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ORIGINAL RESEARCH

Impact of Sjögren's disease on quality of sexual life using the Qualisex score

Alexandra Kachaner ,[1] Raphaele Seror ,[2] Véronique Le Guern,[3] Philippe Dieudé ,[4] Jacques-Eric Gottenberg ,[5] Eric Hachulla ,[6] Valérie Devauchelle-Pensec,[7,8] Aleth Perdriger,[9] Emanuelle Dernis,[10] Marion Couderc ,[11,12] Sophie Berville,[13] Xavier Mariette ,[14,15] Rakiba Belkhir,[16] Gaetane Nocturne [17]

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For numbered affiliations see end of article.

Correspondence to
Dr Alexandra Kachaner; alexandra.kachaner@gmail.com

ABSTRACT

Objective This study aimed to assess the impact of Sjögren disease (SjD) on the quality of sexual life and its determinants using the Qualisex questionnaire.

Methods The Qualisex questionnaire was administered to participants within the ASSESS cohort, a French national multicentric prospective cohort of individuals with SjD. Patients' characteristics and psychometric evaluations were also collected.

Results Among the 395 patients of the cohort, 92 (23%) completed the questionnaire, with a median age of 56 (44–59) years and a female ratio of 92% (85/92). The median Qualisex score was 3.4 (1.1–5.9).
Comparing the first and last quartiles of the Qualisex score, a worst sexual satisfaction was associated with older age (median (IQR) 58 (52–65) vs 52 (41–56) years, p=0.005), higher EULAR Sjögren's disease Patient Reported Index (ESSPRI) (6.8 (5.7–7.7) vs 4.3 (2.8–5.3), p<0.0001) lower SF-36 mental and physical scores (respectively, 43 (38–46) vs 49 (47–53), p=0.0035 and 31 (29–35) vs 35 (30–37), p=0.035), higher Depression and Anxiety scores (HADS) (respectively, 9 (7–11) vs 2 (1–4), p<0.0001 and 11 (8–14) vs 7 (4–10), p=0.006). Interestingly, EULAR Sjögren's disease Disease Activity Index (ESSDAI) score did not differ significantly (4 (1–10) vs 2.5 (1.8–4), p=0.35).
In a multivariable analysis, the Qualisex score remained strongly associated with a higher HADS depression score and, to a lesser extent, with a higher ESSPRI. The inability to obtain a score was associated with older age.

Conclusion In SjD patients, sexual satisfaction assessed with the Qualisex score, was strongly associated with depression and, to lesser extent, with ESSPRI, but not with systemic activity.

WHAT IS ALREADY KNOWN ON THIS TOPIC

⇒ Quality of life in patients with Sjögren's disease (SjD) is known to be compromised. Sexual health constitutes a significant component of overall quality of life.

WHAT THIS STUDY ADDS

⇒ The impact of disease on sexual satisfaction in patients with SjD, evaluated using the Qualisex questionnaire, exhibited a strong correlation with depressive symptoms and a more moderate association with EULAR Sjögren's disease Patient Reported Index (ESSPRI). Notably, no significant association was found with disease activity assessed with the EULAR Sjögren's disease Disease Activity Index score (ESSDAI).

HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

⇒ The thorough assessment of patients diagnosed with SjD should include an evaluation of sexual health, ensuring this crucial dimension of patient care is not neglected.

INTRODUCTION

Sjögren disease (SjD) is a systemic autoimmune disorder that predominantly affects women, with a sex ratio of 9:1. The quality of life for patients with SjD is significantly compromised.[1 2] Quality of life is a multifactorial concept and one of its determinants is sexual life. Research indicated that sexual life is impaired in women with SjD.[3–5] Various studies have employed the Female Sexual Function Index (FSFI), a measure of sexual functioning, to compare sexual experiences between SjD patients and healthy controls. These investigations consistently revealed a lower FSFI in SjD patients compared with controls,[3–9] with a notable decrease in sexually active women within the SjD group.[3] The most important disparities were observed in dyspareunia, desire, lubrication and arousal.[6] Notably, sexual dysfunction did not correlate with EULAR Sjögren's disease Disease Activity Index (ESSDAI) in several studies.[6 7]

A simple instrument, the Qualisex score, has been validated in French patients with rheumatoid arthritis to assess the perceived impact of their disease on their sexual life.[10] Unlike FSFI, which poses more objective questions about arousal, lubrification, desire,

etc, Qualisex focuses on the subjective impact of the disease on sexual life. A higher Qualisex score indicates a more negative impact of the disease on sexual quality of life. The Qualisex questionnaire was assessed in an Italian population of 40 SjD patients, revealing positive correlations with EULAR Sjögren's disease Patient Reported Index (ESSPRI), anxiety and depression, while no correlation was found with ESSDAI. In this study, the median Qualisex score was 4.65.[11]

The main objective of this study was to evaluate the impact of disease on sexual satisfaction with the Qualisex score in a French SjD population, and to establish correlations with patients' characteristics and psychometric evaluations.

PATIENTS AND METHODS

Patients

ASSESS is a French prospective multicentre cohort. 15 internal medicine and rheumatology departments recruited 395 patients who met the American-European Consensus Group criteria for SjD[12] between 2006 and 2009. These patients were prospectively followed for 20 years. The Qualisex questionnaire was distributed to the entire cohort from September 2012 to June 2013.

Data collection

The following data were collected: age, sex, age at diagnosis, disease duration, clinician reported systemic involvement, ESSDAI score[13] and anti-Ro/SSA.

A self-survey was carried out with the following tests: Hospital Anxiety and Depression Scale (HADS),[14] Short Form 36 Health Survey Questionnaire (SF-36)[15] and Qualisex score[10] and the patient symptoms were evaluated using the ESSPRI.[16]

The Qualisex score cannot be calculated for a patient if more than one response is missing or marked as 'not applicable'. In such cases, the questionnaire was deemed 'not available'.

Statistical analysis

Data were expressed as median (IQR) for continuous variables and number (%) for categorical variables.

Statistical analyses were performed on R V.4.3.2.

T-tests or Mann-Whitney U tests were used for quantitative parameters. χ^2 tests or Fisher's exact tests were performed for categorical variables. A p value <0.05 was considered statistically significant. A multivariable linear regression was performed to underscore confounding factors.

RESULTS

169 patients answered the Qualisex questionnaire. Among them, 77 (46%) patients did not obtain a Qualisex score due to either multiple missing responses (n=10) or having declared too many questions as 'not applicable' (n=67) (online supplemental figure 1). In the population with complete questionnaire (n=92), patients were mostly women of middle age with 92% female (85/92) and a median (IQR) age of 56 (44–59) years old. Median (IQR) Qualisex score was 3.4 (1.1–5.9) (table 1). Details of the Qualisex questionnaire were given in online supplemental table 1. A comparison was conducted between patients who completed the Qualisex questionnaire and those who answered the questionnaire but had too many items marked as 'not applicable' to generate a Qualisex score (online supplemental table 2). Patients who completed the questionnaire were significantly younger (56 (44–59) years vs 65 (56–71) years, p<0.0001). Other characteristics showed no significant differences between the two groups.

Comparing first and last quartiles of Qualisex score (table 2) revealed an association between high Qualisex score (corresponding to worst sexual satisfaction) and older age (median (IQR) 58 (52–65) vs 52 (41–56) years, p=0.005), higher ESSPRI (6.8 (5.7–7.7) vs 4.3 (2.8–5.3), p<0.0001) lower SF36 mental and physical scores (respectively, 43 (38–46) vs 49 (47–53), p=0.0035 and 31 (29–35) vs 35 (30–37), p=0.035), higher HADS Depression and Anxiety score (respectively, 9 (7–11) vs 2 (1–4), p<0.0001 and 11 (8–14) vs 7 (4–10), p=0.006).

Table 1 Patients characteristics

	N=92
Age, years, median (IQR)	56 (44–59)
Female, n (%)	85 (92)
Disease duration, years, median (IQR)	8 (6.2–13)
Qualisex, median (IQR)	3.4 (1.1–5.9)
ESSPRI, median (IQR)	5.3 (4.3–7)
VAS Fatigue, median (IQR)	6 (3.5–7)
VAS Pain, median (IQR)	5 (2–7)
VAS Dryness, median (IQR)	6 (4–7)
ESSDAI, median (IQR)	3 (1–8)
Cutaneous, median (IQR)	0 (0–0)
Respiratory, median (IQR)	0 (0–0)
Renal, median (IQR)	0 (0–0)
Articular, median (IQR)	0 (0–0)
Muscular, median (IQR)	0 (0–0)
Peripheral nervous system (PNS), median (IQR)	0 (0–0)
	0 (0–0)
Central nervous system (CNS), median (IQR)	0 (0–0)
Glandular, median (IQR)	0 (0–0)
Constitutional, median (IQR)	0 (0–0)
Haematological, median (IQR)	0 (0–0)
Lymphadenopathic, median (IQR)	1 (0–2)
Biological, median (IQR)	
SF-36 Mental, median (IQR)	47 (43–51)
HADS Anxiety, median (IQR)	8 (6–11)
HADS Depression, median (IQR)	6 (2–8)

ESSDAI, EULAR Sjögren's disease Disease Activity Index; ESSPRI, EULAR Sjögren's disease Patient Reported Index; HADS, Hospital Anxiety and Depression Scale; SF-36, Short Form 36 Health Survey Questionnaire; VAS, Visual Analogue Scale.

Table 2 Comparison of first and last quartile of Qualisex score

	Q1 (n=23)	Q4 (n=24)	P value
Age, median (IQR)	52 (41–56)	58 (52–65)	0.005
Female, n (%)	21 (91)	23 (96)	0.6
Disease duration, years, median (IQR)	8 (6–13.5)	8 (8–12)	0.34
ESSPRI, median (IQR)	4.3 (2.8–5.3)	6.8 (5.7–7.7)	<0.0001
VAS Fatigue, median (IQR)	3 (2–6.5)	8 (6–8)	0.001
VAS Pain, median (IQR)	2 (0.2–6.5)	7 (6–7)	0.05
VAS Dryness, median (IQR)	3.5 (2–5)	7 (5–7)	0.006
ESSDAI, median (IQR)	4 (1–10)	2.5 (1.8–4)	0.35
Cutaneous, median (IQR)	0 (0–0)	0 (0–0)	0.30
Respiratory, median (IQR)	0 (0–0)	0 (0–0)	0.58
Renal, median (IQR)	0 (0–0)	0 (0–0)	NA
Articular, median (IQR)	0 (0–0)	0 (0–0)	0.93
Muscular, median (IQR)	0 (0–0)	0 (0–0)	NA
Peripheral nervous system (PNS), median (IQR)	0 (0–0)	0 (0–0)	NA
Central nervous system (CNS), median (IQR)	0 (0–0)	0 (0–0)	NA
Glandular, median (IQR)	0 (0–0)	0 (0–0)	NA
Constitutional, median (IQR)	0 (0–0)	0 (0–0)	NA
Haematological, median (IQR)	0 (0–0)	0 (0–0.2)	0.83
Lymphadenopathic, median (IQR)	0 (0–0)	0 (0–0)	NA
Biological, median (IQR)	0 (0–1)	1 (0.5–2)	0.12
Anti-Ro/SSA, n (%)	19 (83)	13 (54)	0.06
Reported systemic involvement, n/N (%)	7/20 (35)	8/19 (42)	0.79
SF-36 Physical, median (IQR)	35 (30–37)	31 (29–35)	0.035
SF-36 Mental, median (IQR)	49 (47–53)	43 (38–46)	0.0035
HADS Anxiety, median (IQR)	7 (4–10)	11 (8–14)	0.006
HADS Depression, median (IQR)	2 (1–4)	9 (7–11)	<0.0001

ESSDAI, EULAR Sjögren's disease Disease Activity Index; ESSPRI, EULAR Sjögren's disease Patient Reported Index; HADS, Hospital Anxiety and Depression Scale; SF-36, Short Form 36 Health Survey Questionnaire; VAS, Visual Analogue Scale.

Interestingly, ESSDAI score, anti-Ro/SSA positivity and reported systemic involvement did not differ significantly between groups (respectively, 2.5 (1.8–4) vs 4 (1–10), p=0.35; 19 (83%) vs 13 (54%), p=0.06 and 8/19 (42%) vs 7/20 (35%), p=0.79).

As data on sexual life of male patients with SjD are scarce, an analysis was performed to compare male and female patients. Qualisex did not reveal significant differences between males and females, and other characteristics showed no statistically significant variations, except for a slightly shorter disease duration among male patients (5 (5–6) years vs 8 (7–13), p=0.04). The results should be interpreted cautiously due to the very limited sample size of male patients (n=7) (table 3).

To explore the determinants of the Qualisex score, a multivariable linear regression analysis was performed incorporating age, sex and ESSPRI. Notably, ESSPRI maintained a significant association with the Qualisex score (OR=0.54 (0.28 to 0.80), p value <0.001). When HADS Depression and Anxiety were introduced into the model, HADS Depression emerged as the dominant factor, with an OR (95% CI) of 0.31 (0.14 to 0.47) and a p value <0.001. Meanwhile, ESSPRI retained a modest level of significance (OR (95% CI)=0.28 (−0.01 to 58), p value=0.057). Other variables did not reach significance. These results suggest that the impact of disease on sexual life in patients with SjD is mainly influenced by depression, and to a lesser extent by ESSPRI (table 4).

DISCUSSION

This study explored the impact of SjD on quality of sexual life using the Qualisex score. We found that greater negative impact was associated with higher ESSPRI, increased symptoms of depression and anxiety, and lower quality of life. Interestingly, there was no significant association with systemic disease activity as assessed by the ESSDAI score. Multivariable analysis highlighted a robust relationship between the Qualisex score and depression score.

Major depression and the use of antidepressant treatment are known to be linked with sexual dysfunction.[17 18] While the association between depressive disorders and SjD has been documented in the literature,[1 19–21] other studies have reported a prevalence similar to that in the general population.[18] In the Italian study assessing the Qualisex questionnaire in a population of patients with

Table 3 Comparison between male (n=7) and female (n=85) patients

	Male patients n=7	Female patients n=85	P value
Age, median (IQR)	60 (54–67)	55 (43–59)	0.08
Disease duration, years, median (IQR)	5 (5–6)	8 (7–13)	0.04
Qualisex, median (IQR)	1.6 (0.9–4.3)	3 (1–7.5)	0.33
ESSPRI, median (IQR)	3.3 (2.3–5.8)	5.3 (4.3–7)	0.07
Reported systemic involvement, n/N (%)	1/6 (17)	22/59 (37)	0.41
ESSDAI, median (IQR)	3 (0–11.5)	3 (1–7.5)	0.95
SF-36 Physical, median (IQR)	35 (31–36)	34 (30–38)	0.94
SF-36 Mental, median (IQR)	49 (48–55)	47 (42–51)	0.10
HADS Anxiety, median (IQR)	7 (4.5–9.5)	8 (6–11)	0.25
HADS Depression, median (IQR)	6 (5–7.5)	5 (2–8)	0.78

ESSDAI, EULAR Sjögren's disease Disease Activity Index; ESSPRI, EULAR Sjögren's disease Patient Reported Index; HADS, Hospital Anxiety and Depression Scale; SF-36, Short Form 36 Health Survey Questionnaire.

SjD, HADS depression score was higher with a median (IQR) score of 8 (4–11), compared with 6 (2–8) in our study. Additionally, a higher Qualisex score was observed in the Italian study (4.65 (2.125–6.2)) in contrast to our study (3.4 (1.1–5.9)), supporting the idea of a correlation between depressive symptoms and the Qualisex score.[11] Determining the causal relationship between the quality of one's sexual life and the presence of depression poses a challenge. On one hand, fluctuations in mood might influence the overall quality of one's sexual experiences. Conversely, a compromised quality of sexual life could potentially exert a detrimental impact on one's mood.

SjD can be comorbid with fibromyalgia, especially in cases of high ESSPRI, irrespective of ESSDAI.[19] Patients with fibromyalgia often experience sexual dysfunction.[20] Therefore, screening for depression and fibromyalgia is crucial in patients with SjD.

The study of sexual life is complex due to its multifactorial nature, involving factors such as the relationship with the partner, libido, gynaecological issues (eg, vaginal dryness or dyspareunia), age, menopause and mood disorders. These factors can be intertwined; for instance, vaginal atrophy may lead to dyspareunia and a loss of libido.[21]

Vaginal dryness may mediate the relationship between high ESSPRI and sexual dissatisfaction. Previous research has reported an association between vaginal dryness and sexual dysfunction among SjD patients.[7] In a study involving 199 female patients with SjD, self-reported vaginal dryness was significantly associated with older age, postmenopausal status, peripheral neuropathy, oral and ocular dryness, ESSPRI, and SF-36 mental and general health.[22] However, the association between self-reported vaginal dryness and oral dryness is inconsistent between studies.[3]

Most of our patients are postmenopausal, potentially experiencing vaginal atrophy. A publication has reported a significant association between sexual dysfunction and atrophy observed during genital examination in patients with SjD.[4]

In rheumatoid arthritis, sexual functioning is also compromised, as indicated by lower scores on the FSFI compared with controls.[23] This lower score was associated with age and pain in multivariable analysis. The Qualisex score was evaluated in a study involving patients with rheumatoid arthritis,[10] and the mean score was 3.3, similar to our observations in this sample. Rheumatoid arthritis is also associated with depressive disorder.[24] The Qualisex questionnaire has also been evaluated in patients with fibromyalgia.[11 22] The purpose of using the Qualisex questionnaire across different rheumatic conditions should be systematically evaluated in a comparative study.

In our male population, although there were no significant differences in ESSPRI, HADS, or Qualisex compared with the female population, the limited number of male patients—only 7—might have contributed to a lack of statistical power. The sexual life of male patients with

Table 4 Results of linear regressions

	N	RR (95% CI)	P value
ESSPRI, linear regression adjusted on age, sex and ESSPRI	88	0.54 (0.28 to 0.80)	<0.001
ESSPRI, linear regression adjusted on age, sex, ESSPRI and HADS	80	0.28 (–0.01 to 58)	0.056
HADS, linear regression adjusted on age, sex, ESSPRI and HADS	80	0.31 (0.14 to 0.47)	<0.001

ESSPRI, EULAR Sjögren's disease Patient Reported Index; HADS, Hospital Anxiety and Depression Scale.

rheumatological conditions is rarely studied. However, one study reported impaired sexual life in more than half of male patients with rheumatoid arthritis,[23] emphasising the importance of addressing this aspect.

Previous studies have noted a higher symptom burden in anti-Ro negative Sjogren's patients.[24 25] Our comparison of anti-Ro positivity between the first and last quartiles of the Qualisex scores revealed a trend towards lower positivity in those with higher scores, potentially supporting this hypothesis. The lack of statistical significance may be due to the small sample size.

Our study has some limitations notably the low response rate. However, this outcome may reflect the distress that patients experience when discussing aspects of their sexual life. Additionally, among the 77 not available questionnaires, 67 patients provided more than one 'not applicable' response, which could indicate that the questionnaire failed to engage those with reduced sexual intercourse, leading them to view the questions as irrelevant and select 'not applicable'. This is an important finding in its own right, and we need to work with patient associations to find the best ways of addressing this important issue with patients. An evaluation within the framework of patient education sessions is undoubtedly an interesting avenue. The absence of genital examination and fibromyalgia screening in our population represents another limitation. The study population primarily consists of individuals of menopausal age, which restricts the applicability of the conclusions to younger patients, especially in the absence of a control group. A comparison group comprising healthy subjects would have provided valuable insights, but unfortunately, this questionnaire has not been evaluated in healthy individuals. Pelvic floor distress, which has been significantly associated with sexual dysfunction in patients with SjD compared with controls,[8] was not evaluated in our study. Additionally, data on erectile dysfunction, menopausal status, treatment, comorbidities and relationship characteristics were not collected, although these factors could have provided valuable insights into our results.

In this sample, the sexual impact of SjD appeared substantial. Consequently, the comprehensive evaluation of patients with SjD should incorporate an assessment of sexual life to avoid overlooking this significant aspect of their lives.

CONCLUSION

Patients with SjD reported a higher perceived impact of their disease on sexual life when experiencing higher ESSPRI, increased symptoms of depression and anxiety, and a diminished quality of life. Notably, this impact was not associated with systemic disease activity, as assessed by the ESSDAI score. Physicians should prioritise the evaluation of sexual satisfaction in patients with SjD, especially those with high ESSPRI and symptoms of depression and anxiety.

Author affiliations
[1]Hospital Bicetre, Le Kremlin-Bicetre, France
[2]Rheumatology, Hôpitaux universitaires Paris-Sud, Le Kremlin Bicêtre, France
[3]Department of Internal Medicine, APHP, Paris, France
[4]Rheumatology, APHP, Paris, France
[5]Rheumatology, Hopitaux universitaires de Strasbourg, Strasbourg, France
[6]Lille University School of Medicine, Lille, France
[7]Rheumatology, Brest University and La Cavale Blanche Hospital, Brest, France
[8]EA 22-16, INSERM ESPRI, ERI29, Brest, France
[9]Polyclinique du Maine, Laval, France
[10]Rheumatology, Le Mans Hospital, Le Mans, France
[11]Rheumatology, University Hospital Centre Clermont-Ferrand, Clermont-Ferrand, France
[12]Inserm/Imost UMR1240, Clermont Auvergne University, Clermont-Ferrand, France
[13]Cabinet de gynécologie 2 avenue René coty, Paris, France
[14]Rheumatology, Assistance Publique-Hôpitaux de Paris (AP-HP), Hôpitaux universitaires Paris-Sud – Hôpital Bicêtre, Le Kremlin Bicêtre, France
[15]Université Paris-Sud, Center for Immunology of Viral Infections and Auto-immune Diseases (IMVA), Institut pour la Santé et la Recherche Médicale (INSERM) UMR 1184, Université Paris-Saclay, Le Kremlin Bicêtre, France
[16]Department of Rheumatology, Hôpital Bicêtre, Le Kremlin-Bicetre, France
[17]Universite Paris Sud Faculte de Medecine, Le Kremlin-Bicetre, France

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ORCID iDs
Alexandra Kachaner http://orcid.org/0000-0001-8992-7539
Raphaele Seror http://orcid.org/0000-0002-5523-1856
Philippe Dieudé http://orcid.org/0000-0002-4814-0307
Jacques-Eric Gottenberg http://orcid.org/0000-0002-9469-946X
Eric Hachulla http://orcid.org/0000-0001-7432-847X
Marion Couderc http://orcid.org/0000-0002-2001-1132
Xavier Mariette http://orcid.org/0000-0002-4244-5417
Gaetane Nocturne http://orcid.org/0000-0001-6809-0733

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