

Quality of Life Qualitative Scoping Review: Search Strategy Protocol

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Research question

In the existing qualitative literature, how have people with lichen sclerosus, or other genital inflammatory skin conditions, described the impact of their condition on their health-related quality of life (HRQOL)?

Purpose

To develop an initial long-list of HRQOL concepts of potential relevance and importance to people living with lichen sclerosus, to be further refined with direct input from patients.

Data sources

Electronic database searches

The following electronic database searches will be searched via Ovid®:

- “Embase (1980 to Present)”, via Ovid®
- “Ovid MEDLINE® ALL (1946 to present)”, via Ovid®
- “APA PsycInfo (1806 to present)”, via Ovid®
- “CINAHL Ultimate”, via EBSCOhost

Reference lists

Reference lists of included studies and relevant review papers identified within the electronic database searches will be reviewed for eligible publications.

Eligibility criteria

Eligibility criteria presented in Table 1 will be applied to all sources identified. Criteria have been developed using the SPIDER framework (Sample, Phenomenon of Interest, Design, Evaluation, Research type) (1), which has been demonstrated as more specific than the standard 'PICO' framework for qualitative scoping reviews (2).

Table 1. Eligibility criteria

Study characteristic	Eligible	Ineligible
Sample	■ Patients of any age or gender (or their caregivers) with a diagnosis of: ○ lichen sclerosus ○ lichen planus ○ hidradentis suppurativa ○ genital Crohn disease ○ genital eczema ○ genital psoriasis ○ neuropathic pain conditions: ▪ vulvodynia ▪ penodynia ▪ scrotodynia ▪ pudendal neuralgia ■ Studies enrolling participants with an unclear diagnosis, but which is theorised to be one of the listed conditions, will be eligible.	■ Patients diagnosed with a condition other than those listed ■ Studies enrolling clinicians only
Phenomenon of Interest	Health-related quality of life	-
Design	Studies eliciting or collating descriptions from patients (or the caregivers of paediatric patients), including (but not limited to): ■ Interviews ■ Focus groups ■ Social media listening	■ Studies reporting clinical outcome assessment (COA) measure data only ■ Survey/questionnaire studies will be tagged, and may be included if a lack of studies reporting fully qualitative data are identified. ■ Case studies ■ Reviews will not themselves be eligible for inclusion, but will be recorded and reviewed for relevant citations via hand-searching methods.
Evaluation	Direct quotations from patients (or the caregivers of paediatric patients), or researcher summaries/interpretations of collected data	Studies reporting clinician perspectives only.
Research type	Qualitative or mixed-method studies	Quantitative studies with no qualitative component
Time frame	No restrictions beyond those imposed by the source database	No restrictions beyond those imposed by the source database
Language	No restrictions	No restrictions

Search strategies

Search strategies will identify relevant publications (full papers or conference abstracts) indexed on MEDLINE, Embase, PsycINFO, and CINAHL Ultimate, or included in the hand-searching sources. Separate search strings will be used to account for differences in syntax within each database.

Electronic database searches

Searches will be conducted via the Ovid® and EBSCO platforms as appropriate and include terms for free text and medical subject heading (MeSH) terms, where these are applicable. The proposed search strings, including an example search run, are documented in Table 2–

Table 5 and combine terms for the conditions of interest with terms for relevant qualitative research methods or theories.

Table 2. Search strategy for Ovid MEDLINE® ALL, 1946 to December 18, 2023 (via Ovid)

#	Term	Results
1	Lichen Sclerosus et Atrophicus/ or (lichen scleros?s or leucoplakia or lichen albus or white spot disease or kraurosis vulva* or balantis xerotica obliterans or lichen plan sclereux or kartenblattformige sklerodermie or weissflecken dermatose or dermatitis lichenoides chronica atrophicans).mp.	3,693
2	exp Lichen Planus/ or lichen plan*.mp. or lichen rub* plan*.mp.	12,079
3	Hidradenitis Suppurativa/ or (hidradeniti* adj suppurative*).mp. or (acne adj inversa*).mp.	3,463
4	Vulvodynia/ or vulvodynia.mp. or vestibulodynia.mp. or penodynia.mp. or scrotodynia.mp. or ((vulv* or peni* or peno* or scrot*) adj pain*).mp.	2,664
5	Pudendal Neuralgia/ or (pudendal adj (nerve* or neuralgia* or neuropath*)).mp. or pudendal nerve entrapment*.mp. or pudendal canal entrapment*.mp.	2,296
6	Crohn Disease/ or Crohn*.mp. or ((granulomatous or regional) adj enteritis).mp.	67,608
7	exp Eczema/ or eczema*.mp.	27,495
8	exp Psoriasis/ or psorias*.mp.	64,755
9	or/6-8	155,891
10	exp Genitalia/ or genital*.mp. or vulva*.mp. or labia*.mp. or vagina*.mp. or peni*.mp. or scrot*.mp.	972,169
11	9 and 10	2,395
12	1 or 2 or 3 or 4 or 5 or 11	25,867
13	exp Qualitative Research/ or qualitative*.mp. or ((Content or thematic or narrative) adj analys?s).mp. or grounded theory/ or grounded theor*.mp. or phenomenolog*.mp. or ethnograph*.mp. or Hermeneutics/ or hermeneutic*.mp.	483,436
14	Interviews as Topic/ or interview*.mp.	503,649
15	Focus Groups/ or focus group*.mp.	72,404
16	Social Media/ or social media.mp. or social listening.mp. or messag* board*.mp. or forum*.mp.	55,454
17	(Concept* adj (model* or framework*)).mp.	29,994
18	or/13-17	911,228
19	12 and 18	430

Table 3. Search strategy for Embase, 1974 to December 18, 2023 (via Ovid)

#	Term	Results
1	lichen sclerosus et atrophicus/ or (lichen scleros?s or leucoplakia or lichen albus or white spot disease or kraurosis vulva* or balanitis xerotica obliterans or lichen plan sclereux or kartenblattformige sklerodermie or weissflecken dermatose or dermatitis lichenoides chronica atrophicans).mp.	6,358
2	exp lichen planus/ or lichen plan*.mp. or lichen rub* plan*.mp.	16,460
3	suppurative hidradentis/ or (hidradeniti* adj suppurative*).mp. or (acne adj inversa*).mp.	895
4	vulvodynia/ or vulvodynia.mp. or vestibulodynia.mp. or penodynia.mp. or scrotodynia.mp. or ((vulv* or peni* or peno* or scrot*) adj pain*).mp.	7,541
5	pudendal neuralgia/ or (pudendal adj (nerve* or neuralgia* or neuropath*)).mp. or pudendal nerve entrapment*.mp. or pudendal canal entrapment*.mp.	4,228
6	exp Crohn disease/ or Crohn*.mp. or ((granulomatous or regional) adj enteritis).mp.	128,901
7	exp eczema/ or eczema*.mp.	52,604
8	exp psoriasis/ or psorias*.mp.	123,112
9	or/6-8	291,635
10	exp genital system/ or genital*.mp. or vulva*.mp. or labia*.mp. or vagina*.mp. or peni*.mp. or scrot*.mp.	1,313,301
11	9 and 10	7,959
12	1 or 2 or 3 or 4 or 5 or 11	41,395
13	exp qualitative research/ or qualitative*.mp. or content analysis/ or thematic analysis/ or grounded theory/ or phenomenology/ or ((Content or thematic or narrative) adj analys?s).mp. or grounded theor*.mp. or phenomenolog*.mp. or ethnography/ or ethnograph*.mp. or hermeneutics/ or hermeneutic*.mp.	611,455
14	exp interview/ or interview*.mp.	680,865
15	focus group*.mp.	82,389
16	exp social media analysis/ or social media.mp. or social listening.mp. or messag* board*.mp. or forum*.mp.	86,811
17	exp conceptual model/ or conceptual framework/ or (concept* adj (model* or framework*)).mp.	64,904
18	or/13-17	1,236,652
19	12 and 18	852

Table 4. Search strategy for APA PsycInfo, 1806 to December Week 1 2023 (via Ovid)

#	Term	Results
1	(lichen scleros?s or leucoplakia or lichen albus or white spot disease or kraurosis vulva* or balanitis xerotica obliterans or lichen plan sclereux or kartenblattformige sklerodermie or weissflecken dermatose or dermatitis lichenoides chronica atrophicans).mp.	28
2	(lichen plan* or lichen rub* plan*).mp.	40
3	((hidradeniti* adj suppurative*) or (acne adj inversa*)).mp.	3
4	(vulvodynia or vulvodinia or vestibulodynia or penodynia or scrotodynia or ((vulv* or peni* or peno* or scrot*) adj pain*)).mp.	415
5	((pudendal adj (nerve* or neuralgia* or neuropath*)) or pudendal nerve entrapment* or pudendal canal entrapment*).mp.	107
6	(Crohn* or ((granulomatous or regional) adj enteritis)).mp.	852
7	exp Eczema/ or eczema*.mp.	526
8	psorias*.mp.	761
9	or/6-8	2,049
10	exp Genital Disorders/ or genital*.mp. or vulva*.mp. or labia*.mp. or vagina.mp. or peni*.mp. or scrot*.mp.	25,472
11	9 and 10	31
12	1 or 2 or 3 or 4 or 5 or 11	607
13	exp Qualitative Methods/ or qualitative*.mp. or exp Content Analysis/ or Thematic Analysis/ or Grounded Theory/ or Phenomenology/ or ((Content or thematic or narrative) adj analys?s).mp. or grounded theor*.mp. or phenomenolog*.mp. or Ethnography/ or ethnograph*.mp. or Hermeneutics/ or hermeneutic*.mp.	362,754
14	exp Interviews/ or interview*.mp.	496,245
15	exp Focus Group/ or focus group*.mp.	48,962
16	exp Social Media/ or social media.mp. or social listening.mp. or messag* board*.mp. or forum*.mp.	42,972
17	(concept* adj (model* or framework*)).mp.	37,271
18	or/13-17	765,048
19	12 and 18	96

Table 5. Search strategy for CINAHL Ultimate (via EBSCOhost), run 19 December 2023

#	Term	Results
S1	(MH "Lichen Sclerosus et Atrophicus") OR lichen scleros?s OR leucoplakia OR lichen albus OR white spot disease OR kraurosis vulva* OR balanitis xerotica obliterans OR lichen plan sclereux OR kartenblattformige sklerodermie OR weissflecken dermatose OR dermatitis lichenoides chronica atrophicans	745
S2	lichen plan* OR lichen rub* plan*	2,324
S3	(hidradeniti* N1 suppurative*) OR (acne N1 inversa*)	59
S4	vulvodynia OR vulvodynia OR vestibulodynia OR penodynia OR scrotodynia OR ((vulv* OR peni* OR peno* OR scrot*) N1 pain*)	1,128
S5	(pudendal N1 (nerve* OR neuralgia* OR neuropath*)) OR pudendal nerve entrapment* OR pudendal canal entrapment*	349
S6	(MH "Crohn's Disease") OR (Crohn*) OR ((granulomatous OR regional) adj enteritis)	11,952
S7	(MH "Eczema") OR eczema*	6,583
S8	(MH "Psoriasis+") OR psorias*	13,868
S9	S6 OR S7 OR S8	31,548
S10	(MH "Genital Diseases, Male") OR (MH "Genital Diseases, Female") OR (MH "Genitalia+") OR genital* OR vulva* OR labia* OR vagina* OR peni* OR scrot*	105,111
S11	S9 AND S10	452
S12	S1 OR S2 OR S3 OR S4 OR S5 OR S11	4,888
S13	(MH "Qualitative Studies+") OR qualitative* OR (MH "Content Analysis") OR (MH "Thematic Analysis") OR (MH "Grounded Theory") OR (MH "Phenomenological Research") OR ((Content OR thematic OR narrative) N1 analys?s) OR grounded theor* OR phenomenolog* OR (MH "Ethnographic Research") OR ethnograph* OR hermeneutic*	327,116
S14	(MH "Interviews+") OR interview*	392,646
S15	(MH "Focus Groups") OR focus group*	66,487
S16	(MH "Social Media+") OR social media OR social listening OR messag* board* OR forum*	57,976
S17	(concept* N1 (model* OR framework*))	66,380
S18	S13 OR S14 OR S15 OR S16 OR S17	647,580
S19	S12 AND S18	148

Study selection

As this is a scoping rather than systematic review, a single researcher will screen all citations identified by the electronic database search first by title and abstract (first pass), and secondly by full text (second pass). The reasons for exclusion will be documented for each record using a prospectively designed code system, based on the SPIDER eligibility criteria. The reasons for exclusion at first and second pass will be summarised in a Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) flow-chart.

Publications identified via hand-searching will be reviewed first by title, then by abstract, and then by full text. Eligible publications will be retained for extraction and summarised on the PRISMA flow-chart.

Data extraction and synthesis

Study information data

Study information data will be extracted into a standardised data extraction form in Microsoft Excel®. The following key information (where available) will be retrieved:

- Full study citation
- Population/sample
 - Diagnosis
 - Sample size
 - Sex
 - Gender
 - Age
 - Age at diagnosis/ time since onset
- Study design
 - Study objective
 - Study setting
 - Qualitative methodology

Qualitative data

Patient/caregiver quotes, or author summaries/interpretations of collected data, will be coded using Nvivo, computer-assisted qualitative data analysis software, which facilitates the organisation of data. Descriptions of the impact of the conditions of interest on patients' quality of life will undergo secondary analysis using content analysis techniques (3), in order to categorise patient descriptions into key HRQoL concepts. No pre-defined code list will be used, instead the researcher will immerse themselves in the data and determine concept names that are reflective of the reported experience. Related concepts may be grouped into domains, and related domains may be linked.

References

1. Emory & Henry College. Database Searching - Health Using a Question Framework. Available online at <https://libraryguides.ehc.edu/db-searching-health/frame> (Last accessed 08-Nov-23). 2023.
2. Methley AM, Campbell S, Chew-Graham C, McNally R, Cheraghi-Sohi S. PICO, PICOS and SPIDER: a comparison study of specificity and sensitivity in three search tools for qualitative systematic reviews. BMC Health Serv Res. 2014;14:579.
3. Hsieh H-F, Shannon SE. Three approaches to qualitative content analysis. Qualitative health research. 2005;15(9):1277-88.