


Uncovering the of LS

The Lived Experiences of Women with Lichen Sclerosus

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Objectives


- Increase awareness of LS for health care providers and policy makers
- Analyze the impact of LS on participation and social justice for women
- Discuss the lived experiences of women with LS

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Mini- Assessment

How many of you are familiar with LS?


Cared for someone with LS?

Know nothing of LS? 

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What is Lichen Sclerosis/Sclerosus?


- A skin disorder that can affect **women**, men, or children
- Target area: the vulva/ anogenital area
- May develop on the head of the penis
- May affect other parts of the body



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Etiology




- Unknown
- Several theories
 - Auto immune disease
 - Genetics/Hereditary
 - Hormonally based
 - Infection
 - Local irritation, inflammation and trauma
- NOT contagious



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Incidence

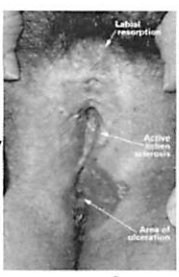
- No definitive data
- Children
 - Young girls
 - Boys
- Women
- Men
- Prevalence in Caucasians

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Signs and Symptoms for Women

- Pruritis and soreness
- Labia resorption
- Fissures and tears
- Hemorrhagic blisters
- Pallor, small or large plaques, atrophy
- Dysuria, dyspareunia and pain on defecation



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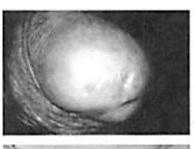
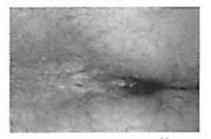
Classic genital lesions in a figure-of-eight pattern around the vulva and anus

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Signs and Symptoms for Men


- Most commonly affects the glans penis and foreskin though a small number may have perianal involvement

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Signs and Symptoms for Men



- Pruritis and soreness
- Difficulty retracting foreskin and poor urinary stream
- Painful erections
- Pallor, atrophy, sclerotic plaques



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Extra-genital locations

17% of LS cases are extra-genital, beginning as mild, nonspecific erythema with mild hypopigmentation


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Slide 10

HA2 cations/explanations needed in slide or speaker's notes
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Prognosis and Progression

- If left untreated, LS can cause:
 - progressive scarring
 - resorption of labia minora
 - narrowing of the opening to the vagina
 - formation of scar tissue
 - skin cancer (rare)



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Differential Diagnosis

- Yeast infection
- UTI
- Vitiligo
- Skin tags
- Squamous cell carcinoma
- Cicatricial pemphigoid
- Lichens planus (differentiated by clinical features on the cutaneous surfaces)
- Discoid lupus erythematosus, morphea and atrophic lichen planus


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Differential Diagnoses

Yeast Infection




Lichen Planus




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Differential Diagnosis


Vitiligo



Skin Tags




Squamous cell carcinoma



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Diagnosing LS


- Physical examination
- Skin biopsy
 - Punch biopsy
 - Snip biopsy
- Consultation
 - Dermatology
 - Gynecology
 - Immunology
 - Pediatrics
 - Urology



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Medical Management

- First line therapy:
 - Ultrapotent Topical Steroids
- Previous standard:
 - Testosterone; progesterone
- Retinoids
- Discontinuing birth control pills
- Xylocaine jelly and lubricants
- Psychosocial counseling
- Avoidance of local irritants, strong soaps and moisturizers




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Slide 14


HA3 This picture was used in 2 slides (12 & 13). Need an explanation /caption under/above each picture to describe content
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Surgical Management

Meatoplasty




Circumcision



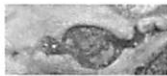
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Surgical Management


Urethral reconstruction



Flap repairs




Perineal urethrostomy




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Nonsurgical Procedures


Cryotherapy



Ultrasound Haifutech



Pulse dye laser




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Nonsurgical Procedures

Treatments reserved for severe cases due to lack of sufficient data on outcomes measures

Ultraviolet phototherapy



Carbon dioxide laser



Effective for extragenital LS


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Complementary/Alternative Therapy


- Vitamin A, C, D and E
- Acupuncture
- Aloe Vera drink
- Tea Tree Oil topical
- Emu oil




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All of the Above Impact the Quality of Life of Affected individual **and** Significant Other



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Understanding the Lived Experiences of Women with Lichen Sclerosis




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Phase One Content Analysis

527 entries from three public forums

- Lichen Sclerosis Support: Dee Troll (442)
- Oprah's Vaginal Lichen Sclerosis/Planus (69)
- Homemaker's Guide to the galaxy (16)
- ❖ Upcoming Phase Two: Phenomenology study


Validation of themes by 4 researchers



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Findings: Main Themes


- Theme 1: Women with LS experience frequent misdiagnosis or delayed diagnosis due to overall lack of knowledge
- Theme 2: Women with LS rely on finding online communities to provide support, increase knowledge, answer questions, and share resources



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Findings: Main Themes


- Theme 3: Women with LS experience significant frustrations and social justice issues
- Theme 4: Women with LS report a profound impact on their quality of life in the areas of participation and psychosocial functioning



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Findings: Main Themes


- Theme 5: Women with LS often seek a variety of alternative treatment in their quest for relief and increased participation




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Patterns and Descriptors Supporting Theme 1

Women with LS experience frequent misdiagnosis or delayed diagnosis due to overall lack of knowledge




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Women with LS often experience a delay in diagnosis

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




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Women with LS are often misdiagnosed

- "Initially, 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 that they could do for me" **Sian**
- Hello! I was recently diagnosed with LS, it took about a year *I was told it was a **yeast infection for the longest time!*** **J**




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Newly diagnosed LS patient often had 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." Shelly




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Women with LS experience disappointment and mourning associated with delayed diagnosis and lack of knowledge

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




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Women with LS desire more data 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, and psoriatic arthristis. Are these all related?" **Rose***




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Women with LS want HCPs to know that LS knows no age

- "I am very apprehensive about this... It does not help that I am in my early **70's.**" **Doreen**
- "I received biopsy results yesterday confirming that I have LS. So, I'm joining the sisterhood...I am **39** y/o active chick." **Loretta**
- My daughter has LS (**she is 4**). **Michelle**




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Women with LS report HCPs do not educate them about LS

- *"Well, the way the doctor made it sound was 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."* Alaina




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Patterns and Descriptors
Supporting Theme 2

Women with LS rely on finding online communities to provide support, increase knowledge, answer questions, and share resources

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




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Women with LS support each other in online communities

" ... 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" Ann




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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?"* Mimi
- *"Guess I really needed to connect with someone who has this ls thing. Gotta go as I want to cry some more. Thanks for listening!"* Ann
- *"Keep encouraging each other! We're all in the same boat, and it's NOT the Titanic."* Vonnie




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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!"* tigger
- *"Hiya, after going back to the clinic i feel a bit more hopeful actually."* bambi




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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 :)*" marriane




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Patterns and Descriptors Supporting Theme 3


Women with LS experience significant frustrations and social justice issues

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Women with LS experience financial burdens associated with lack of coverage and non-formulary and compounded 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.*" GS




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Women with LS are frustrated with HCPs who don't listen to them

... might have to be brave & cheeky and go and see my GP, don't feel too hopeful though, she 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! JN




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Women with LS question the Social Justice in lack of cure, research, 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!" Id 2008
- 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!! !!!*" Michelle




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Patterns and Descriptors Supporting Theme 4


Women with LS report a profound impact on their quality of life in the areas of participation and psychosocial functioning

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Female architecture changes as a result of LS disease process

- "I only found out I had LS after an examination for something totally different at my hospital. *My labia was totally fused together, kind of 'in the middle'*, the only good thing I've noticed is that I pee better now (much quicker!!)" **Sandra**
- "*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.*" **Barbara**




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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!!" J




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Women with LS experience despair R/T their diagnosis and symptoms

I have just been diagnosed with LS (two days ago) ... I am 37 years old with three kids and a husband. *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? **Fabia**





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


Women with LS question link between embarrassment with condition to lack of disclosure

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





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Women with LS experience guilt

"... 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." **Lou**




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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?*" **Gadget**




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Women with LS worry about own prognosis and relationship with significant other

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




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Women with LS are frustrated with the HCP's 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." Jan




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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??




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Patterns and Descriptors Supporting Theme 5


Women with LS often seek a variety of alternative treatment in their quest for relief and increased participation

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LS sufferers try many alternative therapies in their quest for relief

- "Alison ... I also use **Arnica and Comfrey cream** after a flare up to help the scarring and to allow my skin to stretch." Joey
- "I found that changing my diet helped... Oh how I love bread and sweets but I cut them out and took probiotics and vitamins" Anonymous
- "I found that Weleda Calendula Nappy Change Cream , has very similar formula and helps with itching, available at pharmacies" Sunsue




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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..." Im1313
- "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." 1.j.1




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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." bambi



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Conclusion

- LS is an often unrecognized and unknown life altering 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.
- HCPs who are knowledgeable about LS often focus on women's sexual functioning with little consideration of impact on participation and overall quality of life.

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To improve the participation and quality of life of women with LS:




- Increase awareness of LS as a population-based chronic medical condition for women's health practitioners and policy makers
- Advocate for policies and new treatment protocols that support achieving social justice for this group




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