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Real-World Insights into the Treatment Satisfaction and Unmet Needs of Sjögren's Disease: A Patient-Centered Analysis

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Background:

Sjögren's is a chronic autoimmune disease affecting up to 1% of the global population, predominantly women (1-2). It is characterized by dryness symptoms (e.g., dry eyes, mouth and skin) alongside extra-glandular manifestations such as fatigue, joint pain, neuropathies and organ involvement, significantly impacting health and quality of life (HRQoL) (3). Current Sjögren's management includes symptomatic and systemic therapies. Symptomatic treatment is often insufficient in controlling symptoms (4). Available systemic treatments do not address the underlying pathology and have not been proven to be effective in Sjögren's (5). Despite its prevalence, research of Sjögren's patient perspectives is limited (6). This study provides real-world insights into treatment satisfaction with existing therapies and unmet needs, to guide patient-centered care and inform future treatment strategies.

Objectives:

The aim of this study is to better understand the burden, unmet needs and treatment satisfaction among adults with Sjögren's. This abstract covers the objectives of assessing treatment satisfaction and unmet needs of Sjögren's.

Methods:

A quantitative, cross-sectional online survey of adults (≥18 years) diagnosed with Sjögren's, excluding those with concomitant systemic lupus erythematosus, rheumatoid arthritis, and/or systemic sclerosis. Data were collected between December 2023 and September 2024 across eight countries: USA, China, Japan, France, Germany, Italy, Spain and the UK. Participants were recruited via treating physicians or patient associations, ensuring diversity in disease severity and clinical presentation. Survey variables included demographics, symptom burden, emotional well-being, work and financial impacts, and treatment expectations. All analyses were descriptive.

Results:

A total of n=1,155 adults completed the survey (88% female, median age 54 years [IQR: 45.0, 65.0]), with a median diagnosis age of 47 years (IQR: 40.0, 56.0). Concomitant conditions affecting joints (41%), muscles (22%), bowels (19%), and lungs (16%) were commonly reported. Self-reported general health was rated as 'poor' or 'fair' by 65%.

Regarding treatment, 78% (n=896) of participants reported using prescribed therapies for managing Sjögren's symptoms. The most common therapies ever received included eye drops (55%), corticosteroids (51%), non-biological disease-modifying antirheumatic drugs (DMARDs, 46%), NSAIDs (41%), and secretagogues (40%). Of those receiving prescription therapy, 77% either expressed dissatisfaction with their current prescription regimen and/or believed better disease control could be achieved.

Despite existing treatments, 94% (n=1080) weren't fully satisfied with the overall range of therapies available for managing Sjögren's symptoms, with dissatisfaction rates higher in the USA and lower in China. Among those not fully satisfied, 53% felt current treatments only addressed symptoms and not the underlying cause or

systemic nature of Sjögren's disease. While 39% reported some symptom relief, they felt current treatments were insufficient and needed significant improvement.

When asked about their treatment goals, the most common responses were to prevent worsening of the disease (49%, n=571), improve overall symptoms (46%, n=537), improve quality of life (36%, n=416), and reduce unseen organ damage (25%, n=292). Of note, patients perceive their healthcare providers (HCPs) underappreciate the importance of reducing fatigue, reducing tiredness and improving sleep quality (**Figure 1**). A significant portion of patients (55%, n=637) expressed a desire for an alternative treatment to their current Sjögren's medication. However, 42% (n=482) disagreed that they had exhausted all available treatment options to date.

Conclusion:

This real-world study highlights the significant gaps in treatment satisfaction and the unmet needs of adults with Sjögren's. Despite ongoing symptom management, 94% of participants weren't fully satisfied with the overall range of therapies available, pointing to an urgent need for more effective treatments. Additionally, nearly as many participants prioritized improving overall symptoms as those emphasizing the prevention of disease worsening, reflecting the multiple therapeutic priorities of this population. These insights emphasize the need for personalized, patient-centered care, and the development of therapies that not only better alleviate symptoms, but which also treat the underlying disease.

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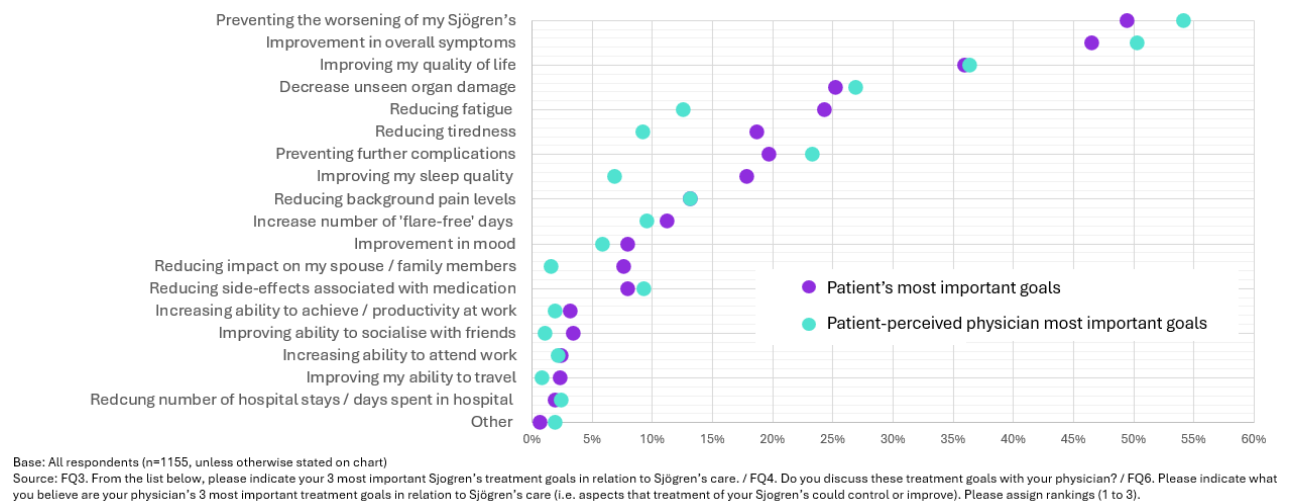


Figure 1. Most important treatment goals for Sjögren's therapy (% ranking in top 3)

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