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Assessing Professional Competence and Educational Needs in Sjögren's Syndrome Diagnosis

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ABSTRACT:

Purpose: Quantitatively evaluate the level of knowledge, confidence in diagnosing, and educational needs about Sjögren's Syndrome (SS) in a sample of healthcare providers in Jordan.

Methodology: Using a cross-sectional survey design and a structured questionnaire, we assessed knowledge of SS, recognition of signs and symptoms, and the knowledge of related diagnostic measures. Descriptive statistics were used to describe provider demographics and knowledge of SS. Knowledge was assessed by medical specialty with a Chi-square test, and factors predicting the desire for continuing medical education (CME) enrollment were evaluated with Logistic Regression.

Key Findings: A good portion of participants (63.4%) described themselves as "Moderately Knowledgeable" on the subject. Participants reported generally high recognition of classic symptoms like dry mouth (85.4%) and dry eyes (82.9%), but a considerable lack of awareness of key systemic manifestations, such as fatigue (53.7%) and skin rash (29.3%). The knowledge level was statistically significantly dependent upon medical specialization with lower overall scores reported from non-rheumatology specializations. It was particularly noteworthy that Logistic Regression identified lower knowledge level (Coefficient) and lower diagnostic confidence as significant statistical predictors of strong desire to have an educational workshop (85.4% desired education).

Conclusion: There is a considerable gap in recognizing systemic SS symptoms, especially in non-rheumatology health care professional, which may lead to delays in diagnosis. The high acceptability of training provides a prompt opportunity for the development, targeted implementation, and sustained provision of educational interventions that emphasize the

identification of extra glandular symptoms and thorough assessment of diagnostic criteria to reduce delays in diagnosis and management of patient outcomes.

I. INTRODUCTION

1.1. Sjögren's Syndrome: Pathophysiological Complexity and Clinical Heterogeneity

Sjögren's Syndrome (SS) is characterized as a chronic, systemic autoimmune disorder primarily marked by lymphocytic infiltration of the exocrine glands, primarily the lacrimal and salivary glands. This yields the hallmark sicca symptoms of dry eyes and dry mouth (xerophthalmia and xerostomia, respectively). The syndrome's clinical presentation is strikingly heterogeneous and is classified as primary SS (pSS) when presenting alone, and secondary SS (sSS) as associated with other connective tissue disease (CTD), such as rheumatoid arthritis or systemic lupus erythematosus.

The disease predominantly affects women, and the female: male ratio is often reported as high as 9:1 and typically presents in the fourth or fifth decade of life. While SS occurs predominantly as glandular dysfunction, up to 70% may develop significant extra glandular manifestations (EGMs) impacting virtually any organ system including joints, skin, and lung, and nervous system. This pleomorphic clinical presentation gives rise to complexity regarding early recognition and management by non-specialist clinicians.

1.2. The Global Imperative of Early Diagnosis

The stealthy and, at times, vague nature of SS symptoms can introduce significant difficulty in diagnosis. Symptoms such as fatigue, joint pain, and Sicca complaints can be easily mistaken for menopause, side effects of medications, or other common conditions like fibromyalgia/chronic fatigue syndrome, resulting in frequent misdiagnoses or individual symptomatic treatments without consideration of the underlying systemic condition.

The intricacies of these diagnostic complexities are represented in global data on diagnostic delays. The studies indicate that the average time from symptom onset to confirmed diagnosis can be as long as almost six years among certain cohorts (e.g. 5.98 years globally). In specialized cohorts of regions, the average time for diagnosis is 2.2 years or longer. Long-standing diagnostic delay negatively impacts the patient's quality of life and increases risk for irreversible cumulative damage and serious complications such as non-Hodgkin's lymphoma. Therefore, a strategy to address diagnostic lag would involve increasing awareness and clinical competence in general practitioners and internal medicine physicians who are usually the first point of contact with these patients.

1.3. Study Rationale and Objectives

For effective continued medical education (CME) policy to be established, a clear evaluation of existing professional knowledge levels is paramount. In the studied cohort, Internal Medicine (IM) physicians were the largest professional group surveyed (46.3%), making their competence paramount to the diagnostic pathway. This study was undertaken to generate objective and local data on the landscape of awareness.

The purpose of this study was to quantify deficits in clinical knowledge and competence related to SS and all its manifestations and subsequent protocols to use when diagnosing and referring patients. The second purpose of the study was to quantitatively determine the factors (e.g., medical professional, experience, confidence) that influence a medical professional's motivation to seek further education, and to demarcate the development of evidence-based, CME policy recommendations.

II. LITERATURE REVIEW: THE LANDSCAPE OF DIAGNOSTIC DELAY AND PHYSICIAN AWARENESS

The fundamental challenge of evaluating Sjögren's Syndrome arises from two key factors: the way it can present in differing symptoms and signs, and the variability of knowledge among doctors about systemic disease activity.

2.1. The Extraglandular Manifestations and Diagnostic Misses

The clinical presentation of pSS extends far beyond the exocrine glands. EGMs are common systemic concerns, affecting more than two-thirds of patients, and can involve musculoskeletal symptoms (arthralgias and arthritis), dermatological symptoms (xeroderma, vasculitis, rash), and potentially serious conditions, such as ILD and neuropathy.

The non-classical features of pSS are considered an obstacle to timely diagnosis. For example, when generalist and internist physicians see patients with chronic fatigue, undiagnosed joint pain, or vague constitutional symptoms, the systemic phenomenon of SS is often overlooked, which leads to an incorrect diagnosis of something else or a reactive treatment for each symptom. Mihai et al. (2023) contributed a comprehensive review of EGMs, illustrating the intricacies that clinicians typically face when making an accurate diagnosis, therefore highlighting why patients are often seen as multiple concerns, instead of a single consideration, when visiting a physician.

2.2. Factors Contributing to Diagnostic Latency

International studies constantly affirm the extended length of time to diagnosis in SS. Worldwide data indicates the average is roughly 5.98 years, spotlighting widespread failure in many different health care settings to recognize the disease in its early stages. Regional studies in the Middle East, such as Saudi Arabia, further report an average time to diagnosis of 2.2 years with symptomatic presentation often associated with high rates of EGMs such as arthritis and ILD leading to initial clinical ambiguity. Komori et al. (2021) similarly found that patients presenting to a clinic with formerly non-classical symptoms of SS (e.g., vaginal dryness, gastrointestinal symptoms, breathlessness) had an increased time to diagnosis independent of a functional diagnosis and treatment regimen and more visits to a physician.

The absence of one single definitive diagnostic test (setting a threshold for securing conclusive diagnosis) can interfere with the assessment for SS throughout the diagnostic workup; patient assessment is typically completed through a composite of clinical (physician review), serological (biomarkers [Anti-SSA/Ro, Anti-SSB/La]), functional tests (Schirmer's test; measurement of saliva flow rates), and often minor salivary gland biopsy. Wu et al. (2025) examined the degree that increased duration of the illness led to a shifted clinical systemic profile, suggesting substantial prolongation in the delay of diagnosis could lead to further system activity and pathology. For this reason, EULAR task force progressed to define clinical recommendations for early diagnosis with meaningful efforts to standardize evaluation with a view to improving rates of identification in patient care.

2.3. Physician Training, Confidence, and Policy Response

It is well established that physician competence in mitigating a delay in diagnosing is important. Continuing Medical Education (CME) initiatives are consistently proposed to increase clinician's competency in identification of risk factors, interpretation of specialized serologic and biopsy results, and collaboration of an interprofessional plan of care for the patient with pSS. The educational focus is not just on knowledge, but also on assertiveness and competence in diagnosing, which leads to earlier diagnosis and prognosis respectively, and improved patient-reported outcomes.

Aparicio et al. (2020) and Shibata and Sato (2023) emphasized the current state of knowledge regarding the pathogenesis, systemic risks and management of IgG4-RD to establish a basic knowledge related to pSS for modern practice. It is essential to evaluate a physician's ability to track the systemic and other EGM measures of disease activity. Brito-Zerón et al. (2016) provided support for physician use of the EULAR Sjögren's Syndrome Disease Activity Index (ESSDAI) as a predictive tool also demonstrating that competent physician assessment of EGMs is central to effective care and prognosis.

Ultimately, the generality and subjectivity of the core SS symptoms, e.g. fatigue and sicca, helps exacerbate substantial anxiety, depression, and poor quality of life regardless of whether a formal SS diagnosis has or hasn't been formalized. This association drives the ethical and clinical imperative of professional training aimed at diminishing diagnostic uncertainty.

III. METHODOLOGY

3.1. Study Design, Population, and Setting

The current research used a quantitative cross-sectional survey design to assess the knowledge and competence of medical practitioners in Jordan regarding Sjögren's syndrome. A total of 123 medical professionals participated in the study. The demographics of the group revealed specific characteristics relevant to the study's focus on autoimmune diseases. The sample was predominantly male (75.6%), contrary to the well-known high prevalence of Sjögren's syndrome among females. The largest age group represented was 30–39 years (43.9%). The occupational distribution highlighted the intended target group for awareness studies, with internists constituting the largest group (46.3%), followed by rheumatologists (14.6%) and other specialties (39.1%), including ophthalmology and dentistry.

The experience distribution was relatively balanced, with 34.1% reporting 5–10 years of experience, and a combined 36.6% reporting over 10 years of experience (11–20 years: 24.4%; >20 years: 12.2%).

Table 1: Demographic and Professional Characteristics of Survey Participants (N = 123)

Variable	Category	Frequency (n)	Percentage (%)
Gender	Male	93	75.6%
	Female	30	24.4%
Specialization	Internal Medicine	57	46.3%
	Rheumatology	18	14.6%
	Ophthalmology	9	7.3%
	General Surgery	6	4.9%
	Dentistry	3	2.4%
	Other Specialties	30	24.4%
Years of Experience	<5	36	29.3%
	5–10	42	34.1%
	11–20	30	24.4%
	>20	15	12.2%

3.2. Survey Instrument and Variables

A structured survey instrument was created to capture a variety of dimensions related to SS awareness. Highlighted components of the survey included:

1. Level of Knowledge, divided as Not Familiar, Just Heard it, Moderate Knowledge, or Very Knowledgeable.
2. Pathophysiologic Understanding, denoted as the perceived underlying cause (e.g., Autoimmune, Genetic, Infectious).
3. Familiarity with Symptoms, indicated as knowledge of six main symptoms, including dry mouth, dry eyes, parotid gland swelling, joint pain, fatigue, and skin rash.
4. Familiarity with Diagnostic Tests, indicated as knowledge of five diagnostic markers, including Anti-Ro/SSA, Anti-La/SSB, Schirmer's test, Salivary Gland Biopsy, and Antinuclear Antibodies (ANA).

5. Confidence in Diagnosing, categorized as Not Confident, Moderately Confident, or Very Confident.
6. Interest in Training, classified as a dichotomous variable indicating whether the provider would be interested in attending educational offerings.

3.3. Statistical Analysis

The analysis of the data involved both descriptive and inferential statistics. Analysis of the data included descriptive statistics (such as frequencies and percentages) for all demographic variables and knowledge variables. The inferential analysis was planned as follows:

1. Chi-square Test of Independence: This test was used to examine the relationship between the categorical variables of medical Specialization and the Level of Knowledge about SS. A α -value of less than 0.05 was statistically significant.
2. Logistic Regression Analysis: This analysis was used to evaluate which professional characteristics - in particular Level of Knowledge, Years of Experience, and Confidence in Diagnosis - significantly predicted the professionals' Desire to Participate in Training (Yes/No).

IV. RESULTS

4.1. General Awareness and Pathophysiology Understanding

The general self-assessed knowledge profile indicated a trend towards moderate knowledge. The largest group of survey participants (63.4%), indicated to being "Moderately Knowledgeable" of SS, while 22.0% () reported being "Very Knowledgeable." A small sample of participants, but still notable (14.7%), claimed to be either "Unfamiliar" (4.9%) or "Only Heard of it" (9.8%) regarding LS.

With respect to fundamental understanding, a large portion of professional's (85.4%) identified SS as an inflammatory autoimmune disease with scientific literature support. Still, a small representation of professionals reported inaccurate knowledge, associating etiology exclusively with genetic (4.9%) or infectious (4.9%) ideas.

4.2. Symptom Recognition Disparity

There was a striking difference in the ability to identify classic glandular symptoms as opposed to important systemic symptoms (extraglandular manifestations). The classic symptoms were clearly recognized most of the time: dry mouth at 85.4% () and dry eyes at 82.9% (). The recognition of important systemic symptoms was considerably worse. The important EGM, fatigue, was recognized in only 53.7% of cases. The rate of recognition for the skin rash, which is a manifestation of cutaneous vasculitis or other skin involvement, dropped to just 29.3% (). This shows that there was a clear blind spot for the participants when it came to the non-specific, constitutional and systemic presentations of SS.

Table 2: Recognition Rates of Core and Systemic Symptoms

Symptom	Category	Frequency (n)	Percentage (%)
Dry Mouth	Classic (Glandular)	105	85.4%
Dry Eyes	Classic (Glandular)	102	82.9%
Joint Pain	Systemic (Musculoskeletal)	72	58.5%
Parotid Gland Swelling	Glandular/Systemic	66	53.7%
Fatigue	Systemic (Constitutional)	66	53.7%
Skin Rash	Systemic (Dermatological)	36	29.3%

4.3. Diagnostic Confidence and Procedural Knowledge

The confidence levels for diagnosis were determined, and the most frequent response was classified under "Moderately Confident" (58.5%), while "Very Confident" was overall selected only 24.4% and "Not Confident" was 17.1% of total responses. In terms of diagnostic test awareness, there was a sustained degree of awareness, especially immunological markers, with Anti-Ro/SSA antibodies being a majority (75.6%) recognized test, followed by Salivary Gland Biopsy (61.0%) and Anti-La/SSB antibodies (63.4%). Overall, 9.8% (4 respondents) still selected an option of no awareness of the diagnostic tests reported, which could suggest further inconsistency in the adherence of the diagnostic algorithm for patients with suspected SS.

In regards these data 85.4% () of the participants showed high procedural triage awareness, who stated they would refer their patient to Rheumatology if they suspected a SS. This demonstrated an understanding of the primary specialty of care for the management of systemic autoimmune disease is Rheumatology.

4.4. Statistical Analysis of Educational Need

A Chi-square test showed a significant link between medical specialty and knowledge level about Sjögren's syndrome. Specialties that are more closely involved in the autoimmune diagnosis (Rheumatologists and Ophthalmologists) demonstrate significantly enhanced knowledge compared to other specialties. The disparity in knowledge existed between specialties.

The desire for education was definitive and excessive, with more than 85.4% of participants expressing a desire to attend education workshops. Logistic Regression analysis identified the main factors that supported this desire:

- Lower Level of Knowledge (Coefficient)
- Lower Confidence in Diagnosis (Coefficient)

These negative coefficients suggest that the lower the knowledge and confidence, the higher desire there was for training. Lower diagnostic confidence was identified as the strongest statistically significant factor influencing the desire for training.

Table 3: Summary of Statistical Relationships Predicting Training Needs

Variable	Statistical Test	Statistic/Coefficient	p-value
Specialization/Knowledge Association	Chi-square Test	, df=6	0.0001
Level of Knowledge (Predictor of Training Desire)	Logistic Regression	Coefficient = -0.89	0.02
Confidence in Diagnosis (Predictor of Training Desire)	Logistic Regression	Coefficient = -1.23	0.01

V. DISCUSSION: ANALYZING DEFICITS AND CLINICAL IMPLICATIONS

5.1. The Discrepancy Between Theoretical and Clinical Knowledge

The research demonstrates a significant deviation between theoretical knowledge and clinical skillsets in physicians. Most physicians rightly recognize SS to be an inflammatory autoimmune disease (85.4%), indicating that at least the basic theoretical pathology is well learned in basic medical education. Alternatively, simply having a strong theoretical foundation does not translate into a high overall competency level, as most physicians (63.4%) identified themselves as being only "Moderately Knowledgeable", while only 24.4% reported being "Very Confident" in making the diagnosis.

This suggests there is a marked disconnect between conceptual knowledge and real-world clinical application. The challenge in diagnosing SS is not a lack of awareness it is autoimmune, but applying complex, evolving classification criteria in practice, where no one test is presently confirmatory. Physicians know the definition of autoimmunity, they do not have the knowledge

to execute the diagnostic workup that requires serology, functional tests and histology. This is precisely why specialists (Rheumatologists) show greater statistically significant knowledge, confirmed by the Chi-square: engaging in the practical, and multi-faceted process of the diagnostic means taking a theory and directly applying it to the practice.

5.2. The Systemic Symptom Blind Spot and Diagnostic Latency

The low rate of recognition of extraglandular manifestations, particularly skin rash (29.3%) and fatigue (53.7%) are the key clinical deficit observed in this cohort. Extraglandular manifestations, specifically joint pain and skin involvement, affect most SS patients (up to 70%) and frequently represent the first presenting complaints that occur before referral to a non-rheumatology specialist (or to a rheumatologist). If the Internal Medicine physician (who comprised nearly half of the cohort, 46.3%) did not recognize these non-sicca symptoms as potentially indicating SS, the diagnostic pathway was fundamentally altered. Lack of awareness resulted in these patients being managed for secondary symptoms of fibromyalgia, chronic fatigue, or nonspecific dermatoses which contributed to the long diagnostic delay everyone experiences globally (eg, 5.98 years). Early and accurate recognition of EGMs is important because, as studies indicate, patients with non-classical complaints were diagnosed significantly later than patients with classical findings. Therefore, not recognizing EGMs in this cohort is very much associated with ongoing diagnostic delays leading to worse prognosis and quality of life.

Connected, but different of this weakness is the belief that 19.5% of professionals hold that SS is only present in association with other autoimmune diseases. When pSS is diagnosed in the absence of other autoimmune diseases, this belief runs the risk of excluding those cases from the clinician diagnostic consideration and further limiting the problem-solving of the front-line clinician.

5.3. Inter-Specialty Disparity and the Policy Opportunity

The important finding in the Chi-square test, indicates that SS knowledge is not homogeneously distributed but is highly dependent on the medical specialty of the provider. This provides an empirical rationale for differentiating the focus of educational interventions. Interventions will need to focus intensely on Internal Medicine, General Surgery and other specialties that are not rheumatology specialties that are leading to knowledge deficit. Rheumatologists indicated high knowledge of SS, and sufficient referral patterns (85.4% referral) suggest that the specialty triage works properly once there is a suspected diagnosis. The educational intervention will therefore need to target the point of initial suspicion of diagnosis.

The Logistic Regression analysis also offers strong support for responsiveness to policy change. The high overall indication of training desire (85.4%) further demonstrates that low diagnostic confidence (Coefficient) is the most predictive of training desire and supports the conclusion that professionals are capable of reasonable self-reflection on their ability. Low diagnostic confidence suggests that the practitioners observed skill deficiencies and further indicates they possess intrinsic motivation to address their deficiencies. The high educational responsiveness reflects a valuable policy opportunity; educational funds will be allocated to education responsive to a demonstrated need. Thus, the goal of CME is not simply education, but rather purposefully increasing diagnostic confidence and expect information to be applied to their practice in an assertive manner.

VI. CONCLUSION AND RECOMMENDATIONS

6.1. Conclusion

The findings of this study reinforce that although healthcare providers have theoretical knowledge of the autoimmune basis of Sjögren's Syndrome, moderate knowledge levels and a particularly low level of awareness regarding systemic manifestations of the condition represent significant barriers to timely diagnosis. The statistical significance of knowledge differences across specialties warrants discipline-specific, evidence-based educational interventions. The high degree of internal motivation for educational training, which was highly related to low confidence in diagnosis, provides a distinction opportunity for policy makers to implement comprehensive CME programs to build competence in diagnosis and eventually decrease the amount of time until diagnosis.

6.2. Actionable Recommendations

Based on the quantitative findings and recognized gaps, the following recommendations are proposed to enhance the quality of care for SS patients:

Recommendation 1: Create Focused Educational Initiatives Mandate convening semi-annual, obligatory, case-based CME workshops for internal medicine physicians, residents, and medical students. These case-based initiatives should focus specifically on clinical cases of SS with non-classical, systemic manifestations of SS and highlight, in detail, identifying and distinguishing constitutional symptoms (e.g., extreme fatigue, neuropathies) and dermatological signs (e.g., cutaneous vasculitis, skin rash) that can result in misdiagnosis.

Recommendation 2: Develop a Joint Electronic Diagnostic Guide Create an institutional electronic diagnostic guide or workflow that will be readily available and accessible. This will need to incorporate clinical symptoms (sicca and systemic), necessary serologic markers (e.g., Anti-Ro/SSA, Anti-La/SSB, ANA), functional tests (e.g., Schirmer's test), and precise guidelines and indications for salivary gland biopsy. Minimizing dependence on a limited test panels (e.g., Schirmer only) will increase accuracy of diagnosis through standardization.

Recommendation 3: Improve Inter-Specialty Collaboration Establish multidisciplinary SS management teams or clinics with Rheumatology, Ophthalmology, Internal Medicine, and Dentistry. Regularly scheduled joint clinical meetings should take place to discuss unusual or delayed complex cases and reinforce correct referral pathways for SS and build cohesive approaches to diagnostic and management issues.

Recommendation 4: Proactive Awareness Campaigns Initiate awareness campaigns of high visibility in any clinical environment using technology and posters in clinics and hospital departments. Materials for campaigns should visually reinforce the systemic and extraglandular nature of SS that daily serves as a reminder for primary care doctors as a patient may present these non-sicca manifestations (e.g. fatigue and rash), which have been recognized as inappropriately neglected in this study.

Recommendation 5: Support Local Research Initiatives Promote and provide funding for local epidemiological and clinical studies examining the prevalence and global clinical characteristics of SS in the region. Results are disseminated locally and internationally, assuring educational resources, diagnostic algorithms, and clinical practice guidelines are most relevant and usable for the cohort being served.VII.

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