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Background: Understanding patient disease-related attitudes plays an important role in effective management of axial spondyloarthritis (axSpA). Nevertheless, the patient perspective remains insufficiently explored.

Objectives: To describe patients' axSpA-related fears and hopes and their associations with sociodemographic, disease outcomes and psychological distress.

Methods: The European Map of Axial Spondyloarthritis (EMAS), conducted from July 2017 to February 2018, was a cross-sectional on-line survey of unselected patients with self-reported axSpA from Austria, Belgium, France, Germany, Italy, Netherlands, Norway, Russia, Slovenia, Spain, Sweden, Switzerland, and the UK. Participants were recruited through an online panel and patient organizations. Participant's axSpA-related fears and hopes were freely expressed through open-ended questions (except in France where multiple-choice items were used). Thematic analysis, using the French categories and data-driven codes, was performed and frequencies of specific fears and hopes were subsequently calculated. Associations between disease-related fears and hopes with sociodemographic characteristics, disease outcomes (BASDAI, self-reported spinal stiffness and functional limitation), and psychological distress (General Health Questionnaire, GHQ-12; with a cut-off point of ≥ 3) were

Table 1. Association between patients' fears and sociodemographic and disease outcomes (N: 2166)

Areas of concern		Age (years)	Gender (Male)	Educational Level (University)	Marital Status (Married)	BASDAI (0-10)	Stiffness index (3-12)	Global Limitation (0-54)	GHQ-12 (0-12)
Disease progression (mean \pm SD or %)	Yes	42.4 \pm 11.6	25.9%	47.4%	64.0%	5.7 \pm 1.8	8.6 \pm 2.3	17.7 \pm 12.0	4.5 \pm 4.0
	No	44.0 \pm 13.1	41.3%	54.0%	68.3%	5.3 \pm 2.1	7.3 \pm 2.4	12.3 \pm 11.2	5.4 \pm 4.0
	p-value	0.016*	<0.001*	<0.001*	0.010*	<0.001*	<0.001*	<0.001*	<0.001*
Suffering pain (mean \pm SD or %)	Yes	41.7 \pm 11.5	21.9%	48.8%	64.3%	6.0 \pm 1.7	8.8 \pm 2.2	18.6 \pm 12.4	5.9 \pm 4.1
	No	44.2 \pm 13.1	42.2%	53.0%	67.9%	5.2 \pm 2.1	7.3 \pm 2.4	12.3 \pm 10.9	4.3 \pm 3.9
	p-value	<0.001*	<0.001*	<0.001*	0.105	<0.001*	<0.001*	<0.001*	<0.001*
Stiffness (mean \pm SD or %)	Yes	42.1 \pm 12.3	20.9%	47.5%	65.4%	5.9 \pm 1.7	9.1 \pm 2.0	18.8 \pm 12.2	5.8 \pm 4.1
	No	43.7 \pm 12.7	39.5%	52.7%	67.1%	5.3 \pm 2.0	7.5 \pm 2.4	13.1 \pm 11.4	4.5 \pm 4.0
	p-value	0.021*	<0.001*	0.007	0.372	<0.001*	<0.001*	<0.001*	<0.001*
Loss of mobility (mean \pm SD or %)	Yes	42.2 \pm 11.4	23.9%	50.2%	65.0%	5.9 \pm 1.8	8.9 \pm 2.2	18.6 \pm 12.6	5.8 \pm 4.1
	No	43.9 \pm 13.1	41.1%	52.3%	67.6%	5.2 \pm 2.0	7.3 \pm 2.4	12.3 \pm 10.8	4.3 \pm 4.0
	p-value	0.010*	<0.001*	0.002*	0.281	<0.001*	<0.001*	<0.001*	<0.001*
Loss of independence/ disability (mean \pm SD or %)	Yes	42.0 \pm 11.2	22.4%	49.7%	63.8%	6.0 \pm 1.7	8.8 \pm 2.2	19.7 \pm 12.2	6.2 \pm 4.0
	No	43.9 \pm 13.1	41.1%	52.4%	68.0%	5.2 \pm 2.1	7.4 \pm 2.4	12.1 \pm 10.9	4.2 \pm 3.9
	p-value	0.005*	<0.001*	<0.001*	0.036*	<0.001*	<0.001*	<0.001*	<0.001*
Social isolation (friends, family) (mean \pm SD or %)	Yes	40.2 \pm 10.3	17.8%	49.7%	56.9%	6.2 \pm 1.6	9.3 \pm 2.0	21.3 \pm 12.0	7.2 \pm 4.0
	No	43.9 \pm 12.9	38.8%	52.0%	68.4%	5.3 \pm 2.0	7.6 \pm 2.4	13.1 \pm 11.3	4.4 \pm 3.9
	p-value	<0.001*	<0.001*	0.031*	<0.001*	<0.001*	<0.001*	<0.001*	<0.001*
Loss of job/ inability to work (mean \pm SD or %)	Yes	39.8 \pm 9.6	20.6%	50.6%	61.7%	5.9 \pm 1.8	8.8 \pm 2.1	18.1 \pm 11.6	6.2 \pm 4.0
	No	44.6 \pm 13.3	41.0%	52.0%	68.5%	5.3 \pm 2.1	7.5 \pm 2.5	13.0 \pm 11.5	4.3 \pm 3.9
	p-value	<0.001*	<0.001*	<0.001*	0.005*	<0.001*	<0.001*	<0.001*	<0.001*
Complications during a pregnancy/infertility (mean \pm SD or %)	Yes	30.1 \pm 5.8	2.6%	66.7%	50.9%	5.4 \pm 2.0	8.3 \pm 2.6	20.4 \pm 12.6	5.9 \pm 3.8
	No	44.1 \pm 12.5	37.7%	50.8%	67.7%	5.4 \pm 2.0	7.8 \pm 2.4	13.9 \pm 11.6	4.7 \pm 4.1
	p-value	<0.001*	<0.001*	<0.001*	<0.001*	0.747	0.017*	<0.001*	0.001*
Impact of the disease on my everyday activities (mean \pm SD or %)	Yes	41.0 \pm 11.2	18.1%	49.3%	64.6%	5.9 \pm 1.7	8.9 \pm 2.2	19.2 \pm 11.8	6.2 \pm 4.0
	No	44.2 \pm 13.0	41.8%	52.5%	67.5%	5.3 \pm 2.1	7.4 \pm 2.4	12.6 \pm 11.3	4.3 \pm 3.9
	p-value	<0.001*	<0.001*	0.007*	0.172	<0.001*	<0.001*	<0.001*	<0.001*

* Chi-square and Mann-Whitney to test possible associations between variables.

Table 2. Association between patients' hopes and sociodemographic and disease outcomes (N: 2166)

Areas of concern		Age (years)	Gender (Male)	Educational Level (University)	Marital Status (Married)	BASDAI (0-10)	Stiffness index (3-12)	Global Limitation (0-54)	GHQ-12 (0-12)
To stop disease progression (mean \pm SD or %)	Yes	43.1 \pm 12.1	27.0%	53.6%	63.8%	5.5 \pm 2.0	8.3 \pm 2.4	16.2 \pm 12.1	5.4 \pm 4.1
	No	43.6 \pm 12.9	40.2%	50.8%	68.3%	5.4 \pm 2.0	7.6 \pm 2.4	13.3 \pm 11.5	4.5 \pm 4.0
	p-value	0.486	<0.001*	0.198	0.145	0.429	<0.001*	<0.001*	<0.001*
To be treated/ cured (mean \pm SD or %)	Yes	41.0 \pm 11.7	31.2%	53.5%	65.9%	5.6 \pm 2.0	8.4 \pm 2.5	16.5 \pm 11.9	5.4 \pm 4.0
	No	44.0 \pm 12.8	37.0%	51.2%	67.0%	5.4 \pm 2.0	7.7 \pm 2.4	13.7 \pm 11.6	4.6 \pm 4.0
	p-value	0.000*	0.026*	0.008*	0.005*	0.008*	<0.001*	<0.001*	<0.001*
To eliminate pain (mean \pm SD or %)	Yes	43.0 \pm 11.7	24.2%	50.2%	65.1%	5.9 \pm 1.8	8.7 \pm 2.2	18.3 \pm 11.9	5.4 \pm 4.0
	No	43.6 \pm 13.0	41.2%	52.3%	67.6%	5.2 \pm 2.1	7.4 \pm 2.4	12.4 \pm 11.2	4.5 \pm 4.0
	p-value	0.537	<0.001*	0.291	0.127	<0.001*	<0.001*	<0.001*	<0.001*
To improve my quality of life (mean \pm SD or %)	Yes	42.0 \pm 11.7	21.2%	50.1%	64.6%	5.9 \pm 1.7	9.0 \pm 2.1	18.7 \pm 11.6	5.6 \pm 4.1
	No	43.8 \pm 12.9	40.2%	52.1%	67.5%	5.3 \pm 2.1	7.5 \pm 2.4	12.9 \pm 11.5	4.6 \pm 4.0
	p-value	0.008*	<0.001*	0.001*	0.201	<0.001*	<0.001*	<0.001*	<0.001*
To live without constraints/ limitations (mean \pm SD or %)	Yes	42.6 \pm 11.7	21.4%	48.9%	64.6%	5.8 \pm 1.9	8.9 \pm 2.2	18.5 \pm 12.1	5.7 \pm 4.1
	No	43.6 \pm 12.9	39.6%	52.4%	67.5%	5.4 \pm 2.0	7.5 \pm 2.4	13.2 \pm 11.4	4.6 \pm 4.0
	p-value	0.212	<0.001*	0.202	0.301	<0.001*	<0.001*	<0.001*	<0.001*
For an effective treatment (mean \pm SD or %)	Yes	42.9 \pm 11.6	21.8%	52.0%	65.3%	5.7 \pm 1.9	8.7 \pm 2.2	17.8 \pm 11.8	5.7 \pm 4.0
	No	43.6 \pm 13.0	40.7%	51.5%	67.3%	5.3 \pm 2.1	7.5 \pm 2.4	13.0 \pm 11.5	4.5 \pm 4.0
	p-value	0.445	<0.001*	<0.001*	0.156	<0.001*	<0.001*	<0.001*	<0.001*
To improve mobility (mean \pm SD or %)	Yes	43.2 \pm 12.0	24.3%	51.4%	64.7%	5.8 \pm 1.8	8.9 \pm 2.2	18.3 \pm 12.0	5.7 \pm 4.1
	No	43.5 \pm 12.8	38.6%	51.7%	67.3%	5.4 \pm 2.0	7.5 \pm 2.4	13.3 \pm 11.5	4.6 \pm 4.0
	p-value	0.753	<0.001*	0.240	0.508	0.001*	<0.001*	<0.001*	<0.001*
To exercise (mean \pm SD or %)	Yes	42.2 \pm 11.9	20.3%	51.9%	62.0%	5.7 \pm 1.8	8.9 \pm 2.2	17.3 \pm 11.7	5.6 \pm 4.0
	No	43.6 \pm 12.8	39.1%	51.6%	67.8%	5.4 \pm 2.0	7.6 \pm 2.4	13.6 \pm 11.7	4.6 \pm 4.0
	p-value	0.059	<0.001*	0.362	0.044*	0.007*	<0.001*	<0.001*	<0.001*

* Chi-square and Mann-Whitney to test possible associations between variables.

explored through mean and contingency analysis and significance was confirmed by Mann-Whitney and Kruskal-Wallis tests.

Results: 2846 axSpA patients participated in EMAS: mean age was 43.9 \pm 12.3 years, 61.3% were female and 48.1% university-educated. Mean disease duration was 17.2 \pm 12.4 years, disease activity (BASDAI) 5.5 \pm 2.0 and psychological distress (GHQ-12) 5.0 \pm 4.1. The most frequent reported fears were fear of disease progression (32.9%), suffering pain (30.5%), and loss of mobility (30.0%). Accordingly, the most frequent hopes were to halt disease progression (32.5%), eliminate pain (30.7%), and access effective treatment (23.3%). Female patients and those with lower educational level more frequently expressed disease-related fears, while married patients less frequently reported fears. Patients with poorer disease outcomes and higher psychological distress more frequently reported disease-related fears.

Conclusion: Higher physical and psychological burden was significantly associated with expressing fears relating to axSpA. Defining the concerns that are important for patients needs to be considered in order to improve patient-physician communication and shared decision-making with regard to treatment options and goals.

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