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ORIGINAL RESEARCH

International Map of Axial Spondyloarthritis (IMAS): results from the perspective of 5557 patients from 27 countries around the globe

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ABSTRACT

Background The International Map of Axial Spondyloarthritis (IMAS) is a global initiative aimed to assess the impact and burden of axial spondyloarthritis (axSpA) and identify the unmet needs from the patient's perspective.

Method IMAS is a collaboration between the Axial Spondyloarthritis International Federation (ASIF), the University of Seville, Novartis Pharma AG and steered by a scientific committee. IMAS collected information through an online cross-sectional survey (2017–2022) from unselected patients with axSpA from Europe, Asia, North America, Latin America and Africa who completed a comprehensive questionnaire containing over 120 items.

Results 5557 patients with axSpA participated in IMAS. Mean age was 43.9 ±12.8 years, 55.4% were female, 46.2% had a university education and 51.0% were employed. The mean diagnostic delay was 7.4 ±9.0 years (median: 4.0), and the mean symptom duration was 17.1 ±13.3 years. 75.0% of patients had active disease (Bath Ankylosing Spondylitis Disease Activity Index ≥4), and 59.4% reported poor mental health (12-item General Health Questionnaire ≥3). In the year before the survey, patients had visited primary care physicians 4.6 times and the rheumatologist 3.6 times. 78.6% had taken non-steroidal anti-inflammatory drug ever, 48.8% biological disease-modifying antirheumatic drugs and 43.6% conventional synthetic disease-modifying antirheumatic drugs. Patients's greatest fear was disease progression (55.9%), while the greatest hope was to be able to relieve pain (54.2%).

Conclusions IMAS shows the global profile of patients with axSpA, highlighting unmet needs, lengthy delays in diagnosis and high burden of disease in patients with axSpA worldwide. This global information will enable more detailed investigations to obtain evidence on the critical issues that matter to patients around the world to improve their care and quality of life.

WHAT IS ALREADY KNOWN ON THIS TOPIC?

⇒ Axial spondyloarthritis (axSpA) is a chronic inflammatory disease that affects patients' physical and mental health, as well as their social and work life.

WHAT THIS STUDY ADDS?

⇒ This study analyses the impact of axSpA in more than 5000 patients worldwide.

HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY?

⇒ These data provide a more detailed and regional understanding of patients with axSpA unmet needs and their physical and mental health.

INTRODUCTION

Axial spondyloarthritis (axSpA) is a chronic inflammatory rheumatic musculoskeletal disease with a predilection for the axial skeleton.[1] AxSpA comprises patients with definite radiographic sacroiliitis (radiographic axSpA), without radiographic sacroiliitis (non-radiographic axSpA (nr-axSpA).[2] Patients with axSpA frequently experience peripheral (arthritis, enthesitis and dactylitis) and extramusculoskeletal manifestations such as uveitis, inflammatory bowel disease and psoriasis.[3]

Longer diagnostic delay is associated with higher disease activity, poorer function, worse spinal mobility, greater evidence of radiographic damage and worse treatment response.[4] In this sense, a recent systematic review of worldwide patients has shown a diagnostic delay of 6.4 years.[5] Therefore, reducing diagnostic delay in patients with axSpA should be one of the key priorities of healthcare professionals (HCPs).

Monitoring disease activity is crucial to prevent progression in patients with axSpA. A longitudinal study has shown that ongoing disease activity contributes to the radiographic progression of the spine in axSpA, this being

more pronounced in males and at earlier stages of the disease.[5] In addition, reduced quality of life in patients with axSpA is mainly associated with disease activity and worsening of functionality.[6]

Functional disability is also an important consequence of axSpA, particularly affecting patients' working lives.[7 8] Furthermore, the presence of comorbidities in patients with axSpA is common, highlighting the increase in cardiovascular morbidity.[9]

Although the Assessment of SpondyloArthritis international Society (ASAS)-European Alliance of Associations for Rheumatology (EULAR) updates their recommendations for the management of axSpA,[1] a more patient-oriented approach is needed to understand the impact of living with the condition such as the functional limitations and barriers they experience in their daily lives, as well as their fears and hopes. For this reason, given the lack of evidence from the patient's perspective, the Atlas of Axial Spondyloarthritis in Spain was created by patients for patients with the aim of gathering and analysing self-reported data that would help to explain their needs more exhaustively. The rapid dissemination of this Atlas led to its expansion at the European level, giving rise to the European Map of Axial Spondyloarthritis (EMAS) and consequently its global expansion to the International Map of Axial Spondyloarthritis (IMAS), which now comprises a total of 27 countries in Europe, Asia, North America, Latin America and Africa.

This study aims to present the scope of the IMAS study, study population distribution and characteristics, as well as provide main findings of the global burden of disease.

METHODS

Study design and survey development

The beginning of this international axSpA project started by Atlas of Axial Spondyloarthritis in Spain 2017, an initiative promoted by the Spanish Federation of Spondyloarthritis Associations, conducted by the research group Health & Territory Research (HTR) of the University of Seville and the Max Weber Institute, with the collaboration of the Spanish Society of Rheumatology. It was sponsored by Novartis Farmacéutica, Spain.[10] Subsequently, 12 European countries joined the project (between 2017 and 2018): Austria, Belgium, France, Germany, Italy, the Netherlands, Norway, Russia, Slovenia, Sweden, Switzerland and the UK, becoming the EMAS.[11] Due to the great impact of EMAS, countries from all over the world joined the project, resulting in a final sample of 5557 patients from 27 countries, and is now known as the IMAS. The IMAS initiative is a research collaboration between the Axial Spondyloarthritis International Federation, the HTR group of the University of Seville, and Novartis Pharma AG, together with a scientific committee composed of patient representatives, rheumatologists, psychologists and health researchers.

Settings

IMAS collected information through an online cross-sectional survey (2017–2022) of unselected patients with axSpA from Europe, Asia, North America, Latin America and Africa (figure 1). The questionnaire was administered via an online survey platform managed by Ipsos. This questionnaire was translated into the main language of each of the 27 participating IMAS countries. Patients completed a comprehensive questionnaire containing over 120 items on sociodemographics, health behaviours, diagnosis and disease characteristics, comorbidities, mental health (12-item General Health Questionnaire [GHQ-12]), healthcare utilisation, pharmacological treatments, disease activity (Bath Ankylosing Spondylitis Disease Activity Index [BASDAI]), physical activity and functioning, employment and disease-related fears and hopes. More information on the particular items, their domains and the specific questions can be found in the EMAS seminal article.[11]

Participants and recruitment

Patients were recruited on a voluntary basis from an internal Ipsos panel and local patient organisations between 2017 and 2022. The questionnaire was administered via an online platform for survey data collection. Coordination of the patient survey and data collection was led by Ipsos S.A. The sample eligibility criteria were as follows:

- Age ≥18 years.
- Residents in the specified country.
- A self-reported diagnosis of axSpA (either AS or nr-axSpA).

Variables

In the present study, sociodemographic variables, life habits, patient-reported outcomes, diagnosis characteristics, disease manifestations, treatments, comorbidities, fears and hopes are reported. The measurement and categories of variables are shown in table 1.

Patient-reported outcomes were collected from the following scales:

- Spinal Stiffness Index: an index developed by the University of Seville specifically for the IMAS survey to assess the degree of spinal stiffness experienced by patients in the spinal column, distinguishing between the cervical, dorsal and lumbar areas. For these three areas, the degree of stiffness was asked: no stiffness (scored as 1), mild (scored as 2), moderate (scored as 3) and severe (scored as 4). The index is obtained as the sum of the scores collected in the three areas, with a range between 3 and 12 points. Higher values of the index indicate greater spinal stiffness.[10] The Pearson correlation between morning stiffness (Q5-BASDAI) and time of morning stiffness (Q6-BASDAI) were 0.332 and 0.248, respectively. Furthermore, the correlation between spinal stiffness index and global BASDAI scale (0–10) was 0.415

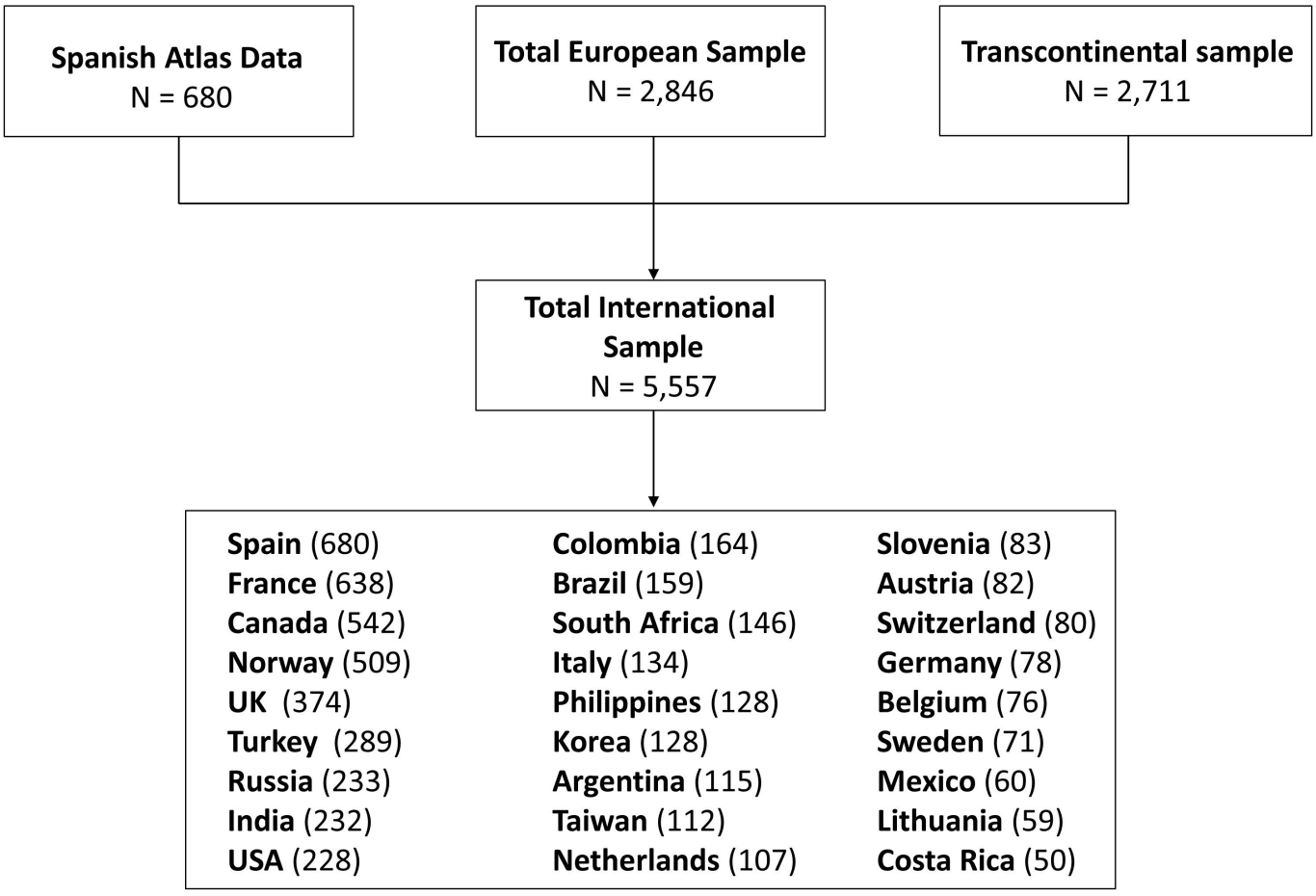

Figure 1 International Map of Axial Spondyloarthritis sample recruitment flow chart.

- Functional Limitation Index: an index developed by the University of Seville specifically for the IMAS survey to assess the degree of limitation in 18 activities of daily life: dressing, bathing, grooming, tying shoe laces, moving about the house, climbing stairs, getting into/out of bed, using the bathroom, shopping, preparing meals, eating, household cleaning, walking down the street, using public transportation, going to the doctor, driving, doing physical exercise and having sex. For these 18 areas, the functional limitation was asked: no restriction (scored as 0), low (scored as 1), medium (scored as 2) and high (scored as 4). The index is obtained as the sum of the scores obtained in the 18 areas, with a range between 0 and 54 points. Higher values of the index indicate higher functional limitation.[10] The Pearson correlation between global BASDAI scale (0–10) and functional limitation index was 0.357
- BASDAI: a self-administered questionnaire that evaluates disease activity in patients with axSpA. It includes six questions relating to the following symptoms: fatigue; pain in the spinal column; inflammation/pain in joints other than the neck, back, and hips; areas of localised tenderness (also called enthesitis, or inflammation of tendons and ligaments); and the level and duration of stiffness in the morning, all assessed on a 0–10 numeric rating scale.[12] The overall BASDAI has a range from 0 to 10. Cut-off point at 4 indicates active disease (BASDAI ≥4).
- GHQ-12: is a screening measure of common mental health disorders in the general population, including symptoms of anxiety, depression, social dysfunction and loss of confidence.[13 14] The overall GHQ-12 has a range from 0 to 12. Cut-off point at 3 indicates risk of poor mental health (GHQ score ≥3).

Study population

A total of 5557 patients with axSpA participated in the IMAS. The region with the highest number of participants was Europe (n: 3493), followed by North America (n: 770), Asia (n: 600), Latin America (n: 548) and Africa (n: 146; figure 2).

Bias and statistical methods

For those variables with missing values, reduced sample sizes are reported to eliminate unwanted bias in these variables. The results are presented as summary statistics, with mean, median and SD for continuous variables, and frequency and percentages for categorical variables. Data analysis was conducted using SPSS V.26.0.

Table 1 Variables, questions and measurements/categories included in this analysis

Variables	Questions	Categories/measures
Sociodemographic		
Age	Please specify your age	In years
Gender	Please specify your gender	Male, female
Marital status	Please select your marital status	Single, married, divorced or separated, widow or widowed
Education level	Please select your level of education completed	No schooling, primary school, high school, university
Employment status	What is your current employment status?	Employed, unemployed, temporary sick leave, permanent sick leave, retired or early retired, homemaker, student
Life habits		
Physical activity	Do you do any physical or sporting activity, including walking?	Yes, no
Smoking	Please select the option that best describes your current smoking behaviour	Non-smoker, socially, less than 10 cigs/week, 10–20 cigs/week, 21–60 cigs/week, over 60 cigs/week
Alcohol consumption	Please select the option that best describes your alcohol consumption behaviour	Never, occasionally, 1–3 times per month, 1–2 times per week, 3–5 times per week, every day
Patient association membership	Are you a member of any support group or association for spondylitis/spondyloarthritis?	Yes, no
Diagnosis characteristics		
Age at onset of first symptoms	Age of onset of first symptoms (pain, inflammation, stiffness) associated with spondylitis/spondyloarthritis	In years
Age at diagnosis	Age at which you were diagnosed with spondylitis/spondyloarthritis	In years
Diagnostic delay	Calculated based on the age at diagnosis	In years
Symptom duration	Calculated based on the age of onset of first symptoms	In years
HLA-B27	What was the result of the genetic test (HLA-B27)?	Positive, negative
Medication		
NSAIDs	Have you ever been treated with a non-steroidal anti-inflammatory drug (NSAID) for your spondylitis/spondyloarthritis?	Yes, no
bDMARDs	Have you ever been treated with a biologic for your spondylitis/spondyloarthritis?	Yes, no
csDMARDs	Have you ever been treated with a conventional synthetic disease-modifying antirheumatic drug (csDMARD) for your spondylitis/spondyloarthritis?	Yes, no
Disease extramusculoskeletal manifestations		
Uveitis	Please indicate whether you have been diagnosed with any of the following:	Uveitis
Inflammatory bowel disease	Please indicate whether you have been diagnosed with any of the following:	Inflammatory bowel disease
Psoriasis	Please indicate whether you have been diagnosed with any of the following:	Psoriasis
Mental comorbidities		

Continued

Table 1 Continued

Variables	Questions	Categories/measures
Anxiety	Please indicate whether you have been diagnosed with any of the following:	Anxiety
Depression	Please indicate whether you have been diagnosed with any of the following:	Depression
Sleep disorders	Please indicate whether you have been diagnosed with any of the following:	Sleep disorders
Fears and hopes		
Fears	Please, describe your fears in relation to your spondylitis/spondyloarthritis axial SpA (AS):	List of 33 fears
Hopes	Please, describe your hopes in relation to your spondylitis/spondyloarthritis axial SpA (AS)	List of 24 hopes

bDMARDs, biological disease-modifying antirheumatic drugs.;

RESULTS

Of the 5557 patients included in IMAS, the mean age was 44 years, more than half were women, 2 in 3 were married and almost half had achieved a university education. Furthermore, half of IMAS patients were employed, only 7.2% were unemployed and nearly 20% were on sick leave (temporary or permanent). Regarding lifestyle habits, most of them engaged in physical activity, 70.1% of patients did not smoke, 30.0% did not consume alcohol and 40.2% did so only occasionally. In addition, less than half belonged to a patient organisation (table 2).

Regarding the patient-reported outcomes, patients had a mean (±SD) BASDAI score of 5.4 (±2.1), mean spinal stiffness score of 7.5 (±2.5), mean score for functional limitation index of 19.8 (±15.4), and mean GHQ-12 score of 4.7 (±4.1). Furthermore, three out of four had active disease and more than half were at risk of poor mental health. With respect to diagnostic characteristics, the mean (±SD) age of participants at symptom onset was 26.8 (±11.3) years, while mean age at diagnosis was 33.9 (±11.6) years. The mean diagnostic delay of participants was 7.4 years (±9.0), and the median was 4.0 years. Finally, patients have been living with the disease for a mean of 17.1 years (±13.3). 71.1% of patients presented an HLA-B27 positive test. Three out of four patients had taken NSAIDs, while less than half had taken bDMARDs or

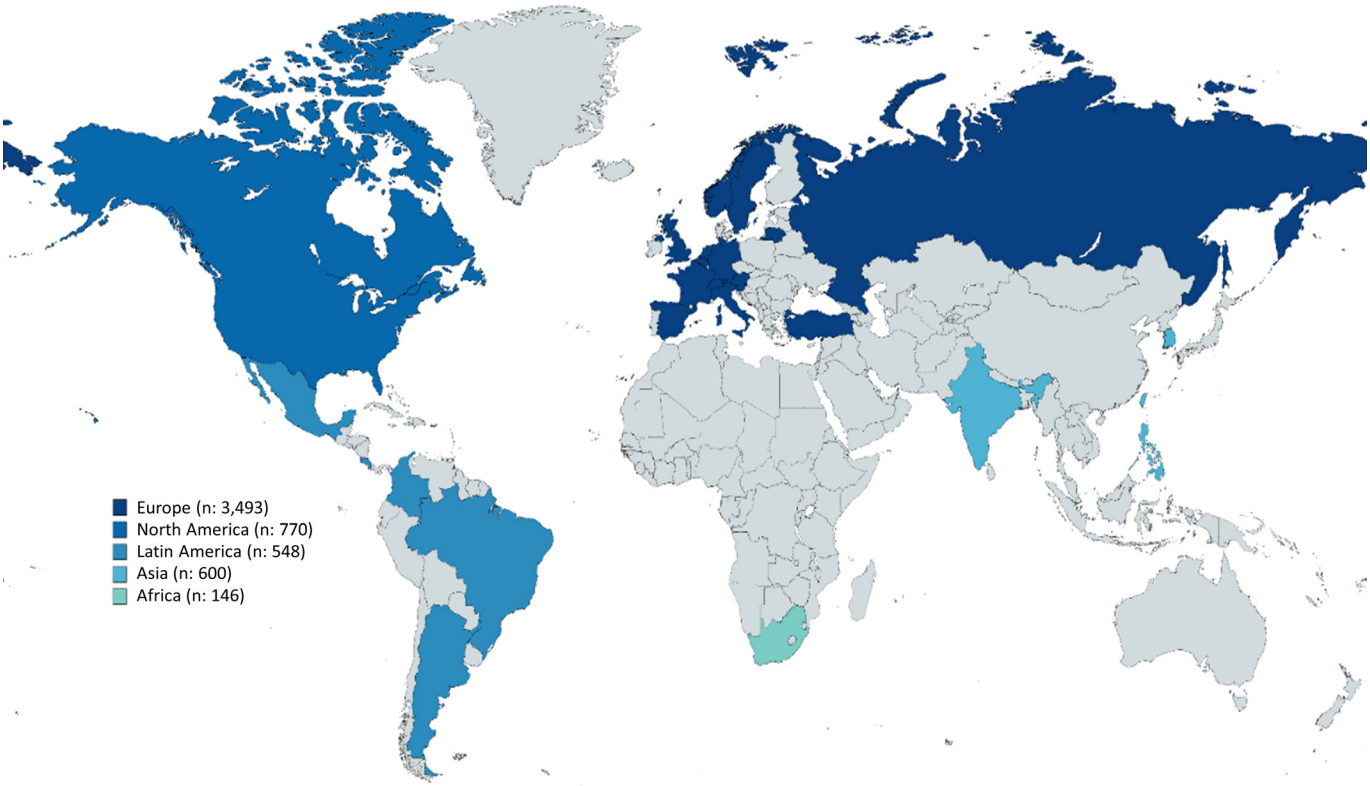

Figure 2 Distribution of International Map of Axial Spondyloarthritis patients by region (n=5557).

Table 2 Main sociodemographic characteristics and lifestyle habits of patients with axSpA (N: 5557, unless differently specified)

	Mean±SD or n (%)
Sociodemographic	
Age, years	43.9 ±12.8
Gender, n=5555	
Female	3080 (55.4)
Marital status, n=5552	
Single	1288 (23.2)
Married	3674 (66.2)
Divorced/separated	510 (9.2)
Widow/widowed	80 (1.4)
Education level	
No schooling	40 (0.7)
Primary school	321 (5.8)
High school	2627 (47.3)
University	2569 (46.2)
Employment status, n=5183	
Employed	2641 (51.0)
Unemployed	373 (7.2)
Temporary sick leave	653 (12.6)
Permanent sick leave	415 (8.0)
Retired or early retired	616 (11.9)
Homemaker	365 (7.0)
Student	120 (2.3)
Life habits	
Physical activity, n=5476	
Yes	4468 (81.6)
Smoking, n=5288	
Non-smoker	3708 (70.1)
Alcohol consumption, n=5462	
Never	1638 (30.0)
Patient association membership	
Yes	2407 (43.3)

axSpA, axial spondyloarthritis.

Table 3 Patient-reported outcomes, extra-musculoskeletal manifestations, disease characteristics, treatments and mental comorbidities of patients with axSpA (N: 5557, unless specify)

	Mean ±SD or n (%)
Diagnostic characteristics	
Age at onset of first symptoms, years, n=5432	26.8 ±11.3
Age at diagnosis, years, n=5433	33.9 ±11.6
Diagnostic delay, years, n=5327	7.4 ±9.0
Symptom duration, years, n=5421	17.1 ±13.3
HLA-B27 positive, n=3465	2464 (71.1)
Extramusculoskeletal manifestations	
Uveitis, n=5050	1171 (23.2)
Inflammatory bowel disease, n=5156	724 (14.0)
Psoriasis, n=2265	461 (20.4)
Patient-reported outcomes	
BASDAI (0–10), n=5295 Active disease (BASDAI ≥4)	5.4 ±2.1 3971 (75.0)
Spinal Stiffness Index (3–12), n=5371	7.5 ±2.5
Functional Limitation Index (0–54), n=5482	19.8 ±15.4
GHQ score (0–12), n=5351 Risk of poor mental health (GHQ score ≥3)	4.7 ±4.1 3177 (59.4)
Treatment	
Use of NSAIDs, n=4991	3921 (78.6)
Use of csDMARDs, n=4911	2139 (43.6)
Use of bDMARDs, n=5034	2456 (48.8)
Mental comorbidities	
Anxiety, n=5244	1774 (33.8)
Depression, n=5239	1629 (31.1)
Sleep disorders, n=5216	1902 (36.5)

axSpA, axial spondyloarthritis; bDMARDs, biological disease-modifying antirheumatic drugs; csDMARDs, conventional synthetic disease-modifying antirheumatic drugs; NSAIDs, non-steroidal anti-inflammatory drugs.

csDMARDs. Of the extramusculoskeletal manifestations evaluated, 23.2% had uveitis, 14.0% had inflammatory bowel disease and 20.4% had psoriasis. While for risk of mental health comorbidities, one out of three presented a probable diagnosis of anxiety, depression and sleep disorders (table 3).

All regions had a mean age of 44 years with the exception of Asia (38 years). The gender proportion was balanced (or slightly higher in the female gender) in Europe and the Americas; however, the majority of patients were men in Asia and women in South Africa. Almost half of the patients in Europe and North America had a university education, while South Africa and Asia had the highest proportion of patients who were members of patient organisations. Patients in South Africa reported the longest diagnostic delay, the highest proportion of active disease and the highest proportion of poor mental health, compared with Asia which had the best results. The highest proportion of patients with severe spinal stiffness was in South Africa, followed by Europe and North America. Finally, more than half of the patients in the Americas had taken biologics, whereas this figure was close to 40% in the rest of the regions (table 4).

The most frequent fears reported were disease progression (55.9%), suffering pain (55.1%), loss of mobility (48.7%) and loss of independence (44.8%), while the

Table 4 Regional differences in patients with axSpA (N: 5557, unless specify)

	Mean ±SD or n (%)				
	Europe	North America	Latin America	Asia	South Africa
Age	44.7±12.9	44.4±14.2	44.2±11.6	38.4±10.6	44.7±10.3
Female gender, n=5555	2049 (58.7)	479 (62.3)	307 (56.0)	125 (20.8)	120 (82.2)
University level	1667 (47.7)	445 (57.5)	221 (40.3)	182 (30.3)	54 (37.0)
Member of patient organisations	1484 (42.5)	303 (39.4)	165 (30.1)	330 (55.0)	125 (85.6)
Diagnostic delay, n=5327	7.7±8.8	9.0±11.0	5.9±8.6	4.2±5.4	10.8±10.6
Active disease (BASDAI ≥4), n=5295	2464 (76.3)	571 (74.2)	398 (72.6)	411 (68.5)	127 (87.0)
High level of spinal stiffness, n=5418	1391 (41.5)	252 (32.7)	121 (22.1)	139 (23.2)	76 (52.1)
Poor mental health (GHQ-12 ≥3), n=5351	1997 (60.8)	418 (54.3)	349 (63.7)	311 (51.8)	102 (69.9)
bDMARDs (ever), n=5034	1337 (45.0)	476 (61.8)	359 (65.5)	222 (37.0)	62 (42.5)

axSpA, Axial Spondyloarthritis; BASDAI, Bath Ankylosing Spondylitis Disease Activity Index; bDMARD, Biological Disease-modifying Antirheumatic Drugs; GHQ-12, 12-item General Health Questionnaire.

most frequent hopes were eliminating pain (54.2%), stop disease progression (51.8%), improve quality of life (45.0%) and finding new techniques or drugs to fight the disease (42.5%).

DISCUSSION

Data from this worldwide sample of patients with axSpA have highlighted the extent of the disease burden and the difficult journey to diagnosis experienced by these patients.

The results showed a mean of delay of 7.4 years before diagnosis, being the highest in South Africa (10.8 years) and lowest in Asia (4.2). This is slightly higher than that reported in a recent meta-analysis by Zhao *et al*[15] which showed a mean diagnostic delay of 6.7 from a review of 64 different studies on patients with axSpA.[15] Our cohort, despite being relatively young (43.9 years), report symptoms of the disease for a long period of time (17.1 years of symptom duration). These results are unacceptable by most international standards and highlight the need to improve diagnostic tools (eg, specific biomarkers development and interpretation of imaging techniques) for the diagnosis of patients with axSpA. Furthermore, the application of referral strategies in the clinical context is essential to reduce the delay in diagnosis of patients.[16]

In addition, this analysis of IMAS patients has shown a severe physical burden, including high disease activity, spinal stiffness and functional limitations. This deterioration of patients' physical health is accompanied by poor mental health, specifically that spinal involvement is associated with increased rates of anxiety and depression.[17] In this context, these functional parameters such as pain intensity and spinal stiffness may be reduced with physical therapy.[18] South African patients in IMAS cohort presented worse physical, mental health and spinal stiffness compared to Asians, who had the best outcomes. In addition, lifestyle habits may influence this impact on physical health, as patients who smoke show longer duration of morning stiffness, less spinal mobility, higher disease activity and worse quality of life.[19] Although, 70% of IMAS patients did not smoke and 30% never consumed alcohol. This highlights the positive lifestyle habits adopted by many patients with axSpA.

Regarding extra-musculoskeletal manifestations, 23.2% of the IMAS patients had uveitis and 14.0% had inflammatory bowel disease, contradicting a recent meta-analysis that showed a lower prevalence of uveitis (5.7%) and inflammatory bowel disease (4.1%).[20] However, another study showed that 27% of patients had uveitis.[21] The recent phenotype study of patients with axSpA from the IMAS cohort showed that the region with the highest proportion of uveitis and psoriasis was North America (31.0% and 26.0% respectively), while inflammatory bowel disease was most frequent in South Africa (24.0%).[22] It is important to emphasise that extramusculoskeletal manifestations occurrence increase overtime and are frequent in patients with axSpA; therefore, management through the choice of the correct treatment for each extramusculoskeletal manifestation is essential for the management of the whole disease.

More than 30% of IMAS patients had a diagnosis of poor mental health including anxiety, depression and sleep disorders. These psychological disorders in patients with axSpA are similar to a recent meta-analysis of 29 studies reporting 35% of patients had anxiety and 29% depression symptoms.[23] Suffering from these psychological disorders could aggravate other factors related to the patient's life and influence axSpA disease. Similarly, other studies showed that anxiety and depression were associated with more severe disease activity, functional impairment and less work productivity.[24 25] Furthermore, 59.4% of IMAS patients were at risk of poor mental

health measured by the GHQ-12. The subsample of European IMAS patients with poorer mental health also reported higher disease activity, especially symptoms of anxiety and depression, being unemployed or on sick leave, greater functional limitation, and were younger.[26] Therefore, we argue early referral of patients by rheumatologists and primary care physicians to mental health specialists is essential.

Compared with IMAS patients with axSpA, European (EMAS) patients had similar diagnostic characteristics, disease activity and mental health.[11] The consistent results of the key metrics between IMAS and EMAS (eg, unacceptable diagnostic delay) highlight that these are global unmet needs despite the differences across regions in axSpA phenotype and healthcare systems.

It is however very important in our view that the situation in regions outside Europe is also reported, and IMAS is one of the rare global studies, in which the situation around the diagnosis and care of SpA can be analysed on the global level. Therefore, looking at European and not-European patents in the global perspective is one of the main strengths of this study.

IMAS is the largest survey of people with axSpA to date, with 5557 respondents from 27 countries globally. With respect to the sample of patients with axSpA in the ASAS-perSpA (Peripheral involvement in spondyloarthritis) and ASAS-COMOSpA (COMOrbidities in SPondyloArthritis) cohorts, IMAS patients were of similar age, higher proportion of women, longer diagnostic delay and higher disease activity.[27 28] Furthermore, consistent with the findings of the ASAS-COMOSPA and other international studies, Latin America reported higher prevalence of peripheral arthritis and enthesitis than EU patients. HLA B27 positive in Latin American patient's trends to be lower than European, with a wide range of per cent according to the country.[29–31] However, IMAS not only captures the rheumatological characteristics of the disease but provides a comprehensive understanding of the patient's perspective on psychological health, functional limitations in daily activities, work and social life issues, as well as patients' hopes and fears. All this knowledge could have beneficial implications for the diagnosis, management and follow-up of patients with axSpA by HCPs knowing the profile of the patients, the characteristics of their diagnosis as well as the impact caused on their physical and mental health.

In this sense, the implementation of appropriate equitable health policies aims to improve the health and well-being of the population and especially of the most vulnerable groups, such as people with chronic inflammatory and autoimmune diseases to which spondyloarthritis belongs. In this regard, in 2022, 9.2% of GDP (gross domestic product) of OECD (Organization for Economic Cooperation and Development) countries was allocated to healthcare expenditure, being the countries with the highest proportions US (16.6%), Germany (12.7%) and France (12.1%), although countries such as Canada and Japan are above 10%. In most Central and Eastern European OECD countries, as well as in Latin American OECD countries, healthcare expenditure represented between 6% and 9% of their GDP. Finally, health expenditure as a percentage of GDP was below 6% in Mexico, Luxembourg and Turkey.[32] In 2019, these percentages of health spending in some low-income and lower-middle-income countries reached only 3.9% of their GDP.[33]

According to the Global Burden of Disease Study 2021, 221 million people suffered from other musculoskeletal disorders in 1990, rising to 494 million in 2020, and is projected to exceed 1 billion by 2050.[34] Due to the progressive and alarming increase in their prevalence, it is important to prioritise the treatment of these musculoskeletal diseases. In this sense, the Community Oriented Program for the Control of Rheumatic Diseases study provides estimates of musculoskeletal symptoms, including pain, stiffness and loss of mobility.[35]

Furthermore, musculoskeletal conditions are an important cause of disability and, therefore, should be considered when designing health policies,[34] providing early access to the specialist—in this case the rheumatologist—for diagnosis and management as well as increasing access to diagnostic equipment, including MRI scan and HLA-B27 tests. In addition, the development of these health policies should take into account equity in access to care and spatial distribution of resources, as previous studies have shown a lack of access to specialist healthcare services for rheumatic and musculoskeletal patients, especially those living in rural and/or remote areas.[36] Finally, recommendations of international scientific societies such as the EULAR, the American College of Rheumatology, or specifically the SpondyloArthritis International Society (ASAS) for axSpA should also be taken into account, as they establish guidelines based on evidence and the criteria of international experts and clinicians on the diagnosis, management and follow-up of patients with musculoskeletal conditions, which should be taken into account when designing and implementing health policies.[1 37 38]

Hence, due to the significant impact of axSpA disease on patients and the healthcare inequalities across countries and regions, the healthcare resources available for axSpA should be increased, improving early referral to a rheumatologist and access to testing, reducing the diagnostic delay and disease burden of these patients.

Challenges such as long diagnostic delay, high disease activity, functional limitations and disability are common to patients with axSpA regardless of place of residence or socioeconomic status. Specifically, the IMAS study has identified difficulties in early diagnosis worldwide, although particularly high in South Africa and North America. These limitations in the early diagnosis of axAspA could be due to factors such as reduced access to diagnostic equipment such as MRI or HLA-B27 testing, as well as the shortage of rheumatologists and general practitioners with specific training in spondyloarthritis.

In addition, there are inequalities in access to healthcare due to distances to rheumatologists - particularly in countries such as Canada or Russia - or due to the greater use of private healthcare systems in countries such as South Africa or the USA caused by shortcomings in the public system. For treatments, patients in South Africa had used NSAIDs and csDMARDs more frequently, whereas bDMARDs were used more frequently in the Americas. However, in Asia, we found the lowest proportion of use of NSAIDs and bDMARDs.[22] These differences could be due to barriers to access to these innovative treatments by specific patient groups.

Another critical unmet need of patients with axSpA is their mental health status. In this context, as the present study shows, about 60% of patients with axSpA report poor mental health, most likely as a consequence of coping with the disease. Mental health—an important and often neglected area of health—should be one of the key priorities for improvement in the field of axSpA because of its impact on patients' emotional, psychological and social well-being.

It is essential to raise awareness of all the issues and unmet needs in patients with axSpA to reduce the burden of disease and improve the quality of life

However, IMAS has some limitations. First, the survey was based on self-reported data and we were not able to confirm participants' diagnosis or support their responses with clinical assessments. Thus, patient-reported outcomes data such as BASDAI or GHQ-12 scores may also suffer from self-report bias. No lab values or imaging for the assessment of disease activity and severity were available. Another limitation is the use of non-validated scales or indices to assess functional limitations in daily activities and spinal stiffness. These indices were developed during the preliminary phase of survey development, when patients expressed concern that existing measures did not capture all aspects of their disease such as limitations and stiffness. In addition, the sample size of each of the countries is different, which gives greater weight to the countries with a larger sample, and the Arab and black ethnic groups less well represented. In addition, the results on access to HCPs and medication should be interpreted with caution due to the large number and diversity of countries that participated in IMAS. Furthermore, it should be noted that the patients were not recruited by academic centres but were recruited on a voluntary basis from an internal Ipsos panel and local patient organisations. Moreover, the potential selection bias could indicate bias due to the fact that the patients were frequently young, with a slightly higher proportion of women, most of them married and almost half with university education. The reasons for this gender bias could be reflected to women's greater willingness to participate in online surveys.[39] Finally, the proportions of patients who did physical activity and employed patients is higher than in other studies.

Despite these limitations, this data set provided by IMAS will allow for more detailed global and regional research to obtain evidence on critical issues that matter to patients, such as functional limitations, spinal stiffness, mental health, as well as unmet needs. The IMAS study includes a cohort of more than 5000 patients with axSpA, including patient-reported outcomes with the purpose of investigating both the clinical aspects of the disease as well as their experiences living with axSpA. The efforts of the researchers were recognised when IMAS won the EFPIA (European Federation of Pharmaceutical Industries and Association) Connecting Healthcare 2021 Awards for its ability to bring patients and medical professionals together in an initiative aimed at improving the level of care and quality of life of patients with axSpA globally. In addition, IMAS has been extensively disseminated in international peer-reviewed journals and at international conferences.[8 10 11 26 40–44]

The present manuscript has been developed based on an abstract published in EULAR 2023 about global IMAS data.[45] A deeper analysis of the inter-region differences in the phenotype of IMAS patients is published elsewhere.[38] In addition, the future of IMAS is to raise awareness of topics of interest such as diagnostic delay and the patient's journey to diagnosis, healthcare utilisation, disease activity, gender differences, work-related issues or mental health.

CONCLUSIONS

For the first time, this study presents aggregate global results from IMAS, the largest survey of axSpA patients in terms of geographic scope. IMAS has shown the global profile of patients with axSpA, highlighting unmet needs, lengthy delay in diagnosis, high disease activity, high functional limitations, spinal stiffness and substantial mental health burden in patients with axSpA worldwide. This global information will enable a more detailed and regional understanding of patients with axSpA to improve their unmet needs and their physical and mental health. IMAS provides insight into how this patient group copes with the challenges of living with this chronic disease, which should be considered by HCPs when treating and managing these patients.

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