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Impact of Patient and Physician Alignment on Sjögren's Disease Severity: a Real-World Survey on Patients' Clinical Outcomes and Health-Related Quality of Life

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KEY FINDINGS & CONCLUSIONS

- Proportions of aligned/misaligned patients vary significantly by country. Among those who are misaligned, more patients have a worse perception of their Sjogren's disease severity than their physician's perceived severity and this is consistent across countries. This may suggest differing perceptions of disease severity between patients and physicians.
- The impact of dryness, pain, and fatigue may be underestimated by physicians when assessing patients' disease severity, with more misalignment seen where the proxy ClinESSDAI score indicated worse severity.
- A more holistic approach is needed to assess the impact of SjD on quality of life. More disease-specific quality of life measures are needed to better assess the impact of SjD on patients, alongside future research to fully assess the impact of systemic activity on the patient experience.

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INTRODUCTION

- Sjögren's disease (SjD) imposes a significant burden on affected patients and currently there are no licensed treatments available that target the underlying aetiology.(1) The Clinical EULAR Sjögren's Syndrome Disease Activity Index (ClinESSDAI) is a standard measurement for systemic disease activity. However, the impact of patient and physician misalignment on patient outcomes remains poorly understood.
- We aimed to examine the degree of alignment between patient- and physician- perceived disease severity and alignment between patient- and physician-perceived disease severity with proxy(2) ClinESSDAI scores.

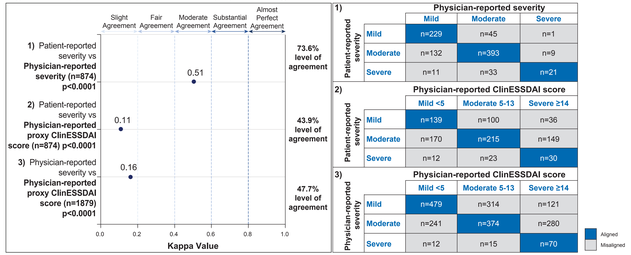
METHODS

- Data were drawn from the Adelphi Real World Sjögren's Disease Specific Programme™, a cross-sectional survey of rheumatologists and patients with SjD across France, Germany, Italy, Spain, and the United States from June – October 2018. Physicians reported perceived disease severity (mild, moderate, severe) and characteristics or signs of systemic involvement to allow a proxy ClinESSDAI score to be calculated for consulting SjD patients with systemic involvement.
- Patients self-reported their perceived disease severity (mild, moderate, severe), dryness, fatigue, and pain (scored 1–10, 10 = worst imaginable).
- Patients were grouped into 'mild <5', 'moderate 5-13', or 'severe ≥14' based on published cut off values(3) for the physician-provided proxy ClinESSDAI scores.
- Kappa analysis (1 = perfect agreement, 0 = agreement of chance, <0 = agreement less than chance) was used to assess the degree of alignment between:
  1. Patient- and physician-reported perceived disease severity
  2. Patient-reported perceived disease severity and proxy ClinESSDAI score
  3. Physician-reported perceived disease severity and proxy ClinESSDAI score
- ANOVA, Fisher's exact and Chi2 tests compared characteristics between alignment groups; p<0.05 indicated statistical significance.

RESULTS

- Rheumatologists (n=319) reported data on 1,879 patients, of whom 888 self-reported data. Mean (SD) age was 53.2 (12.2) years, and 89% were female.
  - Patient- and physician-perceived severity showed a 73.6% (n=643) level of agreement (κ=0.51, moderate agreement)
  - Patient-reported severity and proxy ClinESSDAI score showed a 43.9% (n=384) level of agreement (κ=0.11, slight agreement)
  - Physician-reported perceived severity and ClinESSDAI score showed a 47.7% (n=923) level of agreement (κ=0.16, slight agreement; all p<0.0001; **Figure 1**)
- Patient characteristics are summarised in **Table 1** for the three kappa alignments, split by aligned and misaligned patient subgroups.
- Proportions of aligned/misaligned patients vary significantly when analysed by geographical region for all kappa alignment groups (all p<0.05; **Table 1**).
- Patients reporting greater perceived severity than their physician and ClinESSDAI score, misaligned groups 2 and 4, had higher patient-reported dryness, pain and fatigue scores (all p<0.05; **Figure 2**).

Figure 1. Kappa analysis of patient and physician alignment



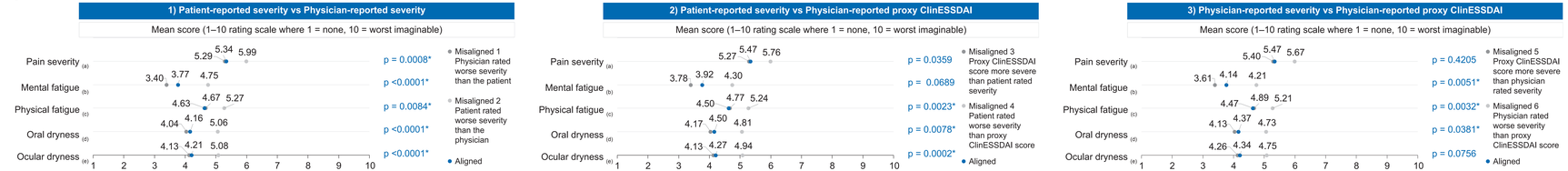
Abbreviations: clinical EULAR Sjögren's syndrome disease activity index (clinESSDAI); p<0.05 indicated statistical significance. A kappa value of 1 indicates perfect agreement and a value of 0 indicates a level of agreement equivalent to chance.

Table 1. Patient demographics and clinical characteristics for kappa alignment groups

	1) Patient-reported severity vs physician-reported severity				2) Patient-reported severity vs physician-reported proxy ClinESSDAI				3) Physician-reported severity vs physician-reported proxy ClinESSDAI			
Alignment groups	**Misaligned 1 Physician rated worse severity than the patient (n=55)**	**Misaligned 2 Patient rated worse severity than the physician (n=176)**	**Aligned (n=643)**	**p-value**	**Misaligned 3 Proxy ClinESSDAI score more severe than patient rated severity (n=285)**	**Misaligned 4 Patient rated worse severity than proxy ClinESSDAI score (n=205)**	**Aligned (n=384)**	**p-value**	**Misaligned 5 Proxy ClinESSDAI score more severe than physician rated severity (n=715)**	**Misaligned 6 Physician rated worse severity than proxy ClinESSDAI score (n=268)**	**Aligned (n=896)**	**p-value**
Patient age, mean (SD)	58.27 (13.41)	53.77 (11.70)	52.68 (11.29)	0.0021* (AN)	53.53 (11.33)	54.32 (11.39)	52.47 (11.84)	0.1619 (AN)	53.01 (11.85)	54.34 (11.96)	53.10 (12.51)	0.2804 (AN)
Patient gender, n (%)												
Female	52 (94.5)	156 (88.6)	571 (88.8)	0.4592 (FE)	253 (88.8)	184 (89.8)	342 (89.1)	0.9407 (FE)	629 (88.0)	242 (90.3)	806 (90.0)	0.3832 (FE)
Patient ethnicity US, n (%)												
White	19 (73.1)	48 (77.4)	186 (89.4)	0.0189 (FE)	90 (83.3)	54 (87.1)	109 (86.5)	0.2321 (FE)	151 (76.6)	60 (85.7)	197 (80.7)	0.9128 (FE)
Patient ethnicity Europe, n (%)												
White	27 (93.1)	110 (96.5)	419 (96.3)	0.4451 (FE)	172 (97.2)	139 (97.2)	245 (95.0)	0.7483 (FE)	485 (93.6)	188 (94.9)	597 (91.6)	0.1742 (FE)
Geographical region, n (% per row)												
France (n=95)	4 (4.2)	21 (22.1)	70 (73.7)		25 (26.3)	40 (42.1)	30 (31.6)		100 (34.8)	51 (17.8)	136 (47.4)	
Germany (n=225)	16 (7.1)	26 (11.6)	183 (81.3)		81 (36.0)	34 (15.1)	110 (48.9)		140 (38.9)	41 (11.4)	179 (49.7)	
Italy (n=79)	4 (5.1)	28 (35.4)	47 (59.5)	0.0002* (CH)	42 (53.2)	13 (16.5)	24 (30.4)	<0.0001* (CH)	168 (46.7)	42 (11.7)	150 (41.7)	0.0007* (CH)
Spain (n=179)	5 (2.8)	39 (21.8)	135 (75.4)		29 (16.2)	56 (31.3)	94 (52.5)		110 (30.5)	64 (17.7)	187 (51.8)	
US (n=296)	26 (8.8)	62 (20.9)	208 (70.3)		108 (36.5)	62 (20.9)	126 (42.6)		197 (38.6)	70 (13.7)	244 (47.7)	
Time since diagnosis (years), mean (SD)	5.59 (6.08) (n=41)	4.97 (5.18) (n=136)	4.41 (5.11) (n=484)	0.2438 (AN)	5.00 (5.68) (n=229)	4.82 (4.63) (n=156)	4.14 (5.05) (n=276)	0.1516 (AN)	4.73 (5.30) (n=594)	4.53 (4.73) (n=201)	4.29 (5.03) (n=692)	0.3081 (AN)

Abbreviations: Standard deviation (SD), United States (US), Europe: France, Germany, Italy, Spain, clinical EULAR Sjögren's syndrome disease activity index (clinESSDAI), EULAR Sjögren's syndrome patient-reported index (ESSPRI), ANOVA (AN), Fisher's exact test (FE), Chi2 test (CH); p<0.05 indicated statistical significance (*).

Figure 2. Patient reported symptom burden for aligned and misaligned groups



Abbreviations: clinical EULAR Sjögren's syndrome disease activity index (clinESSDAI). ANOVA statistical analysis compared characteristics between alignment groups; p<0.05 indicated statistical significance (*). Bases (a)[1] n=42, [2] n=149, aligned n=534; (b)[1] n=53, [2] n=175, aligned n=629; (c)[1] n=51, [2] n=173, aligned n=625; (d)[1] n=54, [2] n=174, aligned n=630; (e)[1] n=54, [2] n=175, aligned n=633. (a)[3] n=253, [4] n=168, aligned n=304; (b)[3] n=276, [4] n=203, aligned n=378; (c)[3] n=275, [4] n=200, aligned n=374; (d)[3] n=279, [4] n=201, aligned n=378; (e)[3] n=279, [4] n=203, aligned n=380. (a)[5] n=307, [6] n=127, aligned n=297; (b)[5] n=331, [6] n=150, aligned n=383; (c)[5] n=329, [6] n=148, aligned n=379; (d)[5] n=333, [6] n=150, aligned n=381; (e)[5] n=334, [6] n=151, aligned n=384.

References

1. Ramos-Casals et al., *Ann. Rheum.* Dis. 2020: 79, 1: 3-18; **2.** Proxy ClinESSDAI scores were calculated by capturing the components of the ClinESSDAI, using this scoring guide: Seror, Raphaële et al. *RMD open.* 2015. vol. 1,1 e000022; **3.** de Wolff, Liseth et al. *Clin. Exp. Rheumatol.* 2020. vol. 38 Suppl 126,4: 283-290.

Limitations

The DSP is not based on a true random sample of rheumatologists or patients and is reflective of the consulting patient population. While minimal inclusion criteria governed selection, participation was influenced by rheumatologist and patient willingness to complete the survey. Kappa can be affected by data with higher frequency. When a category has higher prevalence than the others, k may be low even if there is substantial agreement. Kappa is affected by base sizes, with higher levels of variation when the overall base size is small. Proxy ClinESSDAI scores were categorised into mild, moderate or severe using published cut off values.(3) Patient and physician reported disease severity was categorised based on patient or physician perception of the patient's current disease severity, and open to their own interpretation of the terms 'mild', 'moderate', and 'severe'. Perceived severity, therefore, may not align with disease activity, as measured by the ClinESSDAI.

Disclosures

Data collection was undertaken by Adelphi Real World as part of the Adelphi Sjögren's Disease Specific Programme (DSP), of which Novartis was one of multiple subscribers. The Sjögren's DSP dataset is an Adelphi-owned product; Novartis did not influence the original survey through either contribution to the design of questionnaires or data collection. Publication of survey results was not contingent on the subscriber's approval or censorship of the publication.