

## The Vulva Clinic in Umeå, Sweden – 18 Years of Challenges

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There have always been women with vulvar problems, but there have not always been vulva clinics. The Vulva Clinic in Umeå started in 1985, and since then there has been an enormous increase in the interest in vulvar diseases. When we started there were few reports published and only very few colleagues to consult and discuss with. Starting up a vulva clinic meant breaking new ground.

Many symptoms in vulvar diseases are dermatological, but there is an increasing group of women with vulvar dysaesthesia who really need multidisciplinary treatment. Women may either be referred by other phy-

sicians or self-referred. Some come to the genitourinary department first, after which they are referred to the vulva clinic. On average, 300–400 patients per year come to the vulva clinic.

When the clinic first opened, and for many years after that, gynaecologist and dermatologist together saw all patients. I believe this approach to be necessary in order to get a concordant view from the beginning.

It is crucial to have an experienced and dedicated nurse at the vulva clinic as the contact person for patients. The nurse answers the telephone, gives advice and takes a formal history, which she presents. This is the basis for deciding priority; when the patient should get an appointment at the clinic. The nurse is of importance for the patients as they call her whenever there is a problem concerning their disease and treatment, and she becomes a trusted confidant for many of these women.

It is also very important to have a counsellor or psychologist as a member of the vulva team. Many patients have had longstanding symptoms, which have severely interfered with their lives, and they need professional counselling as part of their treatment.

My approach has always been psychosomatic, which is a necessity when seeing women with e.g. vulvar dysaesthesia. Therefore the

counsellor is also a member of our vulva team. Not all women need to see a psychologist/counsellor, but should be given the opportunity when needed.

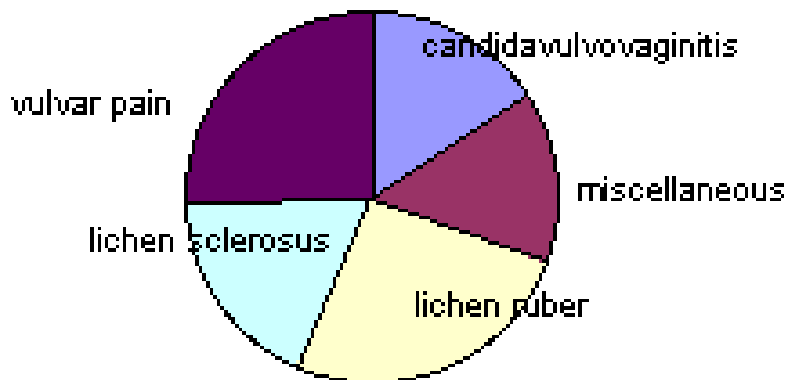
Another important member of the vulva team is the pathologist, who should be subspecialised in vulvar disease. This opens up the possibility of discussions and helps with making the best diagnosis.

A close collaboration with a specialised dentist is also needed, as many patients with symptoms from the genital mucous membranes have symptoms from the oral mucous membranes as well, and treatment thus needs to be integrated.

- *Miscellaneous* includes itching dermatitis such as eczema, psoriasis, lichen simplex
- *Lichen ruber* includes both “ordinary” lichen ruber and erosive lichen, with erosive lichen in the majority
- *Vulvar pain* includes vulvar dysaesthesia and vulvar vestibulitis syndrome

### Vulvar vestibulitis syndrome and vulvar dysaesthesia

Vulvar vestibulitis syndrome and vulvar dysaesthesia are conditions of pain, divided into two main groups, provoked and spontaneous, respectively. This terminology was revised in 2001 by the ISSVD (International Society for the Study of Vulvovaginal Disease).



The five large groups of patients at the Vulva Clinic in Umeå.

The largest group of localised vulvar dysaesthesia is vulvar vestibulitis syndrome. It is important to dismiss other causes of pain, e.g. dermatological conditions, where pain is secondary. A patient with vulvar dysaesthesia has no visible changes, the skin and mucous membranes being unaffected. The patient is often postmenopausal, and the pain is diffuse and constant, not provoked. The women with vestibulitis, on the other hand, are young, almost always <25-30 years, with a provoked pain, e.g. at penetration. There is tenderness and often also erythema in the vestibulum near the introitus. Treatment of these patients is long-term, and a team of specialists including counsellor/psychologist is needed.

### **Lichen ruber and erosive lichen**

Lichen ruber was first described in 1869, but erosive lichen not until 1982. Erosive lichen is one of the most severe diseases within dermatology as it affects several mucous membranes and heals with scarring,

causing severe symptoms such as difficulties in eating and swallowing.

Approximately 2/3 of the patients with cutaneous lichen also have lesions in the mucous membranes, whereas only about 1/5 have lesions in the mucous membranes. These figures emphasise the need of close collaboration with a specialist dentist who can help in taking care of these patients. It is also necessary to ask patients with cutaneous lichen about symptoms from the mouth and/or genital area, and investigate whether there are signs of the disease elsewhere. It is also important that dentists inquire about symptoms from the genital area or the skin.

Patients with erosive lichen have initially often been misdiagnosed. Symptoms are severe with pain, bleeding and a burning sensation and patients have ulcers both in the vulva, vagina and mouth. After some time they also get adhesions, making symptoms even worse. These patients need regular appointments at the vulva clinic as well as with a

specialist dentist. Treatment is immunosuppressive which also calls for regular check-ups. I believe erosive lichen is one of the toughest challenges within the field, and treatment must be individualised. These patients constitute a large group at our clinic due to a well established collaboration with a specialist dentist and a general and oral pathologist.

### **Lichen sclerosus**

Lichen sclerosus is a disease on its own, but related to lichen ruber. Some patients have symptoms of both diseases, e.g. lichen sclerosus in the vulva and lichen ruber in the mouth. Patients are severely affected by itch interfering with daily life and sleep. Some years ago no treatment, apart from surgery, was available, but now ultrapotent steroids are used with excellent results. Treatment is life-long and it is important that patients restart treatment as soon as symptoms reappear.

### **Candidavulvovaginitis**

The diagnosis chronic and/or recurrent candidavulvovaginitis seems to be increasing among women with candidosis. Acute candida infections cause typical symptoms of itching and soreness, but the recurrent infection causes more diffuse symptoms such as burning and pain. The physical examination also gives more discrete signs than does the acute infection. It is absolutely necessary to have a diagnosis by microscopical examination and

culture. In Umeå we have the advantage of having a laboratory that provides us with the pattern of resistance of these organisms. Patients often need long-term treatment.

### **Itch/miscellaneous**

The fifth and final group comprises patients with itching dermatoses such as eczema, psoriasis and lichen simplex. When handling these patients it is always important to inquire about other dermatological

conditions and look for symptoms from other parts of the body, which often have to be examined in order to make a proper diagnosis. Patients should be treated to be relieved of the itching, and must be told to maintain therapy if symptoms recur.

These women all need treatment by a professional vulva team. However, this team is not, nor should it be, the same for all patients, as symptoms, and accordingly treatment, differ. The initially most important mem-

bers of this team are the dedicated and experienced vulvologist and the nurse at the vulva clinic.

Most patients in these five groups have seen several doctors and/or midwives before referral to our vulva clinic. They have severe symptoms and have suffered a long time, emphasising the need for proper care-taking and long-time follow-up to make sure that treatment, information and prescription have been the best possible.