Barriers to diagnosing and treating vulval lichen sclerosus: a survey study

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How this fits in:

Previous research has identified a significant diagnostic delay and misdiagnosis of vulval lichen sclerosus (VLS), a condition most commonly presenting to primary care. Health care professionals (HCPs) in primary care share the concerns of women with VLS citing frequent misdiagnosis, embarrassment and lack of knowledge as barriers to diagnosis. In this survey, 92.6% of HCPs felt further education would be useful with 37.7% never having participated in learning on vulval skin disease, self-directed or otherwise. Key enablers identified to facilitate timely VLS diagnosis and treatment include: a comprehensive education programme for HCPs, implementation of standardised pathways of care and development of a VLS diagnostic criteria to be implemented in primary care workflow.

Abstract

Background

Vulval lichen sclerosus (VLS) is a chronic inflammatory condition that is frequently misdiagnosed and under-recognised. To date, qualitative research focuses on lived experience of VLS, with women attributing diagnostic delay to poor interactions with health care professionals (HCPs) often due to lack of knowledge. In the UK, women with VLS are most likely to present to primary care.

Aim

To establish HCPs perspectives on identification, management and education of vulval skin disease, with a focus on VLS.

Design and Setting

A survey was distributed to HCPs working in primary care.

Method

The survey was distributed via professional networks and at events. Analysis comprised of descriptive statistics, Spearman's rank correlations, and thematic analysis.

Results

Of 122 respondents, 53 were General Practitioners (GPs) and 59 were GP trainees. 37.7% of respondents had never participated in teaching nor learning on vulval skin disease. Confidence in the identification of vulval skin disease positively correlated with experience, exposure and female gender. The top identified barriers to diagnosis and treatment included lack of knowledge, embarrassment, and absence of VLS diagnostic criteria. Almost all participants (97.5%) felt VLS diagnostic criteria would be helpful in clinical practice.

Conclusion

This study provides insight into the barriers to diagnosing and treating VLS in primary care. HCPs recognise deficiencies in training, referral pathways and lack of tools to support VLS diagnosis. Training should include skills to address stigma and embarrassment. This study highlights the importance of developing interventions to overcome barriers, expediting diagnosis and treatment, such as reproducible diagnostic criteria.

Keywords: Dermatology, Primary health care, General practice, Lichen Sclerosus, Vulval Lichen Sclerosus, Qualitative Research

Introduction

Vulval lichen sclerosus (VLS) is a chronic inflammatory skin condition $^{1,\,2}$ affecting up to 1 in 300 patients referred to dermatology. VLS has a bi-modal distribution, presenting more frequently in pre-pubertal girls (approximately 1 in 900) and post-menopausal women (up to 3 in 100). However, the exact prevalence and incidence are unknown, with poor recognition and misdiagnosis leading to an underestimation of cases. $^{1,\,7,\,8}$

Women with VLS typically present experiencing soreness, pruritus, burning and dryness. ^{1, 4, 9} On examination there is often whitening of vulval skin, ecchymoses and fissuring, most commonly in a figure of 8 pattern in the anogenital area. ¹ This can progress to irreversible changes to the vulval architecture such as clitoral phimosis, fusion of the labia and obstruction of the urethra. ^{4, 10, 11} VLS impacts daily activities such as toileting and psychosexual functioning, ^{12, 13} furthermore carrying at least a 20 fold relative risk of vulval cancer when compared to women without VLS. ¹⁴

Women with VLS most often present to primary care, ^{1, 9} where early diagnosis, appropriate treatment and patient education can improve symptoms, restore quality of life, minimise scarring and reduce cancer risk. ^{15, 16} However, identification and delineation of vulval skin disease, including VLS, can be

challenging. Misdiagnosis of VLS as thrush or menopausal changes, amongst other conditions, is common, leading to a delay in correct diagnosis, effective treatment and symptom relief. ^{6, 8, 15, 17} There is no decision aid or criteria to aid diagnosis of VLS in primary care. ¹⁸

In a recent qualitative study, there was an overarching theme of missed opportunities, with patients reporting barriers to diagnosis such as dismissal of concerns, lack of HCP knowledge and receiving an incorrect diagnosis. ¹⁷ In addition, qualitative studies found that women experience embarrassment and shame due to the nature of VLS and its symptoms, leading to delayed presentation. ^{8, 17} This study aims to explore possible reasons for these missed opportunities for diagnosis and treatment by investigating the perspectives and experiences of HCPs working in primary care.

Method

A mixed-methods survey study consisting of Likert scales, ranking and free text questions was distributed to professional networks via e-mail and WhatsApp. Sampling was opportunistic using primarily local networks such as Health Education England GP training network, Next Generation GP East Midlands, East Midlands Clinical Research Network and GP trainees East Midlands. In addition, paper copies for completion were distributed at regional GP trainee teaching. There was no financial or material incentive for taking part in the survey. Ethical approval was received by the University of Nottingham's School of Medicine Ethics Committee (FMHS 330-0723).

Surveys were completed online (via JISC¹⁹) or by paper from November 1st, 2023, to December 14th, 2023, and responses were anonymously exported into Excel. Paper copies of the survey were stored in a locked filing cabinet, in a secure building, until data was inputted into Excel. These have been disposed of confidentially. The survey data and analysis are stored on the University of Nottingham's Microsoft OneDrive, accessible only by user identifiers and password protected.

Likert scales between 1 (low) – 5 (high) were used to assess:

- frequency and confidence in examining the vulva
- confidence identifying, diagnosing and treating vulval skin disease/VLS
- frequency of teaching/learning, if received
- how useful further education and a diagnostic tool would be.

Participants were also asked which diagnostic tool format would be most useful, to rank their top three barriers to VLS diagnosis and treatment, of twelve predefined options, and to explain their choices (appendix 1). In addition to the free text question to discuss barriers, there was a free text box to specify any other barriers and another for comments on any topics covered by the survey.

Data analysis

Quantitative data

Demographic and survey data were analysed using descriptive statistics. Spearman's rank tests (s), calculated using SPSS v.28, explored potential relationships between participants' confidence levels and other variables, with a Bonferroni correction adjustment alpha (adjusted p value) of <0.003. s of -1 or 1 are considered as a strong relationship, whereas correlations closer to 0 are weaker. To analyse the ranking of barriers, a weighted score was calculated.

Cases with missing data were excluded from analysis for each variable investigated.

Qualitative data

Survey responses were coded in NVivo 14.23, and descriptive themes were developed inductively²⁰ using a semantic approach to thematic analysis, with codes strictly driven by the data. Analysis phases included familiarising with the data, generating codes, and reviewing and defining descriptive themes. Two researchers (AC, LC) independently coded the data, with a third researcher (RL) comparing the codes and highlighting inconsistencies. Both coders are from medical backgrounds and recognise the influence that this may have on data analysis. However, the third researcher from a non-medical background was included to ensure accurate recognition of the content. The final coding and descriptive themes were collectively agreed between the three researchers.

Results

A total of 122 participants completed the survey (Table 1). The majority were female (74.6%) and GP trainees (48.4%) or GPs (43.4%) with a mean age of 39.5 years.

Table 1. Participant Characteristics (n = 122)					
Gender					
91 (74.6%)					
29 (23.8%)					
2 (1.6%)					
39.5					
41.0					
35.7					
•					
59 (48.4%)					
53 (43.4%)					
5 (4.1%)					
4 (3.3%)					
1 (0.8%)					

Years in the profession				
<1 year	19 (15.6%)			
1-5 years	61 (50.0%)			
6-10 years	12 (9.8%)			
11-20 years	12 (9.8%)			
>20 years	18 (14.8%)			
Mean length	5.9			
Ethnicity	-			
White British	66 (54.1%)			
Any other white background	5 (4.1%)			
Indian	13 (10.7%)			
Pakistani	12 (9.8%)			
Any other Asian background	4 (3.3%)			
African	14 (11.5%)			
Any other black/African/Carribean background	3 (2.5%)			
Any other mixed or multiple ethnic background	2 (1.6%)			
Prefer not to say	3 (2.5%)			

Female participants see female genitalia and perform vulval clinical examination more frequently than males. Females most frequently reported performing examinations of the vulva 'more than once a week', whereas male HCPs reported '2-3 times a month' most frequently (Figure 1).

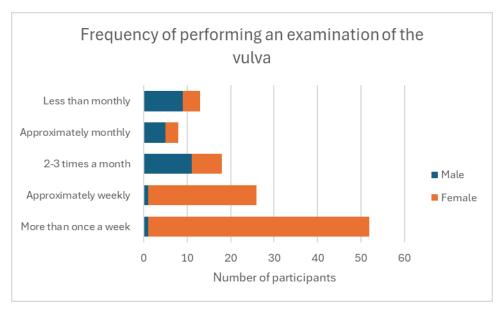


Figure 1. Participant frequency of performing an examination of the vulva

Education and training on vulval skin disease

44 (36.1%) participants responded 'yes' to receiving organised teaching, and 23 (18.9%) responded 'yes' to receiving self-directed learning relating to vulval skin disease with a mean teaching length of 2 hours. However, 37.7% of participants

did not receive organised teaching nor participated in self-directed learning. Most participants felt that further education on VLS would be helpful, with 92.6% of participants reporting it as 'fairly useful' or 'very useful' overall.

Confidence identifying and managing vulval skin conditions

Female participants rated themselves as significantly more confident than males in all skills associated with diagnosing vulval skin disease. 'Initiating treatment for patients with VLS' was the only skill where there was no significant difference in confidence between males and females (Table 2.). Table 2. displays the confidence of participants in aspects of diagnosis and management of vulval skin disease as measured by a Likert scale. A value of '1' represents 'not confident at all' and '5' represents 'very confident'. An increasing mean value correlates with higher levels of confidence in this skill.

Table 2. Participant confidence levels	Mean Likert scale response (95% Confidence Interval)	
	Females	Males
Confidence level examining the vulva	3.96 (3.79-4.12)	3.14 (2.73-3.54)
Confidence level identifying vulval disease on examination	3.91 (3.43-3.80)	2.79 (2.45-3.14)
Confidence level identifying vulval lichen sclerosus on examination	3.60 (3.43-3.78)	2.97 (2.64-3.29)
Confidence level initiating treatment for patients with vulval lichen sclerosus	3.36 (3.09-3.64)	2.83 (2.45-3.21)

Helpfulness of diagnostic criteria and preferred format

68.8% of participants felt clear VLS diagnostic criteria would be very helpful, and 28.7% felt it would be fairly helpful. An integrated template in a clinical system (e.g. Ardens, F12) was the most preferred tool format, followed by weblink.

Correlations between HCP confidence and characteristics

Spearman's rank correlations were used to explore the relationships between HCP confidence in their skills and their characteristics (Table 3). Frequency of seeing female genitalia as part of their role and confidence identifying vulval skin disease had the strongest positive correlation (0.616). Correlations between female gender and confidence identifying VLS (0.254), examining the vulva (0.313) and identifying vulval skin disease (0.315) were most weakly correlated. All correlations in Table 3. were significant with an adjusted p value (Bonferroni correction) of <0.003.

Table 3. Correlations between HCP confidence and characteristics.			
Correlation factors	R		
Frequency of seeing female genitalia as part of their routine clinical practice and confidence in identifying vulval skin disease	0.616		
Frequency of examining the vulva and confidence in examining the vulva	0.505		

Gender (female) of participant and confidence in examining the vulva	0.313
Gender (female) of participant and confidence in identifying vulval skin disease	0.315
How long the participant had been in the job role and confidence in examining the vulva	0.408
How long the participant had been in the job role and confidence in identifying vulval skin disease	0.483
Frequency of seeing female genitalia as part of their routine clinical practice and confidence in identifying VLS on examination	0.458

Participants' opinions on the barriers to diagnosis and treatment of VLS

Participants were asked to rank the top 3 barriers to diagnosis of VLS from a list of twelve pre-defined options and a free-text option. Participants' highest-ranking barriers to diagnosis and treatment of VLS were lack of knowledge, lack of clear diagnostic criteria, and patients are embarrassed to talk about vulval problems. Lack of knowledge was the most consistently selected, highest ranked barrier (Figure 2).

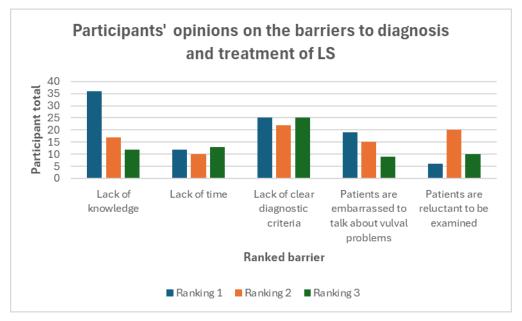


Figure 2. Participants' opinions on the barriers to diagnosis and treatment of VLS.

Qualitative data analysis

Six descriptive themes were developed from 25 inductive codes from analysis of the free text data (Figure 3).

Qualitative analysis							
Descriptive themes	Codes						
Diagnostic Challenges	Absence of diagnostic criteria	Clinical photography is inappropriate	Malignancy concerns	Non-specific or unclear symptoms			
	Difficulty differentiating from other conditions	Normal variation complicates diagnosis	Lack of thorough examination	Misdiagnosis as thrush or candidiasis			
Lack of knowledge and education	Inadequate educational resources		Reliance on experiential learning				
	Paucity of formal training		Poor patient awareness				
Lack of HCP skills	Lack of HCP confidence		Lack of HCP	experience			
	Lack of HCP knowledge		Uncertainty around treatment and management				
Organisational problems	Lack of clarity of referral pathways						
	Appointment access issues		Tim	e constraints			
Stigma around vulval conditions		Patient reluctan	ce to be examined				
	Patient embarrassment		Patient reluct	ance to discuss			
Challenges related to HCP gender		Male HCP relu	ctance to examine				

Figure 3. Descriptive themes and codes

Diagnostic challenges

Participants expressed confusion over whether diagnostic criteria were available and whether referral is needed to confirm VLS diagnosis: "I diagnose based on symptoms and examination findings. Not aware of diagnostic criteria" (Female GP, age 40-49, 1-5 years in job), which may have contributed to delays in diagnosis and misdiagnosis that were observed by clinicians: "Vulval symptoms are often treated as Candida for years" (Female GP, age 50-59, >20 years in job). This is exacerbated by reports of VLS presentation being unclear due to the variation in normal vulval appearance: "Sometimes it is obvious, but other times I'm not sure if it is post-menopausal changes" (Female GP trainee, age 30-39, 1-5 years in job). HCPs recognised there is uncertainty among the patients themselves, particularly when recognising VLS symptoms and signs versus normal menopausal changes: "Women present very late with scarring. They think it's normal as they age" (Female GP, age 50-59, >20 years in job).

Lack of knowledge and education

According to participants, there is a lack of formal training and limited experience around vulval skin conditions among HCPs, resulting in reduced confidence in

treating and diagnosing them: "Many GPs do not do additional obstetrics and gynaecology training now so are not confident in diagnosing vulval conditions or gynae problems" (Female GP, age 50-59, >20 years in job). Participants felt that they rely on exposure to the condition in practice for learning: "I have not had formal teaching on this but did spend some time in vulval dermatology clinics during GP training; without this I would have significantly less confidence" (Male GP, age 18-29, 1-5 years in job).

Lack of HCP skills

Participants described confusion about whether the treatment and management of vulval conditions falls under primary or secondary care, alongside caution when using topical steroids: "I'm not sure if all patients need to see a consultant prior in order to have diagnosis confirmed or if ok to trial treatment" (Female ANP, age 50-59, 1-5 years in job); "There is always a bit of a reluctance to commence topical steroids and knowing the potency appropriate" (Female GP Trainee, age 30-39, 1-5 years in the job). Participants also reported a preference to refer to other professionals instead of diagnosing themselves, some citing concerns over missing malignancy: "[...] This means I am more likely to refer to specialists for confirmation if I am unsure about the criteria, or how to safely treat" (Female GP, age 30-39, 1-5 years in job).

Organisational problems

A lack of resources in general practice was felt to be a barrier to diagnosis by participants. This included no easy access to educational resources, particularly those with clinical photographs, hindering accurate identification of vulval skin disease. Lack of female GPs to facilitate appointments was reported; a barrier particularly as patients prefer to see a female doctor for vulval issues, resulting in an increased burden of work on female clinicians: "In my practice, an overall lack of female GPs creates a barrier as often these patients wish to see a female doctor and so there is a burden of work on the available female doctors" (Female GP, age 50-59 years, >20 years in job). Referral to specialists may also be delayed by unclear referral pathways: "I think some clear indication of the pathways locally would be helpful to ensure timely referral to specialists" (Female GP Trainee, age 30-39, 1-5 years in job). Furthermore, a lack of adequate time in appointments was felt to contribute to incorrect and missed diagnosis: "We are very short of time in general practice" (Female GP, age 50-59, >20 years in job).

Stigma around vulval conditions

Participants recognised the challenges that patients face in seeking help for vulval conditions, adding further complexities to diagnosis. These include embarrassment and reluctance to discuss sensitive information or be examined: "Patients do find it difficult to talk about private issues relating to their genitals and I feel extra consultation skills are required [...]" (Female ANP, age 30-39, 1-5 years in job). Embarrassment was felt to be an underlying reason for this: "[...] they may feel embarrassed to come to see doctors about this" (Male GP trainee, age 18-29, 1-5 years in job).

Challenges relating to HCP gender

A lack of experience in vulval conditions for male clinicians was reported, caused by both a patient reluctance to be examined by male clinicians and a reluctance from male clinicians themselves to undertake female genital examination. Male participants described patient preference for female clinicians when genital examination is a possibility: "Female patients are reluctant to be examined by male doctors for intimate examinations" (Male GP trainee, age 18-29, 1-5 years in job). Female participants similarly reported lack of examination done by their male colleagues and a tendency for them to refer elsewhere which can leave males lacking experience and confidence in this area: "I find that male colleagues often refer patients with these issues to see female clinicians which may delay the diagnosis/mean they see less so aren't as confident in the diagnosis" (Female GP trainee, age 18-29, 1-5 years in job).

Discussion

Summary

This study uniquely explores the barriers to diagnosing and treating VLS from the perspective of HCPs in primary care. Several barriers were described in the data, including lack of confidence and experience in the skills essential for VLS diagnosis. Less frequent exposure to vulval examinations and time spent in the job role were correlated with a lack in confidence. Female participants performed vulval examinations more frequently than males and there was a weak correlation between confidence in the skills associated with VLS diagnosis and female gender. The relative inexperience of male clinicians translates into fewer opportunities for experiential learning resulting in poorer confidence in diagnostic skills. This leads to a cycle where clinicians with poor confidence may be more reluctant to examine, resulting in an avoidance of experiential learning and inexperience. There was a shortfall of relevant education and training amongst the study participants which is likely to contribute to poor confidence in all participants. Lack of knowledge and educational opportunities were consistently recognised throughout the qualitative data, including reference to lack of awareness amongst patients as well as clinician knowledge gaps.

Female participants rated themselves significantly more confident than males in examining the vulva, identifying vulval skin disease and treating VLS in the survey. Whilst significant, the correlation between female gender and confidence in these skills was weak. There is a well-recognised 'gender confidence gap' in the literature so this correlation may be underestimated.²¹ Participants acknowledge opportunities for male clinicians to examine are limited due to patients feeling and less embarrassed when examined clinicians. Participants recalled patients who did not want to be examined by male clinicians, and male clinicians who were reluctant themselves, feeling deskilled due to limited exposure. As a result, participants reported cross-referral to female colleagues in primary care, potentially impacting patient care by delaying diagnosis and discouraging patients from seeking examination with male clinicians further. 17

Organisational challenges within primary care and the interface with secondary care were also found to pose barriers to VLS diagnosis and treatment e.g. time constraints and referral pathways. Whilst it is difficult to create time in primary care, referral pathways should be well established and standardised including 'Advice and Guidance' when appropriate. Criteria for 'Advice and Guidance' or referral should be clear and bespoke to vulval patients, especially given the challenges of teledermatology in this group.

Women's health and dermatology are known to have historically low priority in medical school curricula. ^{22, 23} Over one third of participants had neither received teaching nor participated in relevant self-directed learning in vulval skin disease. However, results suggested that regardless of teaching received, participants considered that more could be useful. This reinforces the need for targeted, easily accessible, relevant educational resources for primary care clinicians. The differences in appearances of VLS in skin of colour was mentioned in the survey data. Future educational resources should include diverse photography and information to ensure equality.

Supporting HCPs in the diagnosis of VLS via a diagnostic tool to be accessed through existing clinical systems was considered a helpful suggestion. Almost all participants (97.5%) felt provision of clear diagnostic criteria for VLS would be helpful, particularly an integrated template within a clinical system. Of the 3 participants who said the criteria would be 'neither helpful nor unhelpful', all examined female genitalia as part of routine practice weekly or more. This regular exposure may influence their view on the helpfulness of diagnostic criteria, as this was positively correlated with confidence levels in identifying VLS.

Participants consistently highlighted challenges diagnosing VLS, expressing uncertainty over the differential diagnoses, management guidelines and whether diagnostic criteria were available. Variation in VLS presentation, normal variation and absence of diagnostic criteria was felt to make diagnosis difficult. Thus, research into clear, validated and evidenced based diagnostic criteria, suitable for use in primary care, should be prioritised.

Stigma around vulval conditions emerged as a theme in the qualitative data. Participants recognised that patients are reluctant to seek help due to embarrassment. Embarrassment is more common in women and higher in consultations requiring intimate examinations, leading to medical avoidance.²⁴ Shame and embarrassment are associated with negative health outcomes and mental health conditions.^{25,26} These feelings are a reason for delayed presentation of vulval conditions as well as a hindrance to communication. Addressing embarrassment, shame and stigma in relation to vulval symptoms is something that requires societal-level change, however HCPs also have an important role to play and can aim to address it in their individual interactions with patients. Acknowledgement of stigma and recognition of embarrassment may help validate patients' feelings and improve their experience.²⁶ Integrating education on consultation skills into future vulval skin disease teaching initiatives could further enhance the patient-doctor relationship.

A lack of awareness among patients of what is normal was also cited as a barrier to diagnosis, further emphasising the importance of educational initiatives, not only for HCPs but also for the public. Participants felt that educating patients and raising awareness of symptoms of VLS may increase the likelihood of seeking help, expediting their diagnosis.

Strengths and limitations

A strength of this study is its singularity in collecting quantitative data on the confidence of clinicians in diagnosing and treating VLS as well as their perspectives on doing so. It complements the existing literature on the shortcomings in diagnosing and treating VLS, providing some explanation for these challenges. Greater depth of insight could have been obtained by conducting a study with direct contact with participants i.e. an interview or focus group study. Using a survey meant that limited qualitative data could be gathered via free text responses; however, it was a practical method given our resources and has provided novel viewpoints.

Participants mainly comprised of GPs and GP Trainees in the Midlands, UK. This limits the generalisability to HCPs in primary care across the UK and did not allow for analysis between different clinicians nor different regions. This is reflective of the opportunistic recruitment, largely reliant on the professional networks of the authors. To increase sample size, the advert was sent to many different WhatsApp groups, e-mail lists and the local TeamNet site. It is therefore difficult to estimate the number of eligible HCPs that viewed the advert and subsequently the response rate. The sample is however broadly representative of the UK GP workforce with regards to ethnicity and age, though there were over three times the number of female participants than males. Whilst there are more female than male GPs in the UK as of 2023,²⁷ the national ratio is smaller.

GPs and GP trainees comprised most of our respondents (91.8%), due to the professional networks of authors but likely also due to their more active role in diagnosing skin disease. Future research in this area should focus on the experiences of other HCPs in primary care.

Another limitation was the presence of 12 missing responses over 3 questions due to participants not answering every question. Despite this, saturation of themes was reached, and expectation of sample size was exceeded.

Comparison with existing literature

This study is the first to explore the perceptions of HCPs on VLS treatment and diagnosis. HCPs echo the experiences of women with VLS in the qualitative literature. There was overlap in themes and subthemes around diagnosis in the existing qualitative literature, exploring the experience of patients, with those identified in this study. Patients and HCPs found lack of HCP knowledge, embarrassment, frequent misdiagnosis as thrush and potential malignancy concerning. Phere is an unmet need for education of HCPs on vulval skin disease and the consequent lack of knowledge leads to misdiagnosis. Both groups acknowledged the frequent misdiagnosis of VLS as vulval candidiasis and the effect of embarrassment on consultations. Participants in this study felt further education on vulval skin disease in primary care would be beneficial, substantiating the calls for HCP education to be a priority as in previous studies.

Variation in practice in facilitating testing for sexually transmitted infections²⁹ and female pelvic examinations³⁰ has been described in primary care with similar barriers to this study identified. In a qualitative study of the use of female pelvic examinations by GPs, the authors found similar findings in capability (education and confidence), opportunity (time constraints) and motivation (concerns about embarrassing patients).³⁰ The 'COM-B' behaviour change model, used in both of these studies, identifies which component of behaviour, capability, opportunity, or motivation needs to be modified for an intervention to be successful.³¹ This could be considered in future implementation of changes for vulval examination.

This survey identified that 98% of participants would find a diagnostic criteria helpful which mirrors the findings of a James Lind Alliance Priority Setting Partnership.³² This partnership established diagnostic criteria as the second most important research priority for lichen sclerosus. In addition, this is the first study to quantify the confidence in clinical skills relevant to vulval skin disease and women's health, correlating them with participant characteristics.

Implications for research and/or practice

Gaps identified in vulval skin disease education provide opportunity for attainable improvement. A comprehensive education program for integration into the training of HCPs in primary care to incorporate consultation skills, presentation of vulval disease, and differential diagnoses, could improve patient outcomes.

Implementation of standardised pathways of care, including guidance on which speciality to refer, as well as accessing advice and guidance services more frequently, would streamline the patient journey. Aspirational standards of care have been published by the British Society for the Study of Vulval Disease and should be considered when such pathways are being developed.³³ Finally, future research could focus on how VLS diagnostic criteria could be integrated into the primary care workflow.

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Bibliography

- 1. De Luca DA, Papara C, Vorobyev A et al. Lichen sclerosus: The 2023 update. Front Med (Lausanne). 2023; 10:1106318.
- 2. Nair PA. Vulvar Lichen Sclerosus et Atrophicus. J Midlife Health. 2017;8(2):55-62.
- 3. Powell JJ, Wojnarowska F. Lichen sclerosus. Lancet. 1999;353(9166):1777-83.
- 4. Topal IO, Sayilgan AT, Kalcin S. An uncommon cause of vulval pruritus in childhood: Lichen sclerosus. Turk Pediatri Ars. 2014;49(1):86-7.
- 5. Lewis FM, Tatnall FM, Velangi SS et al. British Association of Dermatologists guidelines for the management of lichen sclerosus, 2018. Br J Dermatol. 2018;178(4):839-53.
- 6. Leibovitz A, Kaplun VV, Saposhnicov N et al. Vulvovaginal examinations in elderly nursing home women residents. Arch Gerontol Geriatr. 2000;31(1):1-4.
- 7. Jablonowska O, Wozniacka A, Szkarlat S et al. Female genital lichen sclerosus is connected with a higher depression rate, decreased sexual quality of life and diminished work productivity. PLoS One. 2023;18(4):e0284948.
- 8. Bentham GL, Manley K, Halawa S et al. Conversations between women with vulval lichen sclerosus: a thematic analysis of online forums. BMC Womens Health. 2021;21(1):71.
- 9. Cooper SM, Gao XH, Powell JJ et al. Does treatment of vulvar lichen sclerosus influence its prognosis? Arch Dermatol. 2004;140(6):702-6.
- 10. Chmel R, Novackova M, Fait T et al. Clitoral Phimosis: Effects on Female Sexual Function and Surgical Treatment Outcomes. J Sex Med. 2019;16(2):257-66.
- 11. Guerrero A, Venkatesan A. Inflammatory Vulvar Dermatoses. Clin Obstet Gynecol. 2015;58(3):464-75.
- 12. Kirby L, Gran S, Orekoya F et al. Is urinary incontinence associated with vulval lichen sclerosus in women? A cross-sectional study. Br J Dermatol. 2021;185(5):1063-5.
- 13. Kirby L, Gran S, Kreuser-Genis I et al. Is urinary incntinence associated with lichen sclerosus in females? A systematic review and meta-analysis. Skin Health Dis. 2021;1(1):e13.
- 14. Halonen P, Jakobsson M, Heikinheimo O et al. Lichen sclerosus and risk of cancer. Int J Cancer. 2017 May 1;140(9):1998-2002. doi: 10.1002/ijc.30621. Epub 2017 Feb 10.
- 15. Rees S, Owen C, Baumhauer C et al. Vulval lichen sclerosus in primary care: thinking beyond thrush and genitourinary symptoms of the menopause. Br J Gen Pract. 2023;73(730):234-6.
- 16. Kolitz EM, Pineider J, Mauskar MM et al. The impact of an encounter with a gynaecologic dermatologist on quality of life, health literacy and education satisfaction for patients with vulvar lichen sclerosus: A survey study. Skin Health Dis. 2022;2(3):e89.
- 17. Arnold S, Fernando S, Rees S. Living with vulval lichen sclerosus: a qualitative interview study. Br J Dermatol. 2022;187(6):909-18.
- 18. Hasegawa M, Ishikawa O, Asano Y et al. Diagnostic criteria, severity classification and guidelines of lichen sclerosus et atrophicus. J Dermatol. 2018;45(8):891-7.
- 19. Jisc. Jisc Online Surveys; Accessed 30/07/2024. Available from: https://www.jisc.ac.uk.
- 20. Braun V, Clarke, V. Using thematic analysis in psychology. Qualitative Research in Psychology. 2006;3(2):77-101.

- 21. Beyer S. B, E. Gender Differences in Self-Perceptions: Convergent Evidence from Three Measures of Accuracy and Bias. Personality and Social Psychology Bulletin. 1997;23(2).
- 22. Keitt SK, Wagner C, Tong C, Marts SA. Positioning women's health curricula in US medical schools. MedGenMed. 2003;5(2):40.
- 23. Sharma M, Murphy R, Doody GA. Barriers and facilitators for implementation of a national recommended specialty core-curriculum across UK medical schools: a cross-sectional study using an online questionnaire. BMJ Open. 2022;12(3):e053565.
- 24. Consedine NS, Krivoshekova YS, Harris CR. Bodily embarrassment and judgment concern as separable factors in the measurement of medical embarrassment: psychometric development and links to treatment-seeking outcomes. Br J Health Psychol. 2007 Sep;12(Pt 3):439-62. doi: 10.1348/135910706X118747. .
- 25. Dolezal L. The phenomenology of shame in the clinical encounter. Med Health Care Philos. 2015 Nov;18(4):567-76. doi: 10.1007/s11019-015-9654-5.
- 26. Saraiya T, Lopez-Castro T. Ashamed and Afraid: A Scoping Review of the Role of Shame in Post-Traumatic Stress Disorder (PTSD). J Clin Med. 2016 Nov 1;5(11):94. doi: 10.3390/jcm5110094.
- 27. England N. General Practice Workforce 2024; Accessed 30/07/2024. Available from:
- https://app.powerbi.com/viewr=eyJrIjoiZTEwODNkOTItZjVmYS00OTNjLWJhNDktNjdkYTRlOGY3Njg4IiwidCI6IjM3YzM1NGIyLTg1YjAtNDdmNS1iMjIyLTA3YjQ4ZDc3NGVIMyJ9.
- 28. Wehbe-Alamah H, Kornblau BL, Haderer J et al. Silent no more! The lived experiences of women with lichen sclerosis. J Am Acad Nurse Pract. 2012 Aug;24(8):499-505. doi: 10.1111/j.1745-7599.2012.00715.x. Epub 2012 Apr 30. 29. McDonagh LK, Saunders JM, Cassell J et al. Application of the COM-B model to barriers and facilitators to chlamydia testing in general practice for young people and primary care practitioners: a systematic review. Implement Sci. 2018 Oct 22;13(1):130. doi: 10.1186/s13012-018-0821-y.
- 30. Williams P, Murchie P, Cruickshank ME et al. What influences GPs' use of pelvic examination? A qualitative investigation in primary care. Br J Gen Pract. 2023 Jun 29;73(732):e528-e536. doi: 10.3399/BJGP.2022.0363.
- 31. Michie S, van Stralen MM, West R. The behaviour change wheel: a new method for characterising and designing behaviour change interventions. Implement Sci. 2011 Apr 23;6:42. doi: 10.1186/1748-5908-6-42.
- 32. 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. 2019;180(5):1236-7.
- 33. British Society for the Study of Vulval Disease. Standards of Care for Patients with Vulval Conditions. Accessed 31/07/2024. Available from: https://bssvd.org/wp-content/uploads/2022/06/BSSVD-Standards-of-Care-vulval.pdf