



Patient Experience of Lichen Planus: A Qualitative Exploration of Signs, Symptoms, and Health-Related Quality of Life Impacts

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ABSTRACT

Introduction: Lichen planus (LP) is an inflammatory skin disorder that can present in various forms across the body, including lesions on the skin (cutaneous LP [CLP]), scalp (lichen planopilaris [LPP]), and mucosal regions (mucosal LP [MLP]). Qualitative exploration of the patient experience of LP, notably symptoms and impacts on health-related quality of life (HRQoL), is limited. A scarcity of research was also identified relating to emotional wellbeing impacts of CLP patients. Two qualitative studies were conducted with LP patients to address these gaps.

Methods: Study 1 consisted of exit interviews conducted with a subset of adult patients with MLP ($n = 5$), CLP ($n = 4$), and LPP ($n = 4$) enrolled in an LP clinical study in the United States (US) to explore the patient experience. Study 2 consisted of independent qualitative interviews conducted with adult CLP patients

($n = 13$) from the US and Germany to further explore impacts on emotional wellbeing.

Results: Exit interviews found that itch, pain, and skin lesions were most frequently reported as signs/symptoms of LP. Itch and skin lesions were experienced across all LP subtypes, while pain was only reported by CLP and MLP patients. These signs/symptoms impacted HRQoL including emotional wellbeing (frustration, embarrassment), daily activities (oral hygiene, clothing options), social functioning (intimacy, social activities), and physical functioning (chewing/swallowing, opening/moving mouth). Impacts on activities of daily living (ADL) and physical functioning were mostly experienced by MLP patients. Independent qualitative interviews, which further explored impacts of CLP on patients' emotional wellbeing, identified frustration, worry, sadness, embarrassment, and depression as the most frequently experienced.

Conclusion: The findings contribute to the literature by providing qualitative insights into signs/symptoms and HRQoL impacts of LP, from the adult patient perspective. The findings also highlight the importance of considering assessment of HRQoL impacts in future clinical LP research, particularly impacts on emotional wellbeing when selecting instruments for assessment of HRQoL in the CLP population.

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Key Summary Points

Why Carry Out This Study?

Limited qualitative research is available regarding the patient experience of lichen planus (LP), particularly for cutaneous lichen planus (CLP) and lichen planopilaris (LPP) subtypes.

This study aimed to conduct qualitative research with LP patients via two qualitative interview studies to: (1) gain insight into the patient experience of LP and (2) provide further insight into the impact of LP on patients' emotional wellbeing, with a particular focus on CLP patients.

What Was Learned from the Study?

This study provides valuable insights into the patient perspective of the signs, symptoms, and HRQoL impacts associated with LP.

This study also confirms the importance of assessing the psychological effects of CLP as part of any HRQoL assessment in future research.

on the body including lesions on the skin (cutaneous LP [CLP]), the scalp (lichen planopilaris [LPP]), and mucosal regions (mucosal LP [MLP]). CLP is the most common form of LP and is characterized by a subacute or chronically progressive appearance of polygonal purple papules [6]. LPP is the follicular variant of CLP and presents as active patches at the center of the scalp, along the frontal hairline and/or in the eyebrows [6]. LPP has a sexual predilection for females [4] and can also be induced by hair transplantation or cosmetic surgery [6]. If left untreated, LPP can lead to irreversible scarring and alopecia [6]. MLP presents as asymptomatic white lesions (reticular, papular, plaque-like) or painful erosive/ulcerative and erythematous lesions that most commonly affect the oral mucosa but can also involve the genitalia or conjunctiva [4, 6, 8]. An estimated 30–50% of patients with oral MLP have concomitant CLP [9]. While most instances of CLP resolve spontaneously within 1–2 years, LPP and MLP tend to be more resistant to treatment [7].

Symptoms of LP include itch, pain, and a burning sensation at the affected area [3, 10–13]. Hair loss, scaling, and scalp tenderness are also experienced in LPP patients [4] and stinging, soreness, and tenderness in MLP patients [11, 12]. In online forums (such as PatientInfo), patients with various LP subtypes describe how these symptoms can have a significant impact on health-related quality of life (HRQoL). Qualitative studies in MLP indicate that painful oral lesions affect patients' physical functioning and daily life by impairing their ability to eat, perform oral hygiene care, and speak [11, 13, 14]. Patients' emotional wellbeing is also affected due to the chronicity, unpredictable clinical behavior, and potentially malignant nature of MLP [14, 15]. While no qualitative studies appear to exist that explore HRQoL impacts for CLP or LPP patients, there are some quantitative studies that suggest a significant impact on aspects of emotional wellbeing, social functioning, and activities of daily living (ADL) in these patients, as indicated by patient-reported outcome (PRO) measures designed to assess HRQoL [16, 17]. The limited qualitative research exploring the patient experience of LP, particularly for the different

INTRODUCTION

Lichen planus (LP) is an inflammatory immune-mediated skin disease that mostly affects middle-aged adults aged 30–60 years [1, 2]. Global prevalence is estimated to be 0.5–1% of the population [3, 4] and may affect more female adults than males [5]. Diagnosis is based on clinical presentation and is typically confirmed by biopsy [6, 7]. LP can present in various forms

subtypes, highlights the need for more in-depth qualitative studies in this patient population. Patient insights through qualitative research can help identify important and relevant concepts and can inform the selection of suitable PRO measures for use in clinical trials, observational studies, and clinical practice.

Several HRQoL PRO measures are available for use in specific subtypes of LP, most notably the Chronic Oral Mucosal Disease Questionnaire (COMDQ) [18] for use in MLP and the Scalpdex [19] for use in LPP. The COMDQ-26 comprises 26 items grouped into four domains: pain and functional limitation, social and emotional, medication and treatment, and patient support. A shorter 15-item version (COMDQ-15) is also available [20]. The Scalpdex comprises 23 items grouped into three domains: symptoms, functioning, and emotions. Both instruments demonstrate relatively strong coverage of key impact concepts identified in the qualitative literature and described in online forums. However, there appear to be no disease-specific PRO measures assessing HRQoL impacts in CLP. While the Dermatology Life Quality Index (DLQI) is a widely used questionnaire to assess quality of life (QoL) in patients with dermatological disorders [21], including LP [17, 22, 23], it may have its limitations in this population. Despite the instrument covering six domains of impact (symptoms and feelings, daily activities, leisure activities, interpersonal relationships, work/study, and treatment), it does not have sufficient coverage of impacts on emotional wellbeing, which have been highlighted as important to LP patients. Evidence suggests a bidirectional relationship between mental health status (i.e., stress, anxiety, and depression) and the development or course of skin diseases, further highlighting the need to understand the extent of psychological effects on patients' HRQoL [24, 25]. Thus, further qualitative research is needed to understand the impact of LP on patients' emotional wellbeing, with a particular focus on CLP patients. This will help inform what instrument(s) may be suitable for use in CLP.

The overall objective of this qualitative research was to explore the signs and symptoms

of LP and their impact on HRQoL from the patient perspective. A further objective was to better understand emotional wellbeing impacts in CLP patients.

METHODS

This research consisted of two qualitative interview studies involving concept elicitation (CE) methods to explore the patient experience of LP: (1) exit interviews with a subset of adult CLP, LPP, and MLP patients from the United States (US) enrolled in an LP clinical study and (2) independent qualitative interviews with adult CLP patients from the US and Germany to further explore the impact of CLP on patients' emotional wellbeing. The interview studies were conducted in parallel. Figure 1 provides an overview of the research design (Fig. 1).

Compliance with Ethics Guidelines

Ethical approval and oversight for the exit interviews was obtained as part of the clinical study (clinicaltrials.gov ID: NCT04300296, EUDRACT: 2019-003588-24) from the following independent institutional review boards (IRB) and ethics committees: Advarra IRB, Columbia, Maryland, United States; Mayo Clinic IRB, Rochester, Minnesota, United States; University of Miami Human Subjects Research Office, Miami, Florida, United States; and Western Institutional Review Board, Puycap, Washington, United States. Ethical approval and oversight for the independent qualitative interviews was obtained from Western Copernicus Group Independent Review Board (WCG IRB; reference: 20216826). The studies were performed in accordance with the Helsinki Declaration of 1964 and its later amendments, and all participants provided informed consent indicating that their data would be used for medical research purposes and that the study results may be published.

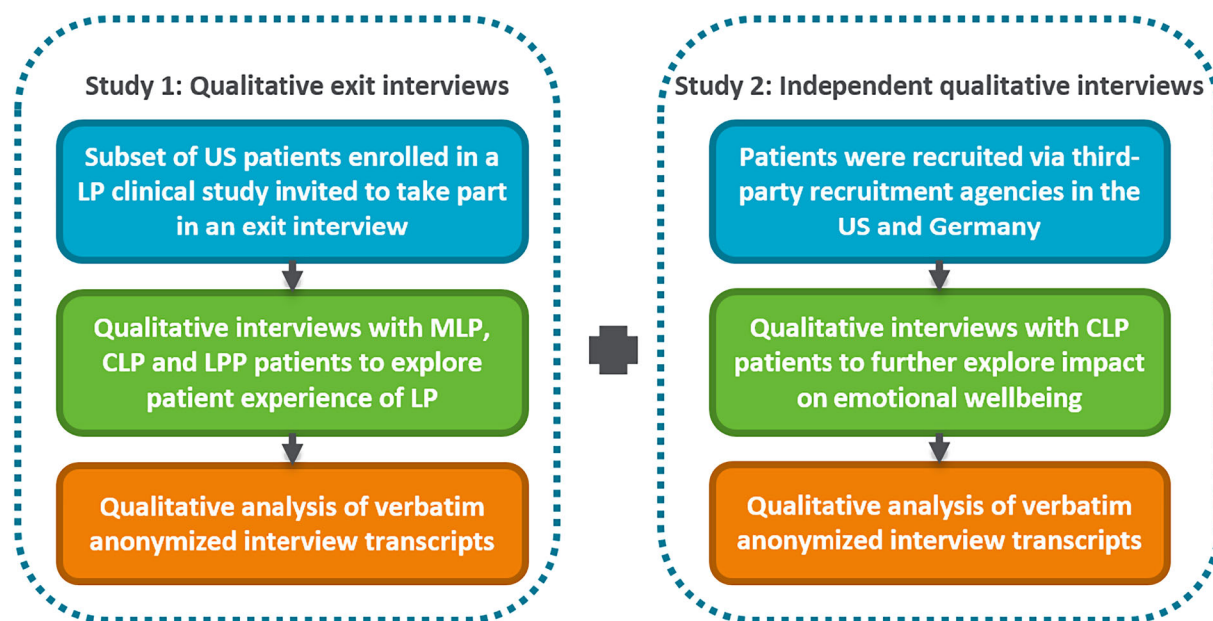


Fig. 1 Overview of research design

Study 1: Qualitative Exit Interviews

Sample and Recruitment

A purposive sampling method was used which included recruiting patients enrolled in an LP clinical study in the US. Patients were invited to take part in an exit interview once they had completed all treatment periods at Week 32 of the study. Participation was voluntary and patients could opt out from taking part in the interview. Patients in the clinical study had to be at least 18 years of age; have biopsy confirmed CLP, MLP, or active LPP eligible for systemic therapy based on an investigator global assessment (IGA) rating of ≥ 3 (moderate or severe); and inadequate response to topical corticosteroids of high–ultrahigh potency in the opinion of the investigator. Patients were excluded if they had LP pigmentosus, paraneoplastic MLP, LP that was predominantly a bullous variant, MLP of the oral cavity or gastrointestinal involvement requiring the patient to use parenteral nutrition or a feeding tube, burnt-out cicatricial alopecia (alopecia of Brocq), frontal fibrosing alopecia without active patches of LPP, scarring alopecia without active inflammation, or a clinical history suspicious for lichenoid drug eruption. Socio-

demographic and clinical information was also collected to characterize the interview sample.

Interview Procedure

Interviews were 60 min and conducted via telephone by trained qualitative interviewers. A semi-structured interview guide, informed by a targeted qualitative literature review in LP, was used to guide the discussions. The CE section of the interview, which aimed to explore the patient experience of LP, lasted approximately 30 min and consisted of broad, open-ended questions designed to facilitate spontaneous elicitation of concepts. Participants were asked to think about their entire LP experience, from when they were first diagnosed to their present day-to-day experience, including good days and bad days with LP. Focused questions were then used if pre-identified concepts of relevance (i.e., itch and pain) had not emerged or been fully explored.

Qualitative Analysis

All interviews were audio-recorded and transcribed verbatim, with identity information redacted. Interview transcripts were analyzed using thematic analysis methods in Atlas.Ti software (version 8) [27]. Participant quotes pertaining to signs, symptoms, and impacts of

LP were assigned corresponding concept codes in accordance with an agreed coding scheme. Codes were applied both deductively (based on prior knowledge) and inductively (as emerging from the data). Differences between LP subtypes were also captured.

Study 2: Independent Qualitative Interviews

Sample and Recruitment

Patients for the independent qualitative interviews were recruited by third-party recruitment agencies via referring clinicians in the US and Germany. Eligible patients had to be at least 18 years of age, have a clinician-confirmed diagnosis of CLP based on medical history, clinical signs, and results of any diagnostic technique deemed necessary (e.g., biopsy, dermoscopy, allergy test), and have mild, moderate, or severe disease based on an IGA rating of ≥ 2 . Exclusion criteria were reflective of Study 1.

The target sample size was driven by principles of concept saturation (i.e., the point at which no new relevant concepts are likely to emerge with further interviews) [28]. Based on previous research, a minimum of 10 patients was deemed sufficient [29]. A quota sampling approach was employed to ensure a range of key demographic and clinical characteristics. All participants were compensated for their participation.

Interview Procedure

All interviews were 60 min and conducted via telephone by trained qualitative interviewers in the patients' native language using a semi-structured interview guide. The CE section of the interview, which aimed to explore the impact of CLP on patients' emotional wellbeing, lasted approximately 10–15 min. All participant-facing study documents and the interview guide were translated into German by certified translators to ensure they were appropriately adapted for the German interviews.

Qualitative Analysis

All interviews were audio-recorded and transcribed verbatim, with identity information redacted; German interviews were further translated into

English. Interview transcripts were analyzed in Atlas.ti (version 8) [27], using the same thematic analysis approach as described for Study 1.

RESULTS

Study 1: Qualitative Exit Interviews

Demographics and Clinical Characteristics

Thirteen US adults (female $n = 12$ [92.3%]; mean age [range] 56.5 [30–75] years) with MLP ($n = 5$), CLP ($n = 4$), and LPP ($n = 4$) participated in an exit interview (Table 1). Most participants had moderate LP ($n = 10/13$, 76.9%; MLP [$n = 4$], LPP [$n = 4$], CLP [$n = 2$]), based on baseline IGA score (Table 1).

Signs/Symptoms

Participants reported ten key signs and symptoms of LP during the exit interviews: itch, pain, skin lesions, burning sensation (MLP and CLP only), hair loss (LPP only), mouth ulcers (MLP only), red gums (MLP only), tingling sensation (LPP only), dry skin (CLP only), and scarring (CLP only) (Fig. 2). Relevant quotes for each concept are shown in Table 2.

The most frequently reported signs and symptoms were itch ($n = 10/13$, 76.9%), followed by pain ($n = 7/13$, 53.8%), and skin lesions ($n = 7/13$, 53.8%). Itch and skin lesions were experienced across all LP subtypes (MLP, CLP, LPP), while pain was only reported by CLP and MLP participants. Eight participants described areas of the body where they experienced itch, the most common being the arms, legs, and head (all $n = 2$). Itch was most frequently reported to be triggered by stress ($n = 3/5$). Pain was described as most commonly occurring in the mouth ($n = 5/7$) and was reported to be most frequently aggravated by eating in general ($n = 4/6$) or eating spicy foods ($n = 3/6$). Five participants described the location of their skin lesions, with the hands, feet, and legs most commonly mentioned (all $n = 2$). A burning sensation was reported ($n = 6/13$, 46.2%) by MLP and LPP participants. For MLP participants, this was experienced in their mouth ($n = 4$) and for LPP participants, this was experienced on their scalp when scratched

Table 1 Demographic and clinical characteristics for exit interview participants (Study 1)

Characteristics	MLP (<i>n</i> = 5)	LPP (<i>n</i> = 4)	CLP (<i>n</i> = 4)	Total (<i>N</i> = 13)
Gender, <i>n</i> (%)				
Female	4 (80.0%)	4 (100%)	4 (100%)	12 (92.3%)
Male	1 (20.0%)	0	0	1 (7.7%)
Age, years				
Mean	46.8	66.5	58.8	56.5
Min, max	30, 73	55, 75	44, 66	30, 75
Ethnicity, <i>n</i> (%)				
Non-Hispanic, non-Latino, or non-Spanish	5 (100%)	4 (100%)	4 (100%)	13 (100%)
Race, <i>n</i> (%)				
Black/African American	2 (40.0%)	0	4 (100%)	6 (46.1%)
White	1 (20.0%)	4 (100%)	0	5 (38.5%)
Asian	1 (20.0%)	0	0	1 (7.7%)
American Indian/Alaska Native	1 (20.0%)	0	0	1 (7.7%)
IGA severity of LP ^a , <i>n</i> (%)				
Moderate	4 (80.0%)	4 (100%)	2 (50.0%)	10 (76.9%)
Severe	1 (20.0%)	0	2 (50.0%)	3 (23.1%)

^aModerate = IGA score of 3; severe = IGA score of 4.

IGA investigator global assessment, LP lichen planus, CLP cutaneous lichen planus, LPP lichen planopilaris, MLP mucosal lichen planus.

(*n* = 2). Hair loss (*n* = 4/13, 30.8%), mouth ulcers (*n* = 4/13, 30.8%), tingling sensation (*n* = 3/13, 23.1%), red gums (*n* = 3/13, 23.1%), dry skin (*n* = 2/13, 15.4%), and scarring (*n* = 1/13, 7.7%) were also reported.

The signs and symptoms considered most bothersome to participants differed between LP subtypes, with most MLP participants reporting pain as most bothersome (*n* = 2/3, 66.7%), most CLP participants reporting itch as most bothersome (*n* = 2/3, 66.7%), and most LPP participants reporting hair loss as most bothersome (*n* = 3/4, 75.0%) (Fig. 2; Table 2).

Impacts on Patient Functioning and HRQoL

The impacts of LP on participants' functioning and HRQoL are grouped into six domains: emotional wellbeing, ADL, social activities/relationships, physical functioning, work/school, and sleep. As shown in Fig. 3, participants were

generally impacted by their LP, regardless of the LP subtype. Example quotes for each impact domain are shown in Table 3. Impact on emotional wellbeing was reported by all but one participant (*n* = 12/13, 92.3%; CLP [*n* = 4], LPP [*n* = 4], MLP [*n* = 4]), with feelings of embarrassment/self-consciousness (*n* = 7/12, 58.3%) being the most frequently mentioned, followed by frustration/annoyance (*n* = 6/12, 50.0%). Embarrassment/self-consciousness was most commonly attributed to the participants' physical appearance (e.g., due to skin lesions, hair loss, mouth ulcers) (*n* = 7), while frustration/annoyance was most frequently attributed to itch (*n* = 3). Other emotional impacts included concern/nervousness/anxiousness (*n* = 4), bad mood (*n* = 3), and depression (*n* = 3). The impact on ADL was mostly experienced by MLP participants (*n* = 9/13, 69.2%; MLP [*n* = 5], LPP [*n* = 2], CLP [*n* = 2]) and included difficulties

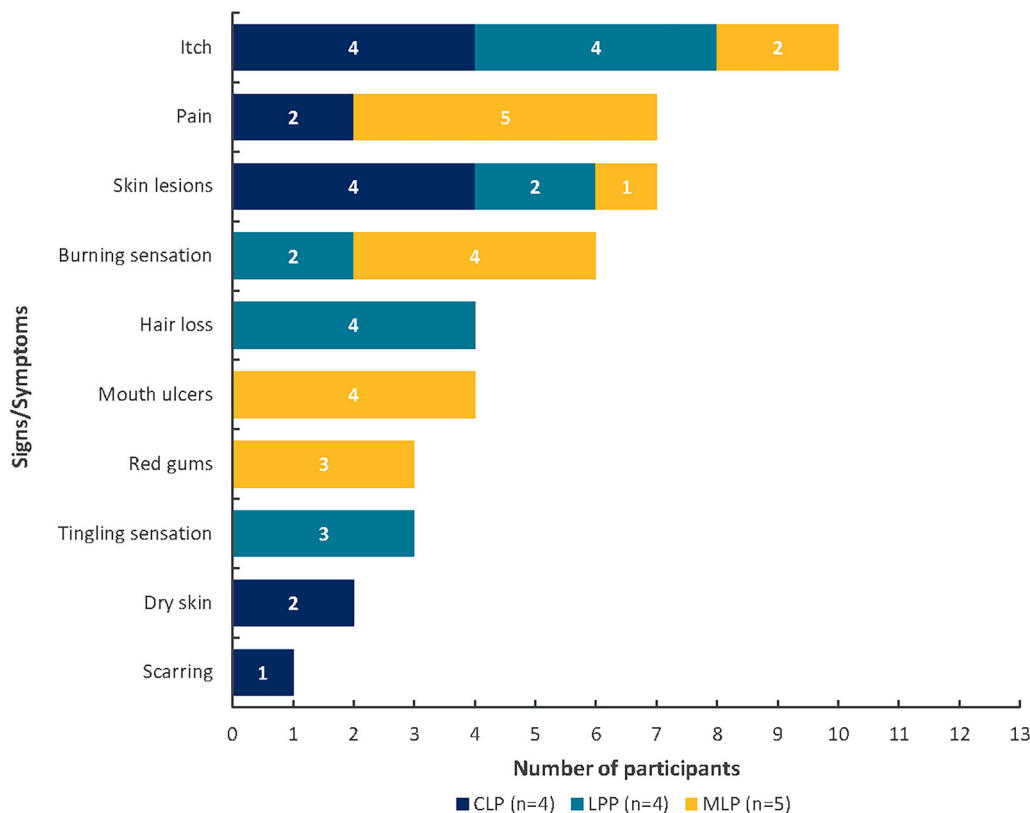


Fig. 2 Signs and symptoms reported by CLP, LPP, and MLP participants

with oral hygiene ($n = 4$), food and drink intake (e.g., avoidance of spicy, hot, or hard foods) ($n = 3$), and changes in clothing options to cover lesions/hair loss ($n = 3$). The signs/symptoms most frequently reported to impact ADL were pain ($n = 6$) and skin lesions ($n = 5$). Impact on social activities/relationships ($n = 8/13$, 61.5%; MLP [$n = 4$], LPP [$n = 2$], CLP [$n = 2$]) was reported to mainly affect participants' intimacy with their partner ($n = 5$) and participation in social events/activities ($n = 5$). Reduced intimacy was attributed to oral and genital pain ($n = 3$), appearance of skin lesions ($n = 1$), itching ($n = 1$), and hair loss ($n = 1$). Impact on physical functioning was primarily reported by MLP participants ($n = 6/13$, 46.2%; MLP [$n = 5$], LPP [$n = 1$]) and included difficulties chewing/swallowing when eating ($n = 5$) and opening/moving the mouth when speaking, smiling, or laughing ($n = 4$) due to pain, burning sensation, and/or mouth ulcers. Other domains less frequently mentioned were impacts on work/school ($n = 3/13$, 23.1%; CLP [$n = 1$], LPP

[$n = 1$], MLP [$n = 1$]) and sleep ($n = 1/13$, 7.7%; CLP) (Fig. 3; Table 3).

Study 2: Independent Qualitative Interviews

Demographic and Clinical Characteristics

Thirteen adults (female $n = 8$ [61.5%]; mean age [range] 53.5 [22–76] years) with CLP from the US ($n = 11$) and Germany ($n = 2$) participated in an independent qualitative interview (Table 4). All participants had either moderate ($n = 7/13$, 53.8%) or severe ($n = 6/13$, 46.2%) CLP based on their IGA score (Table 4).

Impact on Emotional Wellbeing in CLP Patients

Fifteen impacts on emotional wellbeing were discussed by participants during the interviews. Example quotes for each emotional wellbeing concept are provided in Table 5. The most frequently mentioned impacts of CLP were

Table 2 Overview of signs/symptoms reported by participants during the exit interviews (Study 1)

Sign/symptom	Number of participants ($N = 13$)	Example participant quotes
Itch	$n = 10/13$	<i>‘It’s just—it’s like a—almost like an itchy, tingling sensation. Just feels like you have to scratch it.’</i> (Female participant aged 55 with moderate LPP)
Pain	$n = 7/13$	<i>‘Uh, if I eat, it hurts. If I talk, it hurts. If I smile, it hurts. When they’re at their worst—at the worst that they can be, everything hurts. Everything triggers the pain, no matter what you do, when they’re at their worst.’</i> (Male participant aged 30 with moderate MLP)
Skin lesions ^a	$n = 7/13$	<i>‘Uh, at first it’s just tiny bumps...’</i> (Female participant aged 66 with severe CLP)
Burning sensation	$n = 6/13$	<i>‘All the times it’s burning.’</i> (Female participant aged 73 with moderate MLP)
Hair loss	$n = 4/13$	<i>‘Well, the loss of hair, the hair seems to fall out much more easily, as well as the with it getting thinner, then they can see the red scalp.’</i> (Female participant aged 72 with moderate LPP)
Mouth ulcers	$n = 4/13$	<i>‘So when I got a mouthful [of ulcers]. When it was just unbearable. There were so many and they didn’t heal, right away I went to the doctor.’</i> (Male patient aged 30 with moderate MLP)
Red gums	$n = 3/13$	<i>‘It just is always red. Yeah. I don’t think it ever goes away, in my opinion.’</i> (Female participant aged 45 with moderate MLP)
Tingling sensation	$n = 3/13$	<i>‘That goes with the itching is, you know, it’s at times a tingling, irritating type situation.’</i> (Female participant aged 72 with moderate LPP)
Dry skin	$n = 2/13$	<i>‘It’s dry. It dries my skin out. It’s dry. They’re dry.’</i> (Female participant aged 66 with severe CLP)
Scarring	$n = 1/13$	<i>‘Well the main thing was it wasn’t so much the itching, but, you know, had, um, like I said, scarring. It was, um, after they did dry, I did have like little black marks.’</i> (Female participant aged 64 with moderate CLP)

^aParticipants used multiple terms to describe their skin lesions, including: rash, spots, bumps, hives, ulcers, sores, and pimples. Participants also noted discoloration with their lesions, describing them as red, dark, black, and purple. CLP cutaneous lichen planus, LPP lichen planopilaris, MLP mucosal lichen planus.

frustration/annoyance ($n = 11/13$, 84.6%) and worry/nervousness/anxiousness ($n = 11/13$, 84.6%), followed by feeling sad/upset ($n = 8/13$, 61.5%), embarrassed ($n = 7/13$, 53.8%), or depressed ($n = 7/13$, 53.8%). Most participants who felt frustrated/annoyed ($n = 9/11$, 81.8%) described aspects of their condition that caused this, including pain ($n = 3$), itch ($n = 2$), and

flare-ups/when the disease is most severe ($n = 2$). Of the participants who discussed factors that caused them to feel worried/nervous/anxious ($n = 8/11$, 72.7%), the most frequently reported causes were visibility of skin lesions (e.g., when wearing t-shirts or shorts in public) ($n = 4$) and lack of improvement/the possibility of symptoms worsening ($n = 4$). Over half the

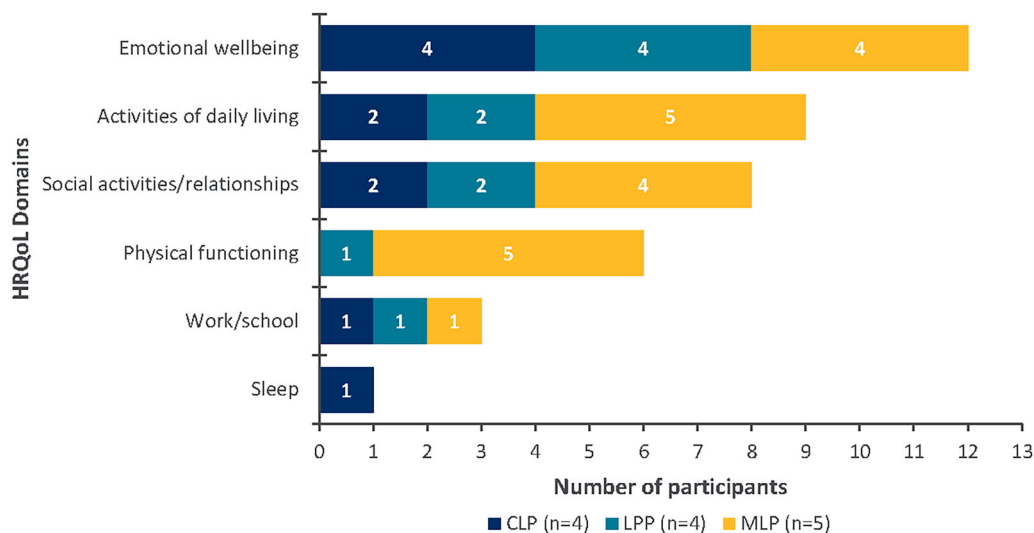


Fig. 3 HRQoL impact domains reported by CLP, LPP, and MLP participants

participants who reported embarrassment also mentioned visibility of skin lesions as the cause of their embarrassment ($n = 4$). Reasons provided by five of the participants who experienced feeling sad/upset included acute flare-ups ($n = 2$), the need to dress differently to minimize the visibility of skin lesions ($n = 1$), having to explain persistent itching ($n = 1$), and lack of resolution in symptoms ($n = 1$). Of the four participants who provided a reason for feeling depressed, most mentioned lack of resolution/no improvement in symptoms as the cause of their depression ($n = 3$). Several other emotional impacts were mentioned less frequently, namely stress ($n = 2/13, 15.4%$), helplessness ($n = 2/13, 15.4%$), feeling uneasy/unsettled ($n = 2/13, 15.4%$), confusion ($n = 1/13, 7.7%$), fear ($n = 1/13, 7.7%$), burden ($n = 1/13, 7.7%$), defeat ($n = 1/13, 7.7%$), hypervigilance ($n = 1/13, 7.7%$), and guilt ($n = 1/13, 7.7%$) (Table 5).

DISCUSSION

While there is extensive clinical literature reporting the presentation and symptomology of LP [4, 6, 7, 12], qualitative exploration of patients’ signs, symptoms, and impact on HRQoL is limited, particularly for the different clinical subtypes. Specifically, no qualitative studies appear to exist for CLP or LPP. As such,

this research sought to address this gap by exploring the experience of LP for the different LP subtypes in adult patients, including gaining a better understanding of the impact on emotional wellbeing in CLP patients.

Participants reported several signs and symptoms associated with LP, the most frequent of which were itch, pain, skin lesions, and a burning sensation. While itch was reported by participants with all subtypes of LP, fewer MLP participants reported experiencing itch compared with CLP and LPP participants. This finding aligns with previous qualitative literature that indicates that itch is not a prominent symptom of MLP [11]. By contrast, pain was only reported by CLP and MLP participants, despite the clinical literature indicating that pain is also a key symptom of LPP [30]. The lack of LPP participants reporting pain in this study could be due to the small sample size; as such, this finding should be interpreted with caution. No CLP participants spontaneously reported experiencing a burning sensation in the exit interviews, which aligns with the literature that burning sensation is a more prominent symptom of LPP and MLP [4, 11, 31]. However, this finding should not be taken to indicate that CLP patients do not experience a burning sensation, as pre-study recruitment discussions with participants indicate that some CLP patients may experience this symptom and, where this

Table 3 Overview of impact domains/concepts reported by participants during the exit interviews (Study 1)

Impact domain (<i>N</i> = 13)	Impact concepts			Example participant quotes
	Number of MLP participants (<i>n</i> = 5)	Number of CLP participants (<i>n</i> = 4)	Number of LPP participants (<i>n</i> = 4)	
Emotional wellbeing (<i>n</i> = 12/13)	<ul style="list-style-type: none"> Embarrassed/self-conscious (<i>n</i> = 3) Bad mood (<i>n</i> = 3) Frustrated/annoyed (<i>n</i> = 2) Depressed (<i>n</i> = 1) Sad/upset (<i>n</i> = 1) 	<ul style="list-style-type: none"> Embarrassed/self-conscious (<i>n</i> = 2) Frustrated/annoyed (<i>n</i> = 1) Worried/nervous/anxious (<i>n</i> = 1) Depressed (<i>n</i> = 1) Bothered/burdened (<i>n</i> = 1) Self-esteem (<i>n</i> = 1) 	<ul style="list-style-type: none"> Frustrated/annoyed (<i>n</i> = 3) Worried/nervous/anxious (<i>n</i> = 3) Embarrassed/self-conscious (<i>n</i> = 2) Depressed (<i>n</i> = 1) Bothered/burdened (<i>n</i> = 1) Sad/upset (<i>n</i> = 1) Self-esteem (<i>n</i> = 1) Fearful (<i>n</i> = 1) 	<p><i>‘Um, [itching] makes me irritated and, um, uncomfortable. Makes me feel just a little aggravated because it’s just like one more thing added to the other list of symptoms that I already have.’</i> (Female participant aged 45 with moderate MLP)</p> <p><i>‘I was most embarrassed about it. Certain clothes I couldn’t wear that I used to wear. I wear clothes that will cover it up.’</i> (Female participant aged 61 with moderate CLP)</p> <p><i>‘Well other aspects have been affected too. I mean you don’t want to be with people when you’re feeling, you know, depressed and anxious.’</i> (Female participant aged 72 with moderate LPP)</p>
ADL (<i>n</i> = 9/13)	<ul style="list-style-type: none"> Oral hygiene (<i>n</i> = 4) Food/drink intake (<i>n</i> = 3) Shopping (<i>n</i> = 1) Travelling (<i>n</i> = 1) 	<ul style="list-style-type: none"> Clothing options (<i>n</i> = 2) 	<ul style="list-style-type: none"> Clothing options (<i>n</i> = 1) Gardening (<i>n</i> = 1) Styling hair (<i>n</i> = 1) 	<p><i>‘There’s soreness if I brush my teeth... I accidentally hit my gums with the toothbrush, um, it kind of leaves a redness and, uh, pain there every time that I brush.’</i> (Female participant aged 41 with moderate MLP)</p> <p><i>‘...everything has to be really soft... even like if I have a piece of bread and it has a little bit of a crust on it that’s a little drier than the middle part of the bread, it can be—it’s almost like eating razorblades.’</i> (Female participant aged 45 with moderate MLP)</p> <p><i>‘It’s just I have to try and cover my spots...I can’t wear shorts because my leg is messed up. I can’t wear t-shirts...I can’t wear sandals ’cause it’s on the top of my feet.’</i> (Female participant aged 44 with severe CLP)</p>
Social activities/relationships (<i>n</i> = 8/13)	<ul style="list-style-type: none"> Intimacy with partner (<i>n</i> = 3) Social events/activities (<i>n</i> = 2) 	<ul style="list-style-type: none"> Social events/activities (<i>n</i> = 2) Intimacy with partner (<i>n</i> = 1) Social isolation (<i>n</i> = 1) 	<ul style="list-style-type: none"> Intimacy with partner (<i>n</i> = 1) Social events/activities (<i>n</i> = 1) Relationship with friends (<i>n</i> = 1) 	<p><i>‘Uh, I don’t really do a lot of sports, but, uh, still let’s just say I can’t kiss anybody. That’s probably the most physical. Can’t really kiss anybody.’</i> (Male participant aged 30 with moderate MLP)</p> <p><i>‘I tend not to want to go [to social events] ’cause I don’t know when it might flare up again.’</i> (Female participant aged 72 with moderate LPP)</p>

Table 3 continued

Impact domain (N = 13)	Impact concepts			Example participant quotes
	Number of MLP participants (n = 5)	Number of CLP participants (n = 4)	Number of LPP participants (n = 4)	
Physical functioning (n = 6/13)	<ul style="list-style-type: none"> • Chewing/swallowing (n = 5) • Opening/moving mouth to speak, laugh, smile (n = 4) • Exercising/mobility (n = 1) • Urinating (n = 1) • Maintaining weight (n = 1) 	<ul style="list-style-type: none"> • Exercising/mobility (n = 1) 		<p><i>“There’s the pain from eating and swallowing.”</i> (Female participant aged 41 with moderate MLP)</p> <p><i>“It hurts to talk...I mean if there were any general conversations you were having with anybody, even a smile or talking, it, it hurted. It was painful.”</i> (Male participant aged 30 with moderate MLP)</p>
Work/school (n = 3/13)	<ul style="list-style-type: none"> • Communication (n = 1) 	<ul style="list-style-type: none"> • Colleagues’ opinions (n = 1) • Work activities (n = 1) 	<ul style="list-style-type: none"> • Concentration (n = 1) 	<p><i>“...it’s hard to, you know, concentrate on say a lesson or something if, um, I’m trying not to itch it or scratch it. And therefore, my attention is diverted from what I’m doing.”</i> (Female participant aged 72 with moderate LPP)</p>
Sleep (n = 1/13)		<ul style="list-style-type: none"> • Sleep (n = 1) 		<p><i>“It would, it would last, um—sometimes I would itch all night. I mean I couldn’t sleep, and I would just put anything on just to cool it down, but sometimes I couldn’t sleep at night.”</i> (Female participant aged 44 with severe CLP)</p>

ADL activities of daily living, CLP cutaneous lichen planus, LPP lichen planopilaris, MLP mucosal lichen planus.

concept was assessed, conceptual saturation may not have been met due to the small sample size of CLP patients in the exit interview sample. Other signs and symptoms that were reported by only one subtype of LP included hair loss and a tingling sensation on the scalp, both of which are recognized in the clinical literature as symptoms associated with primary cicatricial alopecias like LPP [4, 32, 33]. Further, two thirds of MLP participants described the appearance of red gums, which has been previously documented as a clinical sign of oral LP [34].

These signs and symptoms were also reported to have a significant impact on participants’ HRQoL. Consistent with previous literature [11, 13, 14], MLP participants reported that painful oral lesions affect physical functioning and ADL by impairing their ability to eat,

perform oral hygiene care, and move or open their mouth to speak, laugh, or smile. Oral discomfort was reported to be triggered or intensified by spicy, hot, or hard foods/liquids, leading to dietary alteration and avoiding activities in most MLP participants [11, 35, 36]. Further, some CLP and LPP participants described how concerns about the visibility of skin lesions/hair loss had led to changes in their clothing habits to hide affected areas of the body. While this finding was identified in a previous study that implemented the DLQI in patients with CLP [16], the current studies provide direct qualitative evidence from the patient perspective. Notably, across the LP subtypes, participants reported substantial impact on their emotional wellbeing, which they attributed to various aspects of their condition. These included (but were not limited to) feelings of

Table 4 Demographic and clinical characteristics for independent qualitative interview participants (Study 2)

Characteristics	<i>N</i> = 13
Location, <i>n</i> (%)	
US	11 (84.6%)
Germany	2 (15.4%)
Gender, <i>n</i> (%)	
Female	8 (61.5%)
Male	5 (38.5%)
Age, years	
Mean	53.5
Min, Max	22, 76
Ethnicity ^a , <i>n</i> (%)	
Non-Hispanic, non-Latino, non-Spanish	9 (69.2%)
Hispanic, Latino, Spanish	2 (15.4%)
Not asked	2 (15.4%)
Race ^a , <i>n</i> (%)	
Black/African American	5 (38.5%)
White	3 (23.0%)
Asian	1 (7.7%)
Not specified	2 (15.4%)
Not asked	2 (15.4%)
IGA severity of LP ^b , <i>n</i> (%)	
Moderate	7 (53.8%)
Severe	6 (46.2%)

IGA investigator global assessment, LP lichen planus, US United States.

^aData on race and ethnicity were not collected for German participants due to sensitivities with collecting this type of data in Germany.

^bModerate = IGA score of 3; severe = IGA score of 4.

frustration/annoyance primarily due to itch, and embarrassment associated with their physical appearance. This is reflective of previous literature that LP has a significant impact on patients' psychological wellbeing [15–17]. LP was also reported to impact social functioning across the LP subtypes, with participants

mentioning reduced intimacy and avoidance of social activities due to their symptoms. While impaired sexual function has been previously documented in relation to vulvovaginal MLP [37, 38], in the current study, participants across LP subtypes described aspects of their condition that affected intimacy with their partner, including oral or genital pain (MLP), appearance of skin lesions and itching (CLP), and hair loss (LPP). The present study supports findings from previous literature that work/school activities are less frequently impacted in LP patients [11, 16]. Impaired sleep, which was only mentioned spontaneously by one CLP participant, has been documented to be a significant impact in patients with dermatological disorders, including oral MLP [39], due to itch, pain, and reduced psychological wellbeing [40]. While these findings largely align with the literature, they add an important contribution in that, previously, there were no qualitative insights in the literature describing the patient experience of CLP and LPP from the patient perspective, and limited qualitative insights from the MLP patient perspective.

This research also specifically focused on aspects of emotional wellbeing in CLP patients, given the importance of emotional impacts in LP and the absence of disease-specific instruments available in CLP. CLP participants in both studies reported several impacts on their emotional wellbeing, including (but not limited to) frustration/annoyance, worry/nervousness/anxiousness, embarrassment, and depression. Such findings are consistent with previous quantitative literature that CLP has a significant impact on emotional wellbeing [16]. However, the current study provides a more in-depth understanding of the ways that CLP patients' emotional wellbeing is impacted from the perspective of patients themselves. In particular, participants described that the cosmetic appearance of skin lesions caused them to feel embarrassed about their appearance and anxious or nervous about the visibility of skin lesions, particularly when wearing t-shirts and shorts in public. Participants described feeling depressed about the lack of resolution in symptoms and expressed worry that their symptoms may not improve or could worsen.

Table 5 Overview of emotional wellbeing impacts reported by CLP participants during the independent qualitative interviews (Study 2)

Emotional impacts	Number of participants (N = 13)	Example participant quotes
Frustrated/ annoyed	n = 11/13	<i>‘Just frustrated just the fact that I’m itching or I’m, I’m feeling pain or just sometimes I just don’t want to deal with it, you know, it’s like every day, just have a day off, you know, that kind of feeling.’</i> (Male participant aged 45 with severe CLP, US)
Worried/ nervous/ anxious	n = 11/13	<i>‘...I would say probably nervousness as a result of having to like, um, of having to like deal with any like patches or lesions or things like that. Uh, that would maybe be like visible for example.’</i> (Male participant aged 22 with moderate CLP, US)
Sad/upset	n = 8/13	<i>‘Yes, just when it’s so acute, when the flare-up is so acute that it makes you sad, to the extent that you cry then.’</i> (Female participant aged 61 with moderate CLP, Germany)
Embarrassed/self-conscious	n = 7/13	<i>‘...it was in the summer I think too, so I really like felt like I couldn’t enjoy being outdoors as much. I just didn’t want to wear like short sleeve shirts or something like that. I was embarrassed about it.’</i> (Female participant aged 45 with moderate CLP, US)
Depressed	n = 7/13	<i>‘I don’t, you know—uh, I live with the hope that maybe in months it’ll just go away, uh, or in years, but it hasn’t in the past four years. So yeah, I feel depressed.’</i> (Male participant aged 65 with severe CLP, US)
Stressed	n = 2/13	<i>‘I do experience—like when I have some, some of my bumps...Um, and my skin sometimes I can get a little bit stressed...’</i> (Male participant aged 45 with severe CLP, US)
Uneasy/unsettled	n = 2/13	<i>‘So, I wasn’t embarrassed. It was just more so just kind of going a little uneasy with having to explain.’</i> (Female participant aged 52 with severe CLP, US)
Helpless	n = 2/13	<i>‘And in the beginning, I feel helpless.’</i> (Female participant aged 76 with severe CLP, US)
Confused	n = 1/13	<i>‘...also, just the experience of having a chronic illness that doesn’t necessarily go away that easily. Um, so yeah, I had more emotional reaction to it, frustration, confusion.’</i> (Male participant aged 45 with severe CLP, US)
Fearful	n = 1/13	<i>‘...I’m always checking my skin to see if there’s anything there and hoping that nothing comes back again...’</i> Interviewer: ‘So that is more what you’re afraid of?’ ‘Yes’ (Female participant aged 52 with moderate CLP, Germany)
Burdened	n = 1/13	<i>‘I found the side effects of the medications I was given at least as much of a burden as the illness itself.’</i> (Female participant aged 52 with moderate CLP, Germany)
Defeated	n = 1/13	<i>‘Cause I was already just trying to get used to living life now...before I got diagnosed with it, I just like, I just felt defeated.’</i> (Female participant aged 45 with moderate CLP, US)

Table 5 continued

Emotional impacts	Number of participants (N = 13)	Example participant quotes
Hypervigilant	n = 1/13	<i>“Emotionally it makes me feel, um, I would say just makes me feel more vigilant, more focused, more connected to my body, more listening to it more.”</i> (Male participant aged 45 with severe CLP, US)
Guilty	n = 1/13	<i>“You sometimes feel guilty because it’s not fair to, you know, your spouse or it’s not fair to your kids or your grandkids because you can’t do everything that they would like you to do that you want to do. I mean it’s cut back on social activities.”</i> (Male participant aged 65 with severe CLP, US)

CLP cutaneous lichen planus, US United States.

Persistent or severe symptoms were reported to cause participants to feel frustrated or annoyed with their condition. While several participants reported sadness, the reasons were variable (e.g., severity of symptoms, lack of symptom resolution, and having to change clothing habits to cover lesions). These findings confirm that CLP significantly impacts patients’ psychological wellbeing, in addition to other domains of HRQoL (as previously described). As such, when considering how best to assess HRQoL in CLP populations, capturing the emotional impacts of CLP should also be considered. For example, the DLQI would not be considered appropriate as a standalone measure for assessing HRQoL in CLP patients as it lacks coverage of important impacts on emotional wellbeing.

CE methods used in qualitative interviews remain the gold standard for providing in-depth understanding of the patient experience. Such findings are paramount for identifying concepts that are relevant and important to patients and can help inform selection of appropriate outcome instruments in clinical research [41]. For the exit interviews, one benefit is that the evidence generated was obtained during a time when participants were actively monitoring their condition as part of an LP clinical study and therefore it is assumed that participants would have been more acutely aware of their disease experience.

Some limitations of this study should also be noted. An important limitation is the inclusion of relatively few participants who may not be

representative of a wider population. Although the exit interview sample included participants with a range of LP diagnoses, the sample size within each subtype was relatively small and there was a greater proportion of participants with moderate LP, presenting a limitation in the analysis and interpretation of these data. Further, participants were selected based on a clinician-confirmed primary diagnosis of CLP, MLP, or LPP and no pre-defined quotas were used to target patients with specific regions of the body where quality of life may be more greatly affected (e.g., nail involvement, genital regions). However, considering the rarity of specific presentations like nail involvement, the inclusion of these participants may not generalize to the wider LP patient population. To our knowledge, this is the first qualitative study exploring patients’ perceptions of the signs, symptoms, and impact on HRQoL associated with CLP and LPP subtypes. Therefore, despite the small sample size, this research not only adds to the qualitative literature available in MLP [11, 13–15], but also provides preliminary insights into the experience of CLP and LPP from the patient perspective. A further limitation is that participants for the exit interviews were predominantly female; however, this is reflective of the literature, which suggests that LP may affect more females than males [5]. Additionally, itch and pain were specifically probed for during the exit interviews, which may over-represent the prevalence of these

concepts compared with others identified in this research.

CONCLUSION

The results of this qualitative research contribute to the literature by providing insights into the adult patient experience of LP (namely the signs, symptoms, and impact on HRQoL) across three LP subtypes. This research also highlights that in addition to assessing key symptoms of LP, consideration should be given to the assessment of impact on HRQoL in future LP research; in particular, highlighting the importance of considering impacts on emotional wellbeing when selecting instruments for the assessment of HRQoL in CLP patient populations.

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Compliance with Ethics Guidelines. All participants provided informed consent indicating that their data would be used for medical research purposes and that the study results may be published. The studies were performed in accordance with the Helsinki Declaration of 1964 and its later amendments. Ethical approval and oversight for the exit interviews was obtained as part of the clinical study (clinicaltrials.gov ID: NCT04300296, EUDRACT: 2019-003588-24). Independent institutional review board (IRB) and ethics committee approvals were obtained from the following: Advarra IRB, Columbia, Maryland, United States; Mayo Clinic IRB, Rochester, Minnesota, United States; University of Miami Human Subjects Research Office, Miami, Florida, United States; and Western Institutional Review Board, Puylap, Washington, United States. Ethical approval and oversight for the independent qualitative interviews was obtained from Western Copernicus Group Independent Review Board (WCG IRB; reference: 20216826).

Data Availability. The datasets generated and/or analyzed during the current study are not publicly available in order to protect participant confidentiality.

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