

PAIN

A Qualitative Study on Experiences After Vulvar Surgery in Women With Lichen Sclerosus and Sexual Pain



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ABSTRACT

Introduction: Lichen sclerosus (LS) of the vulva can profoundly affect sexual interaction because of painful fissures and narrowing of the vaginal introitus. Successful surgical treatment is usually defined as restoration of (pain-free) penetrative sexual activity.

Aims: To evaluate the impact of surgery on (dyadic) sexual functioning and pleasure and psychological well-being.

Methods: Nineteen women with anogenital LS participated in audiotaped, qualitative, individual interviews after surgery to re-enable sexual intercourse.

Main Outcome Measures: Physical, sexual, and psychological experiences were analyzed using the constant comparative method.

Results: Vulvar surgery resulted in a decrease of sexual pain in 13 of 19 patients (68%). Of these 13 patients, 4 were completely free of pain and the other 9 patients expressed a shift from preoperative sexual pain to postoperative sexual discomfort. These women reported improved sexual functioning, increased sexual activity and intimacy with the partner, and reinstated feelings of being an adequate woman and sexual partner. In 1 of the 19 patients (5%), surgery did not result in decreased sexual pain, yet she continued to have intercourse. Five of the 19 patients (26%) stopped having intercourse because of pain; one woman had secondary vaginismus and another woman, in retrospect, had premonitory generalized unprovoked vulvodynia. Four of these women were unable to communicate with their partner about sexual matters and to change their sexual repertoire (satisfactorily) once they had ceased intercourse (attempts). Eighteen women (95%) reported a decrease of LS symptoms in daily life.

Conclusion: Vulvar surgery seems an effective treatment for most women with LS who experience sexual pain owing to anatomic or epithelial changes and who wish to resume intercourse. To assess whether women might benefit from such surgery and/or whether (additional) sexual counseling is indicated, preoperative sexological couple-based consultation is needed. This consultation should exclude comorbid vaginismus and generalized unprovoked vulvodynia and index the couple's pre-existing sex life, including sexual communication skills, and the ability to incorporate non-coital pain-free sexual activities.

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INTRODUCTION

Lichen sclerosus (LS) is a chronic inflammatory skin disease of the anogenital area, presumably with an autoimmune

etiology.¹ The disease occurs in women of all ages but especially in older women. In women, the prevalence is estimated to be 1 in 300 to 1 in 1,000.² The true incidence and prevalence of LS are unknown because of the different medical disciplines involved in treating LS, the asymptomatic nature of this disease in some women, and the frequent misdiagnosis of this condition.³ In women, LS can lead to anatomic changes, such as resorption of the labia minora, phimosis of the clitoral hood, labial fusion, and narrowing of the vaginal entrance (ie, introital stenosis). The epithelium might show changes, such as thinning and fine wrinkling (“cigarette paper”; atrophy), patchy white discoloration

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(hypopigmentation), fissures and erosions, and small foci of bleeding underneath the epithelium (purpura, ecchymosis). Symptoms include vulvar itching, irritation, burning, and pain, which can cause significant emotional distress and sexual difficulties.^{4,5}

Although there are limited data on the sexual functioning of women diagnosed with LS, the few available studies have indicated that sexual dysfunctions and sexual distress are common.^{6–11} Findings have suggested that approximately 75% of women with LS develop dyspareunia owing to erosions, fissures, or introital stenosis.⁶ Together, these studies highlight the need to attend to sexual functioning when treating patients with LS. Moreover, clinical experience has shown that a considerable number of women with LS express the need for improved sexual functioning, including the ability to engage in intercourse (ie, vaginal penetration).

Standard treatment for LS (ultra-potent topical corticosteroids^{3,12,13}) is aimed at decreasing symptoms, but findings have suggested that this treatment does not alleviate sexual problems significantly.¹¹ This might be due to the fact that treatment addresses only the inflammation, not the scarring and distortion, of vulvar architecture. For anatomic (ie, narrowing of the vaginal entrance) or epithelial (eg, painful fissures) changes that cause dyspareunia or the inability to have penile-vaginal penetration, vulvar surgery might be offered. Several surgical techniques have been described in the literature, with posterior vestibuloplasty (perineoplasty) being the usual procedure.^{14–16} However, little is known about the results of vulvar surgery in women with LS. One study evaluated perineoplasty for the treatment of introital stenosis in women with LS, with a median follow-up period of 34 months, and reported success rates of 86%.¹⁷ Success was defined as “relief of introital dyspareunia after surgery” as assessed with only two non-validated questions, in a telephone interview. Together with other methodologic limitations, this study might have overestimated success rates. Hence, more studies are needed to evaluate treatment outcome in patients with LS undergoing vulvar surgery for the relief of sexual pain complaints.

Whichever treatment approach is taken, successful treatment of sexual pain conditions is most often defined as restoration of (pain-free) penetrative sex.¹⁸ Because LS can profoundly affect the lives and sex lives of women and their partners, the effect of surgery on (dyadic) sexual functioning, sexual behavior (eg, non-coital sexual activity), pleasure, and psychological well-being also should be evaluated. Narrative methods are optimally suited for that purpose, rather than using pre-determined quantitative measurements. Therefore, the first aim of the present study was to analyze the physical, sexual, and psychological experiences of women with LS after surgery to re-enable sexual intercourse. The second aim of the present qualitative study was to explore the causes and consequences in women or couples for whom surgery was not helpful. This knowledge is important for improving treatment decisions and treatment outcome.

METHODS

Participants

During the 5-year period from 2008 up to and including 2012, 23 patients with histologically confirmed LS underwent a surgical procedure of the vulva in our hospital. The great majority of these patients were referred by other gynecologists with the specific objective of evaluating possibilities for surgery. All these heterosexual women experienced (superficial) dyspareunia or the inability to have sexual intercourse owing to anatomic (ie, narrowing of the vaginal entrance) or epithelial (eg, painful fissures) changes. In all patients, surgery was performed to restore penile-vaginal penetration and to relieve sexual pain and was communicated as such with the patients. When the present study started, two patients had developed cancer (vulvar carcinoma and rectal adenocarcinoma, respectively) and they were not invited to participate. Two other women decided not to participate because they were in a stressful period of their life (not related to LS symptoms) and were afraid that the interview would be emotionally taxing. Therefore, the study sample consisted of 19 patients. Their ages ranged from 30 to 72 years (mean = 56.2 years, SD = 10.4 years). Fifteen patients were postmenopausal. Eighteen women (94.7%) were involved in a long-lasting relationship (range = 11–58 years, mean = 35.8 years, SD = 12.3 years) and all these women cohabited with their partner. One woman was involved in a relationship at the time of surgery but was single at the time of the interview. For 12 participants (63.2%), their current partner also was their first sexual partner with whom they had had sexual intercourse. Two women (10.5%) had had one previous partner and five women (26.3%) had had several sexual partners. Fifteen women (78.9%) had children.

With respect to complaint characteristics and surgery details, the diagnosis of LS was established minimally 1 year 3 months and maximally 32 years before surgery. It should be noted that most women had expressed vulvar complaints for many years, which might have been LS symptoms but were not recognized as such. Standard medical treatment was the topical application of 0.05% clobetasol propionate ointment once daily for 1 to 4 days per week and a moisturizing cream once or twice daily. All 19 patients underwent a posterior vestibuloplasty with advancement of the posterior vaginal wall. In addition, four patients underwent an anterior vestibuloplasty with a free vaginal graft (which was performed at a separate occasion in one patient) and four patients underwent correction of clitoral phimosis. One patient underwent a posterior and anterior vestibuloplasty with a free vaginal graft and correction of clitoral phimosis. Details of the surgical procedures are described elsewhere.¹⁹ After the surgical intervention, the use of clobetasol and emollients was discontinued for a few weeks. After this period, the use was individualized. Postoperatively, two patients developed intense focal vulvar pain consistent with nerve entrapment or neuroma. This was the reason one patient underwent a second procedure and another patient underwent a third small excisional procedure

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