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Spotlight on Sjögren's: a patient perspective on burden of illness and unmet needs – results from a real-world survey

Jessica Marvel,[1] Gayle Kenney,[2] Janet Church,[3] Wan-Fai Ng,[4,5] Robert Fox,[6] Yuko Kaneko,[7] Kaori Komori ,[8,9] Gavin Harper ,[10] Lucy Howard,[10] Thom Dewar ,[10] Morgan Fox[10]

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For numbered affiliations see end of article.

Correspondence to
Jessica Marvel;
jessica.marvel@novartis.com

ABSTRACT

Objective Sjögren's is a chronic systemic autoimmune disease characterised by dryness symptoms (eyes, mouth, skin), alongside other systemic manifestations such as fatigue, muscle and joint pain, neuropathies and organ involvement. Despite its prevalence, research into the patient perspective of Sjögren's is limited. This study aimed to better understand the burden, unmet needs and treatment satisfaction among adults with Sjögren's.

Methods Data were collected using a cross-sectional survey of adult patients with Sjögren's across China, France, Germany, Italy, Japan, Spain, the UK and the USA (December 2023 to September 2024). Patients were recruited via physicians or patient advocacy organisations. The Work Productivity and Activity Impairment (WPAI) tool assessed work-related productivity and daily activity impact. Analyses were descriptive.

Results 1155 patients completed the survey. Mean (SD) age was 54.5 (13.0) years; 88.2% were female and 95.3% white. Most frequently reported symptoms were dry mouth, dry eyes, dry skin, physical fatigue/tiredness and joint stiffness/soreness. High emotional burden from Sjögren's (rating 5–7 out of 7) was reported by 57.7%. WPAI scores showed 46.6% work and 48.4% activity impairment. Of those receiving prescription therapy, 77.2% were dissatisfied and/or believed disease control could improve. Among those not fully satisfied, 52.9% felt current treatments only addressed symptoms, not the underlying systemic nature of Sjögren's.

Conclusion The *Spotlight on Sjögren's* study reveals the substantial, multifaceted burden of Sjögren's, extending beyond dryness to significantly impair physical, emotional and functional well-being. Findings underscore the need for comprehensive, patient-centred care and therapies addressing both symptoms and the underlying systemic disease.

WHAT IS ALREADY KNOWN ON THIS TOPIC

⇒ Sjögren's is a chronic systemic autoimmune disease that causes diverse symptoms which can significantly affect patients' quality of life. However, real-world data on its impact, particularly on patients' daily activities, emotional well-being and employment, remains limited.

WHAT THIS STUDY ADDS

⇒ This study highlights the significant symptomatic and emotional burden of Sjögren's, which often presents as dryness-related symptoms, pain, physical and mental fatigue, along with other systemic manifestations, resulting in impaired physical functioning and work activities that leads many patients to adjust their lifestyles. Additionally, the findings characterise the degree of dissatisfaction patients have with existing medications, which underscores the urgent need for the development of new treatment options specifically for Sjögren's disease.

HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

⇒ The findings reveal the need for earlier diagnosis and improved treatments that target the underlying cause of the disease to help ease the overall burden on patients. Future research should focus on improving disease awareness and patient–physician communication.

INTRODUCTION

Sjögren's is a chronic, systemic autoimmune disease characterised by hallmark symptoms of dryness (eg, dry eyes, mouth and skin), alongside other systemic manifestations such as fatigue, muscle and joint pain, neuropathies and multi-organ involvement.[1–5] While the cause remains unknown, dysregulation of both the innate and adaptive immune responses is a key feature.[1] Sjögren's is one of the most common autoimmune rheumatic diseases after rheumatoid arthritis. While estimates of global prevalence range between 0.1% and 1.0%, depending on diagnostic criteria used, some survey-based studies have reported figures as high as 4.8%.[6 7] Sjögren's

can occur independently, without being associated with another autoimmune condition, though it can present alongside other systemic autoimmune conditions such as rheumatoid arthritis, systemic lupus erythematosus or scleroderma.[8]

Patients are typically diagnosed with Sjögren's over the age of 50 years.[9] However, findings from the Sjögren's Foundation's 2021 *Living with Sjögren's* survey suggest that symptoms are experienced much earlier, with 13.6% of patients diagnosed with Sjögren's before reaching 35 years of age, and many patients recalling symptom onset in childhood or early adulthood.[10] Although the disease is more frequently reported in Europe, Sjögren's is widely believed to be underdiagnosed and misdiagnosed in the USA,[11] and other regions (Asia, Latin America and Africa) have limited epidemiological data, contributing to an underestimation of its true prevalence.[12] In addition, the heterogeneous clinical presentation of Sjögren's among patients complicates diagnosis, likely contributing to underdiagnosis and undertreatment.[13] The wide-ranging symptoms experienced can significantly impact patients' daily lives,[14–16] as evidenced through the *Living with Sjögren's survey*, patients suffer from high levels of fatigue, pain, emotional burden and work disability, leading to reduced quality of life (QoL).[10]

Diagnosis of Sjögren's is typically confirmed through clinical assessment. Healthcare professionals (HCPs) primarily use the 2016 American College of Rheumatology (ACR) - European Alliance of Associations for Rheumatology (EULAR) classification criteria to evaluate symptoms and serological markers.[17] From the patient perspective, symptom burden is captured using the EULAR Sjögren's Syndrome Patient Reported Index, while systemic disease activity is assessed using the EULAR Sjögren's Syndrome Disease Activity Index (ESSDAI).[18–22] The ESSDAI is primarily used in clinical trials, with treatment decisions in clinical practice guided by the presence and extent of organ involvement and glandular manifestations, as well as symptomatic burden. Furthermore, some patients with higher ESSDAI scores may report a relatively better QoL, highlighting the complexity of correlating disease activity metrics directly with patient outcomes.[23]

Current treatment strategies for Sjögren's often involve both symptomatic and systemic therapies, with recommendations from EULAR and ACR suggesting a multidisciplinary care approach. The primary focus is typically on improving patient QoL through symptomatic management, particularly by improving dryness-related symptoms with artificial tears, anti-inflammatory eye drops, salivary stimulants and secretagogue pharmaceuticals.[24] Non-steroidal anti-inflammatory drugs are commonly used for pain, while disease-modifying antirheumatic drugs (DMARDs) such as hydroxychloroquine, chloroquine, sulfasalazine or corticosteroids are used to reduce inflammation. However, symptomatic and anti-inflammatory therapies are often insufficient, and suppression of the overactive immune response is necessary to minimise systemic damage.[25] In more severe cases, glucocorticoids or immunosuppressive agents are prescribed, including biologics (eg, tumour necrosis factor inhibitors, rituximab) and conventional immunosuppressants (eg, methotrexate, cyclophosphamide).[25] Hydroxychloroquine is also often used as a first-line or adjunct therapy.[25] However, these current systemic treatments do not target the underlying disease pathology, and to date, no biological or synthetic DMARD has been shown to modify disease progression.[25–27] This therapeutic gap highlights the need for novel interventions that can reduce or prevent the incidence of systemic manifestations and disease progression. The importance of early diagnosis and disease monitoring to prevent additional health complications in patients with Sjögren's has also been recognised.[28]

Despite its prevalence, there is a limited understanding of Sjögren's and the daily burden it has on patients. This is exacerbated by a poor breadth in available real-world data from the patient perspective, caused by a notable variability in individual patients' Sjögren's clinical presentation and experiences of symptoms. This study aimed to describe the daily disease burden and highlight unmet needs and opportunities for improving current treatments and QoL for patients with Sjögren's, using real-world patient-reported data collected from eight countries across Europe, North America and Asia.

METHODS

Study design

This was a non-interventional, cross-sectional study of adult patients who reported having a diagnosis of Sjögren's disease. Data were collected from patients across France, Germany, Italy, Spain, the UK, the USA, China and Japan from 14 December 2023 to 16 September 2024. Patients were eligible for inclusion if they were aged 18 years or older, lived in a country of interest and had a rheumatologist-confirmed diagnosis of Sjögren's as per routine clinical practice and existing guidance.[17] Patients with a diagnosis of coexisting systemic lupus erythematosus, rheumatoid arthritis or systemic sclerosis were excluded from our sampling to ensure that participants had Sjögren's as their main diagnosis, rather than including individuals whose disease occurs in the context of other rheumatic conditions. In addition, patients must also have exhibited at least one symptom of eye, mouth or skin dryness in the 24 hours prior to survey, based on the Novartis Sjögren's Symptom Diary, to ensure the inclusion of patients with active disease.[29]

Two patient recruitment approaches were used within this study. Patients were recruited to participate either by referral from their treating physician, or via a Patient Advocacy Organisation (PAO), although the eligibility inclusion/exclusion criteria remained consistent. The method of recruitment was country dependent and based on the availability of a supporting PAO, as well as local rules and regulations related to contacting patients

directly. Physician referral was used in France, Germany, Italy, China, Spain and Japan. Spain and Japan also used a PAO for patient recruitment, as did the UK and USA.

Patient-reported data and outcome measures

Completion of the patient survey was voluntary. Eligible patients were asked to complete one structured, online survey and were paid an incentive for their participation. The incentive was dependent on the country of residence and local ethical regulations and was either paid directly to the patient or donated to a global charity on their behalf. Participants in Spain did not receive an incentive for completing the survey.

The patient survey contained detailed questions on demographics, use of prescription and over-the-counter (OTC) treatments, as well as satisfaction levels and expectations of treatments. With respect to treatment history, respondents were presented with a structured list of medication categories (each accompanied by examples) and were encouraged to refer to their medication packaging when responding to ensure accuracy in responses. Collection of treatment data were tailored in the survey materials to match those available in the corresponding markets, to ensure accuracy in data collection. In addition, the patient survey contained questions on the physical, symptomatic and emotional burden of Sjögren's and the impact on work, measured using the Work Productivity and Activity Impairment (WPAI) questionnaire.

The WPAI measures impairment in four different domains: absenteeism (work time missed), presenteeism (impairment at work), overall work impairment and overall activity impairment (activities that do not include work) over the 7 days prior to the survey.[30] Scores are expressed as impairment percentages and range from 0 to 100, with higher scores indicating greater impairment.

Data analysis

Data collected from patients from Germany, Spain, France, Italy and the UK were in some instances combined and reported as EU5.

When reporting descriptive results, mean and SD were calculated for continuous variables and frequency counts and percentages were used for categorical variables. All descriptive analyses were performed using IBM SPSS Data Collection Survey Reporter, V.7.5 (IBM Corp., 2010. IBM SPSS Data Collection Survey Reporter: V.7.5. Armonk, New York: IBM Corp.). Missing data were not imputed; therefore, the base of patients for analysis could vary from variable to variable and the denominator has been reported separately for each analysis in the results section.

Informed consent

Before completing the survey, patients provided informed consent electronically using a checkbox. Data were collected in such a way that patients could not be identified directly. Upon receipt by the study team, data were pseudo-anonymised to mitigate against tracing them back to the individual. Data were aggregated before being shared with the subscriber and/or for publication.

RESULTS

Patient population

Overall, 1155 patients with Sjögren's completed the voluntary patient-reported survey. Patients were from the following countries: France (n=27), Germany (n=100), Italy (n=150), Spain (n=127), the UK (n=102), the USA (n=284), Japan (n=167) and China (n=198).

The mean (SD) patient age was 54.5 (13.0) years, and 1019 patients were female (table 1). In the countries that were surveyed for ethnicity; Germany, Italy, Spain, UK and USA, 95.3% of patients self-reported as white. Overall, 28% of patients reported having concomitant conditions, with osteoarthritis being the most common condition (14.5%), followed by Hashimoto's disease (7.2%).

Further information regarding the patient-reported demographics and concomitant conditions can be found in table 1.

Patient perception of symptomatic burden

General health status: The mean (SD) age at Sjögren's diagnosis was 47.6 (12.0) years and the mean (SD) diagnostic delay was 5.3 (8.8) years following initial onset of symptoms (table 2). Regarding general health status, 65.5% of patients rated their health as 'poor' or 'fair'. Overall, 34.5% of the total patient population self-reported their general health status as 'good', 'very good' or 'excellent', compared with 51.1% of patients in the USA. In contrast, 33.5% of patients in Japan rated their health as 'poor', approximately twice the rate observed in the overall cohort (16.6%).

Symptom burden: In the month prior to survey completion, patients experienced a mean (SD) of 10.7 (6.3) symptoms selected from a longer precoded list. The symptom burden varied considerably by country, with patients in the UK reporting a mean (SD) of 15.2 (5.0) symptoms, nearly three times higher than the 5.1 (2.4) symptoms reported in China.

The most commonly reported symptoms were dry mouth (87.1%), dry eyes (86.7%) and dry skin (66.3%). Among the most bothersome and severe symptoms were physical fatigue (63.6%), tiredness (63.4%) and joint stiffness/soreness (52.2%) (table 2, figure 1). Patients experienced their most bothersome symptoms on a mean (SD) of 24.7 (8.2) days per month, with 64.3% reporting daily occurrence. Furthermore, 63.7% of patients reported that their symptom severity fluctuated throughout the day.

Almost all patients (94%) reported experiencing at least one other systemic manifestation of Sjögren's, in addition to sicca symptoms, with a mean (SD) of 1.4 (1.6) organs affected. The most commonly involved systems were the musculoskeletal (joints 32.3%, muscles 17.3%), nervous (10.7%), gastrointestinal (9.7%), pulmonary

Table 1 Patient-reported demographics and clinical characteristics

	Country				
	Overall	**China**	**Japan**	**USA**	**EU5**
	n=1155	**n=198**	**n=167**	**n=284**	**n=506**
Age, years, mean (SD)	54.5 (13.0)	47.8 (11.4)	53.6 (12.7)	62.0 (11.5)	53.2 (12.4)
Gender, n (%)	**n=1155**	**n=198**	**n=167**	**n=284**	**n=506**
Female	1019 (88.2)	167 (84.3)	151 (90.4)	270 (95.1)	431 (85.2)
Ethnicity, n (%)	**n=763**	**n=N/A**	**n=N/A**	**n=284**	**n=479**
White	727 (95.3)	-	-	259 (91.2)	468 (97.7)
Concomitant conditions, n (%)*	**n=1155**	**n=198**	**n=167**	**n=284**	**n=506**
Osteoarthritis	168 (14.5)	11 (5.6)	4 (2.4)	96 (33.8)	57 (11.3)
Hashimoto's disease	83 (7.2)	3 (1.5)	10 (6.0)	45 (15.8)	25 (4.9)
Any cancer, not including lymphoma	50 (4.3)	3 (1.5)	6 (3.6)	31 (10.9)	10 (2.0)
Cardiovascular disease	47 (4.1)	11 (5.6)	1 (0.6)	22 (7.7)	13 (2.6)
Diabetes (type 1 or type 2)	31 (2.7)	3 (1.5)	2 (1.2)	15 (5.3)	11 (2.2)
Chronic kidney disease	24 (2.1)	1 (0.5)	0 (0.0)	11 (3.9)	12 (2.4)
Kidney disease	21 (1.8)	5 (2.5)	4 (2.4)	6 (2.1)	6 (1.2)
Chronic obstructive pulmonary disease	18 (1.6)	2 (1.0)	1 (0.6)	6 (2.1)	9 (1.8)
Postural orthostatic tachycardia syndrome	17 (1.5)	0 (0.0)	0 (0.0)	13 (4.6)	4 (0.8)
Lymphoma	12 (1.0)	0 (0.0)	2 (1.2)	3 (1.1)	7 (1.4)

*Patients were not permitted to participate in the survey if they had concomitant systemic lupus erythematosus, rheumatoid arthritis or systemic sclerosis.
EU5, European countries consisting of France, Germany, Italy, Spain and the UK.

(8.5%) and lymphatic (7.4%) systems (table 2). Neurological symptoms were also prevalent, with 39.1% of patients reporting brain fog, as captured in the precoded symptom list. In relation to physical fatigue, patients rated their mean (SD) fatigue (at its worst) over the preceding 24 hours as 5.6 (2.4) on a 10-point scale, with 41.8% rating it a 7 or higher.

Sleep: The mean (SD) duration of sleep in the month prior to data collection was 6.2 (1.4) hours per night. Only 3.2% of patients rated their sleep quality as 'very good', while 64.8% rated it as 'bad' (defined as waking up feeling unrefreshed on more than three mornings per week). Sleep quality was reported to have a high impact on QoL, with 59.3% of patients assigning a score of 5–7 on a 7-point scale (where 1=no impact, and 7=significant impact).

Impact of disease on patients' emotional well-being

To evaluate the emotional impact of Sjögren's, patients completed a series of well-being questions, rating their experiences on a scale from 1 (not at all) to 7 (a great deal). At data collection, 57.7% of patients reported a substantial emotional and mental health impact (impact rating: 5–7) from Sjögren's (table 3). Of note, 21.6% of patients rated their frustration with symptoms at the maximum level (rating: 7), and 26.1% reported worrying a great deal about their disease getting worse (rating: 7). Overall, 81.9% of patients reported feeling some degree of helplessness as a result of Sjögren's (impact rating: 2–7).

In addition, 30.6% of patients reported experiencing symptoms of depression within the previous month. Among these, 21.5% (n=76/353) were receiving antidepressant pharmacotherapy at the time of the survey.

Approximately half of patients (52.4%) felt at least somewhat comfortable discussing the emotional impact of Sjögren's with their HCP. However, regional differences were observed, for example, a high proportion of patients in China (36.3%) reported feeling uncomfortable discussing their emotional well-being with their HCP. In terms of patient satisfaction, 52.9% of the overall cohort expressed dissatisfaction with the support received from their HCP, with this proportion rising to 67.7% among patients in Japan.

At the time of the survey, 21.0% of patients reported receiving professional support (eg, counselling, therapy) to help manage the emotional consequences of Sjögren's. Nevertheless, 43.7% of patients expressed a desire for such support, with particularly high demand in China, where 57.6% of patients indicated a need for professional emotional support.

Impact of disease on patients' work and career progression

At data collection, 52.0% of patients were employed. Among those employed, approximately half (50.4%) reported that their employer was aware of their diagnosis

Table 2 Symptoms experienced by patients with Sjögren's

	Country				
	Overall	China	Japan	USA	EU5
	n=1155	n=198	n=167	n=284	n=506
Age at diagnosis, years, mean (SD)	47.6 (12.0)	44.8 (11.1)	46.3 (11.2)	52.4 (12.3)	46.5 (11.7)
Time taken for diagnosis from symptom onset, years, mean (SD)	5.3 (8.8)	2.3 (5.5)	3.7 (5.7)	8.3 (10.3)	5.2 (9.1)
Time since formal diagnosis, years, mean (SD)	6.9 (8.0)	3.0 (3.7)	7.3 (7.5)	9.7 (9.7)	6.8 (7.7)
Number of symptoms experienced in the month prior to survey, mean (SD)	10.7 (6.3)	5.1 (2.4)	8.1 (5.8)	14.9 (5.5)	11.4 (5.9)
Current health status (at time of survey completion), n (%)	**n=1155**	**n=198**	**n=167**	**n=284**	**n=506**
Poor	192 (16.6)	22 (11.1)	56 (33.5)	23 (8.1)	91 (18.0)
Fair	565 (48.9)	109 (55.1)	83 (49.7)	116 (40.8)	257 (50.8)
Good	321 (27.8)	61 (30.8)	19 (11.4)	100 (35.2)	141 (27.9)
Very good	70 (6.1)	5 (2.5)	9 (5.4)	40 (14.1)	16 (3.2)
Excellent	7 (0.6)	1 (0.5)	0 (0.0)	5 (1.8)	1 (0.2)
Ten most common symptoms experienced in the month prior to survey, n (%)	**n=1155**	**n=198**	**n=167**	**n=284**	**n=506**
Dry mouth or lips	1006 (87.1)	165 (83.3)	135 (80.8)	266 (93.7)	440 (87.0)
Dry or itchy eyes	1001 (86.7)	151 (76.3)	133 (79.6)	264 (93.0)	453 (89.5)
Dry or itchy skin	766 (66.3)	115 (58.1)	76 (45.5)	228 (80.3)	347 (68.6)
Physical fatigue	735 (63.6)	101 (51.0)	86 (51.5)	217 (76.4)	331 (65.4)
Tiredness	732 (63.4)	48 (24.2)	93 (55.7)	226 (79.6)	365 (72.1)
Joint stiffness/soreness	603 (52.2)	57 (28.8)	59 (35.3)	213 (75.0)	274 (54.2)
Dry nose	567 (49.1)	36 (18.2)	53 (31.7)	194 (68.3)	284 (56.1)
Muscle stiffness/soreness	541 (46.8)	35 (17.7)	51 (30.5)	199 (70.1)	256 (50.6)
Difficulty falling/staying asleep	491 (42.5)	25 (12.6)	47 (28.1)	181 (63.7)	238 (47.0)
Mental fatigue (brain fog)	452 (39.1)	19 (9.6)	47 (28.1)	200 (70.4)	186 (36.8)
Fluctuating symptom severity, n (%)	**n=1155**	**n=198**	**n=167**	**n=284**	**n=506**
No	419 (36.3)	105 (53.0)	61 (36.5)	79 (27.8)	174 (34.4)
Yes, throughout the day	736 (63.7)	93 (47.0)	106 (63.5)	205 (72.2)	332 (65.6)
Number of organs affected, mean (SD)	1.4 (1.6)	0.7 (0.8)	0.9 (1.1)	1.8 (1.7)	1.5 (1.7)
Most common organs affected, n (%)	**n=1155**	**n=198**	**n=167**	**n=284**	**n=506**
Joints	373 (32.3)	39 (19.7)	31 (18.6)	126 (44.4)	177 (35.0)
Muscles	200 (17.3)	13 (6.6)	16 (9.6)	64 (22.5)	107 (21.1)
Nervous system	124 (10.7)	7 (3.5)	12 (7.2)	53 (18.7)	52 (10.3)
Bowel	112 (9.7)	6 (3.0)	5 (3.0)	47 (16.5)	54 (10.7)
Lungs	98 (8.5)	15 (7.6)	6 (3.6)	30 (10.6)	47 (9.3)
Lymph nodes	86 (7.4)	2 (1.0)	11 (6.6)	21 (7.4)	52 (10.3)
Worst level of fatigue during the 24 hours prior to survey, mean (SD)	5.6 (2.4)	4.9 (2.4)	5.1 (2.4)	5.9 (2.4)	5.9 (2.3)
Hours of sleep per night in the month prior to survey, mean (SD)	6.2 (1.4)	6.2 (1.3)	6.1 (1.3)	6.5 (1.4)	6.1 (1.3)
Level of sleep quality in the month prior to survey, n (%)	**n=1155**	**n=198**	**n=167**	**n=284**	**n=506**
Very good	37 (3.2)	6 (3.0)	13 (7.8)	5 (1.8)	13 (2.6)
Fairly good	370 (32.0)	76 (38.4)	38 (22.8)	95 (33.5)	161 (31.8)
Fairly bad	537 (46.5)	99 (50.0)	82 (49.1)	127 (44.7)	229 (45.3)
Very bad	211 (18.3)	17 (8.6)	34 (20.4)	57 (20.1)	103 (20.4)
Impact of sleep quality on overall QoL, n (%)	**n=1155**	**n=198**	**n=167**	**n=284**	**n=506**
1 (no impact)	57 (4.9)	20 (10.1)	15 (9.0)	5 (1.8)	17 (3.4)
2	96 (8.3)	23 (11.6)	17 (10.2)	18 (6.3)	38 (7.5)
3	122 (10.6)	24 (12.1)	28 (16.8)	29 (10.2)	41 (8.1)
4	195 (16.9)	30 (15.2)	25 (15.0)	45 (15.8)	95 (18.8)
5	265 (22.9)	49 (24.7)	46 (27.5)	58 (20.4)	112 (22.1)
6	202 (17.5)	41 (20.7)	24 (14.4)	50 (17.6)	87 (17.2)
7 (significant impact)	218 (18.9)	11 (5.6)	12 (7.2)	79 (27.8)	116 (22.9)

EU5, European countries consisting of France, Germany, Italy, Spain and the UK; QoL, quality of life.

Figure 1 Patient-reported bothersome and severe symptoms. Each symptom experienced by patients in this survey was plotted based on their perception of relative severity and percentage of most bothersome. The average severity and most bothersome scores across all symptoms were calculated, and each symptom was plotted relative to this average. This approach allows for a visual comparison of symptomatic burden.

of Sjögren's, while 35.9% stated that their employer was not aware (table 4). Workplace adjustments due to Sjögren's were common, with 56.7% reporting at least one form of work-related impact. Specifically, 16.5% of patients had transitioned from full-time to part-time work, and 12.3% had moved to a less demanding role as a direct result of their condition. In terms of working hours, 26.7% of patients had reduced their hours, and an additional 32.6% had considered doing so. In total, 14.3% had taken early retirement, 15.0% had voluntarily stopped working and 4.4% reported being compelled to stop working due to Sjögren's. Overall, 25.0% of patients had considered terminating their employment as a direct consequence of the disease, with this proportion particularly high among patients in the USA (34.9%).

Across the total patient population, 19.2% reported needing additional support to perform their work responsibilities. Furthermore, 27.5% of patients indicated that Sjögren's had limited their career options or prevented them from advancing professionally (figure 2).

High levels of work-related functional impairment (presenteeism) were reported. Overall work impairment due to Sjögren's was reported by 46.6% of patients, while 48.4% experienced impairment in their daily non-work activities.

Prescribed and OTC treatments

The majority of patients reported using both prescribed and OTC treatments to help manage their Sjögren's symptoms. Specifically, 91.5% of patients had received at least one prescribed treatment, and 76.3% had used OTC products to support symptom relief (table 5). The most commonly used prescription therapies were eye drops (55.0%), corticosteroids (51.2%) and DMARDs (46.1%). Among OTC treatments, eye drops were also most frequently reported (68.8%), followed by moisturising creams or lotions (50.2%) and saliva substitutes (47.3%).

Further details regarding the use and distribution of treatment types are provided in table 5.

Patient-reported treatment satisfaction and adherence

Patients assessed their treatment satisfaction using two approaches. All participants rated their overall range of available Sjögren's treatments on a scale from 'very dissatisfied' to 'very satisfied'. Additionally, those receiving prescription therapy also evaluated their current treatment specifically, indicating whether they were 'satisfied' or 'not satisfied', and whether they believed better disease control was achievable.

93.5% of participants were not fully satisfied with the overall range of therapies available for Sjögren's (table 5). The primary reason for reduced treatment satisfaction was the perception that prescribed therapies addressed only symptoms without targeting the underlying cause or systemic nature of the disease. Despite this, 28.5% of patients had not discussed their dissatisfaction with their HCP.

Despite ongoing prescription therapy, 77.2% expressed dissatisfaction with their current regimen(s) and/or believed that better disease control could be achieved. Additionally, regardless of their satisfaction level, 59.9% of patients believed that better disease control could be achieved. Notably, 50.6% of patients disagreed with the statement that they had exhausted all available treatment options.

Nearly half of patients (45.5%) self-reported having reduced or discontinued medication without informing their HCP. Among patients who had reduced or stopped treatment, the most commonly cited reason was

Table 3 Patient-reported emotional impact of Sjögren's

	Country				
	Overall	China	Japan	USA	EU5
	n=1155	n=198	n=167	n=284	n=506
Impact on overall emotional well-being and mental health, n (%)	**n=1155**	**n=198**	**n=167**	**n=284**	**n=506**
1 (no impact)	44 (3.8)	16 (8.1)	13 (7.8)	8 (2.8)	7 (1.4)
2	97 (8.4)	27 (13.6)	13 (7.8)	23 (8.1)	34 (6.7)
3	158 (13.7)	26 (13.1)	23 (13.8)	37 (13.0)	72 (14.2)
4	189 (16.4)	25 (12.6)	32 (19.2)	46 (16.2)	86 (17.0)
5	284 (24.6)	54 (27.3)	46 (27.5)	64 (22.5)	120 (23.7)
6	206 (17.8)	44 (22.2)	23 (13.8)	42 (14.8)	97 (19.2)
7 (significant impact)	177 (15.3)	6 (3.0)	17 (10.2)	64 (22.5)	90 (17.8)
Frustrated with Sjögren's symptoms, n (%)	**n=1155**	**n=198**	**n=167**	**n=284**	**n=506**
1 (no impact)	59 (5.1)	29 (14.6)	13 (7.8)	6 (2.1)	11 (2.2)
2	98 (8.5)	18 (9.1)	18 (10.8)	17 (6.0)	45 (8.9)
3	135 (11.7)	26 (13.1)	18 (10.8)	35 (12.3)	56 (11.1)
4	148 (12.8)	23 (11.6)	21 (12.6)	34 (12.0)	70 (13.8)
5	248 (21.5)	45 (22.7)	36 (21.6)	54 (19.0)	113 (22.3)
6	217 (18.8)	41 (20.7)	24 (14.4)	48 (16.9)	104 (20.6)
7 (a great deal)	250 (21.6)	16 (8.1)	37 (22.2)	90 (31.7)	107 (21.1)
Worry that Sjögren's will get worse, n (%)	**n=1155**	**n=198**	**n=167**	**n=284**	**n=506**
1 (not at all)	43 (3.7)	15 (7.6)	10 (6.0)	9 (3.2)	9 (1.8)
2	100 (8.7)	21 (10.6)	20 (12.0)	35 (12.3)	24 (4.7)
3	110 (9.5)	21 (10.6)	19 (11.4)	25 (8.8)	45 (8.9)
4	142 (12.3)	27 (13.6)	24 (14.4)	31 (10.9)	60 (11.9)
5	221 (19.1)	45 (22.7)	40 (24.0)	52 (18.3)	84 (16.6)
6	238 (20.6)	37 (18.7)	29 (17.4)	48 (16.9)	124 (24.5)
7 (a great deal)	301 (26.1)	32 (16.2)	25 (15.0)	84 (29.6)	160 (31.6)
Feel helpless as a result of Sjögren's, n (%)	**n=1155**	**n=198**	**n=167**	**n=284**	**n=506**
1 (not at all)	209 (18.1)	28 (14.1)	35 (21.0)	74 (26.1)	72 (14.2)
2	164 (14.2)	30 (15.2)	23 (13.8)	50 (17.6)	61 (12.1)
3	138 (11.9)	21 (10.6)	14 (8.4)	34 (12.0)	69 (13.6)
4	178 (15.4)	35 (17.7)	32 (19.2)	24 (8.5)	87 (17.2)
5	201 (17.4)	39 (19.7)	32 (19.2)	46 (16.2)	84 (16.6)
6	151 (13.1)	26 (13.1)	16 (9.6)	29 (10.2)	80 (15.8)
7 (a great deal)	114 (9.9)	19 (9.6)	15 (9.0)	27 (9.5)	53 (10.5)
Comfort discussing the impact of Sjögren's on emotional well-being and mental health with HCP, n (%)	**n=1155**	**n=198**	**n=167**	**n=284**	**n=506**
Very uncomfortable	49 (4.2)	5 (2.5)	7 (4.2)	12 (4.2)	25 (4.9)
Somewhat uncomfortable	220 (19.0)	67 (33.8)	36 (21.6)	25 (8.8)	92 (18.2)
Neutral	281 (24.3)	69 (34.8)	44 (26.3)	30 (10.6)	138 (27.3)
Somewhat comfortable	339 (29.4)	45 (22.7)	56 (33.5)	79 (27.8)	159 (31.4)
Very comfortable	266 (23.0)	12 (16.1)	24 (14.4)	138 (48.6)	92 (18.2)
Satisfaction with support received by HCP in relation to the emotional impact of Sjögren's, n (%)	**n=1155**	**n=198**	**n=167**	**n=284**	**n=506**
Very dissatisfied	90 (7.8)	1 (0.5)	9 (5.4)	28 (9.9)	52 (10.3)
Somewhat dissatisfied	137 (11.9)	15 (7.6)	31 (18.6)	37 (13.0)	54 (10.7)
Neutral	383 (33.2)	78 (39.4)	73 (43.7)	81 (28.5)	151 (29.8)

Continued

Table 3 Continued

	Country				
	Overall	China	Japan	USA	EU5
	n=1155	n=198	n=167	n=284	n=506
Somewhat satisfied	375 (32.5)	89 (44.9)	42 (25.1)	72 (25.4)	172 (34.0)
Very satisfied	170 (14.7)	15 (7.6)	12 (7.2)	66 (23.2)	77 (15.2)
Currently receiving professional support to help with the emotional aspects of Sjögren's, n (%)	**n=1155**	**n=198**	**n=167**	**n=284**	**n=506**
Yes	242 (21.0)	47 (23.7)	28 (16.8)	77 (27.1)	90 (17.8)
No	913 (79.0)	151 (76.3)	139 (83.2)	207 (72.9)	416 (82.2)
Desire any professional support to help manage the emotional aspects of Sjögren's, n (%)	**n=1155**	**n=198**	**n=167**	**n=284**	**n=506**
Yes	505 (43.7)	114 (57.6)	71 (42.5)	102 (35.9)	218 (43.1)
No	650 (56.3)	84 (42.4)	96 (57.5)	182 (64.1)	288 (56.9)

EU5, European countries consisting of France, Germany, Italy, Spain and the UK; HCP, healthcare professional.

forgetfulness, reported by 52.0% of this subgroup. Nearly one-third also cited treatment side effects as a reason for discontinuation. Overall, 82.2% of patients reported that side effects had a negative impact on their QoL (impact rating: 2–7). Further information regarding Sjögren's treatment satisfaction and adherence can be found in table 5.

Patients also shared their main treatment goals, including preventing the worsening of Sjögren's (49.4%), improving overall symptoms (46.5%), enhancing QoL (36.0%) and reducing unseen organ damage (25.3%). These main goals closely aligned with what patients believed were their HCPs' priorities: 54.1%, 50.3%, 36.5% and 26.9%, respectively (figure 3). However, patients perceived their HCPs underappreciated the importance of reducing fatigue, reducing tiredness and improving sleep quality. Conversely, patients believed that HCPs placed greater importance on reducing treatment side effects and preventing future complications. However, when patients were asked whether their selected treatment goals had been discussed with their managing physician, over one-third (35.0%) of patients had not discussed these main goals with their HCP.

DISCUSSION

This study described the daily burden experienced by adult patients with Sjögren's in a real-world setting, including the impact on symptoms, emotional well-being, work capabilities, and treatment patterns and satisfaction.

The clinical impact of delayed diagnosis in Sjögren's is well known, highlighting the need for earlier detection to help reduce symptom burden and improve patient outcomes. In our study, most patients received a diagnosis of Sjögren's after experiencing signs and symptoms for more than 5 years. This mean diagnostic delay is consistent with previous findings, such as a German study reporting an average of nearly 6 years between Sjögren's symptom onset and diagnosis.[31] In our study, patients from the USA, UK and Spain reported diagnostic delays exceeding 8 years. However, delays of up to 10 years have been documented in the literature and are widely considered a significant unmet need in Sjögren's care.[32] One likely contributor to this delay is the prevalence of non-specific symptoms, such as fatigue and musculoskeletal pain, that may obscure timely diagnosis.[31] Prolonged diagnostic delays have been associated with significantly poorer health outcomes, including increased symptom severity, which increases the need for HCP visits and places greater demands on healthcare resources, compared with shorter diagnostic times.[31] Consistent with this, we found that patients from the USA and EU5 countries reported experiencing a mean (SD) 14.9 (5.5) and 11.4 (5.9) number of symptoms, respectively, compared with 10.7 (6.3) across the total study population. Additionally, 83.2% of patients from Japan rated their general health status as 'poor' or 'fair', relative to the overall cohort (65.5%). All of this highlights the symptomatic burden experienced by patients with Sjögren's.

Nearly all patients in our study experienced at least one other systemic manifestation in addition to the hallmark dryness symptoms. Furthermore, in over a quarter of cases, patients also reported experiencing additional concomitant conditions. Although conditions such as rheumatoid arthritis, systemic lupus erythematosus and scleroderma can be associated with Sjögren's, patients with these diagnoses were excluded from our study. This was to ensure that participants had Sjögren's as their main diagnosis, rather than individuals whose disease occurs in the context of other rheumatic conditions. The most frequently reported comorbidities in our real-world patient cohort were osteoarthritis and Hashimoto's disease, consistent with previous studies identifying these conditions as common in Sjögren's.[32 33] The presence of comorbidities often compounds health issues, limiting patients' daily and social activities as well as functional abilities, and negatively impacting QoL.[34]

Table 4 Patient-reported impact of Sjögren's on employment

	Country				
	Overall	**China**	**Japan**	**USA**	**EU5**
Employment status, n (%)	**n=1155**	**n=198**	**n=167**	**n=284**	**n=506**
In employment	601 (52.0)	120 (60.6)	85 (50.9)	105 (37.0)	291 (57.5)
Not in employment	554 (48.0)	78 (39.4)	82 (49.1)	179 (63.0)	215 (42.5)
Job changed from full-time to part-time employment, n (%)	**n=1155**	**n=198**	**n=167**	**n=284**	**n=506**
Yes	191 (16.5)	20 (10.1)	23 (13.8)	69 (24.3)	79 (15.6)
No	584 (50.6)	143 (72.2)	44 (26.3)	124 (43.7)	273 (54.0)
Not applicable	380 (32.9)	35 (17.7)	100 (59.9)	91 (32.0)	154 (30.4)
Work hours reduced, n (%)	**n=1155**	**n=198**	**n=167**	**n=284**	**n=506**
Yes	308 (26.7)	69 (34.8)	28 (16.8)	95 (33.5)	116 (22.9)
No	498 (43.1)	94 (47.5)	42 (25.1)	108 (38.0)	254 (50.2)
Not applicable	349 (30.2)	35 (17.7)	97 (58.1)	81 (28.5)	136 (26.9)
Considered reducing work hours, n (%)	**n=1155**	**n=198**	**n=167**	**n=284**	**n=506**
Yes	377 (32.6)	69 (34.8)	20 (12.0)	116 (40.8)	172 (34.0)
No	378 (32.7)	91 (46.0)	37 (22.2)	73 (25.7)	177 (35.0)
Not applicable	400 (34.6)	38 (19.2)	110 (65.9)	95 (33.5)	157 (31.0)
Taken early retirement, n (%)	**n=1155**	**n=198**	**n=167**	**n=284**	**n=506**
Yes	165 (14.3)	33 (16.7)	13 (7.8)	77 (27.1)	42 (8.3)
No	606 (52.5)	125 (63.1)	47 (28.1)	124 (43.7)	310 (61.3)
Not applicable	384 (33.2)	40 (20.2)	107 (64.1)	83 (29.2)	154 (30.4)
Voluntarily stopped working in your job, n (%)	**n=1155**	**n=198**	**n=167**	**n=284**	**n=506**
Yes	172 (14.9)	24 (12.1)	10 (6.0)	84 (29.6)	54 (10.7)
No	608 (52.6)	135 (68.2)	47 (28.1)	120 (42.3)	306 (60.5)
Not applicable	375 (32.5)	39 (19.7)	110 (65.9)	80 (28.2)	146 (28.9)
Made to stop working, n (%)	**n=1155**	**n=198**	**n=167**	**n=284**	**n=506**
Yes	51 (4.4)	7 (3.5)	2 (1.2)	21 (7.4)	21 (4.2)
No	692 (59.9)	146 (73.7)	52 (31.1)	170 (59.9)	324 (64.0)
Not applicable	412 (35.7)	45 (22.7)	113 (67.7)	93 (32.7)	161 (31.8)
Considered terminating your job, n (%)	**n=1155**	**n=198**	**n=167**	**n=284**	**n=506**
Yes	294 (25.5)	33 (16.7)	21 (12.6)	99 (34.9)	141 (27.9)
No	487 (42.2)	125 (63.1)	38 (22.8)	99 (34.9)	225 (44.5)
Not applicable	374 (32.4)	40 (20.2)	108 (64.7)	86 (30.3)	140 (27.7)
Required support to carry out your role, n (%)	**n=1155**	**n=198**	**n=167**	**n=284**	**n=506**
Yes	222 (19.2)	53 (26.8)	25 (15.0)	55 (19.4)	89 (17.6)
No	546 (47.3)	111 (56.1)	37 (22.2)	141 (49.6)	257 (50.8)
Not applicable	387 (33.5)	34 (17.2)	105 (62.9)	88 (31.0)	160 (31.6)
Percentage of overall work impairment	**n=591**	**n=119**	**n=83**	**n=104**	**n=285**
Mean (SD)	46.6 (28.6)	43 (29.7)	51.1 (31.2)	45.5 (26.1)	47.1 (28.2)
Percentage of activity impairment	**n=1155**	**n=198**	**n=167**	**n=284**	**n=506**
Mean (SD)	48.4 (26.3)	42.3 (25.9)	49.8 (29.3)	49.6 (27.1)	49.7 (24.7)

EU5, European countries consisting of France, Germany, Italy, Spain and the UK.

In alignment with the hallmark symptoms of Sjögren's, the most common symptoms experienced by patients were dryness of the mouth, eyes and skin. Besides glandular involvement, the joints and muscles were the most affected organs, which highlights the significance of musculoskeletal involvement in the clinical presentation of this population. Supporting this, a separate study found that 96% of patients experienced arthralgia.[35] Beyond

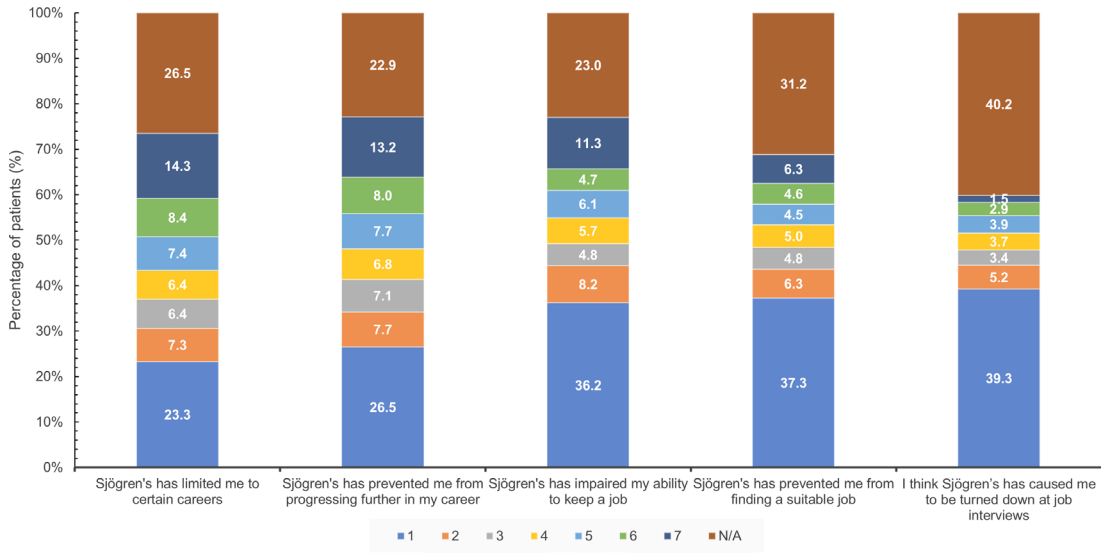

Figure 2 Patient-reported impact of Sjögren's on career progression. Patients rated their perception of impact on a scale from 1 (not at all) to 7 (a great deal).

dryness, physical fatigue and tiredness were among the most frequently reported clinical manifestations, with physical fatigue also rated as the most bothersome symptom. With the majority of patients experiencing their most bothersome symptom at least every other day, this highlights the persistent nature of fatigue experienced by patients. Fatigue is notably prevalent in autoimmune diseases, affecting 60–70% of patients compared with approximately 20% of healthy adults[36] and is associated with increased disability and emotional distress.[37] In addition, the mean (SD) duration of sleep in the month prior to data collection was 6.2 (1.4) hours per night and 64.8% of patients rated their sleep quality as 'bad' (defined as waking up feeling unrefreshed on more than three mornings per week), below the recommended levels of 7–9 hours per night.[38] Our data is consistent with the published literature.[39] Related to this, mental fatigue was experienced by 39.1% of patients in this study, and such cognitive impairments may further exacerbate the feeling of physical fatigue. The sustained high symptom burden in patients with Sjögren's has been identified as a key predictor of reduced health-related QoL over time.[40]

Along with a high symptomatic burden, Sjögren's also has significant psychological impacts. Studies show that patients with Sjögren's are at increased risk of developing mental health conditions such as anxiety and depression compared with the general population,[41 42] with a UK study reporting a clinical depression prevalence of 15%.[43] In line with this, we found that many patients were experiencing emotional difficulties directly related to their condition; frustration with symptoms and concerns about disease progression were common, indicating high levels of emotional distress. Although many patients felt comfortable discussing their emotional well-being with their HCP, a lower proportion of patients in China reported feeling comfortable doing so, indicating a gap in communication between patients and providers. Furthermore, despite this general comfort with disclosure on mental health matters, most patients were dissatisfied with the emotional support provided by their HCP. As a result, nearly half of patients expressed a desire for additional professional support to help manage the emotional aspects of their condition. This suggests a persistent gap in patient care with regard to mental health support currently provided across global healthcare systems. The importance of monitoring and addressing emotional well-being as part of comprehensive disease management is underscored not only by the increased risk of psychological disorders, but also by the potential effects of long-term immunosuppressant use.[34] These medications have been linked to side effects including hormonal imbalances, changes in physical appearance, anxiety and depression, which can have a detrimental impact on patients' mental health.[34] Although some patients in this study reported stopping their medications due to adverse effects, the overall impact of side-effects on QoL was reported to be relatively low by the wider patient population.

The significant symptomatic and emotional burden of Sjögren's appeared to create considerable workplace challenges for patients, often requiring them to make adaptations such as reducing work hours or relying on additional support to remain in employment. Some patients reported having to stop work entirely. This high level of work impairment was likely due to the burden of symptoms that limited patients' functional capacity. Severe dryness symptoms, in particular, have been shown to be detrimental to work productivity, and reduced participation in society and associated financial pressures can also impact patients' QoL.[16 44] These real-world observations are supported by data from the WPAI instrument, where impairment was comparable to that of patients with rheumatoid arthritis, with one study reporting high rates of presenteeism (38.4%) and overall productivity

Table 5 Prescribed and OTC treatments for Sjögren's and patient-reported treatment satisfaction

	Country				
	Overall	**China**	**Japan**	**USA**	**EU5**
Received prescribed treatments by HCP, n (%)	**n=1155**	**n=198**	**n=167**	**n=284**	**n=506**
Yes – currently receiving	896 (77.6)	174 (87.9)	112 (67.1)	213 (75.0)	397 (78.5)
Yes – previously received	161 (13.9)	22 (11.1)	33 (19.8)	45 (15.8)	61 (12.1)
No	98 (8.5)	2 (1.0)	22 (13.2)	26 (9.2)	48 (9.5)
Treatment options ever prescribed by HCP, n (%)*	**n=1155**	**n=198**	**n=167**	**n=284**	**n=506**
Prescription eye drops	635 (55.0)	76 (38.4)	74 (44.3)	182 (64.1)	303 (59.9)
Corticosteroids (eg, prednisone / prednisolone, hydrocortisone, dexamethasone)	591 (51.2)	104 (52.5)	52 (31.1)	137 (48.2)	298 (58.9)
DMARDs (eg, hydroxychloroquine, chloroquine, sulfasalazine)	533 (46.1)	96 (48.5)	0 (0.0)	190 (66.9)	247 (48.8)
NSAIDs (eg, naproxen, ibuprofen, aspirin)	469 (40.6)	30 (15.2)	37 (22.2)	161 (56.7)	241 (47.6)
Secretagogue tablets	457 (39.6)	28 (14.1)	93 (55.7)	143 (50.4)	193 (38.1)
Immunosuppressants (eg, azathioprine, methotrexate, cyclosporine)	337 (29.2)	76 (38.4)	14 (8.4)	69 (24.3)	178 (35.2)
Prescription fluoride/medical toothpaste	306 (26.5)	13 (6.6)	0 (0.0)	126 (44.4)	167 (33.0)
Antibiotics†	255 (22.1)	31 (15.7)	11 (6.6)	83 (29.2)	130 (25.7)
Antidepressants	228 (19.7)	6 (3.0)	24 (14.4)	89 (31.3)	109 (21.5)
Sleeping pills	218 (18.9)	6 (3.0)	43 (25.7)	59 (20.8)	110 (21.7)
Traditional Chinese medicine	112 (9.7)	33 (16.7)	22 (13.2)	34 (12.0)	23 (4.5)
Biological therapy	107 (9.3)	5 (2.5)	0 (0.0)	31 (10.9)	71 (14.0)
Other prescription treatment(s)	240 (20.8)	31 (15.7)	32 (19.2)	80 (28.2)	97 (19.2)
I cannot remember the name of the treatment(s)	25 (2.2)	3 (1.5)	11 (6.6)	1 (0.4)	10 (2.0)
Never taken prescribed treatment	98 (8.5)	2 (1.0)	22 (13.2)	26 (9.2)	48 (9.5)
Satisfaction with prescribed treatment(s), n (%)	**n=896**	**n=174**	**n=112**	**n=213**	**n=397**
Satisfied, AND I believe this is the best that can be achieved for Sjögren's	204 (22.8)	32 (18.4)	24 (21.4)	42 (19.7)	106 (26.7)
Satisfied, BUT I believe better control could be achieved for Sjögren's	359 (40.1)	97 (55.7)	18 (16.1)	75 (35.2)	169 (42.6)
Not satisfied, BUT I believe this is the best that can be achieved for Sjögren's	162 (18.1)	29 (16.7)	40 (35.7)	39 (18.3)	54 (13.6)
Not satisfied AND I believe better control could be achieved for Sjögren's	171 (19.1)	16 (9.2)	30 (26.8)	57 (26.8)	68 (17.1)
Reduced or stopped taking prescribed treatments without informing HCP, n (%)	**n=896**	**n=174**	**n=112**	**n=213**	**n=397**
All the time	9 (1.0)	1 (0.6)	4 (3.6)	0 (0.0)	4 (1.0)
Often	16 (1.8)	5 (2.9)	0 (0.0)	1 (0.5)	10 (2.5)
Sometimes	149 (16.6)	38 (21.8)	25 (22.3)	24 (11.3)	62 (15.6)
Rarely	234 (26.1)	53 (30.5)	31 (27.7)	63 (29.6)	87 (21.9)
Never	488 (54.5)	77 (44.3)	52 (46.4)	125 (58.7)	234 (58.9)
Reasons for reducing/stopping prescribed treatment, n (%)	**n=408**	**n=97**	**n=60**	**n=88**	**n=163**
Forgot to take it	212 (52.0)	68 (70.1)	24 (40)	25 (28.4)	95 (58.3)
I do not like the side effects caused by taking the medication	119 (29.2)	16 (16.5)	17 (28.3)	47 (53.4)	39 (23.9)
I do not feel like it is working	91 (22.3)	17 (17.5)	13 (21.7)	27 (30.7)	34 (20.9)
I am worried about the long-term effects on my body from taking this medication	87 (21.3)	11 (11.3)	10 (16.7)	27 (30.7)	39 (23.9)
I do not think I need to take the medication as frequently as prescribed	55 (13.5)	15 (15.5)	10 (16.7)	14 (15.9)	16 (9.8)
I prefer not to take the medication	41 (10.0)	6 (6.2)	11 (18.3)	7 (8.0)	17 (10.4)

Continued

Table 5 Continued

	Country				
	Overall	**China**	**Japan**	**USA**	**EU5**
I control my symptoms with non-drug treatments/home remedies	26 (6.4)	5 (5.2)	4 (6.7)	6 (6.8)	11 (6.7)
I cannot afford the medication as frequently as it is prescribed	25 (6.1)	5 (5.2)	4 (6.7)	15 (17.0)	1 (0.6)
I control my symptoms with non-prescription/OTC treatments	19 (4.7)	2 (2.1)	4 (6.7)	3 (3.4)	10 (6.1)
I do not think they are knowledgeable about Sjögren's	15 (3.7)	0 (0.0)	6 (10.0)	4 (4.5)	5 (3.1)
I heard about its side effects on Facebook/other social media	8 (2.0)	1 (1.0)	1 (1.7)	0 (0.0)	6 (3.7)
I do not feel like I have enough information about the medication	6 (1.5)	2 (2.1)	1 (1.7)	1 (1.1)	2 (1.2)
My medication instructions are unclear	3 (0.7)	0 (0.0)	1 (1.7)	1 (1.1)	1 (0.6)
I do not trust my doctor	2 (0.5)	0 (0.0)	1 (1.7)	1 (1.1)	0 (0.0)
A friend or family member taking this medication got sicker	1 (0.2)	0 (0.0)	0 (0.0)	0 (0.0)	1 (0.6)
Other	25 (6.1)	1 (1.0)	2 (3.3)	7 (8.0)	15 (9.2)
Used OTC treatments, n (%)	**n=1155**	**n=198**	**n=167**	**n=284**	**n=506**
Yes – currently receiving	677 (58.6)	87 (43.9)	41 (24.6)	244 (85.9)	305 (60.3)
Yes – previously received	205 (17.7)	53 (26.8)	44 (26.3)	30 (10.6)	78 (15.4)
No	273 (23.6)	58 (29.3)	82 (49.1)	10 (3.5)	123 (24.3)
OTC treatments used, n (%)	**n=1155**	**n=198**	**n=167**	**n=284**	**n=506**
Eye drops/artificial tears/lubricants/ointments	795 (68.8)	107 (54.0)	70 (41.9)	271 (95.4)	347 (68.6)
Moisturising lotions/creams	580 (50.2)	28 (14.1)	40 (24.0)	244 (85.9)	268 (53.0)
Saliva substitutes	546 (47.3)	18 (9.1)	49 (29.3)	232 (81.7)	247 (48.8)
Vitamin D	527 (45.6)	43 (21.7)	15 (9.0)	233 (82.0)	236 (46.6)
Anti-inflammatories	482 (41.7)	32 (16.2)	22 (13.2)	190 (66.9)	238 (47.0)
Saline nasal spray	440 (38.1)	18 (9.1)	13 (7.8)	199 (70.1)	210 (41.5)
Dry mouth toothpaste	405 (35.1)	13 (6.6)	21 (12.6)	172 (60.6)	199 (39.3)
Antibacterial mouthwash	376 (32.6)	19 (9.6)	33 (19.8)	128 (45.1)	196 (38.7)
Omega-3 fatty acids	342 (29.6)	1 (0.5)	17 (10.2)	181 (63.7)	143 (28.3)
Probiotics	333 (28.8)	16 (8.1)	8 (4.8)	162 (57.0)	147 (29.1)
Fluoride varnish (at dentist)	196 (17.0)	8 (4.0)	16 (9.6)	111 (39.1)	61 (12.1)
Herbal medicines/natural remedies	186 (16.1)	1 (0.5)	6 (3.6)	83 (29.2)	96 (19.0)
Remineralising toothpaste	174 (15.1)	6 (3.0)	17 (10.2)	60 (21.1)	91 (18.0)
Acupuncture sessions	159 (13.8)	4 (2.0)	15 (9.0)	74 (26.1)	66 (13.0)
Traditional Chinese medicine	119 (10.3)	26 (13.1)	25 (15.0)	33 (11.6)	35 (6.9)
Opioids	102 (8.8)	4 (2.0)	0 (0.0)	35 (12.3)	63 (12.5)
Other	110 (9.5)	9 (4.5)	8 (4.8)	42 (14.8)	51 (10.1)
I cannot remember the name of the treatment(s)	10 (0.9)	3 (1.5)	2 (1.2)	0 (0.0)	5 (1.0)
Never	273 (23.6)	58 (29.3)	82 (49.1)	10 (3.5)	123 (24.3)
Satisfaction with treatment, n (%)	**n=1155**	**n=198**	**n=167**	**n=284**	**n=506**
Very dissatisfied	195 (16.9)	3 (1.5)	22 (13.2)	84 (29.6)	86 (17.0)
Somewhat dissatisfied	275 (23.8)	25 (12.6)	44 (26.3)	102 (35.9)	104 (20.6)
Neutral	335 (29.0)	70 (35.4)	52 (31.1)	53 (18.7)	160 (31.6)
Somewhat satisfied	275 (23.8)	87 (43.9)	34 (20.4)	42 (14.8)	112 (22.1)
Very satisfied	75 (6.5)	13 (6.6)	15 (9.0)	3 (1.1)	44 (8.7)
Reasons for reduced satisfaction with treatment options, n (%)	**n=1080**	**n=185**	**n=152**	**n=281**	**n=462**
The treatment(s) only address the symptoms	571 (52.9)	62 (33.5)	84 (55.3)	174 (61.9)	251 (54.3)
The treatment(s) work, but could still be improved	425 (39.4)	75 (40.5)	32 (21.1)	126 (44.8)	192 (41.6)

Continued

Table 5 Continued

	Country				
	Overall	**China**	**Japan**	**USA**	**EU5**
I have to take the treatment(s) too often	265 (24.5)	45 (24.3)	13 (8.6)	60 (21.4)	147 (31.8)
The treatment(s) do not help/work	222 (20.6)	6 (3.2)	40 (26.3)	93 (33.1)	83 (18.0)
The cost of the treatment(s) is too expensive	204 (18.9)	9 (4.9)	14 (9.2)	103 (36.7)	78 (16.9)
The treatment(s) work less well over time	201 (18.6)	41 (22.2)	17 (11.2)	47 (16.7)	96 (20.8)
Side effects of treatment(s) outweigh the benefit	169 (15.6)	26 (14.1)	22 (14.5)	61 (21.7)	60 (13.0)
Inconvenient to take	124 (11.5)	9 (4.9)	7 (4.6)	44 (15.7)	64 (13.9)
They are uncomfortable after taking the medication(s)	97 (9.0)	39 (21.1)	7 (4.6)	24 (8.5)	27 (5.8)
They are uncomfortable when taking the medication(s)	90 (8.3)	28 (15.1)	4 (2.6)	19 (6.8)	39 (8.4)
The treatment(s) make my symptoms worse	30 (2.8)	7 (3.8)	2 (1.3)	11 (3.9)	10 (2.2)
Other	102 (9.4)	9 (4.9)	17 (11.2)	28 (10.0)	48 (10.4)
Impact of treatment side-effects on QoL, n (%)	**n=1059**	**n=180**	**n=126**	**n=274**	**n=479**
1 (no impact)	188 (17.8)	19 (10.6)	24 (19.0)	61 (22.3)	84 (17.5)
2	200 (18.9)	31 (17.2)	25 (19.8)	61 (22.3)	83 (17.3)
3	167 (15.8)	34 (18.9)	19 (15.1)	31 (11.3)	83 (17.3)
4	195 (18.4)	36 (20.0)	18 (14.3)	44 (16.1)	97 (20.3)
5	181 (17.1)	31 (17.2)	24 (19.0)	42 (15.3)	84 (17.5)
6	78 (7.4)	27 (15.0)	10 (7.9)	18 (6.6)	23 (4.8)
7 (significant impact)	50 (4.7)	2 (1.1)	6 (4.8)	17 (6.2)	25 (5.2)
Impact the number of treatments has on overall QoL, n (%)	**n=1059**	**n=180**	**n=126**	**n=274**	**n=479**
1 (no impact)	144 (13.6)	16 (8.9)	19 (15.1)	53 (19.3)	56 (11.7)
2	154 (14.5)	32 (17.8)	23 (18.3)	36 (13.1)	63 (13.2)
3	164 (15.5)	32 (17.8)	14 (11.1)	38 (13.9)	80 (16.7)
4	202 (19.1)	26 (14.4)	27 (21.4)	54 (19.7)	95 (19.8)
5	231 (21.8)	46 (25.6)	26 (20.6)	48 (17.5)	111 (23.2)
6	98 (9.3)	24 (13.3)	10 (7.9)	28 (10.2)	36 (7.5)
7 (significant impact)	66 (6.2)	4 (2.2)	7 (5.6)	17 (6.2)	38 (7.9)

*Collection of treatment data were tailored in the survey materials to match those available in the corresponding markets, to ensure accuracy in data collection. For example, DMARDs were not an approved treatment pathway in Japan for Sjögren's at the time the data were collected.
†Due to the nature of data collection we did not collect reasons for individual treatment choice, and so the reason for antibiotic prescription could not be ascertained.
DMARDs, disease-modifying antirheumatic drugs; EU5, European countries consisting of France, Germany, Italy, Spain and the UK; HCP, healthcare professional; NSAIDs, non-steroidal anti-inflammatory drugs; OTC, over-the-counter; QoL, quality of life.

loss (45.0%).[45] These challenges indicate that current treatments are not fully effective in managing Sjögren's.

In relation to treatments, nearly all patients were receiving or had received prescribed therapies, but most also needed to supplement these with OTC medications. The heterogeneity of Sjögren's leads to variable treatment responses, often necessitating polypharmacy and the involvement of multidisciplinary care teams.[46] Furthermore, long diagnostic delays and high rates of comorbidities may exacerbate symptom severity and duration, further reinforcing the need for polypharmacy.[33] Although the impact of polypharmacy on patients in this study was reported to be low to moderate, a majority of patients felt that available treatments primarily addressed symptoms rather than the underlying cause of the disease. This perception was supported by the fact that many of the most commonly used treatments, such as eye drops (prescription (55.0%) and OTC (68.8%)), moisturising creams (50.2%) and saliva substitutes (47.3%), are primarily directed at relieving symptoms related to dryness. This aligns with prior reports that, due to a lack of therapies targeting the underlying disease, current treatment strategies focus predominantly on symptom management.[24 47] Notably, among those receiving prescription therapy, over three-quarters were either dissatisfied or believed better disease control was achievable, highlighting a substantial unmet need. However, many patients did not communicate their dissatisfaction to their HCPs, indicating a gap in patient–provider dialogue, particularly regarding

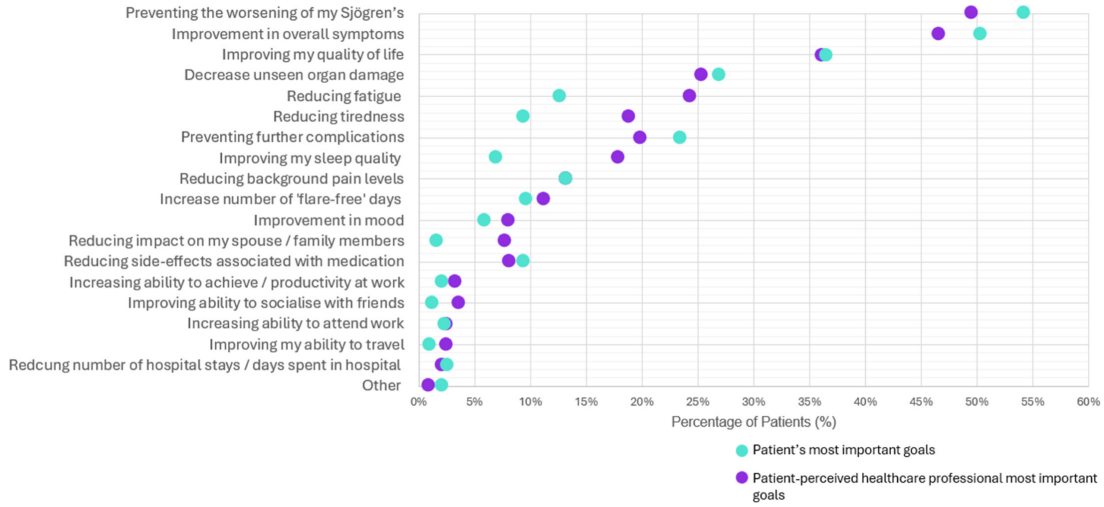

Figure 3 Patient-reported and patient-perceived healthcare professionals most important treatment goals.

treatment decisions. Although the current study did not evaluate specific therapies, emerging treatments may offer meaningful benefits by addressing a broader range of symptoms and potentially slowing or preventing organ damage. However, further research is necessary to ensure these future therapies align with the priorities of a wider patient population.

Regarding treatment goals, there was general alignment between patients' own goals and the goals they perceived their HCPs to have, with shared views of preventing disease progression and improving symptoms. However, patients felt they placed greater importance on reducing fatigue and tiredness, improving sleep quality and minimising the impact on their spouse/family members than they believed their HCPs prioritised. This disconnect may stem from the limited treatment options available to remedy fatigue and sleep disturbances, though patients may still value recognition of these concerns by their HCPs. Similar to what was observed in treatment dissatisfaction, many patients reported not discussing these goals with their HCP, reflecting a missed opportunity to coordinate treatment strategies and again highlighting a gap in patient–HCP communication. These findings reinforce the importance of open and effective dialogue between patients and healthcare providers, consistent with previous studies showing that patients highly value strong communication with their HCPs.[48] Such engagement can help ensure that treatment plans reflect patient goals and expectations, ultimately improving symptom management, disease control and patient satisfaction.

Strengths and limitations

This study has several key strengths. This is the largest global real-world study of patients with Sjögren's, comprising a multinational sample of 1155 patients from eight countries across Asia, Europe and the USA, enabling capture of diverse patient experiences across a wide geographical and cultural spectrum. Patients were required to have a rheumatologist-confirmed diagnosis of Sjögren's as per routine clinical practice and existing guidance to be eligible to participate.[17] These inclusion criteria facilitated a pragmatic sampling approach, enhancing the external validity and real-world relevance of the findings. Furthermore, the study addressed a critical gap in understanding the lived experience of individuals with Sjögren's disease, a perspective often underrepresented in controlled clinical trials.

However, several limitations must be acknowledged. Recruitment methods varied across countries, with patients enrolled via either PAOs or their managing physician. Because the study relied on self-reported data, medical records confirming a full diagnosis of Sjögren's were not collected. Nevertheless, masking questions were included within the screener to help ensure that only appropriate respondents participated, and many survey items could realistically only be answered by Sjögren's patients (eg, Novartis Sjögren's Symptom Diary, and symptom of dryness of the eyes, mouth or skin within 24 hours prior to the survey). Regardless, patients on average had been diagnosed with Sjögren's for a mean (SD) 6.9 (8.0) years, consistent with a real-world population with an established diagnosis of Sjögren's.

This heterogeneity may have introduced selection bias. Patients recruited through PAOs are often more engaged and health-literate, potentially leading to overrepresentation of individuals with higher disease awareness from patient advocacy involvement. Conversely, physician-led recruitment, often occurring during routine consultations, may have disproportionately included patients with more severe disease or more frequent healthcare utilisation, thus skewing the sample towards higher disease burden.

Additionally, voluntary participation introduces the potential for self-selection bias, with more motivated or health-conscious individuals more likely to respond. Physicians may also have introduced unconscious bias in selecting patients to invite. These factors, collectively, may limit the comparability of data across countries and recruitment strategies and could confound the

interpretation of cross-national differences in disease burden or patient perceptions.

Despite these limitations, the study provides valuable real-world insights reflective of clinical practice at the time of data collection. It underscores the value of pragmatic, patient-centred research in capturing dimensions of disease impact often overlooked in clinical trial settings. These findings contribute meaningfully to the understanding of Sjögren's disease and highlight the need for inclusive, methodologically transparent approaches to patient recruitment in future international studies.

CONCLUSION

The findings from this real-world survey highlight the complex and varied daily challenges faced by adults living with Sjögren's. This chronic autoimmune disease creates a significant burden for patients, often presenting as debilitating dryness symptoms, physical fatigue, tiredness and other systemic manifestations affecting multiple organs. The high symptomatic burden impacts patients' functional capabilities, their emotional well-being as well as work productivity. The presence of regular sleep disturbances and neurological issues such as brain fog are likely to further compromise mental health and activities of daily living.

The *Spotlight on Sjögren's* study highlights the current need to reduce diagnostic time and develop new treatment options that target the underlying systemic disease, in addition to symptom management, through comprehensive and patient-centred care approaches that address the physical and emotional burden of Sjögren's. This could help reduce symptom severity and slow disease progression, which would improve patient QoL. Future research should focus on investigating the underlying causes of barriers preventing effective patient–HCP communication, particularly in certain countries such as China, and integrating additional professional support into current healthcare systems to help patients manage the emotional aspects of the disease, alongside monitoring the physical symptoms. Targeted strategies to reduce diagnostic delays, improve treatment options and enhance patient–physician communication could significantly reduce the burden of Sjögren's, improving both QoL and workforce participation.

Author affiliations
[1]Novartis Pharmaceuticals Corporation, East Hanover, New Jersey, USA
[2]Novartis AG, Basel, BS, Switzerland
[3]Sjogren's Foundation Inc, Reston, Virginia, USA
[4]Department of Rheumatology, Cambridge University Hospitals NHS Foundation Trust, Cambridge, UK
[5]HRB Clinical Research Facility, University College Cork, Cork, Ireland
[6]Rheumatology, Scripps Memorial Hospital La Jolla, San Diego, California, USA
[7]Division of Rheumatology, Department of Internal Medicine, Keio University School of Medicine, Tokyo, Japan
[8]Environmental Medicine, Kochi Medical School, Nankoku, Japan
[9]Japanese Sjögren's Association for Patients, Tokyo, Japan
[10]Adelphi Real World, Bollington, UK

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Ethics approval Ethical approval for this study was obtained in all countries where required. In the USA, approval was granted by the WCG (Western Institutional Review Board (IRB) - Copernicus Group, IRB Tracking Number: 20234810) on 26 October 2023. The ethics committee at Saga Memorial Hospital then approved the study in Japan on 17 January 2024, the Shanghai Ethics Committee approved the study in China on 22 March 2024 and the Barcelona Ethics Committee granted approval for Spain on 4 July 2024. Specific ethical approvals were not required in the UK, France, Germany or Italy. The study adhered in its entirety to the IRB-approved protocol, with data collection proceeding only after obtaining the necessary approvals from the relevant ethics committees in each country. Participants gave informed consent to participate in the study before taking part.

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Data availability statement Data are available upon reasonable request. All data, that is, methodology, materials, data and data analysis, that support the findings of this survey are the intellectual property of Novartis Pharma AG. All requests for access should be addressed directly to Gavin Harper (gavin.harper@omc.com).

ORCID iDs
Kaori Komori https://orcid.org/0000-0003-4955-2300
Gavin Harper https://orcid.org/0000-0002-1704-9447
Thom Dewar https://orcid.org/0009-0005-5453-8089

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