Demographics of New Zealand women with vulval lichen sclerosus: is specialist care equitable?

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ABSTRACT

AIM: Vulval lichen sclerosus is an inflammatory genital skin condition associated with poor quality of life, sexual dysfunction and risk of squamous cell carcinoma. The aim of this study was to document the demographics of women with lichen sclerosus seen at specialist vulval clinics.

METHOD: We performed a retrospective review of women with lichen sclerosus seen at a tertiary combined gynaecology/dermatology vulval clinic over 12 months and Auckland Regional sexual health vulval clinics over five years. Data were collected for age, ethnicity, skin biopsy, treatment, referral source and time from symptom onset to diagnosis. Ethnicity was compared with Census data for the Auckland region.

DISCUSSION: Three hundred and thirty-five women were included; 273 from the gynaecology/dermatology clinic and 62 from sexual health. Women seen at sexual health were younger than those seen by gynaecology/dermatology (mean age 45 and 64, respectively; $p<0.0001$). Most referrals were from general practitioners (54%), although self-referrals made up 42% of sexual health consultations. The most common ethnicity was European (82%) followed by Asian (10%), Māori (4%) and Pacific Peoples (3%). Compared with Census data, European women were over-represented and Māori, Pacific and Asian women were under-represented.

CONCLUSION: We found inequitable ethnic representation of women with vulval lichen sclerosus seen at our institution. Causes may include sociocultural beliefs, variations in access to care or ethnic differences in the prevalence of lichen sclerosus. A deeper understanding of underlying issues would enable planning of initiatives to ensure equitable access to specialist care for all New Zealand women with vulval conditions.

Lichen sclerosus is a chronic, pruritic skin condition with autoimmune aetiology and is relatively common, affecting approximately 1% of women.[1] It has a predilection for genital skin, particularly the vulva in women. The cardinal features of the vulval form are skin whitening and atrophy, and eventually destruction of the normal architecture of the vulva. Bullae, ulceration and purpura may also be seen (Figure 1).[2] Common symptoms are itching, pain and dyspareunia.

In addition to scarring with irreversible loss of vulval architecture, lichen sclerosus has an association with differentiated vulval intraepithelial neoplasia (dVIN) and squamous cell carcinoma (SCC).[3] Regular maintenance treatment, most often with potent or ultrapotent topical corticosteroids is required and has been shown to reduce the risk of vulval carcinoma.[4] Due to risk of neoplasia, early diagnosis and long-term follow-up is advised.[5] Vulval disease in general is known to disrupt sexual function as well as normal daily activities, promote anxiety and have other negative psychological effects.[6]

Many women with lichen sclerosus feel embarrassed to seek advice or treatment and therefore typically present in the later stages of disease, often after a period of self-treatment.[7] Late presentation is of concern, because of the association with malignancy and potential for irreversible scarring which may lead to vaginal introital stenosis and sexual dysfunction. Complete fusion with urinary retention can occur.

Figure 1: Vulval lichen sclerosus.

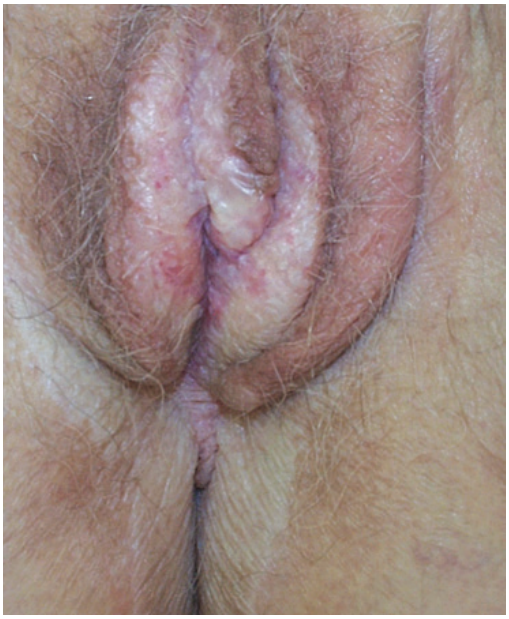


Image courtesy of DermNet New Zealand.

Other than age data, there is a significant lack of available literature on the demographic characteristics women with vulval lichen sclerosus and vulval skin disease in general. In New Zealand, there are a small number of observational studies on vulval skin conditions that include ethnicity data and suggest there may be inequitable ethnic representation. For example, a quality of life of life study in women with vulval dermatoses in Waikato, found none of the participants identified as being of Māori or Pacific ethnicity.[8]

Despite universal, tax-funded healthcare in New Zealand, there remains inequitable health outcomes and access to care between population groups, particularly for Māori.[9] The literature on cervical cancer screening in New Zealand has consistently documented ethnic disparity in screening uptake.[10] Māori, Pacific and Asian women are more likely to cite embarrassment when undergoing cervical screening.[11] This finding is likely relevant to external genital examination.

Anecdotally, it was noted that the majority of women seen with vulval complaints are of European ethnicity. We hypothesise that Māori and Pacific women are under-represented in the population of women presenting with lichen sclerosus. The aim of this study was to document demographics of women with vulval lichen sclerosus presenting to vulval skin clinics in Auckland.

Methods

We undertook a retrospective review of women with a specialist-diagnosis of lichen sclerosus seen at a tertiary combined gynaecology/dermatology vulval clinic at National Women's Health at Auckland City Hospital and the vulval clinic at Auckland Regional Sexual Health Service (SH), which has clinics in Central, North, South and West Auckland. The combined clinic requires referral from a primary care or specialist physician. In contrast, patients may self-refer to SH clinics.

All patients seen at the combined gynaecology/dermatology clinic over the 12-month period from 1 June 2017 to 1 June 2018 were included. A time period of five years from 2 July 2013 to 11 June 2018 was chosen for SH clinics in order to capture a sufficient number of women for comparison. Patient data collected included age, ethnicity, diagnosis, previous skin biopsy, treatment modality, referral source, date of symptom onset as well as date of specialist diagnosis (in order to calculate time from symptom onset to specialist diagnosis). This data was collected from electronic medical records.

Where possible, self-identified ethnicity was collected from patient registration forms and when not available, ethnicity data was collected from the electronic medical record. Both Level 1 and Level 2 ethnicity was recorded and ethnicity was outputted using the Ministry of Health prioritised output method.[12] If multiple ethnicities were identified for a single participant, the prioritised order was Māori, Pacific Peoples, Asian, European, Other. Level 1 ethnicity was additionally outputted using the Ministry of Health total output method (all ethnicities recorded for each participant) in order for comparison to be made against the reference population, the 2013 Auckland Census population.[13]

Data analysis was conducted using Microsoft Excel and IBM SPSS Statistics version 23. Significance for difference between means and confidence intervals was calculated using the two sample t test. Differences in proportions between the two clinics was calculated using Chi squared test (or Fisher's exact test for counts less than five). The significance level was set at α=0.05.

Table 1: Referral sources for women seen at vulval skin clinics.

Referral source	Clinic		Chi square or Fisher's exact p value	Total n=335 (%)
	Gynae/derm n=273 (%)	SH n=62 (%)		
General practitioner	157 (57.5)	24 (38.7)	0.012	181 (54.0)
Gynaecologist	65 (23.8)	0 (0.0)	<0.0001	65 (19.4)
Dermatologist	25 (9.2)	0 (0.0)	0.007	25 (7.5)
Self	0 (0.0)	26 (41.9)	<0.0001	26 (7.8)
Other medical specialist	8 (2.9)	7 (11.3)	0.010	15 (4.5)
Sexual health physician	9 (3.3)	1 (1.6)	0.694	10 (3.0)
Other/allied health	1 (0.4)	1 (1.6)	0.336	2 (0.6)
Unknown	8 (2.9)	3 (4.8)	0.434	11 (3.3)

Gynae/derm = combined gynaecology and dermatology clinic; SH = sexual health clinic.

Results

In total, 680 women were seen in the vulval clinics over the study periods. Of these, 335 (49.3%) had vulval lichen sclerosus and this was the most frequent diagnosis. Two-hundred and seventy-three were seen at the combined clinic and 62 at SH. The mean age of women with lichen sclerosus was 60 years (standard deviation [SD] 17.8, range 8–95). There was very strong evidence that women seen in SH clinics were younger than those seen by gynaecology/dermatology with mean ages of 45 and 64 years, respectively, and a mean age difference of 18 years (95% confidence interval [CI] 14–23, p<0.0001). The mean age of Asian (54 years), Māori (50 years) and Middle Eastern women (30 years) was younger than European women (62 years) and Pacific women (63 years) (p<0.0001).

The median time from symptom onset to diagnosis was 1.4 years (interquartile range [IQR] 2.6). We found very strong evidence that women seen by gynaecology/dermatology had a longer duration of symptomatology prior to diagnosis (3.6 years) compared with women seen at SH (1.1 years), with a mean difference of 2.5 years between the clinics (95% CI 1.5–3.5 years, p<0.0001). Vulval biopsy had been performed in 75% of women and 93% of biopsies confirmed the diagnosis of lichen sclerosus.

Most patients (53.4%) had been referred by their general practitioner (GP) (Table 1). Specialist referrals were most often from gynaecologists, followed by dermatologists and sexual health physicians. Self-referrals accounted for 42% of SH consultations and none of the gynaecology/dermatology consultations.

The most common ethnic group seen was European (82%) followed by Asian (10%), Māori (4%) and Pacific Peoples (3%). Detailed ethnicity data is shown in Table 2. Compared with Census data, European women were over-represented and Māori, Pacific and Asian women were under-represented (Figure 2). There were no significant differences between the clinics in the ethnicities of women seen (p=0.185, level 1, prioritised output).

Discussion

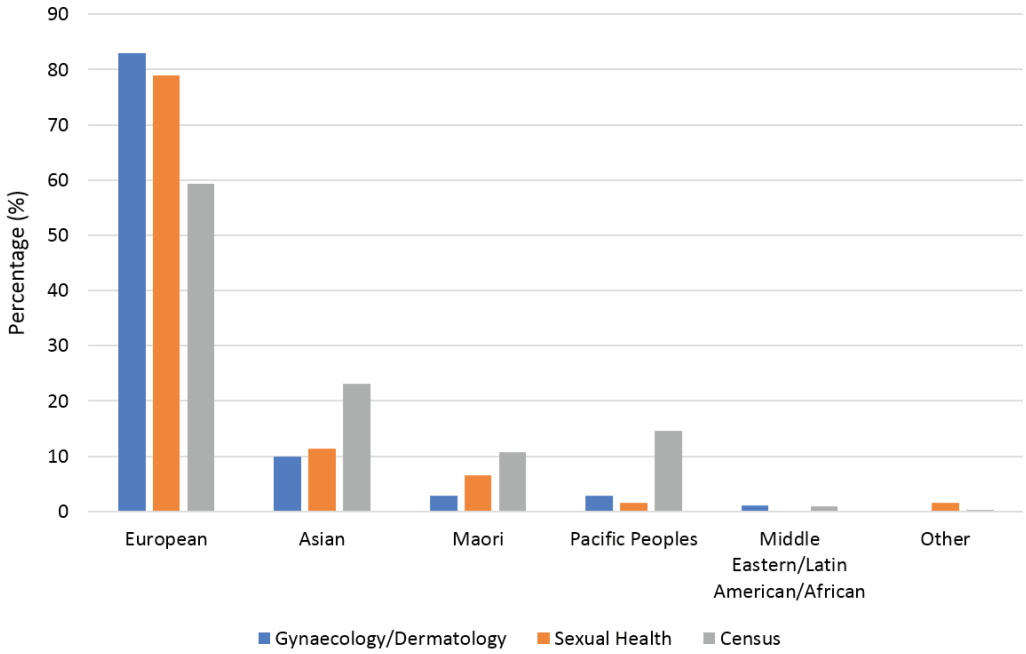
The mean age of women seen in our study was 60 years, in keeping with previous studies showing lichen sclerosus occurs predominantly in post-menopausal women.[14] Women seen in SH clinics were younger, reflecting the younger overall age of patients attending sexual health services. Women in this age group may be more likely to attribute vulval symptoms to sexually acquired infection and thus present to sexual health services for evaluation. In our community, Māori and Pacific women

Table 2: Ethnicity of women seen at vulval skin clinics with a diagnosis of lichen sclerosus (Level 2, prioritised output).

Ethnicity Level 2 – Prioritised output	Clinic		Chi square or Fisher's exact p value	Total n=335 (%)
	Gynae/derm n=273 (%)	Sexual health n=62 (%)		
New Zealand European	192 (68.1)	41 (66.1)	0.524	233 (67.7)
Other European	33 (11.7)	8 (12.9)	0.832	41 (11.9)
Indian	17 (6.0)	4 (6.5)	1.000	21 (6.1)
Māori	8 (2.8)	4 (6.5)	0.246	12 (3.5)
Chinese	9 (3.2)	1 (1.6)	0.695	10 (2.9)
Samoan	7 (2.5)	1 (1.6)	1.000	8 (2.3)
Other Asian	1 (0.4)	1 (1.6)	0.336	2 (0.6)
African	2 (0.7)	0 (0.0)	1.000	2 (0.6)
Southeast Asian	0 (0.0)	1 (1.6)	0.185	1 (0.3)
Middle Eastern	1 (0.4)	0 (0.0)	1.000	1 (0.3)
Fijian	1 (0.4)	0 (0.0)	1.000	1 (0.3)
Niuean	1 (0.4)	0 (0.0)	1.000	1 (0.3)
Latin American	1 (0.4)	0 (0.0)	1.000	1 (0.3)
Not stated	0 (0.0)	1 (1.6)	0.185	1 (0.3)
Total	**273**	**62**	-	**335**

Gynae/derm = combined gynaecology and dermatology clinic.

Figure 2: Ethnicity of women seen in vulval skin clinics with a diagnosis of lichen sclerosus (n=335) compared with 2013 Census data for Auckland Region (Level 1, total output).



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have a younger population distribution than European women, and given that lichen sclerosus most commonly affects women post-menopause the apparent incidence of lichen sclerosus may be falsely lowered by comparing groups by overall numbers of women. It was not unexpected that Māori women had a younger mean age in our cohort; however, interestingly Pacific women with lichen sclerosus had a similar mean age to European women. The overall numbers of Māori and Pacific women seen were too small to draw any firm conclusions, and it is not known how age may factor into cultural considerations that may prevent a woman from disclosing vulval symptoms and presenting to her health professional.

This study adds to the literature documenting the long period of symptomatology in women with vulval skin conditions prior to diagnosis and management.[1] This was longer for women seen by gynaecology/dermatology, which may be indicative of the older cohort of women seen in those clinics as it has been proposed that younger women seek health services at an earlier stage than older women.[15] The SH clinics accept self-referrals, which is also likely to allow earlier clinic review. However, even those seen at SH were symptomatic for more than a year before diagnosis.

Māori, Pacific and Asian women were under-represented in our clinics compared with census data. There is little New Zealand data on ethnicity and inflammatory vulval skin conditions for comparison; however, Pacific women were under-represented in a study of human papilloma virus (HPV)-related VIN (HSIL) spanning 41-years at National Women's Health published in 2005.[16] In an analysis for trends in vulval carcinoma at National Women's Health, authors found all women seen between 1965–1974 were European and in the later cohort (1990–1994) 53/57 were European; there were four Māori and one Pacific Island woman.[17]

Dass and Kuper-Hommel reported 47 women with vulval cancers from Waikato and found Māori women made up 19% of all cases and tended to present younger than European women.[18] This may be due to HPV-related cancers in younger women. Fifteen of these 47 women (31%) had lichen sclerosus. An American study also found ethnic disparity in women with vulval cancers with African, Asian and Pacific women more likely to have advanced stage disease.[19]

A Brazilian study of women seen in dermatology vulval clinics, where lichen sclerosus was the most common diagnosis, found 75% identified as Caucasian, 15% as Afro-Brazilian and 6% as mixed race.[20] The authors do not comment on this finding further, however according to 2010 Census data 66% of the San Paulo population are Caucasian. Interestingly, in men, an Army Medical Centre study found double the incidence of lichen sclerosus in black and Hispanic patients compared with white patients.[21] The authors propose that this may be explained by better access to medical care for minorities through the military.

The two clinics in our study demonstrated different referral pathways. We hoped this may provide information on the significance of physician referral as a barrier to care. The combined gynaecology/dermatology clinic is a tertiary referral clinic and received referrals from GPs as well as a variety of other specialists. In contrast, the majority of referrals for SH clinics came from GPs or patients self-presented. The differences in patient access to the clinics provides a useful comparison when considering potential barriers to care for women with lichen sclerosus. Although differences were not significant there was a higher proportion of Māori women seen in the SH clinic. It is known that access to care including transport and cost of primary care visits is a barrier for Māori.[22] It is important to note however, that despite the ability for patients to self-present, Māori and Pacific women with lichen sclerosus are still under-represented in SH clinics. This finding is particularly interesting given that Māori make up 22% and Pacific women 18% of all women presenting to sexual health (significantly higher than the proportions of these ethnic groups in the Census data). There are likely multiple additional factors, including cultural considerations pertinent to genital skin conditions.

The reasons for these ethnic disparities are unknown. Although there has been little exploratory work in vulval skin disorders, information can be gleaned from the literature on cervical cancer screening in New

Zealand. Since the inception of the National Cervical Screening Programme, Māori and Pacific women have been under-represented. Recent data shows that although coverage has improved for all ethnic groups, the coverage rate of Māori and Pacific women (67.8 and 70.7%, respectively) remains lower than for European women (78.5%).[10] Qualitative studies found Māori and Pacific women were more likely to be embarrassed and nervous about undergoing the smear procedure, with additional concerns over examination of a sacred body part involved with sexual intimacy and reproduction.[11] The study also conducted interviews with under-screened Chinese, Korean and European women, finding that European women were the only group of women who did not cite embarrassment or nervousness as a reason for their delay in seeking screening. A South Auckland study identified some Māori and Pacific interviewees had distrust of the medical system due to Western alignment.[23] This may mean that women of Māori, Pacific or Asian ethnicity are reluctant to present for evaluation of the genital symptoms of lichen sclerosus.

It is possible that Māori, Pacific and Asian women are at lower risk of lichen sclerosus and this may explain the lower numbers presenting. The Auckland Sexual Health data indicate that despite a relatively high proportion of Māori and Pacific women attending the service, these ethnic groups were still under-represented among women with lichen sclerosus compared to European women. This would support the hypothesis that women from these ethnic groups are at lower risk of lichen sclerosus. However, there may be other reasons for the under-representation, including access issues to general practitioners for referral, and the fact that lichen sclerosus is less prevalent in younger women commonly presenting to sexual health services.

Caution is required with the assumption that Māori, Pacific and Asian women are at lower risk of lichen sclerosus. A review of psoriasis cases from 2009–2014 in Auckland sought to test the hypothesis that psoriasis did not appear in Samoan patients, claimed by a previous review in the New England Journal of Medicine.[24] The Auckland review found that Māori and Pacific patients made up 26% of the cases of psoriasis seen at Auckland City Hospital, including Samoans whom represented 6% of all patients.[25] This demonstrates that autoimmune skin conditions like psoriasis are most definitely seen in Māori and Pacific patients, including Samoan patients. International studies have shown lower rates of psoriasis in indigenous populations. However, this may reflect lesser access to healthcare rather than a true reduction in incidence of psoriasis in these populations. In comparison to census population data, Māori and Pacific were seemingly overrepresented in the Auckland study, which may suggest that Māori and Pacific actually have a higher incidence of psoriasis. However, this study was limited by small sample size.

Our study has a number of limitations including the retrospective design. The number of women seen in SH clinics was relatively small reducing accuracy and increasing the chance of type II error when analysing ethnicity differences between the gynaecology/dermatology and SH clinics. Additionally, this study only examined women with lichen sclerosus seen in vulval skin clinics at our hospital and did not capture patients presenting elsewhere, such as to family planning clinics or primary care. It is known referral rates are generally lower for Māori. Ideally our findings require confirmation looking at these sites as well as data outside our region.

In conclusion, we found inequitable ethnic representation in women with vulval lichen sclerosus seen at our institution. Future study is imperative to further explore the true incidence of vulval lichen sclerosus in Māori, Pacific and Asian women and the cultural and other barriers to care, to ensure equitable specialist care for all New Zealand women with vulval conditions.

Competing interests:
Miss Kerckhoffs reports a grant from A+ Trust during the conduct of the study.

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