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Expert-Led Virtual Support for Vulvar Lichen Sclerosus: A Randomized Controlled Trial

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Abstract

Background: Vulvar lichen sclerosus (VLS) is a chronic inflammatory condition that significantly impacts quality of life (QOL). Despite substantial disease burden, psychosocial support remains limited. In particular, available resources are limited to social media groups, which may lack evidence-based guidelines or structured support.

Objective: To evaluate whether participation in a dermatologist- and urogynecologist-led virtual support group improves QOL among women with VLS.

Methods: In this randomized controlled trial of women aged ≥18 years with VLS, the intervention comprised 3 monthly, 60 minute virtual support sessions facilitated jointly by a dermatologist and urogynecologist. The primary outcome was change in Vulvar Quality of Life Index (VQLI) scores assessed at baseline and 3 monthly follow-ups, analyzed using mixed-effects linear regression. Secondary outcomes included VQLI domain scores, and qualitative feedback analyzed using inductive thematic analysis.

Results: Sixty-eight participants (35 intervention, 33 control) were included. The intervention group demonstrated a significantly greater improvement in total VQLI from baseline to final follow-up compared to control ($\beta = -10.3$, 95% CI −14.9 to −5.6; $P < .001$), and a corresponding shift from *Moderate* to *Mild* severity range of impact on QOL. Significant improvements in baseline to follow-up scores were also seen across all 6 VQLI domains in the intervention group compared to the control group. Qualitative themes highlighted that expert facilitation helped empower patients and addressed the need for knowledge sharing.

Conclusion: Expert-led virtual support groups may offer a potentially impactful, accessible, and scalable adjunct to medical therapy.

Keywords

lichen sclerosus, quality of life, patient education, vulvar dermatology, VQLI

Introduction

Vulvar lichen sclerosus (VLS) is a chronic inflammatory skin disorder primarily affecting the anogenital region. Clinical features include pruritus, dyspareunia, and hypopigmented or depigmented atrophic patches with a characteristic crinkly "cigarette paper" texture, often accompanied by fissures and erosions. Autoimmune and genetic mechanisms are implicated in the disease process.[1,2]

Left untreated, VLS can lead to irreversible architectural changes (clitoral hood phimosis, resorption, and agglutination) and carries a 5% risk of squamous cell carcinoma.[2] The condition has a bimodal age distribution, with peaks among prepubertal girls and post-menopausal women, and lifetime

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risk in women at 1% to 2%, although these values likely underestimate true disease burden.[3]

Beyond its physical manifestations, VLS profoundly impacts daily functioning, sexual health, intimate relationships, body image, and psychological wellbeing.[1] Current medical management typically involves long-term high-potency topical corticosteroid therapy with periodic dermatologic and/or gynecologic follow-up.[3] However, complete clinical and symptomatic clearance is achieved in only 11.5% of patients, and even those with substantial medical improvement often experience persistent quality of life (QOL) deficits.[4]

VLS care is often fragmented, with patients reporting feeling dismissed and receiving inadequate education about disease chronicity and self-management.[1,5] Misdiagnosis is common, with diagnostic delays of up to 4.6 years.[6] Combined with patient embarrassment and self-stigma, these barriers create a strong demand for interventions to address the psychosocial burden of the condition.

Patient support groups have demonstrated benefit for individuals managing chronic illnesses by providing emotional validation, practical assistance, and peer connection.[7] For dermatologic conditions specifically, online support communities have shown promise in improving QOL and disease severity.[8] Virtual formats expand access for patients in rural areas, with limited mobility, or experiencing condition-related isolation,[9] and can effectively replicate face-to-face therapeutic processes such as group cohesion and emotional bonding.[10] However, online communities also risk propagating misinformation and may lack evidence-based guidance.[11] Expert-facilitated groups may address this limitation while preserving peer support benefits, though they remain largely unexamined in dermatologic conditions.[8,12]

This study aimed to assess whether participation in a dermatologist- and urogynecologist-led virtual support group could improve QOL among women diagnosed with VLS.

Patients and Methods

Study Design and Participants

This randomized controlled trial was conducted in Edmonton, Alberta, Canada. Participants were recruited from the Vulvar Dermatology Clinic at the Kaye Edmonton Clinic. Eligible participants were adults (≥18 years) with biopsy-confirmed or clinically diagnosed VLS, reliable internet access, and the ability to use Zoom. Participants were recruited at any point in their care trajectory, including newly diagnosed and established patients. Exclusion criteria included individuals in palliative care or inability to provide informed consent. Written informed consent was obtained from all participants. The study received approval from the University of Alberta Research Ethics Board (Pro00139121) and operational approval from the Northern Alberta Clinical Trials and Research Centre.

Sample size was estimated a priori using repeated-measures power analysis targeting the treatment-by-time interaction for a 2-arm study with 4 assessments (baseline and 3 follow-ups), based on considerations outlined by Guo et al.[13] In the absence of pilot data, plausible effect sizes and reasonable variance parameters were informed by published Vulvar Quality of Life Index (VQLI) data.[14] Based on a clinically meaningful effect size of 4.5 VQLI units, residual variance of 64, significance level (α) of .05, and power of 80%, we calculated a target sample size of 70 total participants equally distributed between both groups, with a minimum sample of 48 needed to detect statistically significant differences between treatment and control groups. Full details of assumptions and calculations are provided in the Supplemental File. Participants were randomized to intervention or control groups before baseline assessments using REDCap concealed allocation. The randomization sequence was generated by a statistician. Given the nature of the intervention, blinding of participants and facilitators was not possible. However, the statisticians were blinded. Surveys were self-administered by participants via REDCap, minimizing assessor bias.

Intervention

Both control and intervention groups received a 1 page VLS educational handout at enrollment in addition to standard clinical care (Supplemental Figure 1). The intervention group additionally participated in three 60 minute monthly virtual support group sessions jointly facilitated by a dermatologist and urogynecologist. Sessions accommodated 10 to 15 participants and included: (1) moderated question and answer sessions using anonymously submitted questions and (2) open discussion of participant-identified topics, including symptom management, comorbidities, emotional concerns, disease progression, risk for malignancy, sexual dysfunction, and interpersonal challenges. Participants could disable video and use pseudonyms to support privacy. Sessions were conducted via Alberta Health Services-approved secure Zoom platform and were not recorded. Sessions were scheduled on a rolling basis to accommodate continuous recruitment, with the first session occurring no earlier than 1 month after enrollment. Participants were encouraged to attend 3 consecutive monthly sessions, although this could not always be guaranteed due to scheduling constraints.

Measurement and Outcomes

The primary outcome was QOL assessed using the VQLI, a validated 15-item measure spanning 6 domains: treatment (treatment burden and experience), symptoms, feelings (psychosocial impact, including embarrassment, body image, and symptom-related distress), activities, relationships/sex, and future health concerns (Supplemental Table 1). Items are scored using a 0 to 3 point Likert scale, where increasing

scores reflect greater QOL impairment.[15] Total VQLI score ranges regarding the impact on QOL were as follows: minimal (0-5); mild (6-13); moderate (14-23); severe (24-37); and very severe (38-45).[14,16,17] We acknowledge The British Dermatological Nursing Group (BDNG) as the author of the original instrument.[18] Our selection of the VQLI reflects the priorities established in the recent "call to action" for standardized core outcome set (COS) in vulvovaginal disease.[19] The development of the VQLI incorporated extensive patient focus groups and expert consensus, adhering to the stakeholder-driven methodology recommended for COS development.[15,19]

Clinician-assessed disease severity was not collected at baseline as chart review and standardized in-person severity assessments were not included in the study protocol. The VQLI was selected as a proxy given prior demonstration that VQLI scores correlate with clinician-rated severity and capture key symptom domains essential to clinical assessment.[20]

The primary objective was to compare trajectories of total VQLI score within and between groups across 3 monthly follow-up timepoints. Secondary outcomes included domain VQLI change between baseline and follow-ups, in addition to qualitative data capturing topic preferences, perceived symptom changes, and feedback (Supplemental Table 2). Qualitative data were collected via optional open-ended free-text responses at baseline and follow-ups. Demographic data were collected at baseline (Supplemental Table 3).

Quantitative Analysis

Mixed-effects linear regression modeling with random intercepts for each participant was used to analyze differences in total and domain-specific VQLI scores between and within groups over time and within groups across follow-up. Mixed-effects modeling accounts for the hierarchical nature of the longitudinal data, while allowing for unequally spaced time points and missing outcome values over the course of follow-up.[21] Time at baseline and follow-up was operationalized as a dummy variable included in models as a categorical variable. All descriptive and analytic statistics were conducted on all participants who maintained consent and had complete baseline VQLI data (n = 68). Two participants withdrew after randomization and requested removal of their data in accordance with the approved ethics protocol; their data were therefore excluded. Mixed-effects modeling was used as it appropriately accommodates the resulting unbalanced repeated-measures data.

Qualitative Analysis

Free-text survey responses were analyzed using inductive thematic analysis.[22] Analysis was conducted via shared Excel spreadsheets. Two researchers (R.H. and A.K.) independently reviewed all responses multiple times to achieve data familiarization. Initial codes were generated and grouped into preliminary themes which were reviewed collaboratively, refined into subthemes where appropriate, and finalized by R.H. in consultation with the research team. Qualitative responses were collected via optional free-text fields within the prespecified study surveys rather than iterative interviewing. Data saturation was not used as a stopping criterion; instead, analysis continued until all available free-text responses across both groups and timepoints had been reviewed, coded, and organized into themes.

Results

Participant Characteristics

A total of 70 women participants were enrolled and completed baseline assessments. Two participants subsequently withdrew during the study period prior to follow-ups, resulting in 35 participants in the intervention group and 33 in the control group with case-complete baseline data included for analysis (Supplemental Figure 2). The mean age was 61 ± 11 years (median 64) in the intervention group and 57 ± 14 years (median 58) in the control group. The majority of participants identified as Caucasian (85%, n = 58), and most had never previously attended a support group (91%, n = 62). While baseline demographic characteristics were balanced between groups, mean VQLI was higher in the intervention group, likely reflecting chance imbalance. This informed our selection of a mixed effects modeling to appropriately model within and between group changes over time (Supplemental Table 3).

Quantitative Results

Mixed-effects linear regression modeling demonstrated significantly different quality-of-life trajectories between the intervention and control groups over time (Supplemental Table 4). Relative to the control group, the intervention group experienced a significantly greater decline in average total VQLI scores of 4.1 units (β: −4.1; 95% CI: −8.2 to −0.009), 8.3 units (β: −8.3; 95% CI: −12.6 to −4.0), and 10.3 units (β: −10.3; 95% CI: −14.9 to −5.6) from baseline to the first, second, and third follow-up, respectively.

Within the intervention group, mean estimated VQLI decreased from 21.2 (95% CI: 17.8-24.6) at baseline to 18.4 (95% CI: 14.6-22.1) at the first follow-up (Δ: −2.8, *P*: .069), followed by a decrease to 13.7 (95% CI: 9.8-17.6) at the second follow-up (Δ: −4.7, *P*: .005) and 12.7 (95% CI: 8.5-16.9) at the third follow-up (Δ: −1.0, *P*: .59), representing an overall decrease of 8.5 units (Δ: −8.5, $P < .001$) from baseline to follow-up (Figure 1). Conversely, the control group did not experience any statistically significant changes in mean estimated VQLI at any time point (eg, overall Δ: +1.8, *P*: .24; Figure 2).

Similar decreases among mean VQLI domain scores among the intervention group relative to the control group were observed for all 6 VQLI domains (Supplemental Table 5). Specifically, the intervention group experienced significantly

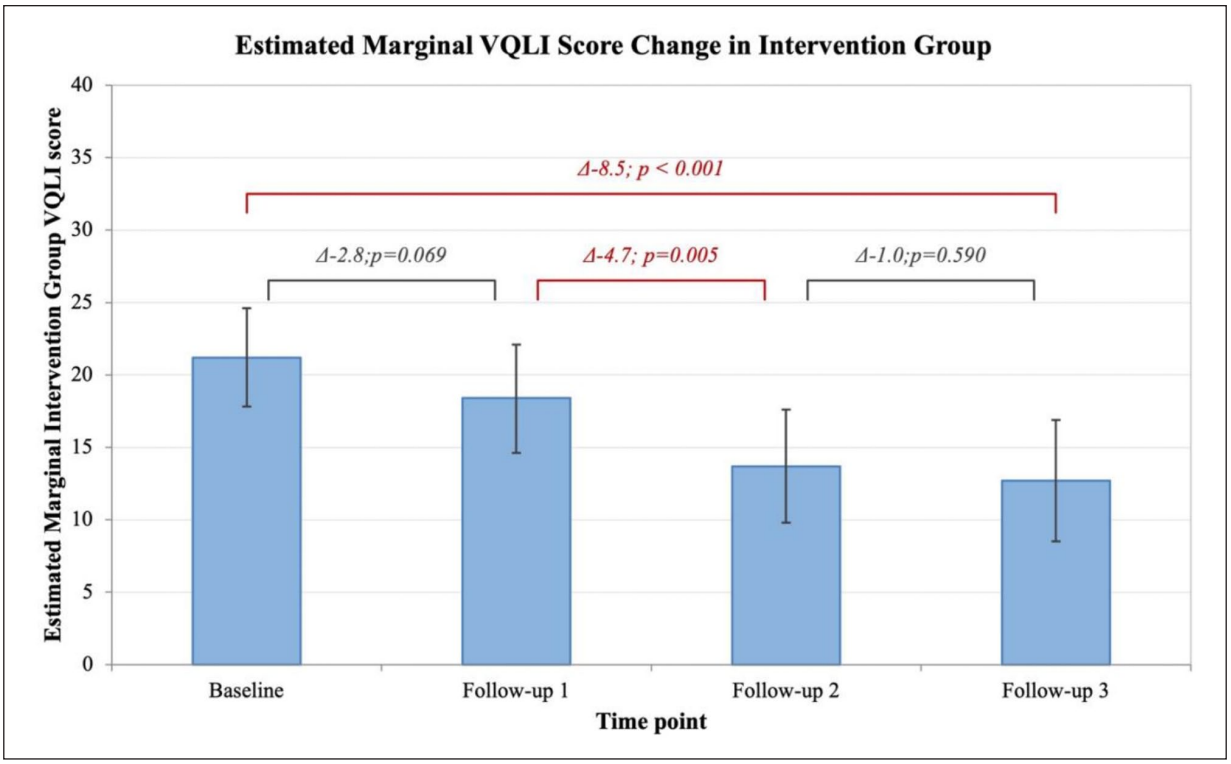

Figure 1. Average VQLI score change from baseline to follow-ups (1-3) in intervention group. VQLI, Vulvar Quality of Life Index.

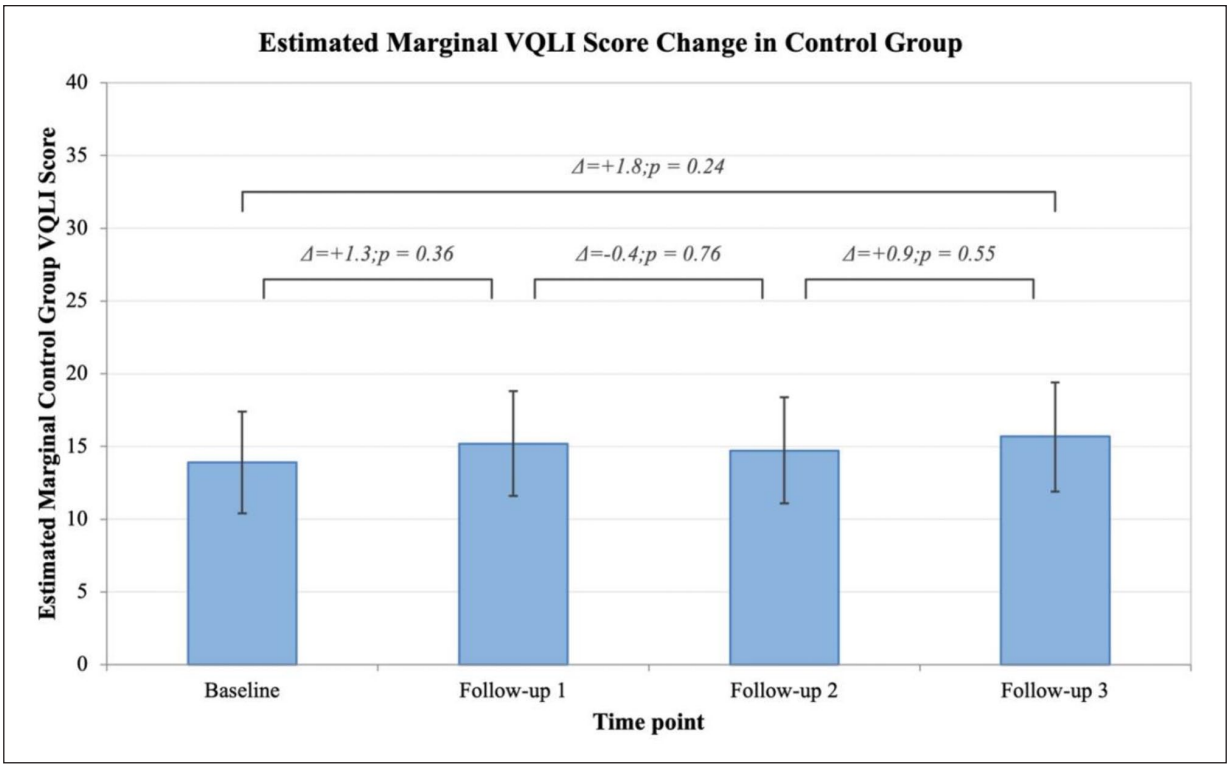

Figure 2. Average VQLI score change from baseline to follow-ups (1-3) in control group. VQLI, Vulvar Quality of Life Index.

Table 1. Themes From the Control Group's Narrative Feedback.

Theme	Illustrative quotes
Gap in knowledge sharing	"*I. . .haven't received. . .educational materials except for one sheet when I was first diagnosed*" "*I need more access to information when I have a flare up*"
Insufficient ongoing provider support	"*I wish I could [have] more follow up appointments [from healthcare providers] just to show that my symptoms aren't made up*" "*What to do if the steroid creams are not relieving symptoms*" "*I still can't get used to applying both creams [because they are] very messy*"

greater declines in scores relative to baseline at all follow-up points for the feelings domain; at the second and third follow-up points for the relationships/sex, symptoms and future health concerns domain; and, at the third follow-up point for the treatment and activities domains.

Qualitative Results

Baseline Topics of Interest. At baseline, 55 out of the 68 participants provided free-text comments on the qualitative survey identifying topics of interest for support group sessions. Seven topics emerged, listed from most to least frequently requested: (1) symptom management in daily life, (2) prognosis and complications, (3) medical knowledge about VLS, (4) impact on sexual function, (5) cancer risk, (6) body image and coping with shame, and (7) dietary modifications (Supplemental Figure 3).

Patient-Reported Symptom Changes. Among intervention participants who completed at least 2 qualitative follow-up surveys, the majority (n = 11/16, 69%) reported mild to significant symptom improvement. Participants attributed these improvements to "incorporation of some of the tips and strategies learned about in our sessions" and having "better understanding of good treatments and ideas for support during flare-up times." Of the 5 participants reporting no change, one noted their symptoms were already well-controlled at baseline. No participants reported worsening of symptoms.

Among control participants who completed at least 2 qualitative surveys (n = 26), 8 (31%) reported mild to significant symptom improvement. Two participants attributed this to learning proper steroid cream application technique from the educational sheet, while 6 did not specify what prompted the change. Fourteen participants (54%) reported no change in symptoms, and 4 (15%) reported worsening symptoms or flares.

Thematic analysis of qualitative feedback from the intervention group showed evolving themes with several subthemes (Supplemental Table 6):

a. *Theme 1: Stigma Surrounding VLS in Everyday Life.* Three subthemes were identified: major social barriers, highlighting the difficulty discussing their condition openly; need for more patient education and accessible resources, with participants expressing strong interest in reliable information sources; and lack of knowledge among health practitioners, with participants expressing concerns about provider knowledge gaps outside specialty clinics.
b. *Theme 2: Empowerment Through Community.* This theme encompassed 2 subthemes: social support, with participants describing feeling validated and less isolated in their experiences; and improved mental health, with participants reporting reduced worries, embarrassment, and anxiety about their condition.
c. *Theme 3: Need for Knowledge Sharing.* Two subthemes emerged: importance of patient storytelling, with participants valuing hearing others' experiences and learning practical coping strategies; and value of expert facilitation, with participants appreciating the informational benefit and proactive symptom management guidance from the joint management with dermatologist and urogynecologist.

Two themes emerged from control group qualitative feedback. The themes did not evolve over the course of the study (Table 1).

a. *Theme 1: Gap in Knowledge Sharing.* Participants expressed that the onus fell disproportionately on them to "do as much research as possible" to understand their condition and managing symptom flares.
b. *Theme 2: Insufficient Ongoing Provider Support.* Participants desired more frequent clinical touchpoints for symptom validation treatment technique reinforcement, and knowledge about second line options.

Discussion

This randomized controlled trial demonstrates that participation in an expert-led virtual support group significantly improves QOL among women with VLS. To our knowledge, this is the first evaluation of a physician-facilitated online support intervention for VLS. Between group analyses demonstrated significantly greater reduction in VQLI scores from baseline to all 3 follow up points in the intervention group

when compared to control. This divergence highlights the incremental and cumulative benefit of structured support beyond standard medical care and educational materials alone.

Within the intervention group, VQLI showed a significant overall reduction of 8.5 units from baseline to final follow-up ($P < .001$), whereas control group scores remained stable through all 3 follow ups. Notably, improvement was most pronounced between the first and second follow-up, suggesting cumulative benefit and supporting a multi-session rather than single-touch model.

When interpreted using VQLI's severity categories,[14,16,17] the intervention group improved from the *Moderate* severity range (14-23) at baseline to the *Mild* severity range (6-13) by the third follow-up. The control group started at the lower end of the *Moderate* severity range (14-23) and did not cross severity categories by the third follow-up. In the absence of a formal minimally clinically important difference (MCID) value for the VQLI, the intervention group's shift across severity categories, together with our qualitative analysis, offers supportive evidence that the intervention's benefits also reflect a clinically meaningful improvement. However, an important consideration to note when interpreting these findings is that the lower baseline severity in the control group may have left less room for measurable change, and the final follow-up scores in both groups were relatively close in magnitude.

The intervention yielded significant improvements in the feelings and relationships/sex domains, with feelings reaching significance as early as the first follow-up. The feelings domain captures embarrassment, body image, and symptom-related distress. This mirrors the qualitative theme of empowerment through community, with recognition of shared experiences mitigating the profound sense of isolation and "being different" reported by participants. Furthermore, the improvement to relationships and sex domain underscores the value of the study's interdisciplinary leadership; the inclusion of an urogynecologist alongside a dermatologist likely facilitated specialized resource-sharing regarding intimacy, maximizing the support available for this high-priority domain.

The activities domain showed significant improvement only at the third follow-up, likely reflecting the latency required to modify ingrained daily behaviors and routines. In contrast, the future health concerns domain, which captures anxiety about long-term prognosis including malignancy and fertility, showed significantly greater improvement in the intervention group from the second follow-up onward, suggesting intervention helped translate prognostic information into a meaningful reduction in worry.

Our qualitative analysis suggests that the intervention group may have provided benefits through both the mitigation of disease-related stigma and isolation while simultaneously improving treatment adherence. In addition to significant quantitative improvements to the symptoms and treatment VQLI domains, intervention group participants specifically noted better understanding of proper topical corticosteroid application and strategies for managing symptom flares. The difference between the intervention and control group aligns with the distinction between health literacy as the "capacity to think" versus the "capacity to act."[23,24] While written materials provided to all participants likely improved cognitive understanding, interactive expert facilitation appeared necessary to bridge the gap to self-efficacy and effective disease self-management.[24]

Control participants in the study noted the burden of self-education, consistent with reports that under 40% of primary care residents feel adequately prepared to manage dermatologic conditions.[25] Our expert-facilitated model preserved established benefits of peer support,[10,26] reducing isolation, increasing hope, and coping strategies, while ensuring the clinical and scientific accuracy often lacking in peer-only formats.[1]

Limitations include the predominantly Caucasian sample (85%), reducing generalizability to diverse populations where cultural determinants of stigma and help-seeking behaviors may differ. Recruitment from a specialized clinic may have selected for patients with higher baseline disease engagement than community populations. The 4 month duration precludes assessment of the long-term durability of the QOL improvements. A further limitation is the baseline imbalance in VQLI scores despite concealed randomization. This difference should be considered when interpreting the magnitude of the observed treatment effect. Future studies should consider larger sample sizes and analysis of a balanced baseline population to better isolate the effect of the intervention.

The knowledge gaps identified should inform continuing medical education in primary care, [25] in addition to integration of these topics into institutional dermatology platforms and primary care toolkits.[27] Future implementation should evaluate a stepped-care model,[23] in which patients transition from expert-led induction phase to a peer-led maintenance group, allowing for scalable support while optimizing specialist availability.[23] Defining the optimal duration of expert involvement, and prospectively identifying newly diagnosed versus established patients to determine the impact of disease chronicity on intervention response, are key priorities for larger studies.

In conclusion, expert-led virtual support groups represent a potentially high-impact and scalable adjunct to medical therapy, designed to be low-cost and accessible, though formal evaluation of implementation burden and cost-effectiveness warrants future study. Our findings support the integration of structured virtual support into routine care to bridge the gap between clinical recommendations, and effective daily management. Furthermore, our model may be adapted for dermatologic and gynecologic conditions where patients face similar barriers to comprehensive care.

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Ethical Considerations

The Health Research Ethics Board at University of Alberta approved our study (approval: Pro00139121) on March 21, 2024.

Consent to Participate

Written consent was obtained for all participants of the study.

Consent for Publication

All participants consented to anonymized publication of their qualitative and quantitative survey results.

Author Contributions

Marlene Dytoc: conceptualization, study design, methodology, supervision, intervention implementation, and drafting of the manuscript. Aakankshya Kharel: conceptualization, study design, data collection, formal analysis (thematic analysis), and drafting of the manuscript. May Sanaee: methodology, intervention implementation, supervision, and drafting of the manuscript. Rose He: formal analysis (thematic analysis) and drafting of the manuscript. Pamela Mathura: study design, methodology, and critical revision of the manuscript. Parsa Abdi: formal analysis (statistical) and critical revision of the manuscript. Samuel A.J. Lowe: formal analysis (statistical) and critical revision of the manuscript.

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Declaration of Conflicting Interests

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Data Availability Statement

The datasets generated during and/or analyzed during the current study are available from the corresponding author on request.

Supplemental Material

Supplemental material for this article is available online.

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