# Influence of doctor-patient relationships and health-related factors on the medical satisfaction of patients with Sjögren's disease

K. Komori[1], M. Komori[2], T. Horino[3], S. Nishiyama[4], M. Takei[5], N. Suganuma[1]

*[1]Department of Environmental Medicine, Kochi Medical School, Kochi University; [2]Department of Otolaryngology, Head and Neck Surgery, Kochi Medical School, Kochi University; [3]Department of Endocrinology, Metabolism and Nephrology, Kochi Medical School, Kochi University, Kochi; [4]Rheumatic Disease Center, Kurashiki Medical Center, Okayama; [5]Division of Haematology and Rheumatology, Department of Medicine, Nihon University, Tokyo, Japan.*

## Abstract

### Objective

*Patients with chronic, incurable conditions rely on their providers to help relieve their symptoms. Dissatisfaction with their care can erode the doctor-patient relationship and reduce the effectiveness of treatment. We investigated the relationships between satisfaction and symptoms, the doctor-patient relationship, and health-related factors in patients with Sjögren's disease (SjD) in Japan.*

### Methods

*Using a questionnaire survey, we evaluated via multinomial logistic regression associations between satisfaction [satisfied, neither (neither satisfied nor dissatisfied), dissatisfied] and symptoms, prescribed medications, anxiety, distress, expectations from treatments, and doctor-patient relationships.*

### Results

*Of 259 patients, 101 (39%) were satisfied, 111 (42.9%) were neither, and 47 (18.2%) were dissatisfied. Patients who were neither or dissatisfied with their current treatment wanted their systemic pain to disappear (adjusted relative risk ratio [aRRR] 3.38, 95% CI 1.66–6.91; aRRR 3.04, 95% CI 1.30–7.15, respectively). Patients who used artificial saliva only were significantly more dissatisfied (aRRR 3.52, 95% CI 1.03–2.04). Both the neither and dissatisfied patients dissatisfied with their doctor's limited understanding of SiD (aRRR 12.69, 95% CI 4.21–38.24; aRRR 32.76, 95% CI 10.09–106.34, respectively) and with the limited opportunities to ask their doctor about their disease (aRRR 0.19, 95% CI 0.06–0.59; aRRR 0.08, 95% CI 0.02–0.24, respectively).*

### Conclusion

*Pain and the use of artificial saliva alone markedly affected medical satisfaction and we expected the future advance in these two areas, pain and dryness, will improve satisfaction. It is most important for doctors to better understand SjD.*

**Key words**

dry mouth, pain, physician-patient relationship, satisfaction, Sjögren's disease

*Kaori Komori, PhD*
*Masahiro Komori, PhD*
*Taro Horino, PhD*
*Susumu Nishiyama, PhD*
*Masami Takei, PhD*
*Narufumi Suganuma, PhD*

*Please address correspondence to:*
*Kaori Komori*
*Department of Environmental Medicine, Kochi Medical School, Kochi University, Kohasu, Okoh-cho, Nankoku, Kochi 783-8505, Japan.*
*E-mail: jm-kaorikomori@kochi-u.ac.jp*
*ORCiD ID: 0000-0003-4955-2300*

*Received on January 15, 2024; accepted in revised form on March 4, 2024.*



*Competing interests: none declared.*

## Introduction

Sjögren's disease (SjD) is a chronic systemic autoimmune inflammatory disease that is best characterised by lymphocytic infiltration of the exocrine glands and epithelium, resulting in the classic sicca symptoms of dry eyes and dry mouth. Along with extensive dryness, patients with SjD experience profound fatigue, chronic pain, major organ involvement, neuropathies, and lymphomas (1, 2). SjD symptoms have a significant impact on patients' quality of life, although many studies are currently being conducted (3). The estimated prevalence of primary SjD varies from 0.09% to 2.7% in the world (4). Patients with primary SjD have a significantly lower health-related quality of life than controls (5).

SjD is a disease with a high burden of illness and seriously impacts patients' quality of life. Their daily suffering can be devastating, and the constant struggle without rest is mentally and physically exhausting. Many symptoms are hidden from sight, and a disregard for their suffering denigrates patients' struggles, and makes them feel invisible and misunderstood (6). There is no cure for SjD; the treatment is mainly symptomatic, and there are still many unknowns (7), which all lead to great patient frustration and anxiety (8). Some patients have severe symptoms and cannot accept that their current symptom state will continue (9). Tackling this cryptic disease requires patient-doctor collaboration and effective communication.

Patient satisfaction with medical treatment is an important factor in practicing effective medicine (10). A systematic review of doctor-patient communication (11) linked higher levels of physician trust and active patient participation in the medical consultation to lower disease activity, better global health, less organ damage, greater treatment satisfaction, fewer medication side effects, and more positive beliefs about disease control and about current and future health. Patients with chronic, incurable conditions rely on their providers to help relieve their symptoms. Dissatisfaction with their care can erode the doctor-patient relationship and reduce the effectiveness of treatment. Examining their backgrounds, needs, and satisfaction with care may help us to identify areas where we can support patients with SjD more effectively. To date, no previous study has examined medical satisfaction in patients with SjD. Therefore, we aimed to investigated the relationships between satisfaction and symptoms, the doctor-patient relationship, anxiety, and distress in patients with SjD.

## Materials and methods

### *Study design*

A questionnaire survey was sent to 510 members of the Japanese Sjögren's Association for Patients (JSAP) in November 2019. The JSAP was established in 1986 to enhance the better understanding of SjD, collect and provide relevant information to improve their quality of life, identify potential patients who have not yet diagnosed, and help patients receive appropriate diagnosis and treatment.

Patients initially diagnosed with SjD only were classified as having primary SjD (12, 13), whereas patients initially diagnosed with rheumatoid arthritis, systemic lupus erythematosus, scleroderma, dermatomyositis and polymyositis, or mixed connective tissue disease and subsequently diagnosed with SjD, were classified as having associated SjD. The treatment of SjD in Japan is conducted according to the Clinical practice guideline for Sjögren's syndrome 2017(14) and is considered complying with the European Alliance of Associations for Rheumatology (EULAR) recommendations (15, 16).

Data were collected regarding the patient's age at diagnosis and current age, current symptoms, and prescribed medications (Table I). Current symptoms were scored using EULAR Sjögren's Syndrome Patient Reported Index (ESSPRI) (17) which uses a numerical scale from 0 to 10 to assess three domains: dryness, fatigue, and pain (articular or muscular or both). The weights of the domains are identical and the mean of the three domain scores represents the final score.

Patients graded their satisfaction with their medical treatment using a three-point scale of satisfied, neither (neither

**Table I.** Characteristics of patients with Sjögren's Disease stratified according to level of satisfaction.

| | Total | Satisfied | Neither | Dissatisfied | |
|---|---|---|---|---|---|
| | n (%) | n (%) | n (%) | n (%) | |
| | 259 (100.0) | 101 (39.0) | 111 (42.9) | 47 (18.2) | *p* |
| Sex | | | | | |
| Male | 8 (3.1) | 3 (3.0) | 4 (3.6) | 1 (2.1) | 0.883 |
| Female | 251 (96.9) | 98 (97.0) | 107 (96.4) | 46 (97.9) | |
| Disease | | | | | |
| Primary SjD | 208 (80.3) | 85 (84.2) | 87 (78.4) | 36 (76.6) | 0.433 |
| Associated SjD | 51 (19.7) | 16 (15.8) | 24 (21.6) | 11 (23.4) | |
| **Diagnosed age (years)** | **54.1 ± 12.1** | **52.0 ± 11.1** | **56.3 ± 12.1** | **53.8 ± 13.6** | **0.034*** |
| Current age (years) | 65.8 ± 11.5 | 63.9 ± 11.1 | 67.6 ± 11.2 | 65.5 ± 12.5 | 0.059* |
| Disease duration (years) | 11.6 ± 8.8 | 11.9 ± 9.2 | 11.3 ± 8.4 | 11.6 ± 9.2 | 0.901* |
| Current symptoms | | | | | |
| Dry eye | 235 (90.7) | 92 (91.1) | 99 (89.2) | 44 (93.6) | 0.672 |
| Dry mouth | 250 (96.5) | 97 (96.0) | 107 (96.4) | 46 (97.9) | 0.848 |
| Dry nose | 121 (46.7) | 42 (41.6) | 53 (47.8) | 26 (55.3) | 0.285 |
| Arthralgia | 112 (43.2) | 41 (40.6) | 48 (43.2) | 23 (48.9) | 0.635 |
| Cutaneous symptom | 79 (30.5) | 32 (31.7) | 31 (27.9) | 16 (34.0) | 0.708 |
| Parotid swelling | 52 (20.1) | 24 (23.8) | 17 (15.3) | 11 (23.4) | 0.253 |
| Headache | 52 (20.1) | 19 (18.8) | 21 (18.9) | 12 (25.5) | 0.587 |
| **Body pain** | **84 (32.4)** | **23 (22.8)** | **44 (39.6)** | **17 (36.2)** | **0.027** |
| Limb paresthesia | 78 (30.1) | 23 (22.8) | 37 (33.3) | 18 (38.3) | 0.099 |
| Fatigue | 137 (52.9) | 50 (49.5) | 62 (55.9) | 25 (53.2) | 0.651 |
| Slight fever | 33 (12.7) | 13 (12.9) | 12 (10.8) | 8 (17.0) | 0.563 |
| **Feeling down** | **89 (34.4)** | **27 (26.7)** | **38 (34.2)** | **24 (51.1)** | **0.015** |
| ESSPRI | 5.5 ± 2.5 | 5.3 ± 2.4 | 5.6 ± 2.5 | 5.9 ± 2.5 | 0.350* |
| Dry | 6.9 ± 2.5 | 6.8 ± 2.3 | 6.8 ± 2.5 | 7.7 ± 2.6 | 0.088* |
| Fatigue | 5.8 ± 2.9 | 5.6 ± 3.0 | 5.8 ± 2.9 | 6.2 ± 2.7 | 0.544* |
| Pain | 4.2 ± 3.2 | 3.6 ± 3.2 | 4.4 ± 3.0 | 4.7 ± 3.5 | 0.087* |
| Prescribed medication | | | | | |
| No medication used | 13 (5.0) | 5 (5.0) | 6 (5.4) | 2 (4.3) | 0.954 |
| Saliva secretagogue | 103 (39.8) | 42 (41.6) | 45 (40.5) | 16 (34.0) | 0.667 |
| Artificial saliva | 51 (19.7) | 15 (14.9) | 21 (18.9) | 15 (31.9) | 0.050 |
| Eye drops | 219 (84.6) | 81 (80.2) | 95 (85.6) | 43 (91.5) | 0.193 |
| Steroid | 60 (23.2) | 25 (24.8) | 27 (24.3) | 8 (17.0) | 0.542 |
| Immunosuppressant | 28 (10.8) | 11 (10.9) | 9 (8.1) | 8 (17.0) | 0.256 |
| Painkillers | 85 (32.8) | 27 (26.7) | 41 (36.9) | 17 (36.2) | 0.248 |
| Anti-anxiety agent | 52 (20.1) | 15 (14.9) | 22 (19.8) | 15 (31.9) | 0.054 |
| **Sleeping pills** | **70 (27.0)** | **17 (16.8)** | **31 (27.9)** | **22 (46.8)** | **0.001** |
| Chinese herbal medicine | 58 (22.4) | 21 (20.8) | 23 (20.7) | 14 (29.8) | 0.405 |
| Other drugs | 79 (30.5) | 35 (34.7) | 32 (28.8) | 12 (25.5) | 0.469 |
| Expectations for treatment | | | | | |
| Disappearance of dry eyes symptoms | 180 (69.5) | 68 (67.3) | 79 (71.2) | 33 (70.2) | 0.826 |
| Disappearance of dry mouth symptoms | 219 (84.6) | 83 (82.2) | 97 (87.4) | 39 (83.0) | 0.547 |
| Disappearance of dry nose symptoms | 87 (33.6) | 32 (31.7) | 37 (33.3) | 18 (38.3) | 0.728 |
| Disappearance of airway dryness | 89 (34.4) | 34 (33.7) | 35 (31.5) | 20 (42.6) | 0.404 |
| Disappearance of joint pain | 90 (34.8) | 32 (31.7) | 40 (36.0) | 18 (38.3) | 0.684 |
| **Disappearance of systemic pain** | **68 (26.3)** | **16 (15.8)** | **36 (32.4)** | **16 (34.0)** | **0.009** |
| Disappearance of itchy skin | 71 (27.4) | 31 (30.7) | 27 (24.3) | 13 (27.7) | 0.583 |
| Disappearance of cold hands and feet | 100 (38.6) | 35 (34.7) | 47 (42.3) | 18 (38.3) | 0.517 |
| Improvement of mood | 72 (27.8) | 26 (25.7) | 31 (27.9) | 15 (31.9) | 0.737 |
| Disappearance of fatigue | 119 (46.0) | 40 (39.6) | 54 (48.7) | 25 (53.2) | 0.228 |

SjD: Sjögren's disease; ESSPRI: EULAR Sjögren's Syndrome Patient Reported Index. *p*: chi-square test; * One-way ANOVA.

satisfied nor dissatisfied), and dissatisfied. Participants were asked about their expectations from their treatments, their relationships with, and what they wished for from their doctor, whether they were anxious or distressed, and their perception of the consultation time. To the questions "Can you ask your doctor about your disease?" and "Do you have any current anxiety or distress?" they could respond yes or no. To indicate their sources of current anxiety and distress, they were to select all that apply from a list of options (exacerbation or progression of their disease, decrease in daily activities, growing old, prescribed medication side effects, economic instability, the incurable nature of their disease, and the lack of understanding by others around them), and to elaborate on any unlisted options with an open-ended response. Similarly, in response to the question "What do you want the doctor

to do?" Again, of the options "Cooperate with doctors in other departments", "Explain our symptoms, progress, and treatment", "Understand SjD more", and "Want to do the necessary tests" they were to select all that apply and to provide an open-ended response for everything else. The consultation time (less than 3 minutes, 3 to 10 minutes, or 10 minutes or more) was based on how long they perceived the consultation to last rather than the actual consultation time. The response options for this questionnaire were adapted from a survey we conducted in 2012.

*Ethical considerations*

The study was approved by the Ethics Committee of Kochi Medical School (ERB-105441) and the Kurashiki Medical Centre. All procedures were performed in accordance with the Declaration of Helsinki. Informed consent was obtained from all study participants.

*Statistical analyses*

For analysis, the degree of patient satisfaction with medical care was classified into three categories: satisfied, neither, and dissatisfied. The associations between patient satisfaction and sex, primary or associated SjD, current symptoms, prescribed medications, expectations from their treatments, and relationships with their doctor (including anxiety, distress, wishes from their doctors, and consultation time) were evaluated using chi-squared tests. One-way ANOVA was used to determine the significance of differences in the mean values of continuous variables (age, diagnosed age, disease duration, and ESSPRI score) across the three satisfaction categories. Multinomial logistic regression models were used to examine the associations between several outcome variables (current symptoms, prescribed medications, expectations from treatments, and relationships with their doctor) and satisfaction categorised as dissatisfied or neither, with satisfied as the reference. The exponentiated coefficients from multinomial logistic regression provided an estimate of the relative risk ratio (RRR) and 95% confidence intervals (CI). The results were adjusted for age and disease duration. To examine the association between artificial saliva and saliva secretagogue use, alone or in combination, and medical satisfaction, multinomial logistic regression models, adjusted for age and disease duration were used. Significance was set at a two-tailed $p<0.05$. All analyses were performed by using Stata 15.1 (StataCorp, College Station, TX, USA).

## Results

Of the 510 JSAP members who received the survey, 276 returned the questionnaire, giving a response rate of 54.1%. We excluded 17 respondents for whom data were missing, resulting in a final sample size of 259. Of these 259 patients, 251 (96.9%) were women and 208 (80.3%) had primary SjD. In terms of patient satisfaction with their medical care, 101 patients (39%) were satisfied, 111 (42.9%) were neither, and 47 (18.2%) were dissatisfied. Patient demographics were similar regardless of satisfaction category, except for a significant difference in age at diagnosis ($p = 0.034$) (Table I).

*Current symptoms, prescribed medications, ESSPRI and expectations for treatment*

Table I shows a chi-square test with three categories (satisfied, neither, dissatisfied) and current symptoms, prescribed medications, and patient expectations from their treatment, and shows a one-way ANOVA with age, diagnosed age, disease duration, and ESSPRI score. There were significant differences in body pain ($p$=0.027), feeling down ($p$=0.015), and prescription sleeping pill use ($p$=0.001). No significant difference in ESSPRI scores was observed; however, a significant difference in patients' expectations about the 'Disappearance of systemic pain' was found ($p$=0.009).

After adjusting our multinomial logistic regression models for age and disease duration, the adjusted relative risk ratios (aRRR) for patients in the neither group were significantly higher than for those in the satisfied group for body pain (2.98, 95% CI 1.56–5.70), ESSPRI-pain score (1.11, 95% CI 1.01–1.22), painkiller use (1.86, 95% CI 1.0–13.42), and disappearance of systemic pain (3.38, 95% CI 1.66–6.91) and fatigue (1.84, 95% CI 1.03–3.29) (Table II). Overall, pain was more problematic for patients in the neither group than for those who were satisfied.

The aRRRs were also significantly higher for dissatisfied patients than for those who were satisfied with respect to symptoms of body pain (2.32, 95% CI 1.05–5.15), limb paraesthesia (2.23, 95% CI 1.04–4.76), and feeling down (3.13, 95% CI 1.50–6.53). Similarly, the RRRs for ESSPRI-scores for dryness (1.20, 95% CI 1.01–1.42) and pain (1.12, 95% CI 1.00–1.26), use of artificial saliva (2.70, 95% CI 1.17–6.25), anti-anxiety agents (2.71, 95% CI 1.18–6.21) and sleeping pills (4.51, 95% CI 2.04–9.95) were significantly higher among those dissatisfied with their care. And as was the case in the neither group, patients dissatisfied with their care wished for the 'Disappearance of systemic pain' (aRRR 3.04, 95% CI 1.30–7.15). In addition to pain, the dissatisfied group experienced more dry mouth and were prescribed more anti-anxiety agents and sleeping pills than the satisfied group.

*Artificial saliva and saliva secretagogue use*

Approximately half of all study participants (52.8%) used neither saliva secretagogues nor artificial saliva. Chi-square testing revealed no significant differences in artificial saliva or saliva secretagogue use across satisfaction groups ($p$=0.195). In contrast, differences in ESSPRI scores for dryness were significant across all categories of artificial saliva and saliva secretagogue use (none: 6.5±2.8, saliva secretagogue only: 6.9±2.3, artificial saliva only saliva: 7.9±1.4, secretagogue-artificial saliva: 8.0±2.0, $p$=0.004). Whereas patients using only artificial saliva had higher ESSPRI-dryness scores than those using a saliva secretagogue alone, their scores were comparable to the ESSPRI-dryness scores in patients using both artificial saliva and a saliva secretagogue. Based on these results, we conducted a multinomial logistic regression analysis with the group using neither artificial saliva nor saliva

**Table II.** Multinomial logistic regression analysis according to current satisfaction status.

| | Satisfied | Neither | | Dissatisfied | |
|---|---|---|---|---|---|
| | | aRRR (95% CI) | *p* | aRRR (95% CI) | *p* |
| Current symptoms | | | | | |
| Dry eye | Ref | 0.86 (0.34-2.20) | 0.759 | 1.45 (0.37-5.71) | 0.593 |
| Dry mouth | Ref | 1.26 (0.30-5.38) | 0.751 | 1.98 (0.21-18.48) | 0.549 |
| Dry nose | Ref | 1.38 (0.77-2.45) | 0.276 | 1.79 (0.86-3.73) | 0.117 |
| Arthralgia | Ref | 1.45 (0.81-2.60) | 0.216 | 1.55 (0.74-3.25) | 0.251 |
| Cutaneous symptom | Ref | 0.89 (0.49-1.63) | 0.703 | 1.07 (0.51-2.28) | 0.851 |
| Parotid swelling | Ref | 0.66 (0.32-1.33) | 0.243 | 0.94 (0.40-2.21) | 0.885 |
| Headache | Ref | 1.18 (0.58-2.41) | 0.645 | 1.65 (0.71-3.83) | 0.246 |
| **Body pain** | Ref | **2.98 (1.56-5.70)** | **0.001** | **2.32 (1.05-5.15)** | **0.038** |
| **Limb paraesthesia** | Ref | 1.75 (0.94-3.27) | 0.077 | **2.23 (1.04-4.76)** | **0.038** |
| Fatigue | Ref | 1.54 (0.88-2.71) | 0.133 | 1.32 (0.64-2.72) | 0.447 |
| Slight fever | Ref | 0.95 (0.40-2.24) | 0.908 | 1.30 (0.48-3.56) | 0.609 |
| **Feeling down** | Ref | 1.54 (0.84-2.82) | 0.158 | **3.13 (1.50-6.53)** | **0.002** |
| ESSPRI | Ref | 1.10 (0.98-1.24) | 0.112 | 1.13 (0.97-1.32) | 0.111 |
| **Dry** | Ref | 1.04 (0.93-1.16) | 0.533 | **1.20 (1.01-1.42)** | **0.035** |
| Fatigue | Ref | 1.05 (0.95-1.16) | 0.304 | 1.10 (0.96-1.25) | 0.160 |
| **Pain** | Ref | **1.11 (1.01-1.22)** | **0.023** | **1.12 (1.00-1.26)** | **0.047** |
| Prescribed medication | | | | | |
| No medication used | Ref | 1.14 (0.33-3.95) | 0.839 | 0.89 (0.16-4.78) | 0.888 |
| Saliva secretagogue | Ref | 0.86 (0.49-1.53) | 0.617 | 0.71 (0.34-1.48) | 0.359 |
| **Artificial saliva** | Ref | 1.17 (0.56-2.46) | 0.673 | **2.70 (1.17-6.25)** | **0.020** |
| Eye drops | Ref | 1.56 (0.74-3.30) | 0.245 | 2.73 (0.86-8.66) | 0.088 |
| Steroid | Ref | 1.02 (0.53-1.94) | 0.964 | 0.64 (0.26-1.58) | 0.338 |
| Immunosuppressant | Ref | 0.93 (0.36-2.41) | 0.877 | 1.97 (0.71-5.45) | 0.193 |
| **Painkillers** | Ref | **1.86 (1.01-3.42)** | **0.045** | 1.57 (0.73-3.38) | 0.246 |
| **Anti anxiety agent** | Ref | 1.30 (0.62-2.70) | 0.484 | **2.71 (1.18-6.21)** | **0.018** |
| **Sleeping pills** | Ref | 1.72 (0.87-3.39) | 0.117 | **4.51 (2.04-9.95)** | **<0.001** |
| Chinese herbal medicine | Ref | 0.99 (0.50-1.93) | 0.967 | 1.66 (0.75-3.67) | 0.210 |
| Other drugs | Ref | 0.75 (0.41-1.36) | 0.339 | 0.65 (0.30-1.43) | 0.286 |
| Expectations for treatment | | | | | |
| Disappearance of dry eye symptoms | Ref | 1.24 (0.68-2.25) | 0.484 | 1.12 (0.52-2.39) | 0.771 |
| Disappearance of dry mouth symptoms | Ref | 1.43 (0.66-3.10) | 0.359 | 1.00 (0.40-2.52) | 0.993 |
| Disappearance of dry nose symptoms | Ref | 1.06 (0.58-1.93) | 0.854 | 1.28 (0.60-2.70) | 0.524 |
| Disappearance of airway dryness | Ref | 0.90 (0.50-1.62) | 0.720 | 1.39 (0.67-2.87) | 0.376 |
| Disappearance of joint pain | Ref | 1.48 (0.81-2.69) | 0.200 | 1.38 (0.65-2.94) | 0.398 |
| **Disappearance of systemic pain** | Ref | **3.38 (1.66-6.91)** | **0.001** | **3.04 (1.30-7.15)** | **0.011** |
| Disappearance of itchy skin | Ref | 0.79 (0.42-1.47) | 0.456 | 0.82 (0.37-1.82) | 0.629 |
| Disappearance of cold hands and feet | Ref | 1.48 (0.83-2.62) | 0.182 | 1.13 (0.54-2.36) | 0.737 |
| Improvement of mood | Ref | 1.25 (0.67-2.35) | 0.484 | 1.48 (0.68-3.20) | 0.325 |
| **Disappearance of fatigue** | Ref | **1.84 (1.03-3.29)** | **0.040** | 2.09 (1.00-4.37) | 0.050 |

aRRR: Relative Risk Ratio adjusted for age and disease duration.

secretagogue (None) as the reference (Table III). Patients in the group using only artificial saliva were at significantly higher risk of being dissatisfied with their care (aRRR 3.52, 95% CI 1.03–12.04) compared with patients using either saliva secretagogue alone or a combination of saliva secretagogue plus artificial saliva. Despite there being more dryness symptoms in the dissatisfied group, there was no significant difference between the satisfied and dissatisfied groups in combined artificial saliva plus saliva secretagogue use.

*Relationships with their doctors*

Our study revealed significant associations between satisfaction and various aspects of the patient-doctor relationship (Table IV). The satisfied group was more likely to ask their doctor about their disease ($p<0.001$), whereas current anxiety or distress was more common in the dissatisfied group ($p=0.001$). Associations between satisfaction level and anxiety over a decrease in activities of daily living ($p=0.016$) and economic instability ($p=0.037$) were significant, as were differences in distress over having an incurable disease ($p=0.002$) and the lack of understanding by others around them ($p=0.006$). Patients in the dissatisfied group were more likely than those in the satisfied group to wish their doctor would collaborate with other departments ($p=0.023$), explain their symptoms, progress, and treatment ($p=0.016$), understand SjD better ($p<0.001$), and perform necessary tests ($p=0.004$). More patients in the satisfied group (38.6%) reported consultation times of 10 minutes or more compared with the dissatisfied group (8.9%; $p<0.001$).

To examine the associations between aspects of patient relationships with their doctor and satisfaction categories (dissatisfied and neither), we used multinomial logistic regression with satisfied as the reference (Table V). After adjustment for age and disease duration, to the question, 'Can you ask your doctor about your disease?', significantly fewer in the neither group (aRRR 0.19, 95% CI 0.06–0.59) and

**Table III.** Multinomial logistic regression analysis for the use of artificial saliva and saliva secretagogue.

| | n (%) | Satisfied 101 (39.0) | Neither 111 (42.9) | | Dissatisfied 47 (18.2) | |
|---|---|---|---|---|---|---|
| | | | aRRR (95%CI) | *p* | aRRR (95%CI) | *p* |
| None | 140 (42.8) | | Ref | | Ref | |
| Saliva secretagogue only | 21 (7.9) | Ref | 0.87 (0.46-1.63) | 0.664 | 0.62 (0.25-1.50) | 0.287 |
| **Artificial saliva only** | 74 (27.9) | Ref | 1.36 (0.41-4.50) | 0.613 | **3.52 (1.03-12.04)** | **0.045** |
| Saliva secretagogue + Artificial saliva | 30 (11.3) | Ref | 1.08 (0.43-2.73) | 0.868 | 1.52 (0.51-4.56) | 0.455 |

aRRR: Relative Risk Ratio adjusted for age and disease duration.

**Table IV.** Patients' relationships with their doctors stratified by satisfaction.

| | Total | Satisfied | Neither | Dissatisfied | |
|---|---|---|---|---|---|
| | n (%) | n (%) | n (%) | n (%) | |
| | 259 (100.0) | 101 (39.0) | 111 (42.9) | 47 (18.2) | *p* |
| Can you ask your doctor about your disease? Yes | **219 (84.6)** | **97 (96.0)** | **92 (82.9)** | **30 (63.8)** | **<0.001** |
| Do you have any current anxiety or distress? Yes | **206 (79.5)** | **68 (67.3)** | **97 (87.4)** | **41 (87.2)** | **0.001** |
| **Anxiety** | | | | | |
| Exacerbation or progression of their disease | 157 (60.6) | 53 (52.5) | 70 (63.1) | 34 (72.3) | 0.055 |
| Decreased in daily activities | **129 (49.8)** | **39 (38.6)** | **63 (56.8)** | **27 (57.5)** | **0.016** |
| Worries about growing old | 112 (43.2) | 36 (35.6) | 54 (48.7) | 22 (46.8) | 0.139 |
| Medication side effects | 87 (33.6) | 30 (29.7) | 40 (36.0) | 17 (36.2) | 0.571 |
| Economic instability | **45 (17.4)** | **13 (12.9)** | **18 (16.2)** | **14 (29.8)** | **0.037** |
| **Distress** | | | | | |
| Incurable nature of their disease | **190 (73.4)** | **63 (62.4)** | **93 (83.8)** | **34 (72.3)** | **0.002** |
| Lack of understanding by others around them | **52 (20.1)** | **12 (11.9)** | **24 (21.6)** | **16 (34.0)** | **0.006** |
| **Wish for their doctor to** | | | | | |
| Cooperate with doctors in other departments | **87 (33.6)** | **25 (24.8)** | **40 (36.0)** | **22 (46.8)** | **0.023** |
| Explain our symptoms, progress, and treatment | **76 (29.3)** | **20 (19.8)** | **42 (37.8)** | **14 (29.8)** | **0.016** |
| Understand Sjögren's Disease more | **63 (24.3)** | **4 (4.0)** | **34 (30.6)** | **25 (53.2)** | **<0.001** |
| Want to do the necessary tests | **29 (11.2)** | **5 (5.0)** | **13 (11.7)** | **11 (23.4)** | **0.004** |
| **Consultation time** | | | | | |
| Less than 3 minutes | 36 (14.1) | 8 (7.9) | 14 (12.7) | 14 (31.1) | **<0.001** |
| 3 to 10 minutes | 161 (62.9) | 54 (53.5) | 80 (72.7) | 27 (60.0) | |
| 10 minutes or more | 59 (23.1) | 39 (38.6) | 16 (14.6) | 4 (8.9) | |

*p:* values: chi-square test.

**Table V.** Multinomial logistic regression analysis according to current satisfaction status for patients' relationships with their doctors.

| | Satisfied | Neither | | Dissatisfied | |
|---|---|---|---|---|---|
| | | aRRR (95% CI) | *p* | aRRR (95% CI) | *p* |
| Can you ask your doctor about your disease? Yes | Ref | **0.19 (0.06–0.59)** | **0.004** | **0.08 (0.02–0.24)** | **<0.001** |
| Do you have any current anxiety or distress? Yes | Ref | **4.41 (2.10–9.30)** | **<0.001** | **3.81 (1.41–10.27)** | **0.008** |
| **Anxiety** | | | | | |
| Exacerbation or progression of their disease | Ref | 1.73 (0.97–3.09) | 0.063 | **2.50 (1.15–5.46)** | **0.021** |
| Decreased in daily activities | Ref | **2.24 (1.27–3.95)** | **0.005** | **2.36 (1.14–4.85)** | **0.020** |
| Worries about growing old | Ref | **1.85 (1.05–3.27)** | **0.033** | 1.72 (0.84–3.51) | 0.139 |
| Medication side effects | Ref | 1.44 (0.80–2.60) | 0.222 | 1.43 (0.68–3.00) | 0.343 |
| Economic instability | Ref | 1.71 (0.76–3.87) | 0.196 | **3.22 (1.29–8.04)** | **0.012** |
| **Distress** | | | | | |
| Incurable nature of their disease | Ref | **2.98 (1.54–5.74)** | **0.001** | 1.68 (0.77–3.66) | 0.192 |
| Lack of understanding by others around them | Ref | **2.40 (1.10–5.27)** | **0.029** | **4.47 (1.84–10.84)** | **0.001** |
| **Wish for their doctor to** | | | | | |
| Cooperate with doctors in other departments | Ref | 1.77 (0.97–3.26) | 0.064 | **2.86 (1.36–5.98)** | **0.005** |
| Explain our symptoms, progress, and treatment | Ref | **2.48 (1.31–4.68)** | **0.005** | 1.79 (0.80–3.99) | 0.157 |
| Understand Sjögren's disease more | Ref | **12.69 (4.21–38.24)** | **<0.001** | **32.76 (10.09–106.34)** | **<0.001** |
| Want to do the necessary tests | Ref | 2.81 (0.94–8.35) | 0.064 | **5.65 (1.79–17.88)** | **0.003** |
| **Consultation time** | Ref | **0.39 (0.24–0.66)** | **<0.001** | **0.20 (0.10–0.40)** | **<0.001** |

aRRR: Relative Risk Ratio adjusted for age and disease duration.

dissatisfied group (aRRR 0.08, 95% CI 0.02–0.24) than in the satisfied group responded affirmatively. When asked, 'Do you have any current anxiety or distress?' patients in the neither and dissatisfied groups were significantly more likely than those in the satisfied group to say yes (aRRR 4.41, 95% CI 2.10–9.30; aRRR 3.81, 95% CI 1.41–10.27, respectively). Similarly, as compared to satisfied patients, those who were neither (aRRR 12.69, 95% CI 4.21–38.24) or dissatisfied (aRRR 32.76, 95% CI 10.09–106.34) with their care were significantly more likely than satisfied patients to want their doctor to better understand SjD. Associations between satisfaction and sources of anxiety and distress were also significant. The aRRR was significantly higher for the neither and dissatisfied groups than for the satisfied group with regard to their 'anxiety over decreased daily activities' (2.24, 95% CI 1.27–3.9; 2.36, 95% CI

1.14–4.85, respectively) and 'distress over lack of understanding around us' (2.40, 95% CI 1.10–5.27, 4.47, 95% CI 1.84–10.84, respectively). The neither group (aRRR 0.39, 95% CI 0.24–0.66) and the dissatisfied group (aRRR 0.20, 95% CI 0.10–0.40) perceived the consultation time as significantly shorter compared to the satisfied group.

## Discussion

Patients' medical satisfaction is very important for the doctor-patient relationship and effective treatment. In our study, 39% of patients with SjD were satisfied with their care and 18.2% were dissatisfied. The Ministry of Health, Labour and Welfare in Japan conducts a healthcare behaviour survey of patients to assess their satisfaction and the conditions under which they receive medical care. In their 2020 Patient Satisfaction Survey of 106,000 patients, 64.5% of all outpatients were satisfied and 3.8% were dissatisfied (18). When we compare these results with ours, we propose that patients with SjD are rarely satisfied with their care. SjD patients continue to have many unmet needs that require our attention.

In our study, medical satisfaction was most associated with pain. ESSPRI Pain scores increased with dissatisfaction. Patients who wanted their pain to disappear were dissatisfied (aRRR 3.04) or neither satisfied nor dissatisfied (aRRR 3.38) with their care. Because pain is a major predictor of poor quality of life in patients with SjD (19), achieving better pain control may increase patient satisfaction. In addition, pain is closely associated with both physical and mental fatigue (20). More than half of the patients in our study experienced fatigue, but only the neither group patients wanted their fatigue to disappear (aRRR 1.84) with their care. Since fatigue was the most troublesome symptom for patients with primary SjD (21), patients' pain and fatigue must be considered together.

About dryness, patients with severe dry mouth were highly dissatisfied with their medical care, especially when their doctors prescribed artificial saliva alone. Although ESSPRI scores for xerostomia were higher in patients prescribed a saliva secretagogue plus artificial saliva than in those prescribed artificial saliva only, there was no significant difference in satisfaction among the patients receiving dual therapy. Therefore, the severity of dry mouth does not appear to directly affect medical satisfaction. Artificial saliva is a traditional treatment, but effectiveness and patient tolerability have been an issue (22). Saliva secretagogues, if available, may ease dryness, but their side effects limit their use, leaving artificial saliva as the only option. Furthermore, although dryness symptoms are progressive, patients may remain on the same treatment they were prescribed during their initial consultation. Saliva measurements should be performed at diagnosis and repeated regularly and treatment adapted accordingly.

Patients with SjD experience more anxiety that affects their daily lives than the general population (23-25). In our study, nearly 80% of respondents reported current anxiety or distress, and patients in the dissatisfied group were more likely to be prescribed anti-anxiety agents and sleeping pills. Our findings suggest that mental health support needs to be integrated into SjD treatment. Furthermore, the dissatisfied groups in our study were more likely to have financial concerns, consistent with a recent study in which 77.3% of patients reported concerns about the cost of managing their SjD (21). Therefore, and a stable financial base that allows treatment to be actively pursued needs to be considered.

Two striking findings related to patient satisfaction emerged from our research: Patients were particularly dissatisfied with their doctor's limited understanding of SiD and with the limited opportunities to ask their doctor about their disease. Previous studies have linked patient dissatisfaction to physicians' lack of understanding of SjD (21, 26, 27). For patients living with SjD, it is the saddest and most painful reality that the doctors they rely on most do not understand their disease. Also, patients with SjD suffer from a lack of understanding not only from their doctors but also from others around them (28). People are more likely to have empathy for patients with visible signs of pain (29). According to Schoofs, "living with SjD is not a journey toward healing or good health, but a downhill journey full of more and worse symptoms; not deadly, just miserable" (30). We would like more people to imagine how hard it is to live with SjD invisible symptoms.

Also, effective physician-patient communication requires good interpersonal relationships (31), as a doctor who expresses and empathises with the patient during the consultation may increase patient satisfaction (10), improve the patient's psychological health and reduce fear and anxiety (32). As our results also showed, long consultation time matters in satisfaction (33). Thus, increased medical satisfaction may motivate patients to fight their disease while being accompanied by their doctor, which may improve treatment adherence. Therefore, bridging the gap between doctors and patients will require a more inclusive environment around SjD that supports health professionals, patient associations, and public awareness campaigns.

It has been reported that the quality of the doctor-patient relationship is higher when seen by experienced physicians (34), but we did not examine the degree of experience or qualifications of physicians. And, it is reported that the receiving way for the medical treatment differs by the sex, and the female patient has less positive perception (35). However, 96.9% were female in this study, which is considered being the result of female SjD patients. Future studies may also need to focus on the medical satisfaction of male SjD patients.

This study has several limitations. First, the data are based on patients' self-reporting and may have been subject to recall bias. In addition, the consultation time perceived by the patients may have differed from the actual time. Second, the response rate of 54% may have influenced the generalisability of the results. Third, although patients were likely to have been diagnosed using the revised Ministry of Health, Labour and Welfare of Japan criteria, some patients were probably diagnosed by the American–European Consensus Group classification crite-

ria for Sjögren's Syndrome (2002) and the American College of Rheumatology classification criteria for Sjögren's Syndrome (2012) (36). It is unclear which criteria were used in every patient. In addition, our results do not necessarily reflect those of the global SjD population because enrolment was limited to patients from Japan. Finally, the questionnaire design has many limitations that need to be addressed in future studies.

## Conclusions

This study is the first to investigate medical satisfaction in patients with SjD in Japan. It highlights the substantial impact of patient satisfaction on the trajectory of disease. Inadequately treated pain and the use of artificial saliva alone markedly affected medical satisfaction in our study, and we expect that future advances in these two areas, pain and dryness, will improve satisfaction. Patients were particularly dissatisfied with their doctors' limited understanding of SjD. It is most important for doctors to better understand SjD so that they can empathise with their patients' struggles. Working together to confront the burdensome aspects of the disease**,** doctors and patients can take the first steps toward effective treatment.

## Acknowledgements

We thank the Japanese Sjögren's Association for Patients, including all of the study participants, for supporting our study.

## References

1. FOX RI: Sjögren's syndrome. *Lancet* 2005; 366(9482): 321-31. https://doi.org/10.1016/s0140-6736(05)66990-5
2. GOLDBLATT F, O'NEILL SG: Clinical aspects of autoimmune rheumatic diseases. *Lancet* 2013; 382(9894): 797-808. https://doi.org/10.1016/s0140-6736(13)61499-3
3. LONGHINO S, CHATZIS LG, DAL POZZOLO R *et al*.: Sjögren's syndrome: one year in review 2023. *Clin Exp Rheumatol* 2023; 41(12): 2343-56. https://doi.org/10.55563/clinexprheumatol/255qsx
4. PATEL R, SHAHANE A: The epidemiology of Sjogren's syndrome. *Clin Epidemiol* 2014; 6: 247-55. https://doi.org/10.2147/clep.s47399
5. SEGAL B, BOWMAN SJ, FOX PC *et al*.: Primary Sjögren's syndrome: health experiences and predictors of health quality among patients in the United States. *Health Qual Life Outcomes* 2009; 7: 46. https://doi.org/10.1186/1477-7525-7-46
6. HAMMITT KM: Sjögren's: the patients' perspective. *Clin Exp Rheumatol* 2020; 38 (Suppl. 126): S25-26.
7. JONSSON R, VOGELSANG P, VOLCHENKOV R, ESPINOSA A, WAHREN-HERLENIUS M, APPEL S: The complexity of Sjögren's syndrome: novel aspects on pathogenesis. *Immunol Lett* 2011; 141(1): 1-9. https://doi.org/10.1016/j.imlet.2011.06.007
8. VIEIRA A, GROSJEAN A, STONE L *et al*.: Sjögren's: the European patients' community perspective. *Clin Exp Rheumatol* 2021; 39 Suppl 133(6): 14-16. https://doi.org/10.55563/clinexprheumatol/8vip9k
9. DE WOLFF L, VISSINK A, VAN NIMWEGEN JF *et al*.: Patient Acceptable Symptom State (PASS) in patients with primary Sjögren's syndrome in daily clinical practice. *Clin Exp Rheumatol* 2022; 40(12): 2303-9. https://doi.org/10.55563/clinexprheumatol/mnqiy9
10. WILLIAMS S, WEINMAN J, DALE J: Doctor-patient communication and patient satisfaction: a review. *Fam Pract* 1998; 15(5): 480-92. https://doi.org/10.1093/fampra/15.5.480
11. GEORGOPOULOU S, PROTHERO L, D'CRUZ DP: Physician-patient communication in rheumatology: a systematic review. *Rheumatol Int* 2018; 38(5): 763-75. https://doi.org/10.1007/s00296-018-4016-2
12. KOLLERT F, FISHER BA: Equal rights in autoimmunity: is Sjögren's syndrome ever 'secondary'? *Rheumatology* (Oxford) 2020; 59(6): 1218-25. https://doi.org/10.1093/rheumatology/keaa009
13. ALUNNO A, GERLI R, BARTOLONI E: Comment on: Equal rights in autoimmunity: is Sjögren's syndrome ever 'secondary'? *Rheumatology* (Oxford) 2021; 60(1): e32-e33. https://doi.org/10.1093/rheumatology/keaa633
14. SUMIDA T, AZUMA N, MORIYAMA M *et al*.: Clinical practice guideline for Sjögren's syndrome 2017. *Mod Rheumatol* 2018; 28(3): 383-408. https://doi.org/10.1080/14397595.2018.1438093
15. PRICE EJ, BAER AN: How to treat Sjögren's syndrome. *Rheumatology* (Oxford) 2021; 60(6): 2574-87. https://doi.org/10.1093/rheumatology/key363
16. RAMOS-CASALS M, BRITO-ZERÓN P, BOMBARDIERI S *et al*.: EULAR recommendations for the management of Sjögren's syndrome with topical and systemic therapies. *Ann Rheum Dis* 2020; 79(1): 3-18. https://doi.org/10.1136/annrheumdis-2019-216114
17. SEROR R, RAVAUD P, MARIETTE X *et al*.: EULAR Sjögren's Syndrome Patient Reported Index (ESSPRI): development of a consensus patient index for primary Sjogren's syndrome. *Ann Rheum Dis* 2011; 70(6): 968-72. https://doi.org/10.1136/ard.2010.143743
18. HEALTH, LABOUR AND WELFARE MINISTRY: Overview of the 2020 Medical Treatment Action Survey. 2020. https://www.mhlw.go.jp/toukei/saikin/hw/jyuryo/20/dl/kekka-gaiyo.pdf.
19. DIAS LH, MIYAMOTO ST, GIOVELLI RA, DE MAGALHÃES CIM, VALIM V: Pain and fatigue are predictors of quality of life in primary Sjögren's syndrome. *Adv Rheumatol* 2021; 61(1): 28. https://doi.org/10.1186/s42358-021-00181-9
20. HACKETT KL, DAVIES K, TARN J *et al*.: Pain and depression are associated with both physical and mental fatigue independently of comorbidities and medications in primary Sjögren's syndrome. *RMD Open* 2019; 5(1): e000885. https://doi.org/10.1136/rmdopen-2018-000885
21. GAIRY K, RUARK K, SINCLAIR SM, BRANDWOOD H, NELSEN L: An innovative online qualitative study to explore the symptom experience of patients with primary Sjögren's syndrome. *Rheumatol Ther* 2020; 7(3): 601-15. https://doi.org/10.1007/s40744-020-00220-9
22. WALL GC, MAGARITY ML, JUNDT JW: Pharmacotherapy of xerostomia in primary Sjögren's syndrome. *Pharmacotherapy* 2002; 22(5): 621-29. https://doi.org/10.1592/phco.22.8.621.33218
23. MILIC V, GRUJIC M, BARISIC J *et al*.: Personality, depression and anxiety in primary Sjögren's syndrome - Association with sociodemographic factors and comorbidity. *PLoS One* 2019; 14(1): e0210466. https://doi.org/10.1371/journal.pone.0210466
24. MIGLIANICO L, CORNEC D, DEVAUCHELLE-PENSEC V *et al*.: Identifying clinical, biological, and quality of life variables associated with depression, anxiety, and fatigue in pSS and sicca syndrome patients: a prospective single-centre cohort study. *Joint Bone Spine* 2022; 89(6): 105413. https://doi.org/10.1016/j.jbspin.2022.105413
25. CUI Y, XIA L, LI L, ZHAO Q, CHEN S, GU Z: Anxiety and depression in primary Sjögren's syndrome: a cross-sectional study. *BMC Psychiatry* 2018; 18(1): 131. https://doi.org/10.1186/s12888-018-1715-x
26. NGO DYJ, THOMSON WM, NOLAN A, FERGUSON S: The lived experience of Sjögren's syndrome. *BMC Oral Health* 2016; 16: 7. https://doi.org/10.1186/s12903-016-0165-4
27. UNGER J, MATTSSON M, DRĂGOI RG *et al*.: The experiences of functioning and health of patients with primary Sjögren's syndrome: a multicenter qualitative European study. *Front Med* 2021; 8: 770422. https://doi.org/10.3389/fmed.2021.770422
28. PERELLA C, STEENACKERS M, ROBBINS B *et al*.: Patient experience of Sjögren's disease and its multifaceted impact on patients' lives. *Rheumatol Ther* 2023; 10(3): 601-14. https://doi.org/10.1007/s40744-023-00531-7
29. PAUL-SAVOIE E, BOURGAULT P, POTVIN S, GOSSELIN E, LAFRENAYE S: The impact of pain invisibility on patient-centered care and empathetic attitude in chronic pain management. *Pain Res Manag* 2018; 2018: 6375713. https://doi.org/10.1155/2018/6375713
30. SCHOOFS N: Seeing the glass half full: living with Sjögren's syndrome. *J Prof Nurs* 2001; 17(4): 194-202. https://doi.org/10.1053/jpnu.2001.24863
31. ISHIKAWA H, HASHIMOTO H, KIUCHI T: The evolving concept of "patient-centeredness" in patient-physician communication research. *Soc Sci Med* 2013; 96: 147-53. https://doi.org/10.1016/j.socscimed.2013.07.026
32. ONG LM, DE HAES JC, HOOS AM, LAMMES FB: Doctor-patient communication: a review

of the literature. *Soc Sci Med* 1995; 40(7): 903-18. https://doi.org/10.1016/0277-9536(94)00155-m

33. MIYAKOSHI N, KUDO D, MATSUYAMA Y *et al*.: Impact of consultation length on satisfaction in patients with chronic low back pain: a nationwide multicenter study in Japan. *Spine Surg Relat Res* 2020; 4(3): 208-15.
34. PASCUAL-RAMOS V, CONTRERAS-YÁÑEZ I, ORTIZ-HARO AB, MOLEWIJK AC, OBRADOR GT, AGAZZI E: Factors associated with the quality of the patient-doctor relationship: a cross-sectional study of ambulatory mexican patients with rheumatic diseases. *J Clin Rheumatol* 2022; 28(4): 183-9. https://doi.org/10.1097/rhu.0000000000001816
35. ELLIOTT MN, LEHRMAN WG, BECKETT MK, GOLDSTEIN E, HAMBARSOOMIAN K, GIORDANO LA: Gender differences in patients' perceptions of inpatient care. *Health Serv Res* 2012; 47(4): 1482-501. https://doi.org/10.1111/j.1475-6773.2012.01389.x
36. TSUBOI H, HAGIWARA S, ASASHIMA H *et al*.: Validation of different sets of criteria for the diagnosis of Sjögren's syndrome in Japanese patients. *Mod Rheumatol* 2013; 23(2): 219-25. https://doi.org/10.1007/s10165-012-0812-9