

Time to Diagnosis of Vulval Lichen Sclerosus: A Systematic Review of Literature

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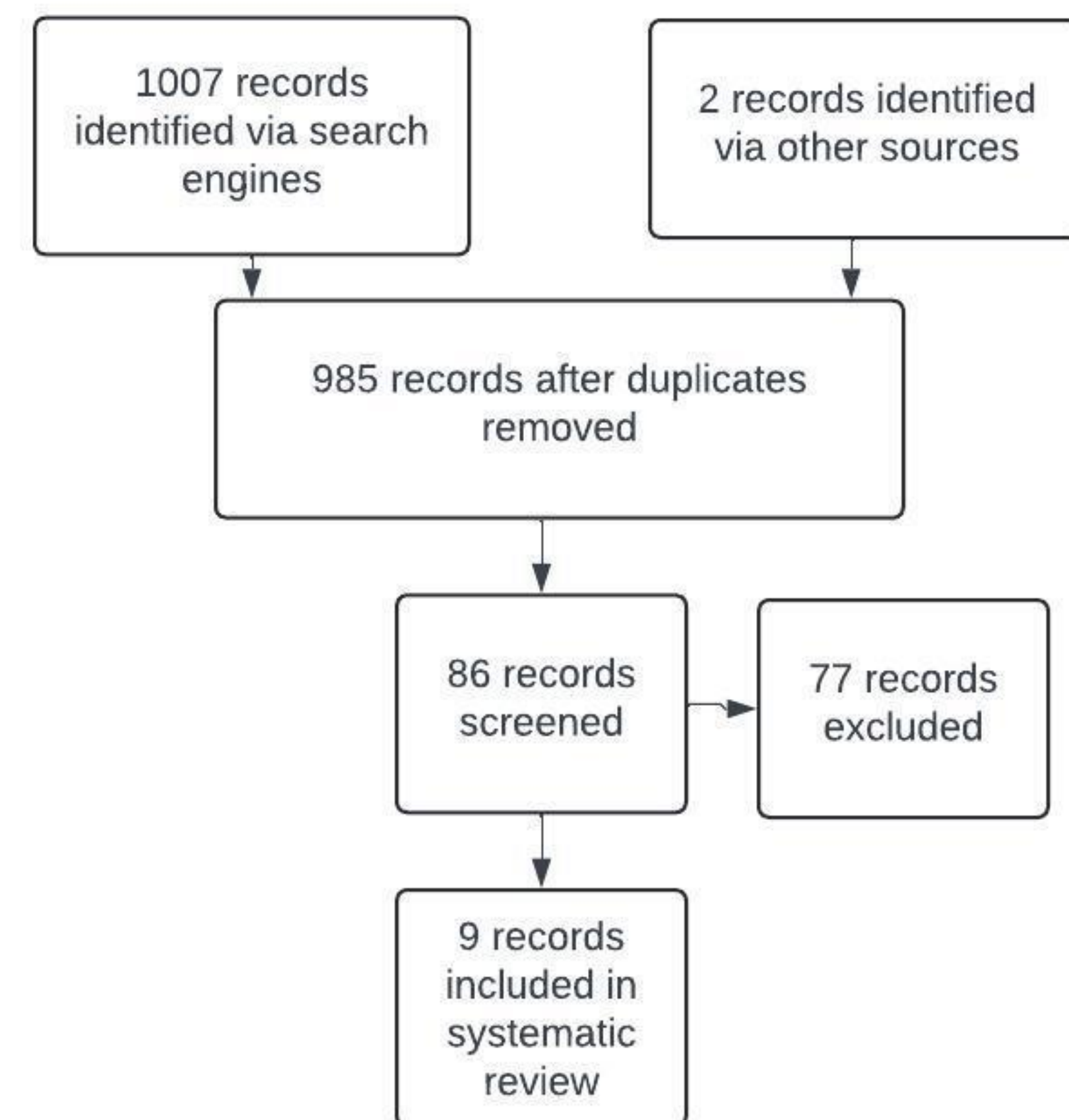
Aims and Objectives

- To examine the duration of time from symptom onset to diagnosis in patients with vulvar lichen sclerosus (LS) described in existing literature
- To explore the patients' perception of delay in diagnosis

Year	Title	Authors	Journal	Findings
2012	Silent no more! The lived experiences of women with lichen sclerosis	Wehbe-Alamah et al	J Am Acad Nurse Pract	Newly diagnosed patient faced symptoms for long time (15 years; 9 months; 7 years; 3 years)
2021	Conversations between women with vulval lichen sclerosis: a thematic analysis of online forums	Bentham et al	BMC Women's Health	Patients experienced problems with obtaining diagnosis (up to 3 years)
2021	Quality of life of women with untreated vulval lichen sclerosis assessed with vulval quality of life index (VQLI)	Wijaya et al	Australian Journal of Dermatology	"Poor QoL on patients with previously untreated VLS using the Vulval Quality of Life Index (VQLI)"
2022	Lichen Sclerosus: Why Do Most Women Struggle With Their Diagnosis?	Steban	Journal of Obstetrics and Gynaecology Canada	"Definitive diagnosis comes only after many unsuccessful consults with a family physician, a walk-in clinic, telehealth, or a gynaecologist, years after troublesome signs and symptoms first present"
2022	Living with vulval lichen sclerosis: a qualitative interview study	Arnold et al	Br J Dermatol	Difficulties in getting a timely diagnosis , experiences of misdiagnosis
2022	"Worse Than Disappointing": Prediagnostic Health Care Challenges of Women With Inflammatory Vulvar Dermatoses	Rivera et al	Journal of Lower Genital Tract Disease	Reduced healthcare efficiency in few paying system and referral network
2022	Vulvar dermatoses: a cross-sectional 5-year study. Experience in a specialized vulvar unit	García-Souto et al	Anais Brasileiros de Dermatologia	Symptom evolution was <1 year in 13 (21%) patients, between 2–5 years in 34 (54.8%), and >5 years in 15 (24.2%).
2022	Demographics of New Zealand women with vulval lichen sclerosis: is specialist care equitable?	Cheng et al	N Z Med J	Women seen at sexual health were younger and more likely to be self-referred than those seen by gynaecology/dermatology
2022	Presenting Symptoms and Diagnosis of Vulvar Lichen Sclerosus in Premenopausal Women: A Cross-Sectional Study	Krapf et al	Journal of Lower Genital Tract Disease	4-year delay in diagnosis described

Methodology

- The search terms (lichen sclerosus), (time) and (lichen sclerosus), (delay) and (lichen sclerosus) were used within the search engines PubMed and Scopus, which generated 1007 records from 1980-2024
- 1 Cochrane review and 1 reference of references were also included
- 24 duplicates were removed and a total of 86 records were screened
- 77 records were excluded as they described management strategies of LS and conditions other than vulvar LS



Results

- 9 publications included information related to delay in diagnosis for LS
- In 2 qualitative studies, patients described having experienced symptoms from ‘7 months’ to ‘15 years’ prior to their diagnosis¹
- Using ‘the Vulval Quality of Life Index’ score, an Australian study reported poor quality of life among untreated women²
- In a study that included 335 women with LS, those whose diagnoses were made in gynaecology/ dermatology clinics after referral from primary care were significantly older, compared to those who were diagnosed at sexual health clinics, where a significant proportion of patients self-referred

Conclusion

- Current literature describes ‘difficulties in obtaining diagnosis’ reported by LS patients
- Paucity of information relating to the duration from symptom onset to diagnosis of LS