

ORIGINAL ARTICLE

## Silent no more! The lived experiences of women with lichen sclerosis

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### Abstract

**Purpose:** Lichen Sclerosis (LS) is an often unrecognized and misdiagnosed chronic inflammatory skin condition of the anogenital area that affects quality of life, bringing severe discomfort and distress to affected men, women, and children. The purpose of this qualitative study is to explore the lived experiences of women with LS.

**Data sources:** Content analysis was conducted of data obtained from three public online forums/blogs used by women with LS. A total of 527 postings/entries were analyzed for patterns and themes by four researchers.

**Conclusions:** Five core themes emerged as a result of this study, revealing feelings of frustration and despair stemming from healthcare providers' lack of knowledge in relation to Lichen Sclerosis, often leading to misdiagnosis, prolonged suffering, and an altered quality of life.

**Implications for practice:** Knowledgeable healthcare providers and additional research into the cause, treatment, and cure of Lichen Sclerosis are needed. Advance-practice nurses stand to play an important role in the areas of education, research, policy making, and clinical practice to advocate for and empower women with LS.

Lichen sclerosis (LS) is a chronic inflammatory skin condition of the anogenital area that affects quality of life, bringing discomfort, desolation, distress, and anxiety, to affected men, women, and children (Edwards & Goldson, 2003; Jones, Scurry, Neill, & MacLean, 2008; Powell & Wojnarowska, 1999; Val & Almeida, 2005). Known as balanitis xerotica obliterans in men, it can develop on the uncircumcised foreskin and head of the penis (Scheinfeld, Keough, & Lehman, 2010).

LS occurs in women of all ages at a range between 6 and 10 times more frequently than in men (Yesudian, Sugunendran, Bates, & O'Mahony, 2005). In women, LS typically affects the anogenital area, although it also appears extragenitally in 15%–20% of those affected (Edwards & Goldson, 2003; Neill, Lewis, Tatnall, & Cox, 2010; Pulgleise & Morey, 2007; Yesudian, Sugunendran, Bates, & O'Mahony, 2005). LS has been diagnosed in children as young as 6 months with an average diagnostic age of 5 years, often following accusations of child abuse because of the presentation of vulva soreness and anal fissures (Poindexter & Morrell, 2007; Wood & Bevan, 1999).

There is a dearth of literature on LS despite the severe physical and psychological consequences the disease presents. The purpose of this qualitative study is to explore the lived experience of women with LS—a topic that remains scarce in the literature. The goal of this study is to fill this identified gap in the literature and to equip advanced practice nurses and other healthcare professionals with the knowledge they need to provide women with LS with timely, patient-centered, and competent evidence-based care.

### Review of the literature

The literature provides little conclusive information about LS (Yesudian, Sugunendran, Bates, & O'Mahony, 2005). The etiology of LS remains unknown (Edwards & Goldson, 2003; Val & Almeida, 2005). However, the evidence confirms an autoimmune association, and lends support to a genetic component as a possible etiology (Chan, Oyama, Neill, Wojnarowska, Black, & McGrath, 2004; Cooper, Ali, Baldo, & Wojnarowska, 2008; Neill, Lewis, Tatnall, & Cox, 2010; Poindexter & Morrell, 2007).

The literature suggests that hormones and local factors, such as trauma, may influence the development of LS (Pulgleise & Morey, 2007; Val & Almeida, 2005; Yesudian, Sugunendran, Bates, & O'Mahony, 2005). Although some European studies of German, Japanese, and U.S. tissue sample of individuals with LS suggest an association between an infectious agent as a cause of LS, neither European nor U.S. studies have ever found the infectious agent in tissue studies of U.S. patients, thereby creating some doubt (Neill, Lewis, Tatnall, & Cox, 2010).

Although some have estimated prevalence rates from 1:300 to 1:1000, the incidence of LS is unknown because of the variety of specialists who treat LS, the often asymptomatic nature of this chronic illness, and the frequent misdiagnosis of this condition (Cooper, Ali, Baldo, & Wojnarowska, 2008; Meffert, 2011; Pulgleise & Morey, 2007). While some literature asserts a higher incidence in White subjects, others assert no racial preference (Meffert, 2011; Powell & Wojnarowska, 1999; Pulgleise & Morey, 2007).

The LS diagnosis is often missed because early signs and symptoms tend to mimic other conditions. Women first experience intractable pruritus, vulvar and perianal soreness, and burning, followed by labia reabsorption, dysuria, dyspareunia, as well as painful defecation (Edwards & Goldson, 2003; Neill, Lewis, Tatnall, & Cox, 2010; Powell & Wojnarowska, 1999). The vulvar skin develops a thin, tissue paper-like appearance with pallor that may appear in a classic figure-of-eight stretching in a vulvar to perianal pattern (Figure 1), often accompanied by papules and/or white plaques (Meffert, 2011; Neill, Lewis, Tatnall, & Cox, 2010; Val & Almeida, 2005). As the condition progresses, patients may experience traumatic fissures and tears with sexual intercourse and defecation (Powell & Wojnarowska, 1999). Five to seven percent of individuals with LS eventually develop squamous cell carcinoma (Meffert, 2011; Pulgleise & Morey, 2007).

LS is usually diagnosed by a physical exam, a skin biopsy, and an autoantibody profile for associated autoimmune disease when indicated (Edwards & Goldson, 2003; Neill, Lewis, Tatnall, & Cox, 2010). Differential diagnoses of LS include candida, urinary tract infections, vitiligo, skin tags, cicatricial pemphigoid, lichen planus, lupus erythematosus, squamous cell carcinoma, vulvovaginitis, psoriasis, eczema, and contact dermatitis (Edwards & Goldson, 2003; Meffert, 2011; Neill, Lewis, Tatnall, & Cox, 2010; Wood & Bevan, 1999; Yesudian, Sugunendran, Bates, & O'Mahony, 2005).

There is no definite cure for LS and most treatments address symptom relief (Edwards & Goldson, 2003; Powell & Wojnarowska, 1999). With moderate evidence to support it, the current recommended first-line treatment for LS is clobetasol propionate 0.05%, a potent



**Figure 1** Lichen sclerosus in a 5-year-old Caucasian female (left) and 9-year-old Caucasian female (right). Notice classic figure-of-eight and fusion of labia.

Note. Adapted with permission from Diepgen, T. L., Yihune, G., et al. Dermatology Online Atlas. Published online at: <http://www.dermis.net/doi/>

topical corticosteroid, applied once or twice daily for 3–6 months (Edwards & Goldson, 2003; Meffert, 2011; Neill, Lewis, Tatnall, & Cox, 2010; Powell & Wojnarowska, 1999; Pulgleise & Morey, 2007; Renaud-Vilmer, Cavelier-Balloy, Porcher, & Dubertret, 2004; Yesudian, Sugunendran, Bates, & O'Mahony, 2005). In one study, 50% of those studied experienced remission (Renaud-Vilmer, Cavelier-Balloy, Porcher, & Dubertret, 2004). Other interventions used in conjunction with the corticosteroids include topical estrogen, progesterone, and immunosuppressive drug tacrolimus, although poorly supported by the literature (Val & Almeida, 2005). One small study found patients benefitted from using a moisturizer daily, following a 1-month course of corticosteroid (Simonart, Lahaye, & Simonart, 2008).

Anecdotal reporting that is not evidence-based supports complementary and alternative therapies, such as vitamin D, retinoids, and emollients including emu oil for use with or in place of corticosteroids (Meffert, 2011; Simonart, Lahaye, & Simonart, 2008; Val & Almeida, 2005). Similarly, surgery, laser, photodynamic therapy and cryotherapy, reserved for severe cases, have little supporting evidence (Neill, Lewis, Tatnall, & Cox, 2010; Pulgleise & Morey, 2007). On the other hand, newer literature lends support to the efficacy of a new treatment pioneered in China and known as high-intensity focused ultrasound (Ruan, Xie, Wang, Jiang, Shi, & Xu, 2010).

Complications associated with LS include secondary bacterial infections and candida (Yesudian, Sugunendran,

Bates, & O'Mahony, 2005). Patients with LS must be educated in good vulvar health and instructed to wear white cotton underwear and avoid irritants such as bubble baths, scented or perfumed detergents, feminine hygiene products, and soaps (Edwards & Goldson, 2003; Neill, Lewis, Tatnall, & Cox, 2010; Yesudian, Sugunendran, Bates, & O'Mahony, 2005).

While the literature addresses some of the physical components of LS, it reveals little of the frustration and stress women experience from delayed or misdiagnosis of the condition, the side effects of current treatments, and the progression of the condition. Women with LS need nurse practitioners (NPs) to listen to and address the frustration, confusion, and anguish they experience as they seek care and answers to their questions and condition.

## Methodology

Inductive content analysis was used for analyzing data obtained from three ongoing electronic public forums/blogs for women with LS that were identified through a Google search of "Lichen Sclerosis" (MommaBlogger, 2007; Oprah Community Members, 2008; Wendy, 2009). These blogs were designated for women with LS and provided means for sharing personal stories and support in relation to this chronic illness. Additional LS forums were discovered but were excluded from this study because they were private and required approved membership. The University of Michigan-Flint Institutional Review Board (IRB) found this study exempt because it used existing data from online public forums. Following the IRB review, data were collected over the course of 1 week from the three identified electronic public forums. The data consisted of 527 online entries posted on the Web between July 7, 2006, and August 19, 2010.

Content analysis is a qualitative research method that is used for the systematic analysis of verbal and/or written messages as well as visual communication (Cole, 1988; Elo & Kyngas, 2008). It is a content-sensitive method focused on providing new knowledge based on valid inferences from existing data (Krippendorff, 1980). In nursing research, it's been found to be best suited for the analysis of multifaceted, large volumes of textual data, especially for sensitive topics that warrant a qualitative approach (Elo & Kyngas, 2008).

Content analysis of virtual data is not a new phenomenon. The literature is rich with examples of qualitative researchers who have analyzed data from blogs (Jones & Alony, 2008) and online communications to explore the nature of social support for individuals with chronic illness (Sanders, Rogers, Gardner, & Kennedy,

2011), the role of online communities for individuals with a rare disease (Lasker, Sogolow, & Sharim, 2005), the role of online cancer support groups (Klem, Reppert, & Visich, 1998), and sexual health of individuals with breast and prostate cancer (Seale, Charteris-Black, MacFarlane, & McPherson, 2010).

## Qualitative rigor

Trustworthiness was established by using multiple data sources—the three different electronic public forums—and having four researchers review the data and participate in the data analysis to further assure triangulation (Creswell, 2003; Krefting, 1991). Members of this research team individually reviewed the data and then met together on several occasions to validate the discovered patterns and themes and ensure credibility of findings. Two of these researchers have extensive backgrounds in qualitative research and women's health issues. Although the three blogs/public forums contained more than 527 entries, the researchers stopped at that number when saturation was reached and additional postings contained redundant material.

## Findings

Five major themes emerged from the content analysis of the 527 public postings. Each theme is subsequently presented with its supporting patterns and descriptors (quotations):

Theme 1: *Women with LS experience frequent misdiagnosis or delayed diagnosis as a result of overall lack of knowledge.*

Content analysis showed that women with LS find healthcare professionals know little about LS. This leaves women suffering from LS in search of answers and support. Once they realize the impact of their disease on their lives, they experience many emotions including mourning over the delay in treatment. Seven patterns supported this theme:

Pattern 1: *Women with LS experience frequent misdiagnosis or delayed diagnosis.*

"[I]nitially, I started going back and forth my GPs office and was told it was simply thrush and given the cream . . . and after . . . years the conclusion was that it was all in my head and that there was nothing more they could do for me."

"Hello! I was recently diagnosis with LS, it took about a year . . . I was told it was a yeast infection for the longest time!"

Pattern 2: *Newly diagnosed LS patients often experienced symptoms for a long time.*

"I have had it for 15 years, but just found out what it was 3 mos ago from the biopsy they did at the time of

surg. My gyn knows nothing either, he wants to send me to a dermatologist, I guess it can't hurt."

" [I]t took 9 months and 8 drs to get our diagnosis. I was so persistent . . . I just didn't just didn't know what! I'm so glad I never gave up . . . I knew something was wrong with my baby!!!"

"Hi. Sorry you have been suffering for a long time, sadly this is a very common story – personally I have had symptoms for at least 7 years or so before I was diagnosed by a biopsy."

Pattern 3: *Women with LS experience disappointment and mourning associated with delayed diagnosis and lack of knowledge.*

"But in my heart I knew that this wasn't all in my head . . . I am really disappointed that this has gone on for over three years when if GPs were more informed about the condition then a diagnosis could have been made earlier."

"Hi, Im 62 and was diagnosed 2 weeks ago . . . I'm afraid, sad, and uninformed."

Pattern 4: *Women with LS want information on the connection between LS and other autoimmune disorders.*

"Has anyone been told that there could be a link to hypothyroidism. I also have other autoimmune disorders. Fybromyalgia, psoriatic [arthritis]. Are these all related?"

"I have heard there is a link between LS and other autoimmune disorders, especially hypothyroidism (which is often diagnosed as fibromyalgia/ME at first)."

Pattern 5: *Women with LS want healthcare professionals to know that LS knows no age.*

"I am very apprehensive about this, as I don't know how I will be able to sit down afterwards. It does not help that I am in my early 70's."

"I received biopsy results yesterday confirming that I have LS. So, I'm joining the sisterhood. Of course I have many questions, but here are my main ones: I am 39 y/o active chick."

"My daughter has LS (she is 4)."

Pattern 6: *Women with LS report healthcare provider (HCP) do not educate them about LS.*

"Well, the way the doctor made it sound that this would all go away in a week and be no problem Not knowing a thing about the condition, I searched it and learned the truth."

Pattern 7: *Lack of knowledge prompted women with LS to seek answers, resources, and support from online communities.*

" . . . In those days there was nothing, and I do mean nothing at all, on the internet about LS and when I started this website, I wanted women to have good information and to feel comforted and hopeful about the future."

"Hello Ladies, I too have just been diagnosed with LS. I am a doctor so, . . . I have read much of the medical lit-

erature regarding LS but I cannot find the one piece of information that would put my mind at ease . . . what I want to know and it seems only another long term sufferer can tell me is . . . does the treatment actually prevent the scarring or is the scarring inevitable? . . . So, those of you who have had this for years . . . please put my mind at ease."

Theme 2: *Women with LS rely on finding online communities to provide support, increase knowledge, answer questions, and share resources.*

Feeling a lack of support from HCPs, women with LS use online sources for support, answers, sharing of resources, and empowerment of self and others. Four patterns supported this theme:

Pattern 1: *Women with LS support each other in online communities.*

"I am sorry but did your doctor say why the shrinking was happening? . . . Does your doctor have any hopes of getting yours into remission? I hope you are doing ok as I know the feeling so well. Its nice to know people are out there and I hope you will let me know how yours is doing. Thanks again."

Pattern 2: *LS sufferers share personal experiences in blogs to help, encourage, and support each other.*

"Scared to get into any relationship with any guy lest I have to deal with this- HELP – what can I do?"

"Keep encouraging each other! We're all in the same boat, and it's NOT the Titanic."

Pattern 3: *Women with LS use the online community to provide hope and empowerment.*

"Keep posting & I hope things improve soon -it is a horrible shock to be diagnosed, but 'knowledge is power' so take control, girl!"

"Hiya, after going back to the clinic i feel a bit more hopeful actually."

Pattern 4: *Women with LS use humor to cope with their condition.*

"Hang in there. Rant to your best friends, cry, learn as much as you can about LS . . . and before you know it, you'll be cracking jokes with your friends about your high maintenance privates :)."

Theme 3: *Women with LS experience significant frustrations and social justice issues.*

Lack of social justice adds to the frustration of women with LS. In addition to facing painful symptoms, these women face the frustrations of economic hardship, lack of provider support, and lack of treatment and cure. Three patterns supported this theme:

Pattern 1: *Women with LS experience financial burdens associated with lack of coverage and non-formulary and compound treatments.*

"I was going to a dermatologist that wasn't even looking at the problem just had his prescription pad handy to write me a monthly prescription to keep me coming and

this economy who can afford a dr. on a monthly basis since I'm self-employed I pay my own medical bills."

Pattern 2: *Women with LS are frustrated with HCPs who will not listen to them.*

"... might have to be brave & cheeky and go and see my GP, don't feel too hopeful doesn't seem to fully appreciate the difficulties I've faced or made any effort to help me get my sex life back, I'm only 32!"

Pattern 3: *Women with LS question social justice in lack of cure, or viable treatment.*

"Crossing your legs is a pipe dream to some and sex is out of the question to others. It is criminal that there are no viable treatments out there that can make this condition tolerable, or can I even go so far as to suggest a cure? I have yet to read or hear of someone that has used any treatment (alternative or conventional) with long term success. Most have only gotten pathetic responses since most doctors don't know what to do with us!"

"Is it easy? No, but you can live with this... you pretty much have to until someone figures out what the hell this condition actually is!! !!!"

Theme 4: *Women with LS report a profound impact on their quality of life in the areas of participation and psychosocial functioning.*

LS has a profound psychological impact on women. Content analysis revealed that women with LS suffer from depression, despair, guilt, worry, embarrassment, and mental anguish. The change in the female architecture as a result of the disease along with the psychological impact creates a feeling of loss of female identity. Nine patterns supported this theme:

Pattern 1: *Female architecture changes as a result of LS disease process.*

"My labia has fused and now just to make matters worse it has spread to my anus which is making it nearly impossible to pass stools. My doctor said it wont spread inside but im sure it has. It feels like raw blisters."

Pattern 2: *Women with LS experience depression over loss of female identity.*

"I was just getting to a point where I might start dating again when I got the news. I am so depressed and can't stop thinking about what will happen and that this is the end of my life with men!!"

Pattern 3: *Women with LS experience despair regarding their diagnosis and symptoms.*

"I feel like my life is over and this feeling of despair is just staying inside me... when will I stop feeling like this? I have to get on with things for my kids instead of staying in my room, crying and reading horrific stories on the internet... is it possible to just go back to being me after being diagnosed?"

Pattern 4: *Women with LS question link between embarrassment with condition and lack of disclosure to HCPs.*

"... but it is ghastly to deal with at any age, especially in your teens when all the examinations are excruciatingly embarrassing :-)"

"Im wondering if it is possible that this condition is not as rare as reported, because many people around my age (76) may suffer in silence because of embarrassment."

Pattern 5: *Women with LS experience guilt as a result of impact of diagnosis on significant others and potential transmission to female offspring.*

"... I am in a relationship but he doesn't know anything yet. I have two children, a boy and a girl and I worry about if I have passed if on to my daughter."

Pattern 6: *LS affects participation in activities of daily living.*

"... I'm utterly miserable. I scratch myself raw so frequently that bathing and showering hurts, sex is completely out of the question... wearing underwear hurts, NOT wearing underwear hurts, crossing my legs has gone out the window. Blue jeans, NO WAY! I am sick to death of this condition. For my immune system, I get chemo every three weeks, and THAT'S easier to deal with than the LS. I have thought about heading down to Mexico and having a doctor remove my labia and giving me a fake one just so I don't have to deal with the pain. How sad is that?"

Pattern 7: *Women with LS worry about own prognosis and loss of relationship with significant other.*

"I am so worried and scared to tell him because I don't want to lose him..."

"I'm frightened, feel quite dirty, can't talk to anyone about this and don't know which way to turn. Will I ever be able to have children? Will I ever be able to have intercourse again? Who will want to be with a woman who can't even do that?"

Pattern 8: *Women with LS are frustrated with the HCPs' lack of knowledge and delayed/ineffective treatments.*

"I am considering going to see a specialist private as my GP admitted that I probably knew more about LS than she did. She gave me a leaflet that she printed off about LS. I don't think that is much good being as I have had these leaflets when first diagnosed 6 years ago. I felt like crying when I left the doctors."

Pattern 9: *Women with LS experience physical and mental anguish.*

"I am scared to death b/c my LS is getting worse and I have no way of slowing or stopping it. I feel like a runaway train headed for disaster and no brakes! The physical part is just some of the problem. One has no idea what this can do to a gal mentally and emotionally. Sometimes I think... thank God I'm married to a wonderful man b/c I would be a dating leper. The flipside, however, is possibly subjecting my husband to a life w/out intimacy??"

Theme 5: *Women with LS often seek variety of alternative treatments in their quest for relief and increased participation.*

Women with LS treat their symptoms by seeking alternative therapies including diet, vitamins, creams, and dilators to obtain relief from their symptoms and to pursue a higher level of participation in everyday activities. The goal of the treatment for these women focuses around redressing anatomic structural changes. Three patterns support this theme:

Pattern 1: *LS sufferers try many alternative therapies in their quest for relief.*

"...I also use Arnica and Comfrey cream after a flare up to help the scarring and to allow my skin to stretch."

"I found that changing my diet helped... Oh how I love bread and sweets but I cut them out and took probiotics and vitamins and... I found that Weleda Calendula Nappy Change Cream, has very similar formula and helps with itching, available at pharmacys."

Pattern 2: *LS sufferers seek creative alternative therapies in their quest for finding answers.*

"This coming week, I will meet with a Naturopath and Acupuncturist to get their opinion..."

"I have e-mailed Dr. OZ. to talk about this on his show, however I received no response. So maybe if everyone e-mailed him he would do a talk show on it. I am also going to contact the doctor show."

Pattern 3: *Women with LS may use dilators to redress anatomic structural changes.*

"Am getting used to using the dilator too, tricky tho as not always convenient! But am trying to use it daily."

## Discussion

This qualitative study discovered a wealth of data that shed light on the lived experiences of women with LS. Congruent with the evidence base found in the literature, participants in this study represented all age groups (Yesudian, Sugunendran, Bates, & O'Mahony, 2005) and many of them expressed their concerns about the relationship between LS and other autoimmune conditions (Chan, Oyama, Neill, Wojnarowska, Black, & McGrath, 2004; Cooper, Ali, Baldo, & Wojnarowska, 2008; Neill, Lewis, Tatnall, & Cox, 2010).

The women with LS used the Internet as an outlet for sharing intimate details of their disease experience and as a source for both providing as well as seeking support. This was consistent with Jones and Alony (2008) who maintain that blogs are a valuable and reliable source for data analysis because they offer the means to and fulfill the needs for self-expression, social contact, and recognition.

The most pressing concern for the women with LS was the lack of HCPs' knowledge and the inherent frustration of trying to obtain an accurate and timely diagnosis. These women's voices confirm that LS is a profoundly

life-changing condition that robs women of their quality of life and their ability to participate in everyday activities. This study discovered a multitude of healthcare needs that remain unmet by HCPs, as well as significant financial, sexual, and psychosocial concerns. Severe anguish and despair were among the most recurrent phenomena encountered by the researchers throughout the data analysis process.

Despite the lack of established scientific evidence, this study revealed that women with LS try anything to alleviate their symptoms. These women want answers, support, and a cure. They also want HCPs to listen to them, understand their plight, be their advocates, and help them find appropriate treatments.

## Implications for practice

LS is often an unrecognized and unknown life-altering chronic condition affecting the anal and genital areas of women as well as some uncircumcised men. Women with LS are often misdiagnosed as their female architecture disappears and their quality of life and ability to participate drastically changes. Few HCPs are knowledgeable about LS and those who are often focus on women's sexual functioning with little consideration of impact on participation and overall quality of life.

Better educated HCPs and additional research on the cause, treatment, and cure of LS are needed to develop the evidence base needed for interventions that address this often misdiagnosed chronic condition. Women with LS have spoken and they want change. Their voices are silent no more! NPs have the ethical and moral obligation to listen to their patients' voices and become their advocates.

This article references LS guidelines from the *American Journal of Obstetrics and Gynecology* (Jones, Scurry, Neill, & MacLean, 2008) and the *British Association of Dermatologists* (Neill, Lewis, Tatnall, & Cox, 2010) as potential resources for NPs struggling to find LS treatment protocols. HCPs need to familiarize themselves with these guidelines and related literature and provide their patients suffering from LS with timely diagnosis, emotional support, and appropriate care.

Social media provides opportunities for NPs to listen to the voices of patients, learn more about symptoms from those affected by LS, share what they learn, provide emotional support, and get feedback and answers through blogs, Twitter, Facebook, and other sites to ultimately improve patient care. These expanding opportunities through current and future social media networks provide NPs, in their varied roles as clinicians, educators, researchers, and policy makers, with the tools needed to address the social injustices associated with LS.

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