An Exploratory Retrospective Social Listening Study to Identify Patient Experiences Associated with Cutaneous Lupus Erythematosus

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CONCLUSIONS

>20%
mentioned rash or pain

26%
mentioned negative feelings

This social listening study was able to describe patients' experiences with CLE. The methodology was able to provide insight on a condition for which patient experiences are not well studied

We were able to describe factors that contribute to reduced HRQoL, as well as healthcare and treatment experiences, even though generalizability of the study may be limited by the low number of patients

Social listening is an important component of understanding patient experiences

INTRODUCTION

- CLE is a **chronic inflammatory autoimmune disease** primarily affecting the skin[1]
- To date, **no targeted treatments** have been approved for CLE[1]
- Painful skin lesions, dyspigmentation, scarring, itch, hair loss, and photosensitivity **negatively impact the quality of life** of patients with CLE[2,3]
- Studies have reported that **patients with CLE fare worse** than their counterparts with other dermatologic conditions, such as acne or non-melanoma skin cancer, and experience a **high burden of psychiatric morbidity**, especially anxiety and depression[2]

OBJECTIVES

Explore the feasibility of identifying patients with CLE and assessing their experiences of living with CLE through social media platforms

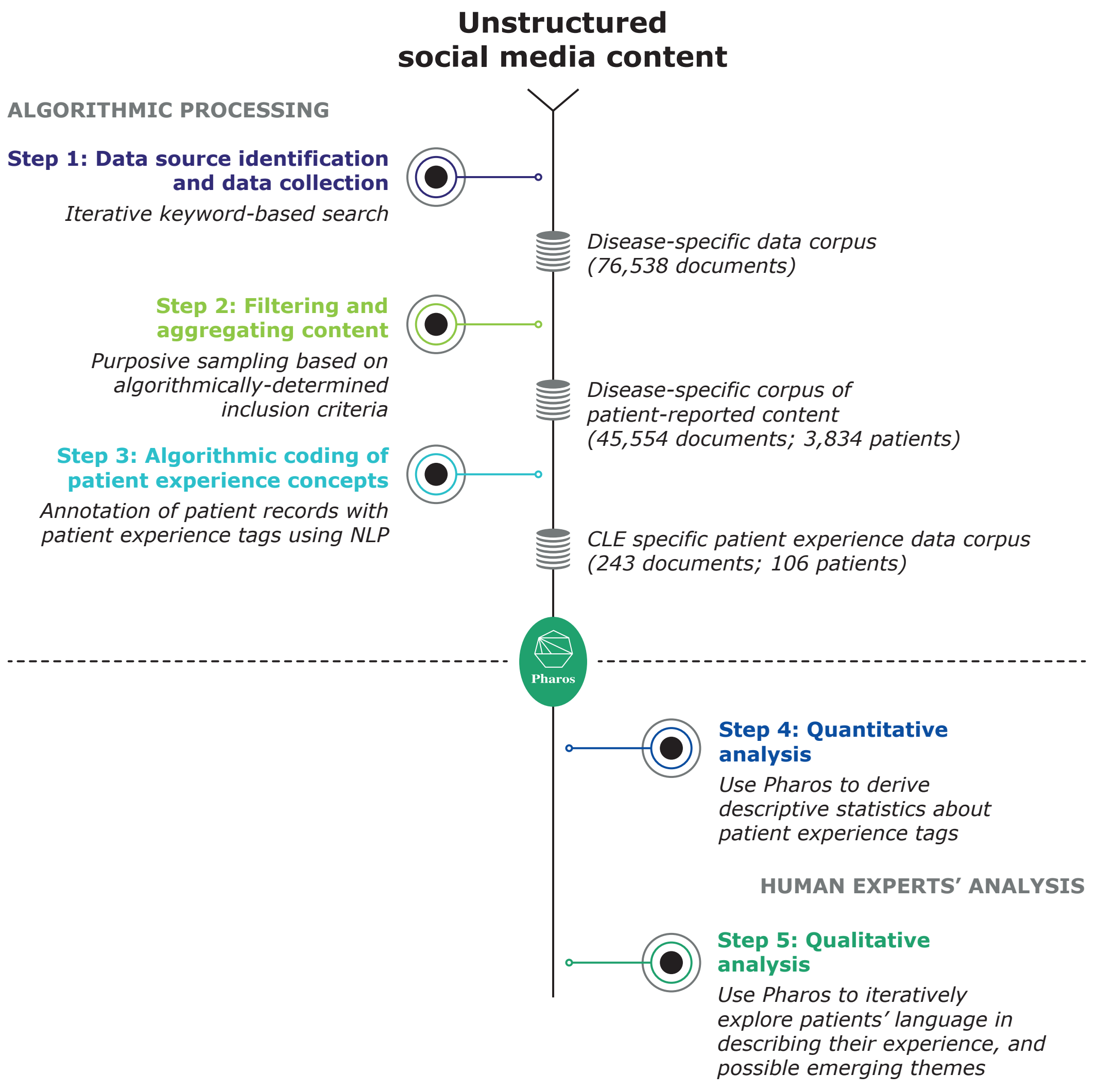
Patient-reported disease burden and relevant HRQoL impacts in CLE, including HRQoL and unmet needs

Patient-reported treatment experiences and unmet needs in CLE

METHODS & PATIENTS

Exploratory, retrospective social listening study performed in 13 English-speaking social media platforms from October 2019 to January 2022

Overview of methodology



Unstructured social media content

ALGORITHMIC PROCESSING

Step 1: Data source identification and data collection
Iterative keyword-based search

Disease-specific data corpus (76,538 documents)

Step 2: Filtering and aggregating content
Purposive sampling based on algorithmically-determined inclusion criteria

Disease-specific corpus of patient-reported content (45,554 documents; 3,834 patients)

Step 3: Algorithmic coding of patient experience concepts
Annotation of patient records with patient experience tags using NLP

CLE specific patient experience data corpus (243 documents; 106 patients)

Step 4: Quantitative analysis
Use Pharos to derive descriptive statistics about patient experience tags

HUMAN EXPERTS' ANALYSIS

Step 5: Qualitative analysis
Use Pharos to iteratively explore patients' language in describing their experience, and possible emerging themes

- Keywords defining CLE were used to search for relevant posts. NLP algorithms were applied to code concepts related to disease burden, HRQoL, and treatment experiences
- Non-NLP analyses included descriptive statistics of key themes/concepts and thematic analysis to describe patient experiences

106 patients with CLE were selected

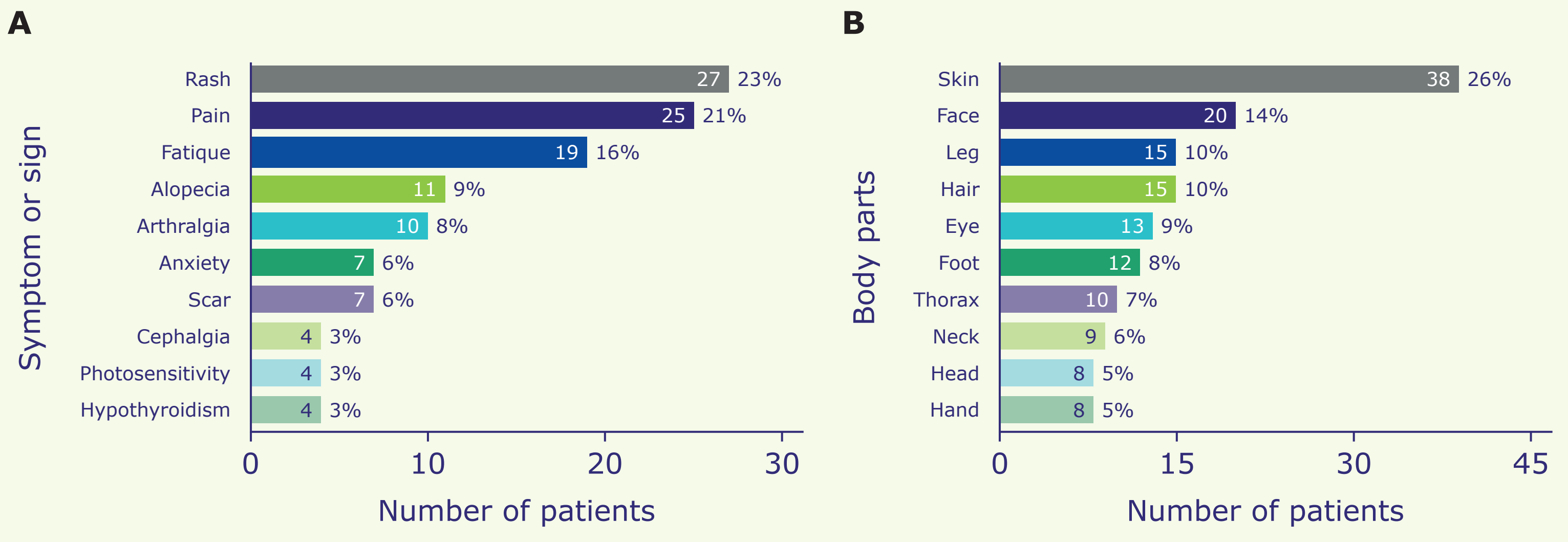
- 243 associated documents
- Some patients authored more than 1 post on a topic (patient mentions)

RESULTS

Symptoms

- Rash was the **most common symptom** mentioned (23% across all symptom mentions), followed by pain (21%) and fatigue (16%)
- The **most frequently reported area of involvement** (or affected body part) was the skin (26% of mentions), followed by the face (14%)

Top 10 most frequently mentioned A) signs and symptoms (n=118 patient mentions) and B) body parts (n=148 patient mentions)



A patient may have mentioned more than 1 sign/symptom or body part

HRQoL

- HRQoL impacts were described by 47 patients (78 documents), with **negative feelings** (26% of documents discussing HRQoL) and **limitations on recreation and leisure** (18%) being discussed most

Example quotes on patient-reported symptoms and impact on HRQoL

RASH "I was diagnosed with subacute cutaneous lupus in 2017 and at that time my hands and feet were in a terrible state with chronic ulceration. The lesions, with me, however, usually on the palm of my hands and soles of my feet. I get a burning feeling beforehand, and my skin becomes very red and inflamed… and, yes, hot hot hot!! I can't really say that they blister as such, but the skin swells and then splits and I do get them on all of my fingers… in the cracks on the underside and down the sides of my fingers!!"

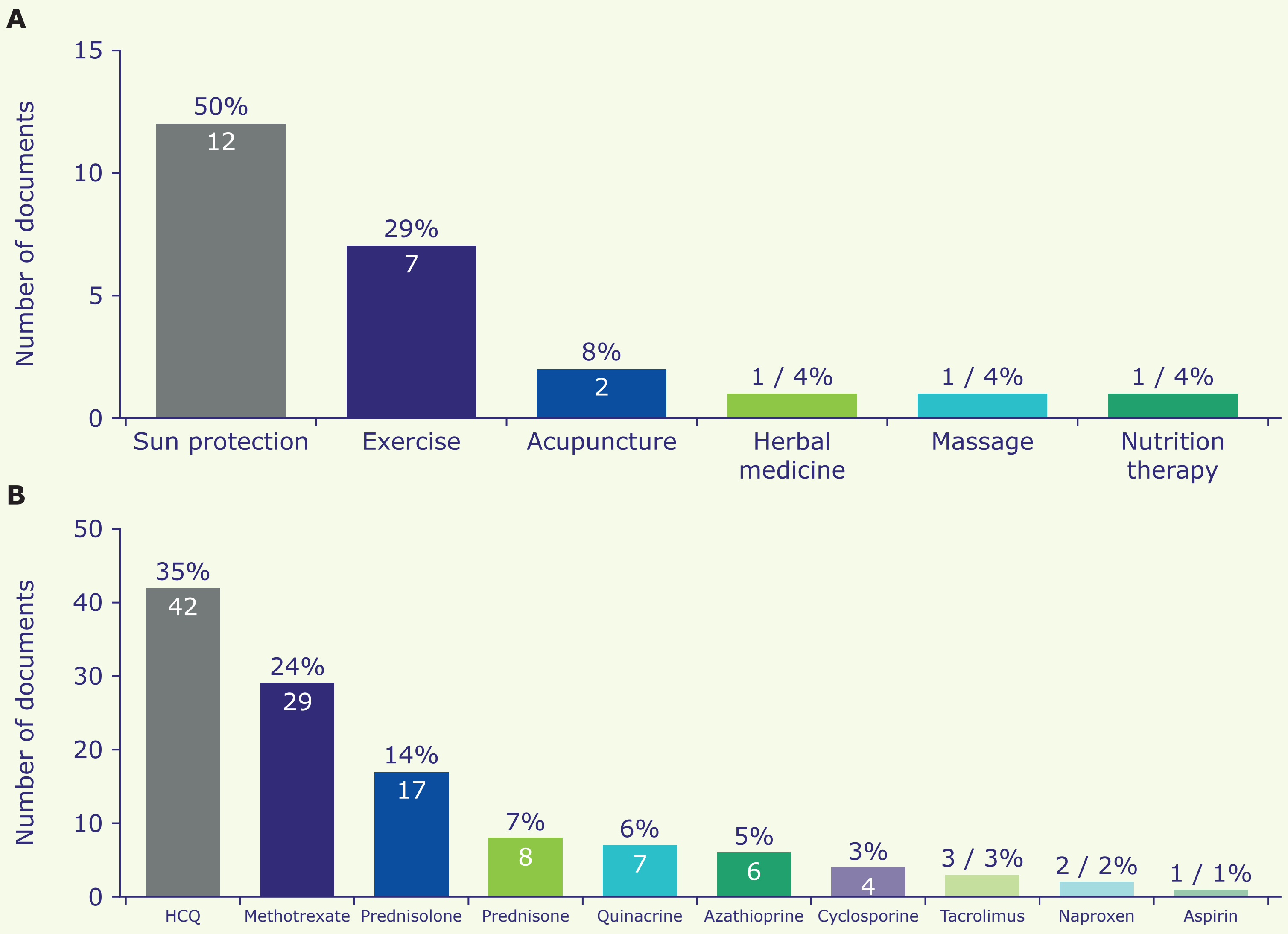
FATIGUE "Hi everyone, I was diagnosed with cutaneous lupus a few years ago and was on medication for a while but have been off it now for some time as they advised my lupus had gone 'dormant'. I have always received very little support with understanding my diagnosis and the symptoms to expect. More regularly now, I am becoming extremely tired, achy and appear to get ulcers in my nose, it can get in the way of my daily living, and I am getting quite frustrated and upset."

NEGATIVE FEELINGS AND RECREATION AND LEISURE "I get tired easily but try and keep active by exercising regularly. When I get any sort of bug it takes me ages to clear, and I get really anxious and panicky when I'm ill. I develop horrendous heat rash in the sun so cannot sit out in the sun without factor 50 and a hat and long sleeves."

Treatments

- Non-drug (n=16 patient mentions) and drug (n=49 patient mentions) treatment options were discussed
- The **most mentioned drug agents** were hydroxychloroquine (35% of documents), methotrexate (24%), and prednisolone (14%)

Top 10 most frequently mentioned A) non-drug treatments (n=24 documents) and B) drug treatments (n=82 documents)



- CLE patients reported **not receiving the attention they require** in healthcare settings, and seem to suffer even more than SLE patients from **misdiagnosis, delayed diagnosis, and contradictory treatment approaches** by dermatologists and rheumatologists
- Negative experiences related to current treatments included **fatigue, brain fog, and lack of sleep**

CLE, cutaneous lupus erythematosus; **HCQ**, hydroxychloroquine; **HRQoL**, health-related quality of life; **NLP**, natural language processing; **SLE**, systemic lupus erythematosus.

1. Ziemer M, et al. *J Dtsch Dermatol Ges.* 2014;12:285–301; **2.** Ogunsanya ME, et al. *Int J Womens Dermatol.* 2018;4:152–158; **3.** Yan D, et al. *Lupus Sci Med.* 2021;8:e000444.

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