Background: The journey of axial spondyloarthritis (axSpA) for most patients is slow and arduous.

Objectives: The goal of this analysis is to describe the journey to diagnosis and further management in axSpA patients.

Methods: 2,846 unselected patients participated in EMAS, a cross-sectional study (2017-2018) across 13 European countries. Descriptive analysis of sociodemographic factors, insurance scheme, diagnostic journey and post diagnosis healthcare utilization was performed. Mann-Whitney test was used to analyse possible differences between BASDAI (+ v - x) and the number of visits to healthcare professionals and follow-up tests undertaken.

Results: Mean age was 43.9 years, 61.3% were female, 48.1% university educated, 67.9% married, 53.9% employed and 81.7% had public health insurance. Mean age at symptoms onset was 26.6 (11.1), while mean age at diagnosis was 33.7 (11.5) and mean diagnostic delay was 7.4 years. Over 50% had a diagnostic delay of ≥4 years. Prior to receiving a diagnosis, patients visited on average 2.6 specialists. The most commonly performed diagnostic tests were x-rays (72.3%), HLA B27 tests (65.4%) and MRIs (64.3%). 78.4% were diagnosed by a rheumatologist while 14.9% received their diagnosis by a GP. Patients who experienced a diagnostic delay of more than a year (n= 2,208) undertook a considerable number of visits to specialists and medical tests in the year prior to participating in EMAS, which increased with disease activity. Patients with active disease (BASDAI +4) reported a higher number of visits to rheumatologists (3.7±3.5 vs 2.9±2.6), general practitioners (6.6±10.0 vs 3.5±4.1), physiotherapists (19.3±25.0 vs 11.7±17.0), and psychologists/psychiatrists (3.4±10.7 vs 1.9±7.7). Patients with active disease also undertook more x-rays (1.8±2.9 vs 1.3±1.9), MRI scans (0.9±1.2 vs 0.6±1.1), and blood tests (4.7±6.4 vs 3.6±3.2). However, one in five patients visited the rheumatologist only once in the year prior to EMAS (21.1%).

Conclusion: Diagnostic delay continues to be a key challenge in the axSpA patient journey, with patients waiting an average of 7.4 years and visiting multiple doctors prior to diagnosis. Once diagnosed, disease management presents a further challenge, as patients with higher disease activity reported more healthcare professional visits as well as medical tests. Safeguarding health and controlling healthcare utilization requires effective disease management, greater education for non-specialists, rapid referral routes for diagnosis and collaborative care between specialists and non-specialists.

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