

An Interview on Vulvar Lichen Sclerosus with Dr. Hope Haefner

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Hope K. Haefner, M.D., is a Professor in the Department of Obstetrics and Gynecology at the University of Michigan Hospitals in Ann Arbor, Michigan where she received her medical degree. Dr. Haefner completed her obstetrics and gynecology residency at the University of Michigan Medical Center in 1990. She completed a fellowship in gynecologic pathology in 1993. She opened the University of Michigan Center for Vulvar Diseases in 1993. It is one of a few clinics in the United States that specializes in treating these conditions. She has a particular interest in lichen sclerosus, lichen planus, vulval intraepithelial neoplasia, and hidradenitis suppurativa. Dr. Haefner is the past president of the International Society for the Study of Vulvovaginal Disease and the American Society for Colposcopy and Cervical Pathology.

She was interviewed by Fabia Brackenbury recently. Below are questions she was asked and her responses.

Fabia Brackenbury: How important do you feel awareness is for lichen sclerosus (LS) and vulval health is?

Hope Haefner: Awareness of vulval health, in particular the vulval condition known as lichen sclerosus, is extremely important.

Fabia Brackenbury: Do you have any suggestions or ideas on how it can be achieved? I have been trying to increase awareness for 20 years and I do not believe media is the way to go. I believe that the women of the world need to start forming communities in their towns and cities and network within their own locality. If many women could do this, the awareness would spread.

Hope Haefner: I agree completely with your thoughts on needing to form communities across the world to increase awareness on vulval lichen sclerosus. This process has been proposed for other vulval problems such as vulvodynia. It has worked well for the Society of Gynecologic Oncology and patients with ovarian cancer. However, they have funding that allows them to put on meetings for patients and family members every few months in various cities. If there were funding for this, I think that is an ideal format for education.

Fabia Brackenbury: I have a group of women on the internet, (mainly with VIN) who wanted to have a name and identity, so that when people have the courage to talk about their vulva issue, they can do so with as much pride as anyone else. I came up with 'Vulvateer' - the women love it because it sounds like Muskateer, the story of the Three Muskateers was all about one for all and all for one. A solid community dedicated to each other. I have, today, put this on my website as a 'teaser' to see if it will encourage or inspire anyone to take some action. It does not have to be loud or on TV, it can be gentle and discreet. I had this quote from

one of my Vulvateers today:

Vulvateer : Rather than saying I have LS or I have some other condition, saying 'I am a vulvateer', I think gives women a sense of pride instead of all the negative things that can come with having a vulva condition. If that makes sense?

Hope Haefner: Could you please expand on what is a Vulvateer?

Fabia Brackenbury: A Vulvateer is the name given to any woman who is living with a vulval skin condition or anyone who is actively supporting the awareness programme to encourage better education and awareness for lichen sclerosus and vulval health. In time, the Association hopes that women will join the Vulvateers Action Group. This will be about starting a meeting and sharing community in your own town or city and taking part in the Vulvuary month. If you want to be more pro-active for LS, then become a Vulvateer and email Fabia to find out how. Next year it would be good to have some information available for every woman in any location in the world, to include in the March 8 International Women's Day (IWD) events. Next year, it is proposed to take a stand at the IWD event in Brighton, England. If you live in Brighton or London and want to take part, help, organize, speak to Fabia.

Hope Haefner: That sounds like a great idea. Let me give you some information that may be helpful to increase patient and provider knowledge of vulval lichen sclerosus. One question you had asked me was on blistering and lichen sclerosus. You asked, when treating LS patients with blistering, what treatment do you find most effective and what advice are you able to give to these patients? First of all, I would want to know if this is really LS. Blistering can occur with many other vulval diseases. The most common is herpes. When herpes first occurs, it is often a blister that lasts for a short period, then becomes an erosion (loss of epidermis). An ulcer is deeper, going into the dermis. Could the patient have pemphigus or pemphigoid? There are other conditions associated with blistering that should be considered. I almost always do a culture for candida because fissures can be from candida.

For erosions and lichen sclerosus, then the treatment depends on where the erosion is occurring. If it is at the 6:00 position of the vestibule, as a fissure, then I initially treat those patients with vaginal dilation, lubrication, topical steroids and at times, topical estrogen. If the "blistering" is from LS, then getting the disease under great control is important. Long term topical steroids (in an ointment base) are required. I occasionally use oral steroids or occasional intramuscular steroids (into the gluteus muscle).

Fabia Brackenbury: Many health care providers believe LS to be a significant trigger for vulval pain/vulvodynia. Are you able to share any information about this – has this been proven to be true?

Hope Haefner: In 2007, one of our research groups published an article entitled, "The Impact of Vulvar Lichen Sclerosus on Sexual Dysfunction" (Haefner HK, Aldrich NZ, Dalton VK, Gagne' HM, Marcus SB, Patel DA, Berger MB. J Womens Health. 2014 Sep;23(9):765-70).

It was a study designed to examine the relationship between LS and sexual dysfunction. The findings were that women with LS reported less frequent sexual activity than healthy controls, as well as a control group of women with Candida. Sexually active women with LS were significantly less likely to report vaginal intercourse than healthy controls or Candida controls. Satisfaction towards the quality of current sexual activity was significantly lower among women with LS compared with both the healthy and Candida control groups. 23.7% of women with LS reported that sexual activity was rarely or never satisfactory as compared with 0% of healthy controls and 6.5% of Candida controls. The conclusion of the study was that women with LS have less frequent sexual activity and less satisfying sexual activity when compared with controls.

While the definition of vulvodynia is associated with a normal appearing vulva, many patients with lichen sclerosus have vulval pain. We tend to treat this pain similarly to the way we treat patients with normal appearing vulvas who have vulvodynia.

Fabia Brackenbury: The current treatments for vulval pain in the UK are usually by the use of oral treatments i.e. amitriptyline, gabapentin, pregabalin, etc. In the UK, we hear a lot about the USA using topical gabapentin, vaginal valium, other topical applications. Do you have any experience of using these and are you able to say how effective topical treatment is in comparison with oral medications?

Hope Haefner: We use many different topical compounded medications. There are a variety of compounding pharmacies in the United States. However, currently one needs to use a compounding pharmacy in the state they live in. Below is a summary of the various compounded medications that are utilized for vulval pain control.

2% amitriptyline + 2% baclofen in water washable base (WWB)	0.5 cc to vulva nightly	Can increase gradually to three times a day
2% amitriptyline + 2% baclofen + 5% gabapentin in WWB	0.5 cc to vulva nightly	Can increase gradually to three times a day
2% ketamine + 6% gabapentin + 2% baclofen in WWB	Apply to skin nightly	Can increase gradually to three times a day
2% ketamine + 6% gabapentin + 2% lidocaine	Apply to skin nightly	Can increase gradually to three times a day
6% gabapentin + 2% baclofen	0.5 cc to vulva nightly	Can increase gradually to three times a day

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Other topical medications that can be used include: 5% lidocaine ointment, estradiol 0.1% and lidocaine 5% in an ointment or Versabase cream. We also use intravaginal valium for vaginal pain.

Fabia Brackenbury: One of the most common complaints for women is the issue of tearing at the vaginal entrance. Are you able to speak about this and offer some helpful guidance on treatments? Possible causes other than LS?

Hope Haefner: Fissures is what you are describing. They are tears on the entranceway, common at the 6:00 position. Fissures have a variety of etiologies—they can be seen with LS, herpes, Crohn’s and Candida, or a combination of these conditions. As mentioned earlier, I tend to do a Candida culture, and identify the yeast species if present. If positive, I treat with an antifungal that that species is generally sensitive to. Health care providers should consider PCR for herpes, and /or HSV 1 and 2 serology. Dependent on the appearance of the vulva, they should consider Crohn’s disease. If it is lichen sclerosus causing the fissure, then topical steroids, including a topical estrogen, as well as vaginal dilators are recommended. The vaginal dilation is performed following the tearing. If that fails, a perineoplasty (excision of the torn area with some skin nearby) can be performed.

Fabia Brackenbury: Do you offer remedial surgery for women who have fused clitoral hoods and can you say what the outcomes are?

Hope Haefner: I try to avoid surgery for prepuce scarring, particularly if the patient is orgasmic. I try many other things to improve orgasm first, such as the WeVibe or other vibrators. On occasion, I will release the prepuce scarring surgically. After the scarring is released, I inject the nearby tissue with triamcinolone at the time of surgery to try to reduce scar reformation. I also have the patient restart topical clobetasol and topical estrogens. I will, on occasion, use a lacrimal duct probe after applying LMX to the prepuce and clitoris (in the operating room or at a post op visit if there is any early reformation of scarring). Drs. Andrew Goldstein and Lara Burrows have published on this topic. They are currently researching a larger population of patients and plan to present their findings in the near future (Goldstein AT, Burrows LJ. Surgical treatment of clitoral phimosis caused by lichen sclerosus. Am J. Obstet Gynecol 2007;196:126).

Fabia Brackenbury: Are there cases where the LS comes back after a few years and affects the hood again?

Hope Haefner: Yes. Reoperation for these cases has been reported. Again, I try to minimize the surgery by encouraging other options to utilize prior to surgery.

Fabia Brackenbury: Are you able to offer any advice on how to avoid clitoral hood fusion?

Hope Haefner: While a study has not been done on this, for years I have recommended that patients with LS or LP lift back on the prepuce as part of their shower routine to hopefully prevent adhesion formation. I believe patient with LS need to keep the disease under good control with long term topical steroids.

Fabia Brackenbury: Are you able to explain the role of Estrogen in the treatment of LS? (Oral, topical and vaginal)

Hope Haefner: Since the women's health initiative, we have seen a rise in patients presenting to our clinic with LS. I think that the topical and systemic estrogens may have kept the symptoms of LS at bay.

Fabia Brackenbury: I have many contacts from the USA who are confused about which doctor is the best to see, a gynaecologist or an gynae oncologist? Or should a USA women see both?

Hope Haefner: A vulval specialist is a health care provider interested in vulval disease. To name of few of these providers, they may be gynecologists, dermatologists, gynecologic oncologists, nurse practitioners or physician assistants with a special interest in vulval disease. The most important thing a patient with lichen sclerosus can do is find a health care provider to work with them and provide close follow-up.

Fabia Brackenbury: Are you able to offer any helpful advice for looking after the vulval skin post surgery for VIN? (This would apply to vulval cancer surgery too.)

After wide local excision of the vulva or radical vulvectomy, I recommend a dressing stay on for 24 hours (sterile 4 x 4's covered by an ABD pad), then after 24 hours, leave the vulva to air as much as possible. Wearing boxer underwear, if underwear must be worn, provides extra air, and less rubbing on the vulva.

In patients with lichen sclerosus, the more common form of VIN we see is VIN differentiated. This is a precancerous condition. It is more worrisome than the precancerous condition of the vulva associated with human papilloma virus, high-grade squamous intraepithelial lesions (HSIL), previously termed vulvar intraepithelial neoplasia 2 or 3 (VIN 2 or 3). The VIN differentiated is treated with wide local excision of the skin with adequate margins (generally 1 cm if possible).

For HSIL of the vulva, laser can be done. HSIL of the vulva also can be seen in patients with lichen sclerosus. Below are the instructions for vulval care after laser.

POST LASER INSTRUCTIONS

Apply cool gel packs for the first 12-24 hours. The cool gel packs should not be left in place throughout the entire 12-24 hour time period; instead it should be applied at 20 minute intervals with 1-2 hours between applications of ice packs.

Take a sitz bath three times per day with warm water and instant ocean, sea salt or Epsom salts. The duration of the bath should be approximately 15-20 minutes per bath and not to exceed three baths per day. Two tablespoons of the salt solution should be placed in a bathtub that is half full.

Pat dry the area gently.

Apply Silvadene cream (not to be used if you have sulfa allergies), Carrington's gel, or Bacitracin afterwards, provided no allergies.

Cleanse the area with salt-water solution after each void or bowel movement, if soiled and irritated. The salt-water solution to be used is 9% sodium chloride solution that is available at pharmacies or can be made by adding 1 tablespoon of salt to 1 quart of water, boiling the solution and cooling it prior to application.

Leave the vulva uncovered at night (no underwear) to allow adequate exposure to the air.

You will be given oral pain medication. At times, this can cause constipation; therefore, a stool softener may be needed.

Within 12-24 hours after laser surgery, redness and swelling on the vulva may occur. The worst pain may occur 2-5 days following the surgery. As the skin heals, it will begin to itch at times. Complete healing of the treated vulval skin generally occurs within 4-6 weeks.

Small amounts of bleeding may occur. If you start soaking a pad with blood in an hour or two hours, you need to contact us. Also, if you develop extreme redness around the lasered area or a foul discharge or fever, please contact your physician.

At times, if laser is performed at the vaginal opening, skin friability may result and tearing may occur. Notify your physicians if this occurs. Additionally, if the labia minora (small lips of the vulva) are lasered, they also can scar together and change the size of the vaginal opening. If these areas were lasered, separate them with gentle traction daily to keep them from attaching to each other. Vaginal dilation may be required.

Avoid intercourse until the region is healed and comfortable

Are you able to give a definition of 'clear margins' in relation to VIN?

The types of VIN are squamous (HSIL) and nonsquamous (Paget's disease and compound nevus with atypia, or melanoma in situ). A clear margin means that no disease is visible with the microscopic examination at the edge of the specimen. I try to get ½ to 1 cm margins for HSIL...but I do not re-excise for HSIL if margins involved. For nonsquamous disease (Paget's) disease, 1 to 2 cm margins are utilized. For compound nevus with atypia, I use ½ cm margin and for melanoma in situ, ½ cm to 1 cm margins. As long as no carcinoma is present (precancer), I do not re-excise for Paget's if the margins are positive. However, for compound nevus with moderate to severe atypia or melanoma in situ, if the margins are involved, I re-excise one time. If VIN differentiated involves the margins, I tend to re-excise.

Fabia Brackenbury: What is the future of Vulval Health Worldwide? How do you see the future for women with vulval conditions? Are there any new treatments? Proposed research? Are you able to say what the ISSVD's vision is for the future of vulva health?

Hope Haefner: Many more health care providers are developing an interest in vulval conditions. New treatments are on the forefront. The latest research is in the genetics of vulval disease. We need to get down to the basics of what is behind the disease, and then work on what will treat it best.