

Living with Vulval Lichen Sclerosus: A Mixed Methods Study

Dr Sophie Rees, Dr Susanne Arnold

Warwick Clinical Trials Unit, University of Warwick

Contact us: livingwithLS@warwick.ac.uk

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Background

- Vulval lichen sclerosus (LS) is a chronic skin condition affecting the ano-genital area
- Symptoms include itching, pain, and changes to vulval anatomy
- There has been little research into the experiences of people living with the condition
- **Aim:** To explore the experience of living with vulval LS from the perspective of people with the condition

Methods

A mixed methods exploratory sequential study using social constructionist grounded theory.

Findings from the qualitative studies will inform the development of a survey.

Patient and Public Involvement – a lay advisory group made up of women with LS has been involved throughout.

Qualitative interviews about living with LS

Cognitive interviews assessing quality of life questionnaires

Focus groups about attitudes towards treatment

Quantitative survey via GP practices

Data collection for the first two elements of the study has been completed.

If you are a GP interested in being a site for the second phase, please get in touch!

Preliminary results from the qualitative interviews about living with LS

- 70 expressions of interest
- 41 fully registered for qualitative study
- 20 interviews completed
- All participants are female
- Mean age = 54 (range 23-78)
- Ethnicity: white n=16; black n=2; mixed/multiple ethnic group n=2

My secret life

“It’s not something you talk about... I don’t discuss this with anyone... this is something that my husband knows, and I know” (Sandra)

Missed opportunities

“She looked at it and she said “You probably have [thrush], try this.” And she recommended nappy cream... Now that was an opportunity for diagnosis missed. I can’t forgive her for that, to be honest” (Sarah)

Treatment interferes with life

“It works but it’s really messy, and that also interferes with my life as well because depending on what I’m going to wear or depending on plans, I have to work around when I’m going to put the cream on.” (Paige)

Preliminary conclusions

- The process of diagnosis was a large element of women’s stories and women identified missed opportunities for diagnosis and a need for improved awareness and knowledge amongst healthcare professionals
- The stigma attached to talking about vulvovaginal issues left women feeling isolated and lonely
- Managing LS involves a substantial amount of ‘work’ by patients and a loss of spontaneity, not only in their sex life
- Peer support is crucial, but witnessing other women’s suffering affected their own emotional wellbeing