

Research Letter

Impact of Axial Spondyloarthritis on Quality of Life: Results From the European Map of Axial Spondyloarthritis (EMAS) Study in France

To the Editor:

The effect of axial spondyloarthritis (axSpA) on patients' quality of life (QOL) has been well assessed in terms of body structures and functions, but literature is scarce in terms of social interactions and activities, work, and fears related to social interactions or activities.¹

A better understanding of patients' daily difficulties is a key issue in rheumatology, as it could positively affect patients' well-being and the management of their disease.² In this context, a large patient survey, the European Map of Axial Spondyloarthritis (EMAS) study, was performed to explore patients' perceptions of axSpA.^{3,4,5} The aim of the present study was to assess the impact of axSpA on QOL and particularly on social interactions, social activities, working issues, and fears, using data from the EMAS French participants.

EMAS was conducted in 13 European countries in 2017–2018⁴; the findings for French patients are presented here. Participants had to be aged ≥ 18 years, to self-report a diagnosis of axSpA (either radiographic or nonradiographic), and to report having seen a healthcare professional due to axSpA in the 12 months prior to participation.

The effect of axSpA was evaluated by an online questionnaire developed by an international scientific committee. Four categories of impact were assessed: social interactions (5 items: spouse, family, friends and colleagues, and frequency of sexual intercourse), social life and frequency of leisure activities (4 items: restaurants, cultural outings, travel, sports), working issues (current sick leave), and fears for the future. Sociodemographic and disease-related data, as well as self-reported comorbidities (anxiety, depression, overweight/obesity, fibromyalgia), were also collected.

The effect of axSpA on QOL was assessed qualitatively: worse or much worse social interactions for at least 1 of the 5 items, less or much less frequent social activities for at least 1 of the 4 items, current sick leave, and at least a positive response to a fear-related question. The key outcome was major impact, defined as having an impact on ≥ 2 aspects of QOL (among social interactions,

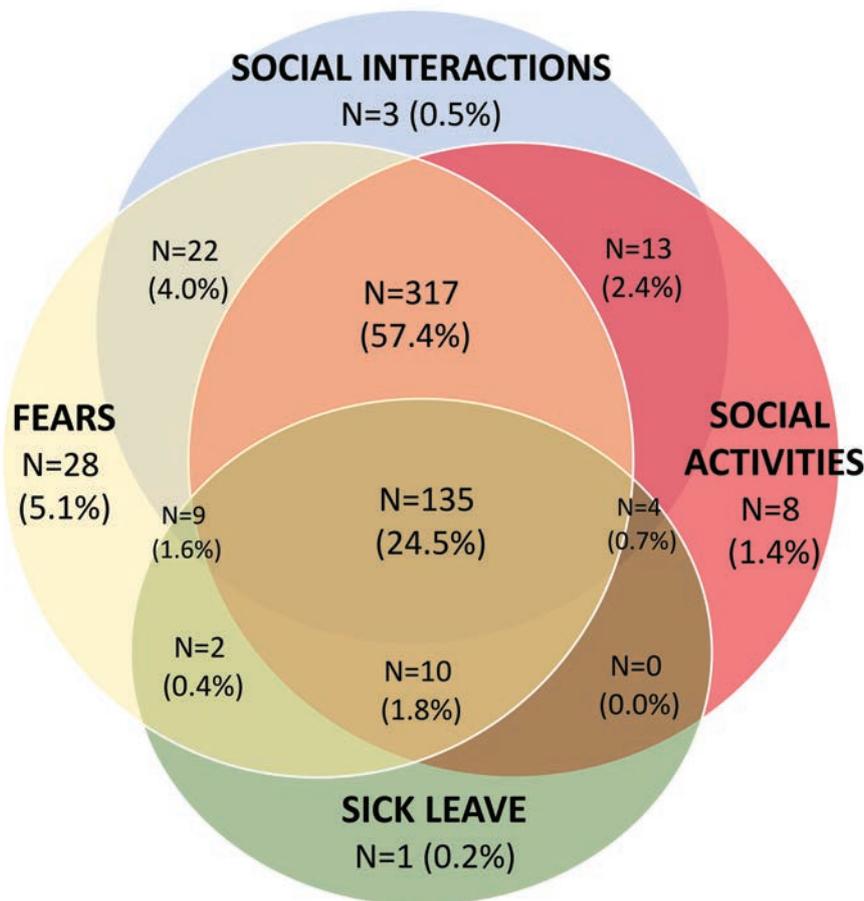


Figure 1. Venn diagram for the 4 domains of quality of life.

Table 1. Factors associated with major impact on quality of life (ie, having ≥ 2 domains affected by axSpA).

	≥ 2 Impacts Mean (\pm SD) or n (%)	< 2 Impacts Mean (\pm SD) or n (%)	Univariable Analysis <i>P</i>	Multivariable Analysis <i>P</i>	Multivariable Analysis OR (95% CI)
Age, yrs	41.5 (\pm 10.9)	42.2 (\pm 12.9)	0.62	NA	NA
Female gender	461 (80.2)	36 (57.1)	< 0.001	0.002	2.6 (1.4–4.8)
Educational level (high school or less)	295 (51.3)	19 (30.2)	0.002	0.029	2.0 (1.1–3.3)
Married/cohabiting	370 (64.3)	42 (66.7)	0.72	NA	NA
Unemployment	268 (48.7)	13 (21.0)	< 0.001	0.001	3.3 (1.7–10.0)
Smoking	188 (32.7)	19 (30.2)	0.68	NA	NA
Symptom duration, yrs	14.3 (\pm 10.5)	13.5 (\pm 9.3)	0.57	NA	NA
bDMARD therapy	366 (64.6)	22 (36.7)	< 0.001	< 0.001	3.0 (1.6–5.3)
Comorbidities (0–4) ^a	1.4 (\pm 1.2)	0.7 (\pm 1.1)	< 0.001	0.001	1.6 (1.2–2.2) ^b

^a Comorbidities corresponded to overweight/obesity, depression, fibromyalgia, and anxiety. ^b OR for ≥ 1 comorbidity. AxSpA: axial spondyloarthritis; bDMARD: biologic disease-modifying antirheumatic drug; NA: not applicable; OR: odds ratio.

social activities, sick leave, or fears). Statistics were descriptive, without imputation of missing data. Univariable and multivariable logistic regression models were built to determine the factors associated with major impact. All variables with $P < 0.20$ in the univariable analysis were included in the multivariable model.⁶

All patients agreed to participate through informed opt-in consent. In this study, no clinical trial was conducted. As it was not an interventional study, no ethics committee approval was required in France. EMAS global results have been published previously.^{3,4,5}

Data from 638 patients were analyzed: mean age $41.5 \pm$ SD 11.1 years, 77.9% women, and mean disease duration $6.9 \pm$ 8.2 years. Disease was active (mean Bath Ankylosing Spondylitis Disease Activity Index $5.9 \pm$ 1.7), and 19.1% participants were on biologics at the time of the survey. Participants frequently reported anxiety ($n = 312$, 50.4%), being overweight/obese ($n = 237$, 38.2%) or depression ($n = 199$, 32.8%).

Overall, 615 (96.4%) patients reported any of the 4 impacts among social interactions, social life, sick leave, and fears (Figure 1). A major impact on QOL (ie, ≥ 2 categories affected) was reported by 575 participants (90.1%).

A total of 505 participants (79.4%) reported a negative effect of axSpA on social interactions with partners, family, friends, or coworkers, particularly in terms of frequency of sexual intercourse. Five hundred forty-eight (86.2%) participants engaged in fewer leisure activities due to their axSpA; more specifically, physical activity or going to restaurants in nearly 80%. More than half of the participants were employed at the time of the survey, whereas 75 (12.0%) and 87 (14.0%) participants were on temporary or permanent sick leave, respectively. Finally, 585 (91.7%) participants reported fears for the future, wherein the main fear reported by the surveyed participants was alteration of daily activities ($n = 453$, 71.0%).

Factors associated with major impact on QOL in univariable and confirmed in multivariable analysis were being unemployed (odds ratio [OR] 3.3, 95% CI 1.7–10.0), biologic use (OR 3.0, 95% CI 1.6–5.3), female gender (OR 2.6, 95% CI 1.4–4.8), low

educational level (OR 2.0, 95% CI 1.1–3.3), and reporting ≥ 1 comorbidity (OR 1.6, 95% CI 1.2–2.2; Table 1).

This study brings to light that $> 90\%$ of patients with axSpA in France describe a major effect of axSpA on their social and working life, particularly in terms of fears for the future. Factors associated with an increased risk of major impact were not related to the activity of the disease, except receiving biologics. However, this association was probably secondary to an indication bias, as these treatments are prescribed in the most severe/active cases of axSpA, which are more likely to affect patients' QOL.⁷ Rather, factors that were significantly associated with major impact were related to the patients' background, experience, and identity; this finding is concordant with previous studies.^{8,9,10} Indeed, sociodemographic characteristics influence patients' understanding and perception of their disease, and ultimately influence their experience and QOL.

These findings underline the need for a multidisciplinary approach to enable more efficient and global management of axSpA, and ultimately improve patients' QOL.

Joanna Kedra¹ , MD, MSc
 Pascal Claudepierre² , MD, PhD
 René-Marc Flipo³, MD, PhD
 Marco Garrido-Cumbrera⁴ , MD, PhD
 Françoise Alliot-Launois⁵, President
 Emilie Desfleurs⁶, PhD
 Laurent Grange⁷, MD, PhD
 Laure Gossec¹ , MD, PhD

¹Sorbonne Université, INSERM, Institut Pierre Louis d'Epidémiologie et de Santé Publique, and Pitié-Salpêtrière hospital, AP-HP, Sorbonne Université, Rheumatology Department, Paris, France;

²Rheumatology Department, Henri Mondor hospital, AP-HP, Université Paris Est Créteil, EA 7379 – EpiDermE, Créteil, France;

³Rheumatology Department, Roger Salengro University Hospital, Lille University, Lille, France;

⁴Health & Territory Research (HTR), Universidad de Sevilla, Spain;

⁵Association Française de Lutte Antirhumatisme (AFLAR), Paris, France;

⁶Medical Affairs, Novartis Pharma, Rueil-Malmaison, France;

⁷Rheumatology Department, Grenoble Alpes University Hospital, Hôpital Sud, Échirolles, and Association Française de Lutte Antirhumatisme (AFLAR), Paris, France.

Novartis funded this study and participated in the study design, research, analysis, data collection, interpretation of data, reviewing, and approval of the publication.

PC has received honoraria for participating in EMAS scientific committee from Novartis Pharma. RMF has received honoraria for participating in EMAS scientific committee from Novartis Pharma. MGC has received honoraria for participating in EMAS scientific committee from Novartis Pharma. ED is an employee of Novartis. L. Gossec received research grants from Amgen, Galapagos, Janssen, Lilly, Pfizer, Sandoz, Sanofi; and consulting fees from AbbVie, Amgen, BMS, Biogen, Celgene, Galapagos, Gilead, Janssen, Lilly, Novartis, Pfizer, Samsung Bioepis, Sanofi-Aventis, and UCB. The remaining authors declare no conflicts of interest relevant to this article.

Address correspondence to Dr. J. Kedra, Sorbonne Université, INSERM, Institut Pierre Louis d'Epidémiologie et de Santé Publique, and Pitié-Salpêtrière hospital, AP-HP, Sorbonne Université, Rheumatology Department, 47-83, boulevard de l'Hôpital, 75013 Paris, France. Email: jkedra.pro@gmail.com.

ACKNOWLEDGMENT

The authors acknowledge the EMAS working group. The EMAS project is a collaboration led by the Health & Territory Research group of the University of Seville, the Ankylosing Spondylitis International Federation, and a steering committee composed of patient representatives and internationally recognized rheumatologists, psychologists, and researchers specializing in axSpA. All authors had access to relevant data and participated in the drafting, review, and approval of this publication.

REFERENCES

1. Sieper J, Poddubnyy D. Axial spondyloarthritis. *Lancet* 2017;390:73-84.
2. Santiago MG, Marques A, Kool M, Geenen R, da Silva JAP. Invalidation in patients with rheumatic diseases: clinical and psychological framework. *J Rheumatol* 2017;44:512-8.
3. Garrido-Cumbrera M, Poddubnyy D, Gossec L, et al; EMAS Working Group. The European Map of Axial Spondyloarthritis: capturing the patient perspective—an analysis of 2846 patients across 13 countries. *Curr Rheumatol Rep* 2019;21:19.
4. Garrido-Cumbrera M, Navarro-Compán V, Zarco P, et al. Atlas of axial spondyloarthritis in Spain 2017: study design and population. *Reumatol Clin* 2019;15:127-32.
5. Garrido-Cumbrera M, Poddubnyy D, Gossec L, et al; EMAS Working Group. Gender differences in patient journey to diagnosis and disease outcomes: results from the European Map of Axial Spondyloarthritis (EMAS). *Clin Rheumatol* 2021;40:2753-61.
6. Bursac Z, Gauss CH, Williams DK, Hosmer DW. Purposeful selection of variables in logistic regression. *Source Code Biol Med* 2008;3:17.
7. Fragoulis GE, Siebert S. Treatment strategies in axial spondyloarthritis: what, when and how? *Rheumatology* 2020;59 Suppl 4:iv79-89.
8. Kreis S, Molto A, Bailly F, et al. Relationship between optimism and quality of life in patients with two chronic rheumatic diseases: axial spondyloarthritis and chronic low back pain: a cross sectional study of 288 patients. *Health Qual Life Outcomes* 2015;13:78.
9. Rusman T, van Vollenhoven RF, van der Horst-Bruinsma IE. Gender differences in axial spondyloarthritis: women are not so lucky. *Curr Rheumatol Rep* 2018;20:35.
10. Putrik P, Ramiro S, Kvien TK, et al. Inequities in access to biologic and synthetic DMARDs across 46 European countries. *Ann Rheum Dis* 2014;73:198-206.