality assessment, data synthesis.

Author 5- Wang Beibei involved in Data Analysis and interpretation.

Author 6 - Yang Yan generated the idea, conceived this study and give advice to every procedure.

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