ORIGINAL RESEARCH

Patient Experience of Sjögren's Disease and its Multifaceted Impact on Patients' Lives

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ABSTRACT

Introduction: The symptoms associated with Sjögren's disease (Sjögren's) are well-documented from the physician's perspective. However, from the patient's perspective, there is limited information on symptoms and their impact on health-related quality of life (HRQoL). This study aimed to provide an expanded understanding of patients' experience of Sjögren's and how symptoms impact HRQoL using a novel multi-method social media listening (SML) approach.

Methods: A total of 26,950 social media posts with relevant content on Sjögren's posted by social media users from the USA, Canada, Australia, UK, France, Germany, Italy, Spain and China were analysed using an artificial intelligence natural language processing tool to explore patient conversations. Symptoms by level of impact on patients were characterised based on 'commonness' and 'bothersomeness'. Applied concept association analysis was used to assess relationships between symptom domains and impact domains. A qualitative framework was applied to explore words and phrases patients use to describe symptoms and their impacts.

Results: Five of the identified symptom domains were very impactful: Pain; Dry Mouth and Throat; Fatigue, Energy and Sleep; Emotional Balance; and Dry Eye. The symptom domains Pain and Dry Mouth and Throat were the most common, while those of Emotional Balance and Fatigue, Energy and Sleep were the most bothersome. Symptom domains most closely associated with four HRQoL impact domains were Fatigue, Energy and Sleep, Dry Mouth and Throat and Dry Eye with Daily Functioning; Fatigue, Energy and Sleep with Financial Health; Emotional Balance with Psychological Wellbeing and Gynaecological Issues with Social Wellbeing.

Conclusion: The results of this SML study show that Sjögren's affects diverse aspects of patients' lives, with symptoms extending beyond dry eyes and mouth and impacting daily living and functioning. Because symptoms may affect patients differently, these results highlight the importance of measuring impact on HRQoL to assess patient outcomes and treatment options in routine clinical practice and clinical trials.

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Key Summary Points

Why carry out this study?

The symptoms associated with Sjögren's disease are well-documented from the physician's perspective; however, from the patient's perspective, there is limited information on symptoms and their impact on health-related quality of life (HRQoL).

Information on patients' experiences with Sjögren's has been traditionally collected using surveys, interviews and focus groups. Social media listening (SML) offers a unique approach for understanding patients' experiences of disease, treatment, outcomes and other factors affecting their lives, thus facilitating the collection of a larger and more diverse array of experiences.

As there are no prior published SML analyses of patient experiences of Sjögren's, this study utilised SML to better understand patient experiences of Sjögren's disease and how its symptoms impact HRQoL.

What was learned from the study?

Sjögren's affects diverse aspects of patients' lives, with symptoms extending beyond dry eyes and mouth and impacting daily living and functioning.

The findings reveal that experiences with Sjögren's are complex and unique to each individual patient, indicating a need to measure the impact of Sjögren's on HRQoL, with the overall aim to assess patient outcomes and treatment options in routine clinical practice and clinical trials.

INTRODUCTION

Sjögren's disease (Sjögren's) is a chronic systematic autoimmune disease typically characterised by the inflammation and dysfunction of exocrine glands [1–3]. Sjögren's can be associated with other autoimmune rheumatic disorders, such as rheumatoid arthritis or systemic lupus erythematosus [1]. Prevalence is extremely variable, ranging from 0.3 to 0.77% in different geographical regions. Sjögren's is more prevalent in women than men, with one study noting a 9:1 female to male ratio [3]. Estimates of overall Sjögren's range from 0.5 to 1% among the general population [3]. There are also country-level differences in the incidence of primary Sjögren's, with reports of incidence ranging from 0.3 to 5.8 per 100,000 persons [4, 5].

Prior research found that patients with Sjögren's experience dry mouth, dry eyes and other extra glandular manifestations across multiple organs and systems [1, 3, 6]. Additionally, patients have identified fatigue as one of the most severe symptoms experienced, describing it as 'debilitating and stressful' [3, 6, 7]. Other symptoms identified include sleep disturbance and impaired sexual function among women [8–11, 13]. Some patients reported periodic acute exacerbations of symptoms, referred to as 'flares' [12]. Symptoms can have varying effects on patients' lives and overall well-being, such as limiting daily activities due to physical limitations and psychological distress [7].

Although the defining symptoms of Sjögren's are well-documented from the physician's perspective, information from the patient's perspective is limited regarding symptoms and their impact on health-related quality of life (HRQoL) [6]. Literature is also sparse on patients' psychological well-being and financial concerns related to disease management, which may impact how patients cope with the disease [13]. Furthermore, patients report that health professionals lack an understanding of Sjögren's and empathy regarding their experiences [3, 6, 14].

Information on patients' experiences with Sjögren's has been traditionally collected using surveys, interviews and focus groups [2, 6, 7, 14]. Social media listening (SML) is an emerging methodology that offers a unique approach for understanding patients' experiences of disease, treatment, outcomes and other factors affecting their lives [15, 16]. SML offers an opportunity for researchers to analyse patients' unsolicited comments and opinions, with prior studies noting that social media users may feel more comfortable sharing their experiences, fears and challenges on social media platforms that offer some greater shield of anonymity than in other contexts [16]. Patients' use of social media in this way has created a large diverse repository of patient-generated data [16].

Publicly available social media content has been previously used to capture patient experiences from different demographics (e.g. LGBTQ patients) and of different diseases (e.g. dry eye disease and presbyopia) [15, 17, 18]. However, there is no prior published SML analysis of patient experiences of Sjögren's. SML facilitates the collection of a larger and more diverse array of experiences than previous studies on Sjögren's, providing insights into existing gaps in the literature. In this study, we utilise SML to better understand, from patients' perspectives, the interaction between Sjögren's symptoms and the impacts of these symptoms on patients' lives.

METHODS

Data Collection and Preparation

Social media posts with relevant Sjögren's content were identified from Twitter, Reddit and patient forums allowing public access to post data, for the period of 1 April 2019 to 31 March 2021. Data were collected from nine countries (USA, Canada, Australia, UK, France, Germany, Italy, Spain and China) in each local language (6 languages in total), using a comprehensive keyword search script developed in English and translated and localised by language expert analysts. Data were then aggregated into three

country clusters for analysis, based on data similarities: English-speaking country cluster (US, Canada, Australia, UK); European Union (EU) market cluster (France, Germany, Italy, Spain) and China.

Analysts reviewed the collected social media post data and cleaned them by removing posts irrelevant to the topic, retweets and forum post headers. Analysts then tagged the posts to denote the type of stakeholder (e.g., patient, family member, friend, healthcare professional) authoring each post. This tagging was done by reviewing post authors' social media biographies, if available, and coding post(s) according to a stakeholder lexicon coding framework customised for this study. Each analyst's tagging was cross-checked by at least one other analyst. Posts that could not be identified by stakeholder type were tagged as 'unknown'. Patient posts were then isolated as the sample for concept creation.

The research for this manuscript was a retrospective analysis of publicly available social media data. All data utilised and presented in this study were obtained from publicly accessible sources without accessing password-protected information. Privacy of patients was respected, and caution was taken in using the information posted by them: all online content was anonymised, complying with the data privacy obligations and the Health Insurance Portability and Accountability Act [19]. Additionally, Novartis Social Media Council approval was obtained for the conduct of this study.

Institutional Review Board (IRB) approval was not sought for this analysis because criteria for IRB submission and approval necessitate that the research involves direct interaction with a human subject or access to identifiable private information, neither of which occurred during this research.
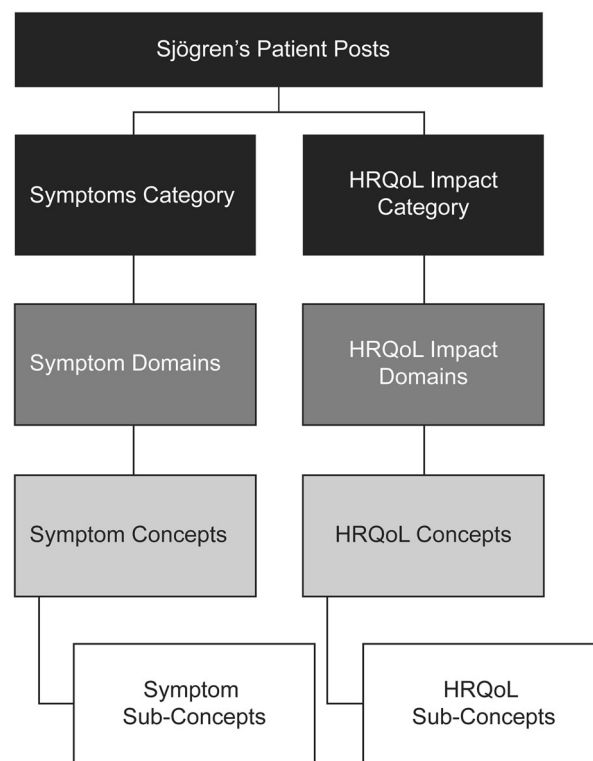
Concept Creation

Cleaned and tagged post data were uploaded to Luminoso, an artificial intelligence (AI)-powered textual analysis tool using natural language processing (NLP) [20]. Analysts used Luminoso

to identify and group relevant and related key-words to form 'concepts', i.e. analysis variables representing patient symptoms or HRQoL impacts. Each symptom concept represented a distinct physical or psychological symptom or experience as described by patients, such as vision issues. Each HRQoL impact concept represented an area of patients' lives impacted by Sjögren's, such as income.

Following qualitative research coding methods described in a prior study [21], similar symptom concepts were grouped into broader symptom domains. For example, Vision Issues were grouped with the related concept 'Eye Irritation' to form the symptom domain of Dry Eye. In some cases, individual concepts (e.g. 'Raynaud's') formed their own symptom domains because they did not cluster with other concepts. Some symptom concepts were further divided into more specific sub-concepts; for example, the symptom concept of Dry Mouth (in the Dry Mouth and Throat domain) was divided into the sub-concepts: Dry, Irritated Mouth and Dental Issues. HRQoL impact domains were classified using the same method (Fig. 1; Electronic Supplementary Material [ESM] Fig. S1).

To ensure reliability of the keyword grouping methodology, four analysts worked in rotating pairs to develop each concept and domain. Each pair independently reviewed the work of other pairs so that each concept and domain was reviewed by at least two analysts who did not participate in its development. The process resulted in a comprehensive qualitative map of concepts and domains related to Sjögren's symptoms and HRQoL impacts. Each concept and domain were labelled with a name that reflected how patients described or referred to it.

Once concept creation was complete, patient posts mentioning a specific symptom or a HRQoL impact from Sjögren's were isolated to create the final sample for symptom and impact analysis.

Fig. 1 Concept creation groups social media posts into categories, domains and concepts. *HRQoL* Health-related quality of life

'Commonness' and 'Bothersomeness' Measurement

Identified symptom and HRQoL impact concepts and domains were measured by their 'commonness' within the final analysis sample. Individual symptom concepts and domains were also given a measure of 'bothersomeness' based on their association with negative sentiment language.

The symptom 'Commonness' was assessed using Luminoso's volume calculator. Commonness was defined as the frequency of a symptom or impact being mentioned relative to the total analysis sample. For example, a 50% commonness indicates that a concept or domain is mentioned in half of the total posts. Throughout this manuscript, the term 'commonness' refers to mention commonness.

The symptom 'Bothersomeness' was assessed using a novel approach to negative sentiment analysis, which captured patient language

sentiment on a scale rather than as a binary. This innovation in patient social media analysis provided a more nuanced understanding of the degree of negative emotions associated with each symptom.

The approach to measuring bothersomeness adapted the 'lexical meter' method used by the creators of Hedonometer to quantify happiness levels expressed in large-scale texts on a continuous 1–9 scale, with 1 as extremely negative and 9 as extremely positive [22]. Hedonometer researchers compiled word lists and ratings based on large-sample word scoring through Amazon Mechanical Turk [23]. They used an expert assessment process to verify that the included words bore meaningful sentiment content and to assign each a happiness score [24, 25]. For example, the word 'annoying' is considered more negative than the word 'terrible', thus the happiness score is 2.82 versus 2.84, respectively [23]. This approach has been described in peer-reviewed manuscripts and cited widely [26].

Patients' social media post data were searched for sentiment keywords, which were then located in Hedonometer's word list to determine their happiness scores. Luminoso's association scoring, a measure of the likelihood of one defined concept to appear in the same post as another defined concept, was used to calculate the association between sentiment keywords and the symptom domains and concepts [18]. The bothersomeness of each symptom domain and concept was calculated as its association with the top five most common sentiment keywords multiplied by their negative sentiment values (an inversion of Hedonometer's happiness scores). The resulting scores were normalised to produce a symptom bothersomeness scale ranging from 1 to 9, with 9 indicating most bothersome.

Impact Framework Development and Symptom/Impact Association

The measures of symptom commonness and bothersomeness were brought together to create a symptom impact framework. Within this framework, symptom domains with lower commonness (< 30%) and lower bothersomeness (scores < 4.0) were categorised as 'less impactful'. Symptom domains with lower commonness but a bothersomeness score of ≥ 4.0 were categorised as 'impactful'. Symptom domains with both higher commonness (> 30%) and higher bothersomeness (scores of ≥ 4.0) were categorised as 'very impactful'.

Luminoso's association scoring was used to calculate the association between symptom and HRQoL impact domains and concepts. Identifying such an association enabled development of a conceptual model of the disease with its underlying symptoms and impact.

RESULTS

Analytic Sample

From a total cleaned and tagged sample of 26,950 posts on Sjögren's from patients, friends, family, healthcare professionals and members of the public across the studied countries, 38% came from the Anglo markets of study, 35% from China and 27% from the EU markets. Of these 26,950 total posts, 6512 patient posts were identified, of which 23% could be linked to a social media account with a known gender identity (analysis only available for posts from Twitter accounts). Of the latter, 85% were from individuals identifying as female. Of the 6512 patient posts, 4231 mentioned a specific symptom or a HRQoL impact of Sjögren's.

Symptoms

The analysis identified 26 distinct individual symptom concepts, which were organised into 16 symptom domains: five symptom domains comprising multiple distinct symptoms and 11 domains representing one individual symptom only.

The identified symptom concepts and symptom domains represent patients' expressions of their Sjögren's experiences. Several symptom concepts and domains have labels that include the names of separate medical conditions, such as 'fibromyalgia' and 'postural

tachycardia syndrome (POTs)', because patients referred to their symptom experiences in these terms. When these terms appear in symptom labels, they are found within speech marks to designate that this refers to Sjögren's patient's language and not to a confirmed medical diagnosis.

Symptom Commonness and Bothersomeness

The symptom domain commonness ranged significantly, from 51% for Pain to only 2% for 'POTs'. The five symptom domains with the highest commonness were Pain (commonness of 51%); Dry Mouth and Throat (41%); Fatigue, Energy and Sleep (40%); Emotional Balance (33%) and Dry Eye (32%) (Fig. 2; ESM Fig. S2).

These five symptom domains were also the most bothersome, but in a different rank order. Emotional Balance was highest in bothersomeness, with a score of 9.0, followed by Fatigue, Energy and Sleep (8.5); Pain (7.8); Dry Eye (7.4) and Dry Mouth and Throat (7.3) (Fig. 2; ESM Fig. S3).

Differences in commonness were found by country cluster. Most notably, Sjögren's impact on pregnancy and birth was mentioned more commonly in patient posts from China (50%) than in general across all posts (16%). Similarly, the Dry Mouth and Throat symptom domain was the most common (53%) in patient posts from China, but only the second most common (41%) in general. This study did not calculate bothersomeness scores for symptoms at a country cluster level.

Temporal Variability in Symptoms

Patients' experience of Sjögren's varied across three timescales. Over the course of a day, patients described peaks in the number and bothersomeness of their symptoms, which occurred in the afternoon and especially during the night. Over days to weeks, they described experiencing 'flares' as intermittent and unpredictable events wherein symptoms severely disrupted their ability to move and think (see Table 1). Finally, patients mentioned an evolution of symptoms over longer time periods (weeks to years), from early indicators, such as dry eye and gynaecological issues, to an expanded, more systemic symptom list that included symptom domains such as stiff and swollen joints, and pain.

Symptom Impact

When the measures of commonness and bothersomeness were brought together into a Symptom Impact Framework, five symptom domains were defined as 'very impactful'. These, ranked according to bothersomeness, were: Emotional Balance; Fatigue, Energy and Sleep; Pain; Dry Eye and Dry Mouth and Throat. Six symptom domains were defined as 'impactful'. The two most bothersome of these symptom domains, with scores > 6.5, were nausea and digestive issues (18% commonness, bothersomeness score 6.7) and 'Neuropathy', Tingling and Numbness (20%, 6.6). The other symptom domains defined as 'impactful' were Feeling Thirsty and Dehydrated; Stiff and Swollen Joints; and Nose and Sinus and Gynaecological Issues. Five symptom domains were defined as 'less impactful': 'Raynauds'; Impact on Pregnancy and Birth; Skin Issues; Lung Problems and 'POTs' (Fig. 3).

Sjögren's symptoms in the 'very impactful' symptom domains of Dry Eye and Dry Mouth and Throat are detailed in previous literature. To broaden the understanding of Sjögren's patient experience, this report focuses on findings on the other 'very impactful' symptom
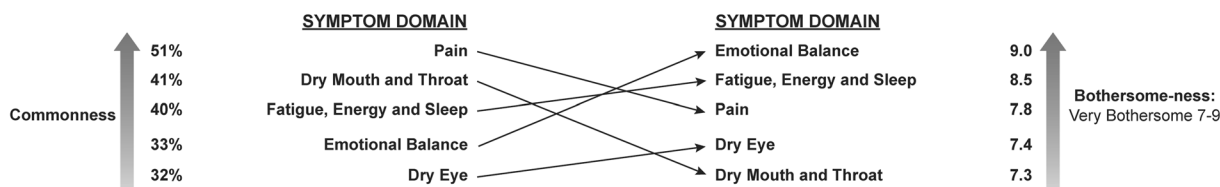
Fig. 2 The top five symptom domains which are most the common (commonness) and most bothersome (bothersomeness), but in a different order

**Table 1** Symptom domain associations with the concept of 'flares'

SYMPTOM DOMAIN	ASSOCIATION WITH FLARES	
'Neuropathy', Tingling and Numbness	0.69	**MORE** STRONGLY ASSOCIATED 55%+
Cognitive Fatigue and Brain Fog	0.66	
Eye Irritation	0.62	
Vison Issues	0.62	
Fatigue and Exhaustion	0.61	
Nausea and Digestive Issues	0.58	
Emotional Struggle	0.58	
Joint, Bone and Muscle Pain	0.57	
Dry Mouth	0.56	
Depression	0.55	ASSOCIATED 50%–55%
Trouble Sleeping	0.54	
Feeling Thirsty and Dehydrated	0.54	
Headaches and Migraines	0.53	
Sore Throat	0.52	
Breathing Problems	0.52	
'Fibromyalgia' and General Body Pain	0.52	
Anxiety	0.52	
Skin Issues	0.49	**LESS** STRONGLY ASSOCIATED <50%
'Raynauds'	0.48	
Difficulty Swallowing	0.48	
Nose and Sinus Dryness	0.48	
Coughing	0.47	
Dental Issues	0.44	
Stiff and Swollen Joints	0.43	
Lung Problems	0.42	
'POTS'(Postural Tachycardia Syndrome)	0.40	

domains: Emotional Balance; Fatigue, Energy and Sleep; and Pain.

Three symptom concepts within Emotional Balance had varying degrees of commonness: Anxiety (15%); Emotional Struggle (15%); and 'Depression' (13%). Emotional Struggle was a distinct cluster of linguistic ideas describing the emotional experiences of patients as they try to navigate life while managing a chronic, disruptive and unpredictable illness.

The symptom domain of Fatigue, Energy and Sleep included the individual symptoms of Fatigue and Exhaustion (24% commonness); Cognitive Fatigue and Brain Fog (22%); and Trouble Sleeping (21%). Cognitive Fatigue and Brain Fog were expressed as more bothersome (bothersomeness score 8.5) than physical Fatigue and Exhaustion (7.5). Further analysis revealed that physical and cognitive fatigue symptoms can be exacerbated by Trouble Sleeping. Furthermore, fatigue can perpetuate Trouble Sleeping by aggravating other symptoms and heightening their perceived bothersomeness.
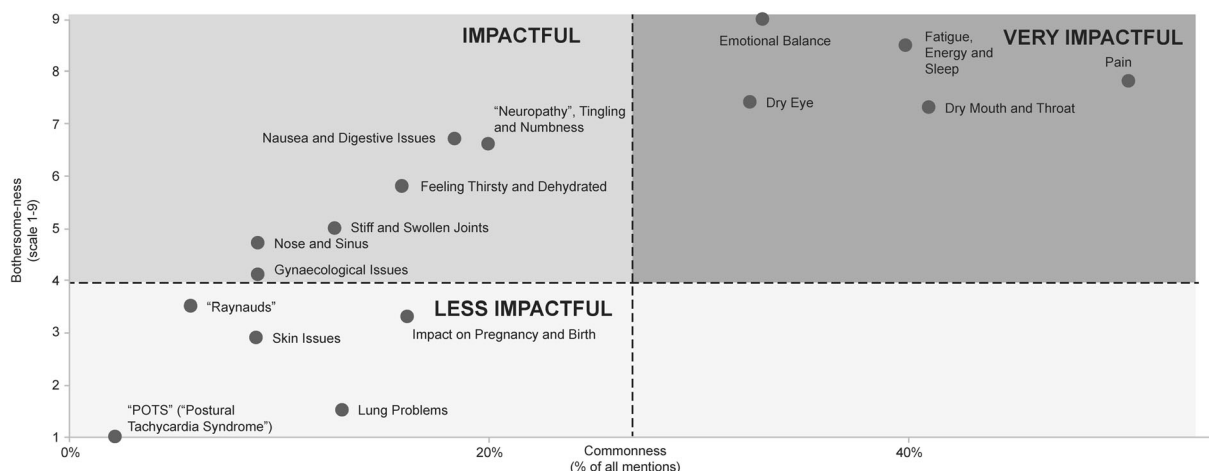
Fig. 3 Symptom impact framework captures the mention of commonness versus bothersomeness

The Pain symptom domain included three individual symptom concepts: Headaches and Migraines (16% commonness); Joint, Bone and Muscle pain (33%); and 'Fibromyalgia' and 'General Body Pain' (19%). While the latter two concepts may seem thematically linked, the terms included in them did not often appear together, and these concepts had different associations with other concepts. From patients' perspectives, pain linked to specific body parts (e.g. eyes, throat) represented a distinct experience from pain impacting the whole body (e.g. 'fibromyalgia').

HRQoL Impact

Sjögren's and its symptoms affected patients in four key domains of HRQoL impact. Table 2 shows the commonness of HRQoL impact domains and concepts. Figure 4 details the association between the HRQoL impact domains and the 'impactful' and 'very impactful' symptom domains. Fatigue, Energy and Sleep had the highest average association, with a score > 0.75 across all HRQoL impact domains.

Daily Functioning (72% commonness) refers to the impact on patients' everyday routines. Sjögren's syndrome constrains what patients feel fit and able to do and burdens them with a need to keep up with medical appointments and treatments. This domain included two very commonly mentioned HRQoL concepts: Activity Constraints and Treatment Burden. The symptom domains of Fatigue, Energy and Sleep and Dry Mouth and Throat were most closely associated with Activity Constraints (association score for both 1.0). Dry Mouth and Throat and Dry Eye had the closest association with Treatment Burden (association score for both 1.0.

The Social Wellbeing (35%) HRQoL impact domain relates to patients with Sjögren's feeling lonely and isolated, finding it harder to maintain close relationships and intimacy and/or to socialise or feel socially confident. The symptom domain of gynaecological issues was most closely associated with social wellbeing (association score 1.0). This domain was also found to be closely associated with Fatigue, Energy and Sleep (association score 0.8).

Sjögren's impacts patients' financial health (31%) by reducing their ability to work and to achieve a good salary while simultaneously increasing their costs due to the need to purchase treatments and remedies. For financial health, Fatigue, Energy and Sleep had the highest association with the impact on both concepts of Income and Costs (association score for both 0.77).

Finally, Sjögren's impacts patients' psychological wellbeing (30%), causing them to feel more fearful and anxious, frustrated, sad and depressed, misunderstood and even ashamed.

Table 2 Daily functioning was the most common health-related quality of life impact domain

HRQoL DOMAIN (COMMONNESS)	INCLUDED HRQoL CONCEPTS (COMMONNESS)
Daily Functioning (72%)	Activity Constraints (41%)
	Treatment Burden (61%)
Social Wellbeing (35%)	Loneliness and Isolation (15%)
	Friendships and Socialising (10%)
	Social Confidence (8%)
	Family and Loved Ones (7%)
	Sex and Intimacy (7%)
Financial Health (31%)	Income (20%)
	Costs (18%)
Psychological Wellbeing (30%)	Fearful and Anxious (18%)
	Frustrated and Angry (11%)
	Sad and Depressed (11%)
	Unseen and Misunderstood (10%)
	Feeling Guilt and Shame (6%)
HRQOoL, health related quality of life	

Thus, emotional balance was most closely associated with psychological wellbeing (association score 1.0). Fatigue, Energy and Sleep had the second closest association (association score 0.76).

Patient posts from the EU countries (France, Italy, Spain, Germany) and those from China were more likely to discuss any HRQoL impact domain than posts from the predominantly English-speaking countries studied (US, UK, Canada, Australia). Patients in China were more likely than patients in other countries to mention the impact of Sjögren's on daily functioning—specifically on their need to take extra rest (43% in China vs. 33% of the full sample). Patients in the EU were more likely to discuss psychological wellbeing and financial health.

DISCUSSION

Expanded Understanding of the Sjögren's Patient Experience

This study enhances understanding of the Sjögren's patient experience by identifying an extensive list of symptom concepts and symptom domains and illuminating the HRQoL domains they impact. This study also contributes to the patient experience literature by introducing the development of a novel impact framework for systematic categorisation of identified symptoms by quantified measures of commonness and bothersomeness.

The NLP analysis of social media posts revealed a longer list of symptoms compared to traditional research methods, a known strength of SML. Prior to this research, symptoms related to the domains of 'Neuropathy', Tingling and Numbness or Nausea and Digestive Issues have not been reported as 'impactful' [14]. In addition to depression and anxiety reported in the previous research, this study revealed an

IMPACTFUL SYMPTOM DOMAIN ASSOCIATION WITH HRQoL IMPACT DOMAINS		DAILY FUNCTIONING	FINANCIAL HEALTH	SOCIAL WELLBEING	PSYCHOLOGICAL WELLBEING
VERY IMPACTFUL	Pain	0.60	0.64	0.64	0.70
	Dry Mouth and Throat	1.00*	0.66	0.61	0.68
	Fatigue, Energy and Sleep	1.00*	0.77*	0.80*	0.76*
	Emotional Balance	0.68	0.65	0.72	1.00*
	Dry Eye	1.00*	0.76*	0.70	0.73
IMPACTFUL	'Neuropathy' , Tingling and Numbness	0.70	0.69	0.78*	0.69
	Dry Nose and Sinus	0.63	0.59	0.50	0.54
	Nausea and Digestive Issues	0.58	0.61	0.55	0.59
	Thirst and Feeling Dehydrated	0.71	0.61	0.56	0.61
	Stiff and Swollen Joints	0.52	0.51	0.52	0.56
	Gynaecological Issues	0.60	0.59	1.00*	0.59

Fig. 4 Symptom domain associations with HRQoL impact domains. Asterisk indicates an association score > 0.75

Emotional Balance domain and Emotional Struggle concept as key aspects from patients' perspectives. Further research is needed to better understand these aspects along with symptom concepts like Cognitive Fatigue and Brain Fog and their impact.

Previous studies have listed female sexual symptoms and dysfunction among the most important symptoms to consider for Sjögren's [10, 11], but the present study categorised Gynaecological Issues as 'impactful' rather than 'very impactful', in part due to lower commonness. This discrepancy might result from the greater impact of other symptoms than previously known, patients attributing symptoms to menopause or other causes versus Sjögren's, wariness of patients to discuss gynaecological issues on the platforms analysed or other reasons, but no conclusions can be drawn from available data. Future research could compare SML to other research methods for learning about sensitive or embarrassing medical topics and experiences. Despite its lower commonness overall, gynaecological issues represented the symptom domain most strongly associated with the Social Wellbeing HRQoL impact domain. This reinforces the importance of this symptom domain to patient lives.

This study identified four core HRQoL impact domains and linked them to the most common symptom domains. Each of these domains include multiple concepts that are closely associated with different symptom domains, suggesting that holistic treatment approaches may be needed to meet patient needs.

The nine-country multilingual approach applied in the present study was more expansive than approaches found in prior studies on Sjögren's. Our findings suggest that certain symptoms may be considered to be more significant for patients in some countries than others and can impact patient lives very differently. Future research could further explore demographic, environmental, cultural and other factors that may impact patients' experience of Sjögren's and drive differences at the country cluster level. Financial health, in particular, may be impacted by various components, such as insurance coverage or treatment costs, which vary by region. This exploration could be enhanced via larger samples of social media posts from additional countries or by collecting data over longer time periods.

Clinical decisions on Sjogren's treatment should be based on evidence, professional judgement, patient experience and patient goals. Study findings can inform physician–patient interaction and shared decision-making in routine clinical practice leading to treatment tailored to patient needs, such as by prioritising the treatment of symptoms that are more impactful. This could improve patients' quality of life, including how they feel, function and interact with the world.

Findings on the variability of Sjögren's symptoms and HRQoL impacts may be used to

create new patient-reported outcomes measures (PROMs) or expand the current tools used to measure Sjögren's presentation and progression. A new Sjögren's-specific PROM capturing HRQoL would be of great value for implementation in routine clinical practice and as an endpoint in Sjögren's clinical trials. Such an instrument may illuminate the heterogeneity that exists in Sjögren's and potentially address the variability in reporting of symptoms like fatigue or pain.

Limitations

The use of social media data in this study enabled a large, multi-country sample to be sourced from large language datasets. This in turn allowed for parsing data via AI technology to both quantify commonness and bothersomeness and support detailed evaluation of individual posts via qualitative analysis. However, SML may not deliver a representative sample of the overall Sjögren's patient population. Posting on social media platforms depends on patients' willingness or motivation to share their experiences [16]. Not all patients have equal access to social media platforms, and this may differ by country, socioeconomic status and other factors [16]. The bias towards younger patients in social media data may also be problematic, considering many Sjögren's patients are between the ages of 50 and 60 years [6]. Additionally, while this study assumed that people self-identifying as Sjögren's patients have been diagnosed, confirming physician diagnosis is not possible in SML projects.

SML may introduce biases, but it is an established and accepted methodological approach used across a range of therapeutic areas [15, 17, 18]. Furthermore, biases are also inherent in other methodologies used to capture patient experiences. Primary market research may be biased by only including paid volunteers, research recruitment exclusively via advocacy groups can be biased by membership demographics and central location research (such as within clinical trials) may be biased by the 'white coat' effect and non-real-world setting. The content people share on SML in a public real-world setting is to a large extent self-curated: there is no bias of remuneration from or participation in a research setting. Thus, SML forms a valuable compliment to a wider body of research methodologies to better understand patients. This value is underscored by the large population that is represented on social media. Research released in October 2022 shows that about 59% of the total global population uses social media, with annualised growth of 4.2% [27].

CONCLUSION

Sjögren's patients struggle with invisible symptoms, beyond the more visible and diagnosable issues of dryness in the eyes and mouth. This study applied an impact framework centred on measures of commonness and bothersomeness to understand the intersection of symptoms and HRQoL impact. Findings reveal Sjögren's patients' experiences to be complex and unique to individual patients, indicating a need to measure Sjögren's impact on HRQoL and compare how outcomes vary between patients and different treatment options both in routine clinical practice and in clinical trials.

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Disclosures. Linda Stone has nothing to declare. Rachel Gervais and Theresa Schmidt are employees of Real Chemistry, a consulting firm with many clients, including life sciences, non-profit, payer and provider organisations. Chiara Perella, Monia Steenackers, Brian Robbins and Pushpendra Goswami are employees of Novartis.

Compliance with Ethics Guidelines. The research for this manuscript was a retrospective analysis of publicly available social media data. All data utilised and presented in this study were obtained from publicly accessible sources without accessing password-protected information. Privacy of patients was respected, and caution was taken in using the information posted by them: all online content was anonymised, complying with the data privacy obligations and the Health Insurance Portability and Accountability Act [19]. Additionally, Novartis Social Media Council approval was obtained for the conduct of this study. We did not seek Institutional Review Board (IRB) approval for this analysis because criteria for IRB submission and approval necessitate that the research involves direct interaction with a human subject or access to identifiable private information, neither of which occurred during our research. The authors of this manuscript consent to the publication of the submitted manuscript and declare that no individual patient data requiring consent have been presented.

Data Availability. The datasets generated during and analysed during the current study are not publicly available due to legal and privacy considerations.

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