

Retrospective Social Listening Study of Patients Living with Systemic Lupus Erythematosus (SLE): Understanding the Patient Experience

PCR251



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CONCLUSIONS

30.1% of SLE patients mentioned pain

23.7% mentioned experiencing negative feelings

Findings reveal varying severity and frequency of symptoms and overall HRQoL impacts associated with SLE across patients

Patients stated that their symptoms were not fully alleviated with current treatment options

Patient perspectives highlight high levels of disease burden and unmet needs that should be considered during drug discovery and development processes

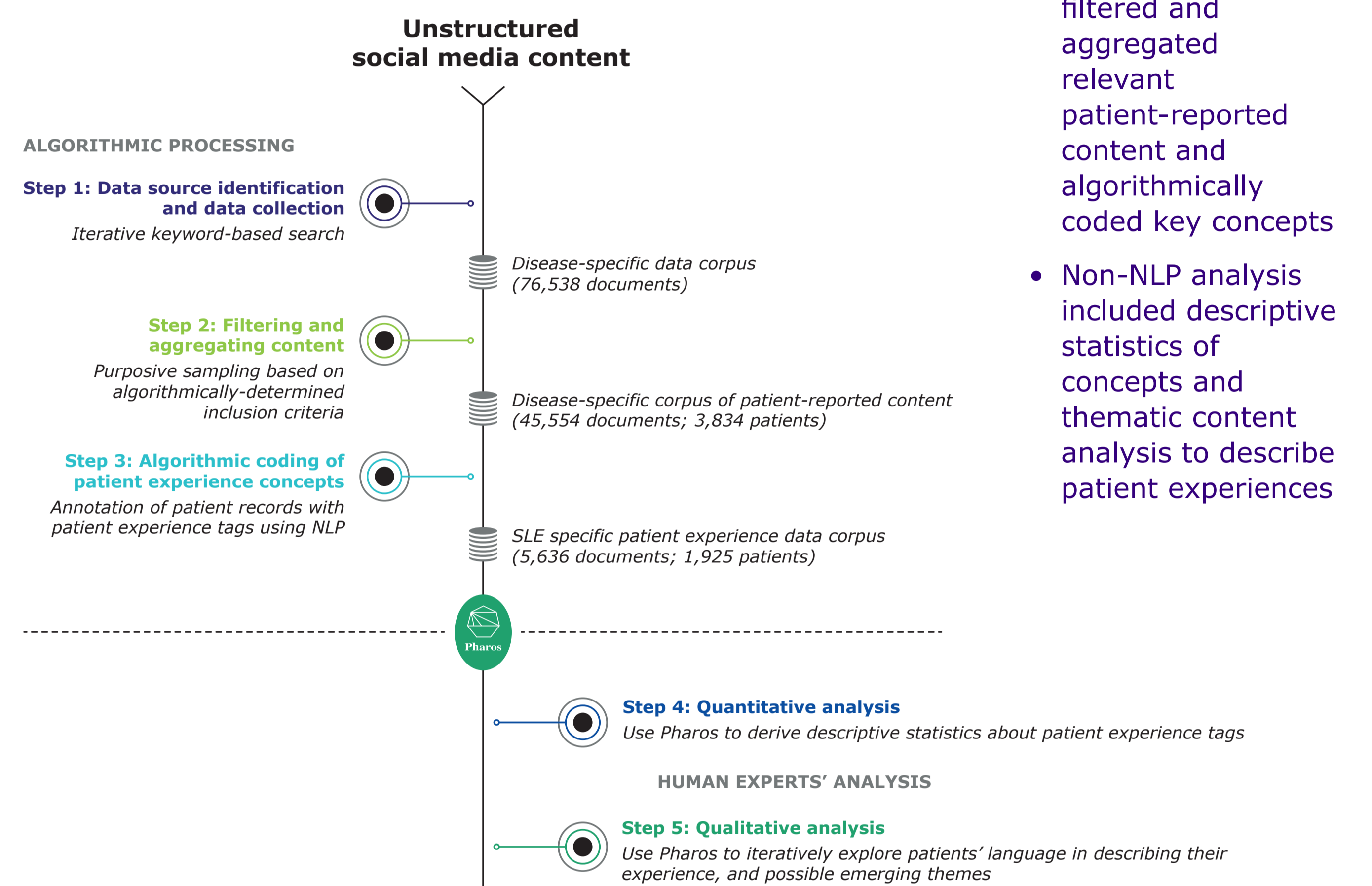
INTRODUCTION

- The **chronic autoimmune disease SLE** has a broad spectrum of clinical manifestations and organ system involvement, with **fluctuating symptoms** and periods of flare and remission^{1,2}
- There is a **high unmet need for effective therapies**; while several drugs can help alleviate symptoms or protect against organ damage, none are curative, and patients often experience side effects that can be as problematic as the disease itself³⁻⁵
- Increasing digital participation and social media discussions** can provide a deeper understanding of patient needs, treatment experiences, and factors that may influence treatment decisions in the real world
- Social listening** is one method to collect patient experience data on disease burden and treatments, employing a mixed-methods research design

METHODS & PATIENTS

Retrospective social listening study executed across 13 English-speaking social media platforms from October 2019 to January 2022

Overview of methodology



- NLP techniques filtered and aggregated relevant patient-reported content and algorithmically coded key concepts
- Non-NLP analysis included descriptive statistics of concepts and thematic content analysis to describe patient experiences

- 1925 patients with SLE were selected, with 5636 associated documents
- There were 2023 mentions of symptoms and 2199 mentions of HRQoL topics

OBJECTIVES

- Explore SLE patient-reported disease burden and HRQoL impacts**
 - Disease-specific symptoms and the overall HRQoL status were described
 - Unsolicited patient reports of impacts affecting overall HRQoL and the most burdensome symptoms were also documented
- Evaluate SLE patient-reported treatment experiences and unmet needs**
 - The level of satisfaction among SLE patients with existing treatment options and/or poorly managed symptoms were investigated

RESULTS

Symptoms

- Pain (30.1%), fatigue (19.0%), and rash (11.8%) were the **symptoms most mentioned** by patients with SLE
- Pain and fatigue were described as the **most burdensome symptoms**

Example quotes on patient-reported symptoms and impact on HRQoL

- Pain**: "I have pain in every bit of my body"
- Fatigue**: "...a lot of fatigue even if I sleep 10 hours a day"
- Rash**: "I found myself in bed, crying from the rash that was all over my body"
- Negative feelings**: "My entire body hurts. Every morning I wake up and find it harder and harder to get out of bed. The depression that comes along with lupus and my hideous rash is horrible. My self esteem is non-existent. I look absolutely hideous"
- Depression**: "I still experience the brain fog, ear and skin issues, chest pain, depression, joint and muscle pain, and some days it's hard to even get out of bed"

HRQoL topics

- The **most common HRQoL topics** discussed by patients included negative feelings (23.7%; includes despondency, guilt, sadness, despair and anxiety), recreation and leisure (14.3%), and healthcare availability (9.3%)

Heatmap showing the impairment (negative impact) of a symptom on HRQoL aspects (n=716 documents)

Symptom or sign	Quality of life facet								
	Activities of daily living	Cognitive capabilities	Energy and motivation	Financial resources	Mobility	Recreation and leisure	Sleep and rest	Transport	Work capacity
Anxiety	0	1	0	2	0	2	4	0	1
Arthralgia	0	2	1	0	4	3	1	0	1
Arthritis	0	1	0	0	8	2	0	0	0
Fatigue	8	21	14	2	14	11	12	0	6
Pyrexia	1	3	1	2	3	1	1	0	0
Cephalgia	2	3	0	0	5	1	0	0	0
Clinical depression	0	2	3	0	1	0	1	0	0
Pain	8	7	5	1	38	16	9	3	6
Neuropathy	0	2	2	0	3	0	0	0	0
Rash	0	2	2	0	0	1	1	0	0

Treatments

- Patients discussed drug (1566 mentions across 1015 patients) and non-drug (482 mentions across 267 patients) treatment options
- The **most common drug therapies** mentioned included hydroxychloroquine (34.4% of drug therapy mentions), prednisone (20.6%), and methotrexate (19.3%)
- Exercise was the **most common non-drug therapy** mentioned (46.1% of all non-drug therapy mentions)
- Patients associated some standard of care treatments with a **decrease in HRQoL** as all symptoms and experiences of negative effects could not be alleviated

Heatmap showing the negative impact of drug treatments on HRQoL aspects (n=716 documents)

Treatment	Quality of life facet					
	Cognitive capabilities	Energy and motivation	Mobility	Negative feelings	Recreation and leisure	Sleep and rest
Warfarin	0	0	2	11	7	3
Prednisone	32	16	22	53	37	21
Prednisolone	3	3	12	16	13	1
Paracetamol	0	3	3	6	4	3
Naproxen	1	1	2	3	1	2
Methylprednisolone	0	1	2	3	1	1
Methotrexate	21	12	17	45	30	12
Quinacrine	2	0	2	4	3	1
Meloxicam	1	0	3	3	2	1
Ibuprofen	3	3	6	10	7	4
Hydroxychloroquine	19	22	33	90	50	17
Cyclophosphamide	1	0	1	3	1	0
Belimumab	0	1	4	6	5	0
Azathioprine	3	1	2	9	8	1
Aspirin	2	1	1	7	7	2