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Living with vulval lichen sclerosis: a systematic review

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Word count: 751

Lichen sclerosis (LS) is an under-researched disorder, particularly from the perspective of individuals who have the condition. A recent James Lind Alliance Priority Setting Partnership identified uncertainties in many aspects of the condition, including its impact on quality of life which was ranked within the 'Top 10' future research priorities.^{1,2} We set out to systematically review the qualitative literature exploring the lived experience of vulval LS (for the full protocol see *PROSPERO ID:CRD42018106947*).³ In PICO terms, the population was adults with vulval LS, there was no intervention nor comparator, and the outcomes were as follows. Firstly, we wanted to explore how LS affects various dimensions of everyday life and self-identity. Secondly, we wanted to explore the lived experience of the diagnosis and treatment. A better understanding of these issues will help healthcare providers to improve care, and enable researchers to identify key patient-focused research questions.

The following databases were searched in May 2018: CINAHL; Embase; Medline; Web of Science; ASSIA; Sociological Abstracts; Index of Theses and Abstracts, using the search terms: 'lichen sclerosis'; 'lichen sclerosis et atrophicus'; 'vulva*'; 'qualitative'; and various qualitative methods

terms. No restrictions were placed on dates. Non-English papers were excluded. Eight journals were hand-searched in October 2018 (list available on Prospero page³). We examined the reference lists of the studies identified for data extraction. Screening was conducted independently by all authors (SR, RS, LK), and data extraction and quality assessment independently by two (SR and LK) using an excel spreadsheet. Mays and Pope's quality assessment criteria for qualitative research was used.⁴

We had intended to conduct a meta-ethnography, but the search results meant that this was not feasible and highlighted the paucity of research in this area. Only three publications met the criteria for data extraction (Figure 1). Of these, two reported findings from the same Dutch study of nineteen women with LS who had undergone vulval surgery,^{5,6} and one was a US-based content analysis of 527 online blog/forum entries.⁷ The quality was mixed. Although the designs were appropriate to the research questions, it was not always easy to follow the iteration between data and the authors' interpretation, and themes were often descriptive rather than conceptual. In terms of relevance, two of the three articles focused on the motivators and experiences of women who opted for vulval surgery. This is a particular subgroup of women with LS, and the experiences of women who have *not* opted for surgery would have been a useful comparator when considering these findings.

This limited evidence does however provide some insight into the experience of vulval LS. Traditional ideas about gender and sexuality shape the experiences and surgery decisions of women with LS, as they feel unable to be a 'normal' woman due to their inability to engage in sexual intercourse.⁵ Vulval surgery may be more successful in lessening the everyday symptoms of LS (e.g. pruritus and fissuring) than in its stated aim of enabling the resumption of sexual intercourse, yet women are counselled that the aim is sex-related.⁶ The authors identified a perception of 'social injustice' at the limited treatment options and lack of knowledge of the condition on the part of health care professionals which resulted in misdiagnosis and delayed access to appropriate treatment.⁷ Women

sought and provided each other with support and space for sharing experiences online, highlighting how online spaces may be useful for women with LS who might otherwise feel isolated.⁷

Questions remain about the extent to which our understanding of other skin conditions is transferable to vulval LS. It is unclear how relevant the findings are beyond their respective socio-cultural and healthcare contexts. More research is needed to examine the unmet needs and care pathways of women with LS. Qualitative and mixed methods designs should be utilised to understand this from the women's perspective. Two of the three reports specifically focused on sexual experiences^{5,6} and, while useful, this is only one dimension of the LS experience as the other study illustrates.⁷ Only one report has examined more generally the experience of women with vulval LS. Although one of the studies raises 'social justice' issues and states that the voices of women are 'silent no more',⁷ LS remains an unknown and stigmatised disease, poorly understood and managed. It is disappointing that so few researchers have explored women's experiences of living with and seeking care for a genital skin disorder of this nature. There is a pressing need for such work to improve access to care and to ensure such care addresses the concerns of the women affected.

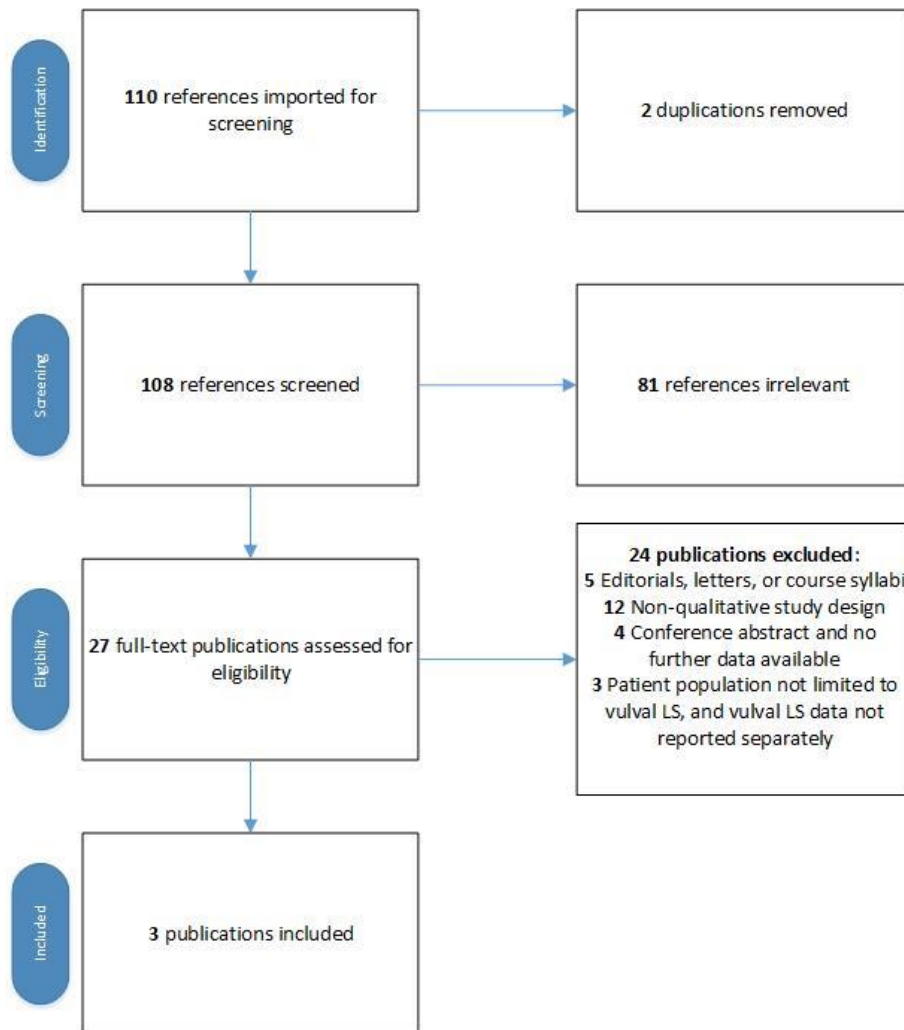


Figure 1 - PRISMA diagram of included studies

The authors have no conflicts of interest to declare.

- 1 Simpson RC, Cooper SM, Kirtschig G, *et al.* Future research priorities for lichen sclerosus – results of a James Lind Alliance Priority Setting Partnership. *Br J Dermatol* 2018 [epub ahead of print] doi:10.1111/bjd.17447
- 2 Lichen Sclerosus Priority Setting Partnership Group. *Final Report: Identifying the most important questions for research*. Nottingham: University of Nottingham, 2018. Available at: <https://www.nottingham.ac.uk/research/groups/cebd/documents/researchdocs/lichen-sclerosus-ssp-report.pdf> (last accessed 4th February 2019)
- 3 Rees S, Simpson R, Kirby L. A systematic review of qualitative research on the lived experience of vulval lichen sclerosus. PROSPERO. 2018. Available at: https://www.crd.york.ac.uk/prospero/display_record.php?RecordID=106947 (last accessed 4th February 2019)

- 4 Mays N, Pope C. Qualitative research in health care: Assessing quality in qualitative research *BMJ* 2000; **320**:50-2.
- 5 Brauer M, van Lunsen R, Burger M, Laan E. Motives for vulvar surgery of women with lichen sclerosis. *J Sex Med* 2015; **12**:2462-73.
- 6 Brauer M, van Lunsen RH, Laan ET., Burger MP A Qualitative Study on Experiences After Vulvar Surgery in Women With Lichen Sclerosis and Sexual Pain. *J Sex Med* 2016; **13**:1080-90
- 7 Wehbe-Alamah H, Kornblau BL, Haderer J., Erickson J. Silent no more! The lived experiences of women with lichen sclerosis. *J Am Acad Nurse Pract* 2012; **24**:499-505.

Appendix 1

Medline search strategy:

Number	Terms	Results
1	Lichen sclerosis et atrophicus.mp. or exp Lichen Sclerosis et Atrophicus	1310
2	lichen sclerosis.mp.	2102
3	1 or 2	2102
4	Exp VULVA/ or vulva*.mp	20317
5	3 and 4	1087
6	qualitative.mp. or exp. QUALITATIVE RESEARCH/	165409
7	5 and 6	3
8	INTERVIEW, PSYCHOLOGICAL/ or INTERVIEW/ or interview.mp.	129001
9	5 and 8	4
10	focus group.mp. or Focus Groups/	29957
11	5 and 10	0
12	questionnaire.mp. or "Surveys and Questionnaires"/	531638
13	5 and 12	21