CONCLUSIONS

30.1% of SLE patients mentioned pain

23.7% mentioined experiencing negative feelings

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.
- 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 itself.
- 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.

OBJECTIVES

Explore SLE patient-reported disease burden and HRQoL impacts
- Disease-specific symptoms and the overall HRQoL status were described
- Unsuccessful 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

METHODS & PATIENTS

Retrospective social listening study executed across 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 selection: Directional keyword search

Step 2: Filtering and aggregating relevant Portuguese language content from documents

Step 3: Algorithmic coding of analytical codes with algorithmic technique using NLP

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

Step 5: Qualitative analysis: Use Framing to broadly explore patients' language and abstractions from their experiences, and possible emerging themes

• 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

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 part 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 feel a lot harder and harder to get out of bed. The depression that comes along with lupus and my kidney pain is horrible. My self-esteem is non-existent. I think absolutely futile”

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 across patients (n=716 documents)

Quality of life facet

Activity of daily living

Cognitive capabilities

Energy and motivation

Mobility

Negative feelings

Recreation and leisure

Sleep and rest

Transport

Work

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

Dosage and frequency

Medication

Invasive treatment

Rehabilitation and exercise

Sleep and rest

Telephone

Emailed

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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 highlighted high levels of disease burden and unmet needs that should be considered during drug discovery and development processes.

30.1% of SLE patients mentioned pain

23.7% mentioned experiencing negative feelings

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

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1925 patients with SLE were selected, with 5636 associated documents

There were 2032 mentions of symptoms and 2199 mentions of HRQoL topics

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