# **PCR229**

# Patients' Journey and Burden of Disease among Axial Spondyloarthritis Patients in Greece: A Cross-Sectional Online Survey

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## **Objectives**

To explore the patients' journey from symptom onset to diagnosis and treatment and to evaluate the humanistic burden, work impairment and the out-of-pocket expenses of axSpA patients in Greece.

# Background

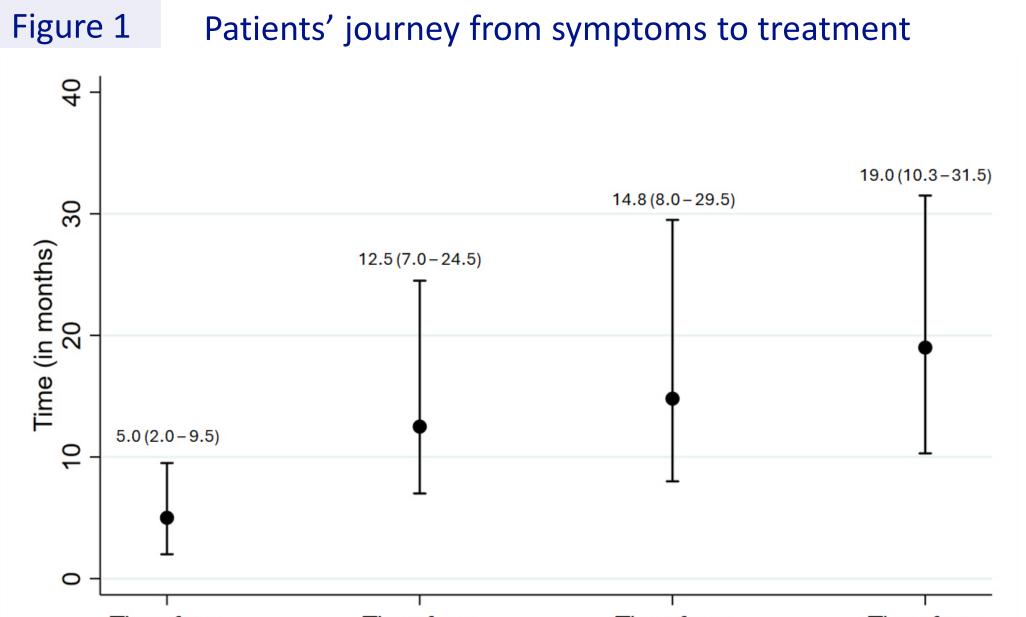
- Axial spondyloarthritis (axSpA) is a chronic inflammatory disease, primarily affecting the spine, with global prevalence between 0.3%-1.4%.<sup>1-4</sup>
- Delayed diagnosis worsens function, increases costs, and reduces quality of life (QoL).<sup>5-7</sup>

# Methods

Study Design

### Conclusions

- This is the first comprehensive analysis of the patient journey, quality of life, work impairment, and out-of-pocket expenses for axSpA patients in Greece.
- Diagnostic delay in this cohort was significantly shorter (19 months) compared to other European studies, which report delays of up to 6 years<sup>8-9</sup>
- High rates of misdiagnosis (63%) indicate a critical need for better diagnostic pathways.
- The substantial indirect costs (€3,321 annually) highlight the economic burden of axSpA on patients and society.



#### Judy Design

Cross-sectional online survey, (Sept-Dec 2023).

### Patients

150 axSpA patients from the Greek association "Reumazin." All were adults who provided consent.

### Study Assessment and Statistical Analyses

Data collection : Data was collected on patients' socio-demographic characteristics, medical history quality of life, work productivity and health-care utilization.

Cost estimation: All costs (€) reflected the year 2023.

- **Out-of-pocket expenses:** Summed outpatient visits, hospitalizations, and treatments.
- Indirect costs: Calculated for absenteeism and presenteeism based on average wages.

Statistical analysis: Costs presented as means with 95% CI. Predictors for delayed treatment initiation were assessed using Cox models (STATA 17.0).

### Results

### Patient characteristics

- 150 (of 164 reached) patients with axSpA participated in this survey.
- 47% were female, with a median age of 57 years (Q1: 45, Q3: 65),
  78% of the participants reported having ≥1 comorbidity,

### Table 1

# Ie 1Clinical profile, and Treatmentof Study Participants (N=150)

N (%)	Clinical profile and treatment (N=150) N=143	
Comorbidities		
Arterial hypertension	52 (36.4%)	
Hypercholesterolemia	43 (30.1%)	
Fibromyalgia	42 (29.4%)	
Osteoporosis	39 (27.3%)	
Depression or anxiety disorder	26 (18.2%)	
Asthma	20 (14.0%)	
Coronary heart disease	16 (11.2%)	
Ocular disease of autoimmune	13 (9.1%)	
etiology		
Diabetes Mellitus	11 (7.7%)	
Non-alcoholic fatty liver	6 (4.2%)	
Crohn's disease or ulcerative colitis	5 (3.5%)	
Cerebrovascular diseases	3 (2.1%)	
amily history of AxSpA	N=110	
Yes	74 (67.3%)	
No	36 (32.7%)	
reatment combinations	N=149	
Only biologics	54 (36.2%)	
Biologics combinations <sup>1</sup>	63 (42.3%)	
Only DMARDs	9 (6.0%)	
DMARDs combinations (excluding biologics) <sup>2</sup>	14 (9.4%)	
Other <sup>3</sup>	4 (2.7%)	
No treatment	5 (3.4%)	

Time from symptom onset to 1st medical seek	Time from symptom onset to visit a rheumatologist	Time from symptom onset to diagnosis	Time from symptom onset to 1st treatment
Seek	meumatologist		

Time is summarized with median (Q1 – Q3)

Figure 2	Factors associated with	time from	symptom to t	reatment	
			Univariate models		Adjusted mod
			HR (95% CI)		HR (95% CI)
Age at diagnosis			1.02 (1.001, 1.03)		1.02 (1.002, 1.04
Residence, n (%)					
Suburban/rural are	a vs. Urban area		0.53 (0.34, 0.82)		0.45 (0.26, 0.80
Education, n (%)		l I		1	
Bachelor's degree v	s. Primary school/Lower-Upper secondary education	<b>-</b>	- 1.54 (1.06, 2.23)		1.62 (1.002, 2.65
Master's/Doctoral d	legree vs. Primary school/Lower-Upper secondary		2.17 (1.21, 3.91)		1.99 (0.95, 4.20
Comorbidities (Each vs	. no)	1			
Arterial hypertensio	n		0.47 (0.32, 0.69)		0.52 (0.33, 0.82
Ocular disease of au	utoimmune etiology		0.43 (0.22, 0.81)		0.91 (0.43, 1.87
Fibromyalgia			0.54 (0.37, 0.80)		1.08 (0.67, 1.74
Symptoms that led to a	seek medical care (Each vs. no)			1	
Joint Pain			0.66 (0.46, 0.93)		0.60 (0.39, 0.92
Swollen Joints			0.57 (0.36, 0.91)		0.68 (0.37, 1.25
Eye Problems			0.44 (0.27, 0.72)		1.04 (0.56, 1.93
Sleep Problems			0.58 (0.41, 0.84)		0.58 (0.41, 0.84
Specialty of the physici	an you first visited				
Pathologist/Genera	l Practitioner vs. Rheumatologist		0.46 (0.27, 0.77)	<b></b>	0.49 (0.25, 0.94
Orthopedist vs. Rhe	umatologist		0.64 (0.40, 1.03)		0.71 (0.40, 1.28
Univariate and multiva	ariate Cox models.	0 1 2	2 3	0 1 2	3

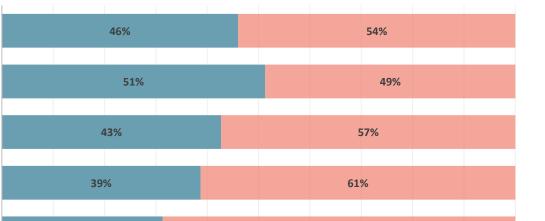
### Figure 3 ASQoL responses

I feel imprisoned in my own home

I can't do things on the spur of the moment

I vent my frustration on my loved ones

It takes me time to start my day



• 97% of participants were receiving treatment for axSpA. (Table 1)

### Diagnosis and patients' journey

- 146 reported experiencing ≥1 symptom that prompted them to seek medical care. The most common symptom was back pain (77%), followed by stiffness (51%).
- The median age at axSpA diagnosis was 44 years.
- Initially, the most frequently consulted specialists were orthopedics (53%) and pathologists/general practitioners (30%).
- More than half had been initially misdiagnosed (63%).
- The most common misdiagnoses were sciatica (40%), and psychosomatics (21%).
- The median time from symptom onset to treatment initiation was 19 months. (Figure 1)
- Residing in suburban or rural areas instead of urban areas, having arterial hypertension, and experiencing joint pain as an initial symptom were associated to a longer time from symptom onset to treatment, while older age was associated with a shorter time to treatment. (Figure 2)

### QoL and work productivity

- The median ASQoL score was 8 (Q1: 5, Q3: 12). Patients' responses are presented in Figure 3.
- Of the participants, 40% were employed at the time of the survey. Work productivity impairments are presented in Figure 4.

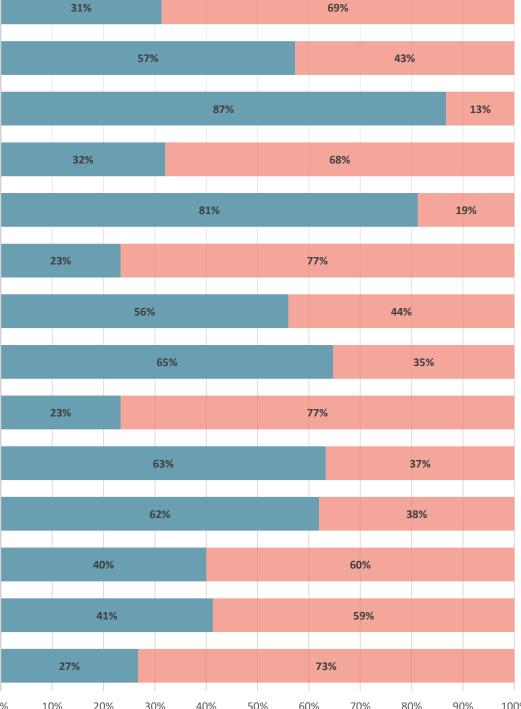
<sup>1</sup>DMARDs, NSAIDs, cortisone, and/or topical treatments; <sup>2</sup>with NSAIDs, cortisone, and/or topical treatments; <sup>3</sup> NSAIDs, cortisone, topical treatments and/or painkillers.

# Table 2Annual out-of-pocket expenses and<br/>indirect cost per patient of axSpA.

Mean (95% CI)	Annual cost (N=141)		
Total out-of-pocket expenses/patient, €	400 (354 – 453)		
Cost of outpatient visits/patient,	125 (103 – 152)		
Private doctor	87 (71 – 107)		
Private doctor (EOPYY)	8 (3 – 18)		
Hospital appointment (morning)	0 (0 – 0)		
Hospital appointment (evening)	30 (20 – 43)		
Cost of hospitalizations/patient, €	0 (0 – 0)		
Cost of any treatment/patient, €	275 (239 – 323)		
Indirect cost/patient, €	3,322 (2,552 – 4,447)		
Absenteeism cost, €	544 (298 – 1,133)		
Presenteeism cost, €	2,778 (2,163 – 3,551)		

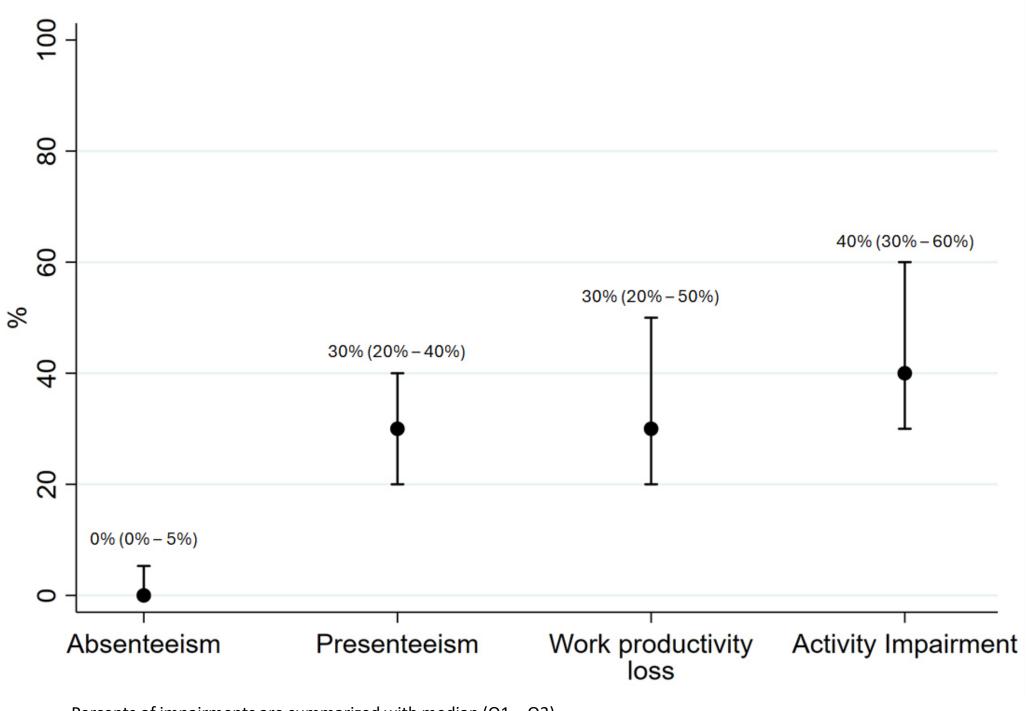
### I feel dependent on others

I often need to stop what I'm doing to rest I get irritated easily by others I have to push myself to do things My condition limits where I can go I can't participate in activities with friends and family I feel older than my age I can't do what I want I often get angry with myself I feel like I'm losing my independence I feel like I can't enjoy my life enough I takes a lot of effort for me to go out and meet other people I have trouble washing myself well I feel tired no matter what I do



#### True Not true

### Figure 4 Work productivity impairment based on WPAI questionnaire.



### Resource use and healthcare cost

- In the past 12 months, 61% of participants visited a private doctor and 57% had at least one hospital appointment.
- Hospitalization occurred in 6% of patients, with a median (Q1 Q3) duration 5 (4 – 10) days.
- The mean annual out-of-pocket expenses per patient was estimated at €400. Indirect cost was estimated at € 3,321. (Table 2)

Absenteeism cost was calculated by multiplying hours lost from work with mean hourly earnings (€21,297 GDP per capita / 245 working days / 8 hours). Weekly presenteeism cost was estimated by multiplying affected hours with reduced productivity percentage and mean hourly earnings. Annual absenteeism and presenteeism costs were weekly costs multiplied by 49 working weeks

Percents of impairments are summarized with median (Q1 - Q3).

AS: ankylosing spondylitis; axSpA: axial spondyloarthritis; CI: confidence interval; DMARDs: Disease-Modifying Anti-Inflammatory Drugs; Q1: upper quartile; Q3: lower quartile; Q0L: quality of life; SpA: spondyloarthritis. WPAI: Work Productivity and Activity Impairment.

Institutions: <sup>1</sup>ECONCARE, Athens 11528, Greece; <sup>2</sup>PanHellenic Federation Reumazin, Thessaloniki, Greece; <sup>3</sup>Patras Patients Association of People with Rheumatic diseases, Patra, Greece; <sup>4</sup>Department of Nursing, University of Peloponnese, Tripoli 22100, Greece; <sup>5</sup>UCB, Athens Greece; <sup>6</sup>UCB, Brussels, Belgium,

**References:** <sup>1</sup>Braun J. Lancet 2007;369(9570):1379-1390; <sup>2</sup>Sieper J. Lancet 2017;390(10089):73-84; <sup>3</sup>Bohn R. Clin Exp Rheumatol. 2018;36(2):263-274; <sup>4</sup>Stolwijk C. Rheum Dis Clin North Am. 2012;38(3):441-476; <sup>5</sup>Yi E. Rheumatol Ther. 2020;7(1):65-87; <sup>6</sup>Santos-Moreno P. Value Heal Reg Issues. 2022;32:88-94; <sup>7</sup>Merino M. Clin Exp Rheumatol. 2021;39(2):1-13; <sup>10</sup>Graham JE. Hippokratia. 2015;19(2):119-124. **Author Contributions**: Substantial contributions to study conception/design, or acquisition/analysis/interpretation of data: **GK, GG, GS, DIL, KL, KK, FA, VK**; Drafting of the publication, or revising it critically for important intellectual content: **GK, GS, KK, FA, VK, DW**; Medical writing: **GS**; Final approval of the publication: **GK, VK, DW**. **Author Disclosures: GG, DIL, KL**: employee of ECONCARE LP which had contracts with UCB, Abbvie, Leo, BMS. **GS**: employee of ECONCARE LP which had contracts with Pfizer via University of the Peloponnese. **KK, FA**: No conflicts of interest. **GK**: Payments from Aristotle University, Thessaloniki. Contracts with UCB, Abbvie, Leo, BMS via consulting firm. **VK**: employee of UCB, Greece. **DW**: employee of UCB, Belgium. **Acknowledgements**: This study was funded by UCB for implementing the statistical analysis and medical writing. We thank the patients and the Greek patients' association "Reumazin", in addition to the investigators and their teams who contributed to this study. The authors acknowledge Frederik Fierensand, UCB, Sergei Kalynych, UCB, Martina Hazlingerova, UCB for publication assistance and Charlotte Frall, Costello Medical, Bristol, UK and Shimaila Siddiqui, Costello Medical, Manchester, UK for editorial assistance. All costs associated with development of this poster were funded by UCB.



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