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A Multidisciplinary Approach to Vulvar Lichen Sclerosus Care

Announcer:
You're listening to *DermConsult* on ReachMD. This episode is sponsored by LEO Pharma. And now, here's your host, Dr. Charles Turck.

Dr. Turck:
This is *DermConsult* on ReachMD, and I'm Dr. Charles Turck. Joining me to discuss how collaborative care can improve outcomes for patients with vulvar lichen sclerosus are Drs. Christina Kraus and Jill Krapf.

Dr. Kraus is a dermatologist at Kaiser Permanente in Southern California. Dr. Kraus, thanks for being here.

Dr. Kraus:
Thank you so much for having me.

Dr. Turck:
And Dr. Krapf is an obstetrician-gynecologist and the Director of the Center for Vulvovaginal Disorders in Tampa, Florida. Dr. Krapf, it's a pleasure to have you with us as well.

Dr. Krapf:
Thank you.

Dr. Turck:
Vulvar lichen sclerosus sits at the intersection of dermatology and gynecology, and patients may present to either specialty. So if we start with the gynecologist's perspective, Dr. Krapf, what clinical features raise suspicion for vulvar lichen sclerosus, and when do you feel it's important to involve a dermatologist?

Dr. Krapf:
Anytime a patient tells me that they have persistent vulvar or perianal itch, my differential diagnosis always includes lichen sclerosus, especially if the patient is peri- or post-menopausal. Other major indicators, especially in my younger patients, include pain with intercourse or recurrent fissuring or tearing.

~~A~~lthough peak times for diagnosis of lichen sclerosus are in menopause and prior to puberty, we know that there are many women of reproductive age that have this condition. So a few years ago, I conducted a study of over 500 women aged 18 to 50, and we actually found that in this age group, they more commonly present with sexual pain and tearing rather than classic itch. That's likely why younger women are often misdiagnosed as having recurrent yeast infections or sometimes as even herpes simplex. So overall, there's an average of a four-year delay in the diagnosis for lichen sclerosus, so detection is really key.

So in exam, the major findings are loss of pigment on the vulva, the perineum, and the perianal area; thickened skin texture, which looks like crinkled wax paper; and fissures and sometimes bruising. And it's really essential to look for architectural change. The disease can cause resorption of the labia minora. It can cause agglutination or sticking of the labia minora to the majora and coverage of the clitoris, either partially or completely—we call this clitoral phimosis—as well as narrowing of the vaginal opening. So it's always essential to check for clitoral adhesions and phimosis, even in patients who aren't symptomatic.

So a gynecologist can involve a dermatologist when the diagnosis is uncertain, atypical, or refractory, and particularly when it's difficult to distinguish from other vulvar dermatoses—for example, psoriasis or eczema, contact dermatitis, other inflammatory conditions. I would also refer to a dermatologist if there's extragenital lesions or if the patient needs a more systemic treatment course, such as a biologic.

Dr. Turck:
Turning to you now, Dr. Kraus, when you're evaluating a patient with suspected vulvar lichen sclerosus, what examination findings help confirm the diagnosis, and when is a biopsy warranted?

Dr. Kraus:
Dr. Krapf really covered some of those classic clinical findings, which are those white atrophic papules and plaques, often with the fissures. I think sometimes patients come in with fissures, and we don't always necessarily think of lichen sclerosus when it should be on our differential, and then purpura because of the dermal fragility.

Of course, it's important to remember that lichen sclerosus can be erosive or hyperkeratotic, so these are also things to think about. And then like Dr. Krapf mentioned, looking for those architectural changes because that's really going to help you distinguish, does this patient have this established disease, and then maybe they have something else going on? Or is it something else entirely, like allergic contact dermatitis or something else? So looking for those architectural changes can be really helpful. The vaginal mucosa is characteristically spared in most cases of vulvar lichen sclerosus, and that can help us a little bit differentiate vulvar lichen sclerosus from erosive lichen planus.

And in terms of when I consider a biopsy, it's anything where you're diagnostically uncertain. If you're not sure if it's lichen sclerosus, if it has a slightly atypical appearance, any concern for malignancy, if you notice new areas where the skin or mucosa is maybe indurated, there's erosion, there's ulceration, there is a persistent lesion that's not responding to therapy, or new pigmentation, those are times when a biopsy is warranted. A failure to respond to conventional therapy would warrant a biopsy. And I really do maintain a low threshold for biopsy in these patients because of the risk of squamous cell carcinoma, especially in my patients who are immunosuppressed.

Dr. Turck:
Now, Dr. Krapf, I'd like to hear about your approach to treating newly diagnosed patients. How do you use high-potency topical corticosteroids, and what do patients need to understand about maintenance therapy and long-term adherence?

Dr. Krapf:
I tell newly diagnosed patients that lichen sclerosus is a chronic inflammatory condition and our goal is management while restoring quality of life and function. It's not simply just treating itch and then stopping therapy.

So gold standard treatment is high potency or ultra-potent topical corticosteroids. Although the most common steroid for lichen sclerosus is clobetasol, there are also other options, and I utilize those options. I try to match the patient's clinical presentation with the appropriate topical steroid choice and dosing regimen. I do prefer an ointment over a cream, though.

So for patients with active lichen sclerosus, I may use a topical steroid ointment once daily for anywhere between two to four weeks and then decrease to every other day for two to six weeks and then down to twice weekly. The exact regimen is individualized, and this is very important. It's based on disease severity and the patient's response.

And once we get down to a twice weekly maintenance regimen, it's really important to continue this even when the symptoms improve. So regular follow-up is important because we need to ~~d~~ assess disease activity, anatomy changes, and adherence to the regimen and really ensure that there's no progression to a pre-cancer or a cancer. Patients with lichen sclerosus have an increased risk of squamous cell carcinoma in the area, so ongoing surveillance and reporting any new changes or areas that look different is essential.

Dr. Turck:
Even with high-potency topical corticosteroids, some patients continue to have persistent symptoms or uncontrolled disease. So, Dr. Krause, how do you approach further treating these patients, and where are you seeing the greatest unmet needs?

Dr. Kraus:
So the first move when disease is labeled as refractory is to really find out if the disease is truly refractory rather than immediately escalating therapies. There are studies that have shown that 30 to 40 percent of patients do report persistent symptoms even after using that standard corticosteroid course.

But true steroid resistance tends to be less common. Usually, there are other reasons a patient may not want to use a steroid. So first, you want to confirm you have the right diagnosis. Assess the patient's adherence and how they're applying their medication. I just saw a patient in clinic yesterday who was applying it to an area that didn't have any lichen sclerosus. So really assess where they're putting their medication; this is often a common culprit of non-adherence. And then identify any confounders. Do they have superimposed allergic contact dermatitis? A candidal or bacterial infection? Is there urinary incontinence or estrogen deficiency that's contributing, and

is that actually driving ongoing symptoms instead of their lichen sclerosus?

And then once you've confirmed, yes, it is truly refractory lichen sclerosus, options to think about are intralesional corticosteroids, usually something like triamcinolone at ten milligrams per cc, usually one cc total. It can vary a little bit. But of course, you don't want to treat any thick areas where you're worried about malignancy. You would want to make sure you're doing a biopsy first before injecting those areas. Topical calcineurin inhibitors like tacrolimus and pimecrolimus are commonly used. They are steroid sparing, but of course, they do have less evidence than our topical steroid regimens, and they can be associated with burning on that skin. And then there's a lot of other mostly case reports and case series looking at systemic therapies like oral retinoids, some biologics off label, and some small molecule inhibitors.

And then thinking about adding adjunctive therapies depending on your patient's disease control and their use of topical steroids; do you think about adding a fractional CO_2 laser or erbium YAG laser if they have more of that hyperkeratotic tissue?

I think really the overarching unmet need in vulvar lichen sclerosus is just the history of a lack of high-quality randomized data and validated standardized outcomes, which makes it really challenging to move beyond our recommendations for first-line topical steroids because of this.

It's really exciting to hear about the promise of small molecule inhibitors, specifically the JAK inhibitors, and I know there's been a few cases reported on systemic JAK inhibition. Some of our studies have shown potential mechanisms that would support that. I know there are studies ongoing looking at topical JAK inhibitors.

Dr. Krapf:
Yes. There is a current study that is ongoing. It's a very large study with 80 sites across the world, which is very exciting for lichen sclerosus research.

Dr. Turck:
For those just joining us, this is *DermConsult* on ReachMD. I'm Dr. Charles Turck, and I'm speaking with Drs. Christina Kraus and Jill Krapf about multidisciplinary management of vulvar lichen sclerosus.

Now, if we look beyond physical findings, Dr. Krapf, what are the psychosocial impacts of vulvar lichen sclerosus, and how do you approach conversations about potentially sensitive topics, particularly with younger patients?

Dr. Krapf:
I think it's important to recognize that vulvar lichen sclerosus can affect much more than just the skin. Patients may experience chronic itch, burning, and pain, but there's also embarrassment, altered body image, anxiety about the appearance of the vulva, and fear about the chronic nature of the condition or the cancer risk that's associated, and this has significant effects on intimacy as well as sexual function.

There was a systematic review and meta-analysis that found sexual dysfunction in roughly 60 percent of women with vulvar lichen sclerosus, and pain during intercourse was particularly common in their findings. So I try to make these conversations routine. Studies show that patients typically don't bring up concerns about sexual health, and doctors really don't ask. So I try to normalize the conversation. I have the patient fill out a questionnaire about sexual function as a part of their preparation for a new visit, and then I do ask about intimacy. I ask about relationships as well as body image.

I want patients of all ages, but particularly my younger patients, to understand that this is not their fault. It's not a sexually transmitted infection. They really haven't done anything to cause this. It's particularly important because vulvar symptoms often carry a lot of stigma, and I emphasize that effective treatment can really control the inflammation and help prevent progression. We don't want the diagnosis to become something that defines how they feel about their body or their sexuality.

Dr. Turck:
Now, when it comes to long-term surveillance, Dr. Krapf, what do you see as the gynecologist's role in monitoring progression and reinforcing adherence over time? And what changes would prompt you to refer to a dermatologist?

Dr. Krapf:
Lichen sclerosus is a chronic condition, and the relationship with the patient often extends over many years between a patient and their gynecologist. So at follow-up, I'm looking at not only whether the patient feels better, but whether the inflammation is controlled and whether there's progression of scarring or architectural changes. Is the patient using the maintenance medication correctly? Are there any things that we can add to facilitate their use of the medication or to simplify their regimen?

I also reinforce that maintenance treatment is not something patients should discontinue once symptoms disappear. I ask specifically

how often they're applying the steroid, where they are applying it to make sure they're applying it in the right locations, whether they have concerns about steroid safety, especially long-term use, and whether there's any inconvenience that's getting in the way of them following the regimen. And I also encourage patients to become familiar with their own vulvar anatomy and really report any changes rather than waiting for their next routine visit.

So for general gynecologists who may not see as many cases of lichen sclerosus, it's completely fine and encouraged to have a low threshold for referral if the condition is atypical or if it's difficult to manage. And this includes uncertain diagnosis, unusual distribution or morphology, persistent symptoms, or if the disease is refractory to standard treatment regimens. And then another indication for referral would be if there's overlap with other vulvar dermatoses.

In addition, there are vulvar specialists, such as myself, who provide specialized scar release procedures for clitoral phimosis and introitus stenosis to decrease pain and restore function. There's a directory of clinicians available through the International Society for the Study of Vulvovaginal Disease, or the ISSVD directory.

Dr. Turck:
And finally, Dr. Kraus, what do you see as the essential elements of long-term collaborative care between dermatologists and gynecologists, uh, particularly when it comes to monitoring for scarring in vulvar squamous cell carcinoma?

Dr. Kraus:
Really, effective co-management between dermatology and gynecology, I think, should center on two main principles. Maintenance therapy is disease-modifying, and so it's a shared responsibility amongst our specialties to really encourage patients to use their maintenance therapy to help maintain normal skin texture and color, prevent scarring, and protect against cancer.

And then the cancer surveillance piece, because, of course, these patients are at risk, especially our older patients and those who have long histories of lichen sclerosus that's been undertreated or untreated or a history of vulvar intraepithelial neoplasia.

Dr. Turck:
Great way to round out our discussion. And I want to thank my guests, Drs. Christina Kraus and Jill Krapf, for joining me to share their perspectives on collaborative care for vulvar lichen sclerosus.

Dr. Kraus, Dr. Krapf, it was great having you both on the program.

Dr. Krapf:
Thank you.

Dr. Kraus:
Thank you so much for having us.

Announcer Close
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