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The International Map of Axial Spondyloarthritis Survey: A US Patient Perspective on Diagnosis and Burden of Disease

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Objective. Axial spondyloarthritis (axSpA) is a chronic inflammatory disease that causes inflammation in the axial skeleton, resulting in structural damage and disability. We aimed to understand the effect of axSpA on work activity, day-to-day function, mental health, relationships, and quality of life and to examine barriers to early diagnosis.

Methods. A 30-minute quantitative US version of the International Map of Axial Spondyloarthritis survey was administered online to US patients aged 18 years and older with a diagnosis of axSpA who were under the care of a health care provider from July 22 to November 10, 2021. This analysis describes demographics, clinical characteristics, journey to axSpA diagnosis, and disease burden.

Results. We surveyed 228 US patients with axSpA. Patients had a mean diagnostic delay of 8.8 years, with a greater delay in women versus men (11.2 vs. 5.2 years), and 64.5% reported being misdiagnosed before receiving an axSpA diagnosis. Most patients (78.9%) had active disease (Bath Ankylosing Spondylitis Disease Activity Index score ≥4), reported psychological distress (57.0%; General Health Questionnaire 12 score ≥3), and experienced a high degree of impairment (81.6%; Assessment of Spondyloarthritis International Society Health Index score ≥6). Overall, 47% of patients had a medium or high limitation in activities of daily living, and 46% were not employed at survey completion.

Conclusion. The majority of US patients with axSpA had active disease, reported psychological distress, and reported impaired function. US patients experienced a substantial delay in time to diagnosis of axSpA that was twice as long in women versus men.

INTRODUCTION

Axial spondyloarthritis (axSpA) is a chronic inflammatory disease that primarily affects the axial skeleton and can cause spinal fusion (1). Inflammatory back pain (IBP) is the predominant clinical manifestation reported, whereas other symptoms include enthesitis, peripheral arthritis, and extra-musculoskeletal manifestations, such as uveitis, psoriasis, and inflammatory bowel disease (2,3). AxSpA comprises both radiographic (traditionally known as ankylosing spondylitis [AS]) and nonradiographic (nonradiographic axSpA [nr-axSpA]) forms (1). Diagnosis of axSpA can be challenging because there are no validated diagnostic criteria and disease awareness is inadequate, which can lead to patients experiencing average diagnostic delays of up to 10 years in the US (4–7), with longer delays reported in women (8).

Patients with axSpA often experience high disease burden and subsequent reduced quality of life (QOL) due to the underlying inflammation that causes chronic pain, stiffness, structural damage, fatigue, and functional disability (9,10). In addition to extra-musculoskeletal manifestations, axSpA is also associated with an increased risk of developing certain comorbidities, including cardiovascular disease, depression, anxiety, and osteoporosis, which may also contribute to reduced QOL and worsened physical function (3,11).

Patient-reported outcomes (PROs) are useful tools to assess the impact of disease on various aspects of patients' daily lives and are recommended as part of disease management and monitoring to include the patient perspective in axSpA (12,13); however, PROs are infrequently used in routine clinical practices, and there are limited reports on patients' experiences living with this

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chronic illness. Understanding the patient experience with axSpA may provide valuable insights and address knowledge gaps in axSpA patient care, and increased patient engagement in management of their disease may improve treatment adherence and outcomes, shared decision-making, patient satisfaction, and overall QOL.

The International Map of Axial Spondyloarthritis (IMAS) survey is an initiative developed to generate insights on patient-reported aspects of disease burden and experience with axSpA through adaptations of the original Atlas of axSpA questionnaire, which was developed in collaboration with patients, the Axial Spondyloarthritis International Federation, and academic clinical experts (14). Prior studies using an adaptation of the IMAS survey have described the impact of axSpA on patients' lives across 13 European countries (14–16); however, the US health care system is unique among systems around the world and may have a distinct effect on the patient journey with axSpA. The IMAS survey applied in this study was adapted to capture how patients with axSpA experience the physical, psychological, social, and employment aspects of the disease and how they are managed within and challenged by the segmented US health care system. The purpose of this study was to generate comprehensive insights about the patient experience with axSpA within the US health care system using the US adaptation of the IMAS survey.

PATIENTS AND METHODS

Study design and patient population. This was a cross-sectional study of the web-based IMAS survey, which collects patient-reported data to generate a report on aspects of disease burden and experience with axSpA. In this US adaptation of the IMAS survey, recruitment was conducted through collaboration with the Spondylitis Association of America (SAA). The survey was made available to patients registered with the SAA via patient advocacy group websites and newsletters and other relevant online panels. Participants were invited to complete a 5-minute online screener for eligibility. Eligible participants were then directly sent the 25-minute quantitative online survey. Participants included US patients aged 18 years and older who had adequate written and oral fluency in English, had a diagnosis of axSpA by a health care provider (HCP), and were under the care of an HCP between July 22, 2021, and November 10, 2021. The study time period was time needed for recruitment to reach or exceed the target of 100 respondents, which was based on statistical precision and allowed for an outcome that offered sufficient generalizability. This study was exempt from institutional review board review according to the US Department of Health and Human Services Policy for Protection of Human Research Subjects (45 CFR 46.104); however, all participants were required to provide electronic informed consent prior to survey completion.

Assessments and outcomes. Survey questions were tailored to reflect features unique to US health care systems and the availability of approved treatments in the US. The sociodemographic and anthropometric characteristics, disability assessment, work life, daily life, lifestyle habits, diagnostic journey, health care resource use, treatment, disease manifestations, comorbid disorders or diseases, psychological health, disease outcomes, and patient disease-related attitudes and treatment goals are presented in the Supplementary Material.

Data collected were patient demographics (age, sex, race, education level, and body mass index), clinical characteristics (form of axSpA [AS or nr-axSpA], smoking status, alcohol consumption, HLA–B27 status, extra-musculoskeletal manifestations, and comorbid disorders or diseases), diagnostic journey (age at symptom onset and diagnosis, time to receiving diagnosis, disease duration, diagnosing physician, misdiagnosis, and type of physicians visited), symptoms (pain, stiffness, and degree of restriction in the spine [score of 1-4]), and employment-related burden (employment status, work-related issues, and perceived impact of axSpA on work).

Additional PRO data were collected to assess specific disease outcomes using the Bath Ankylosing Spondylitis Disease Activity Index (BASDAI; score of 0-10; cutoff of ≥4 for active disease; hereafter referred to as moderate or high disease activity) (17,18), the Assessment of SpondyloArthritis international Society Health Index (ASAS-HI; score of 0-17; cutoff of ≤5 for low degree of impairment) (19), and the General Health Questionnaire 12 (GHQ-12; score cutoff of ≥3 for psychological distress) (20), as well as indices specifically developed for this survey (14), including the Global Stiffness Index (score of 3-12) and the Global Limitation Index (degree of limitation in 18 activities of daily life; score of 0-54).

Data analysis. All study data were analyzed using descriptive statistics. For continuous variables, the mean and SD are presented. Frequencies and percentages are reported for categorical data. No imputation of missing data was done for this study, and the base number for each corresponding variable is reported. All analyses were performed by Ipsos SA.

RESULTS

Study population and characteristics. A total of 228 patients with axSpA (174 with AS and 54 with nr-axSpA) completed the US adaptation of the IMAS survey (Table 1). The overall mean (SD) age for patients with axSpA was 44.5 (14.8) years, and the mean (SD) ages for female and male participants were 46.1 (15.0) and 42.3 (14.4) years, respectively (Supplementary Table 1). Among the patients surveyed, 60.1% were female; 85.5% were White; 76.8% completed college, university, or higher education; and 70.0% were HLA–B27 positive.

Table 1. Demographics and clinical characteristics of patients with axSpA at the time of survey completion

Characteristic	Patients with axSpA (N = 228)
Age, mean (SD), years	44.5 (14.8)
Sex	
Female	137 (60.1)
Male	91 (39.9)
White	195 (85.5)
Body mass index, mean (SD)	27.7 (9.0)
Highest level of education	
Graduate school	61 (26.8)
College or university	114 (50.0)
High school	49 (21.5)
Primary (elementary and middle school)	3 (1.3)
No schooling completed	1 (0.4)
Marital status	
Single	69 (30.3)
Married or domestic partnership	135 (59.2)
Separated or divorced	23 (10.1)
Widowed	1 (0.4)
Health insurance, %	
Private	139 (61.0)
Medicare, Medicaid, or public assistance program	61 (26.8)
Combination public and private coverage	15 (6.6)
No coverage	7 (3.1)
Lost insurance because of COVID-19 pandemic	4 (1.8)
Military	2 (0.9)
Nonsmoker	141 (61.8)
Alcohol consumption behavior	
Never	43 (18.9)
Every day	20 (8.8)
Age at onset of symptoms, mean (SD), years	26.4 (12.3)
Age at diagnosis, mean (SD), years	35.3 (13.7)
Diagnostic delay, mean (SD), years	8.8 (12.0)
Disease duration, mean, years	18.1
No. of different HCP specialists seen before diagnosis, mean (SD)	3 (2.3)
Referred to a rheumatologist for diagnosis	140 (61.8)
axSpA condition	
Ankylosing spondylitis	174 (76.3)
nr-axSpA	54 (23.7)
HLA–B27 positive [no. of patients with HLA-B27 assessment]	115 (70.0) [164]
BASDAI score (0-10), mean (SD)	5.8 (2.3)
BASDAI score ≥4	180 (78.9)
Spinal stiffness index (score of 3-12), mean (SD)	7.9 (2.4)
GHQ score (0-12), mean (SD)	4.2 (3.6)
GHQ ≥3	130 (57.0)
ASAS-HI score (0-17), mean (SD)	9.5 (4.4)
Global Limitation Index (0-54), mean (SD)	17.6 (13.9)
No. of comorbid disorders or diseases, mean (SD)	5.6 (5.7)
Employed	123 (53.9)

Note: Data are presented as n (%), unless otherwise stated.
Abbreviations: ASAS-HI, Assessment of Spondyloarthritis International Society Health Index; axSpA, axial spondyloarthritis; BASDAI, Bath Ankylosing Spondylitis Disease Activity Index; GHQ, General Health Index; nr-axSpA, nonradiographic axSpA.

Additionally, 59.2% were married or in a domestic partnership, 61.8% were nonsmokers, and 18.9% reported that they never consumed alcohol.

Patient journey to diagnosis of axSpA. Overall, the mean (SD) age at the time of symptom onset was 26.4 (12.3) years, and the mean (SD) age at diagnosis of axSpA was 35.3 (13.7) years (Table 1). Similar mean ages at symptom onset were reported for women and men; however, women had a higher mean age at diagnosis compared with men (37.9 vs. 31.4 years) (Figure 1A). A mean (SD) diagnostic delay of 8.8 (12.0) years was reported in the overall patient population, with women reporting a longer mean diagnostic delay compared with men (11.2 vs. 5.2 years).

Most patients (84.6% total; 86.9% women and 81.1% men) reported that back pain was among the axSpA-related symptoms that initiated their visit to an HCP, followed by stiffness (56.6% overall; 60.6% women and 51.1% men) (Figure 1B). Joint pain (56.1% total; 65.0% women and 43.3% men) and fatigue and/or exhaustion (42.5% overall; with much higher prevalence in women vs. men [52.6% vs. 27.8%]) were also frequently reported as symptoms prompting patients to initiate a visit. Patients were seen by an average of three HCP specialists prior to receiving their axSpA diagnosis, with women reporting visits with more HCP specialists compared with men (3.5 vs. 2.3). A total of 147 patients (64.5%) reported that their conditions were misdiagnosed on their journey to diagnosis of axSpA; the most common misdiagnoses reported were other types of back problems (63.3%), anxiety and/or depression (38.8%), fibromyalgia (22.4%), and rheumatoid arthritis (19.7%) (Figure 1C). Rheumatologists were the most commonly reported diagnosing physician (61.8%), and 21.1% and 8.3% of patients received their diagnosis of axSpA from a primary care provider (eg, general practitioner, family physician) and orthopedic specialist, respectively (Figure 1D).

Physical axSpA disease burden at the time of survey completion. Most patients (78.9%) in this study had moderate or high disease activity as assessed by BASDAI scores of 4 or higher (Figure 2A), and the rates were similar between men and women (77.8% and 79.6%, respectively) and among different age groups, with the highest proportion with moderate or high disease activity seen in patients aged 31 to 40 years old (85.7%) (Figure 2B). Patients who reported that they were routinely physically active (ie, involved with sports, exercise, or walking) were less likely to have moderate or high disease activity as measured by BASDAI compared with those who were not physically active (74.0% vs. 90.4%) (Figure 2B). Furthermore, more than one half of patients reported moderate or severe spinal stiffness in the thoracic (53.1%), cervical (56.2%), and lumbar spine (70.6%) (Figure 2C). Patients who had moderate or high disease activity as measured by BASDAI scores of 4 or higher had a higher mean spinal stiffness score compared with those who had a BASDAI score of less than 4 (Figure 2D).

Psychological distress related to axSpA. A total of 57.0% of patients with axSpA in this study reported psychological

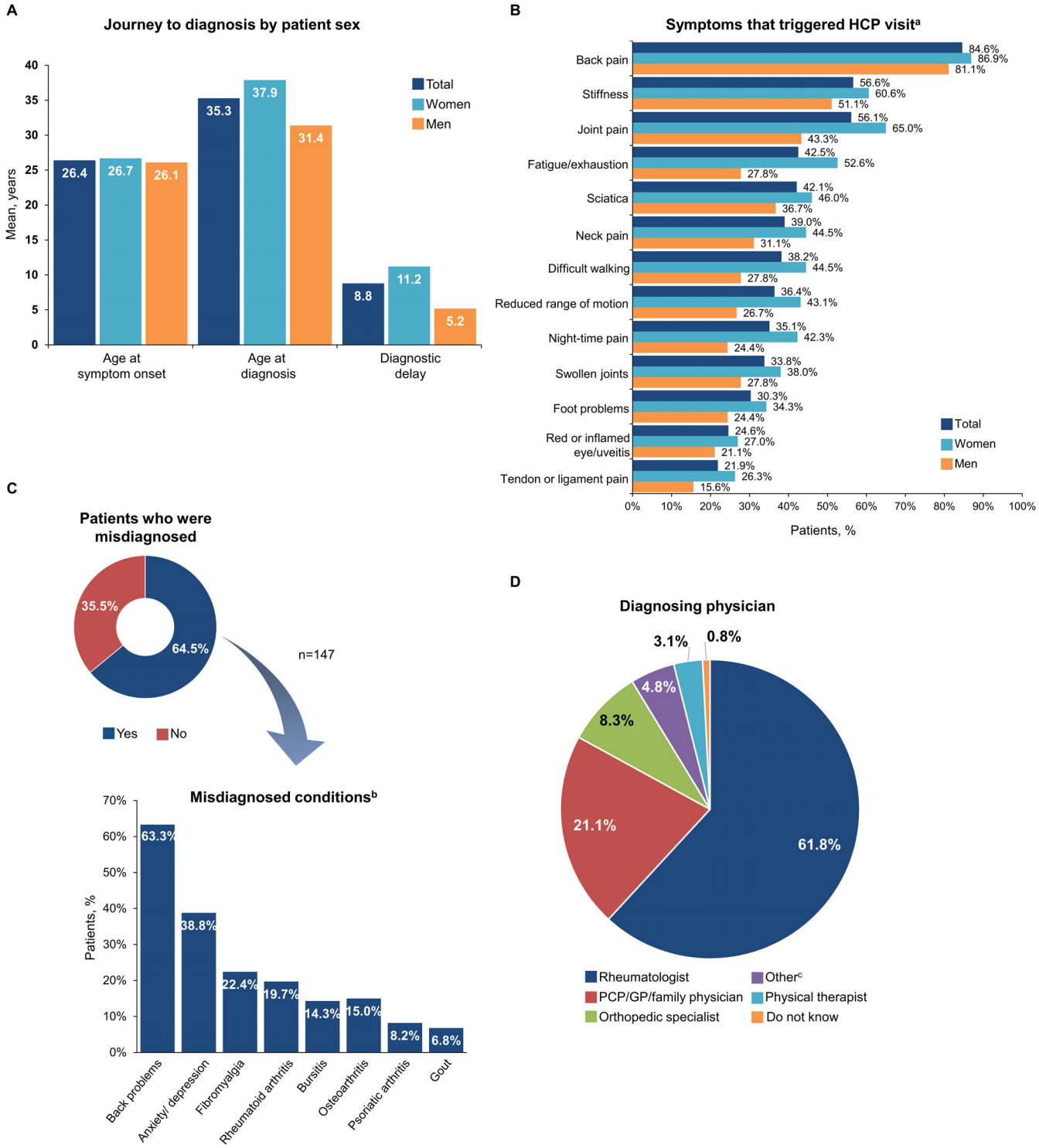

Figure 1. Patient journey to diagnosis with axSpA. **A**, Journey to diagnosis by patient sex. **B**, Symptoms that triggered HCP visit. **C**, Patients whose conditions were misdiagnosed. **D**, Diagnosing physician. [a]Symptoms that triggered a visit to an HCP in more than 15% of patients. [b]Misdiagnosed conditions in more than 5% of patients. Patients could have reported more than one misdiagnosis. [c]"Other" comprised neurologist, radiologist, internist, chiropractor, gastroenterologist, sports physician, and NP/PA. axSpA, axial spondyloarthritis; GP, general practitioner; HCP, health care professional; NP, nurse practitioner; PA, physician assistant; PCP, primary care provider.

distress according to GHQ-12 scores of 3 or higher (Figure 3A), and similar proportions were found between women and men (Figure 3B). Increased proportions of patients reported psychological distress among those aged 18 to 30 and 31 to 40 years (71.8% and 68.6%, respectively). Patients who reported that they were physically active were less likely to report

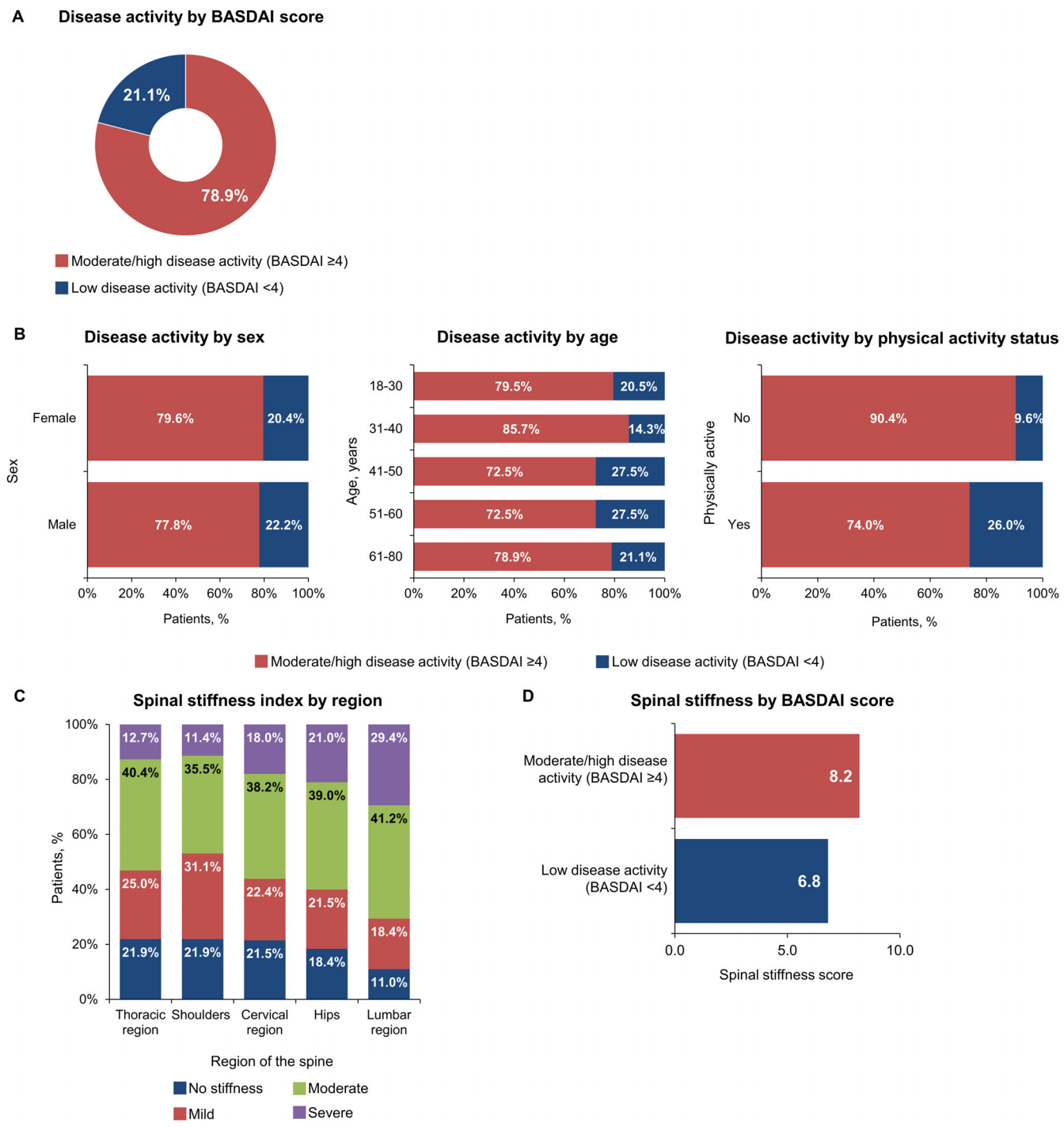

Figure 2. Physical burden of axSpA as assessed by BASDAI and spinal stiffness index. **A**, Disease activity by BASDAI score. **B**, Disease activity by sex, age, and physical activity status. **C**, Spinal stiffness index by region. **D**, Spinal stiffness index by BASDAI score. axSpA, axial spondyloarthritis; BASDAI, Bath Ankylosing Spondylitis Disease Activity Index.

psychological distress compared with those who were not physically active (52.7% vs. 64.4%). Comparable mean spinal stiffness scores were seen for patients irrespective of GHQ-12 scores (Figure 3C). Patients with more active disease (BASDAI score ≥4) were more likely to report psychological distress than those without active disease (61.7% vs. 39.6%) (Figure 3D).

Patient-reported axSpA-related inflammation and comorbid disorders or diseases. More than one half of patients reported experiencing pain and stiffness in the lumbar region of the back (65.4%), in the hips (59.6%), in the spine (56.1%), in the sacroiliac joints (55.3%), and in the cervical region (53.1%) (Figure 4A). There were higher proportions of women

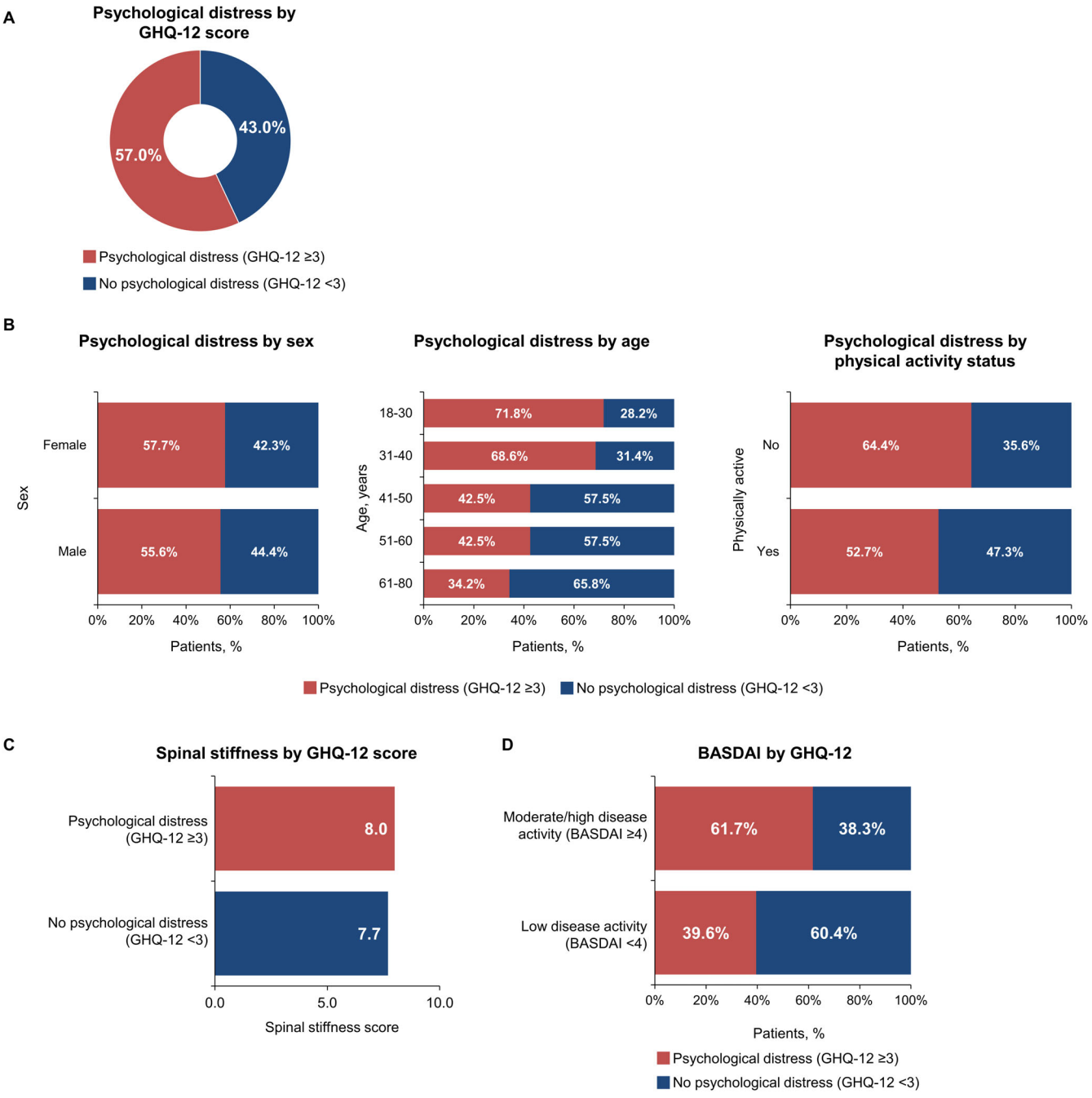

Figure 3. Psychological distress in patients with axSpA. **A**, Psychological distress by GHQ-12 score. **B**, Psychological distress by sex, age, and physical activity status. **C**, Spinal stiffness by GHQ-12 score. **D**, BASDAI by GHQ-12 score. axSpA, axial spondyloarthritis; BASDAI, Bath Ankylosing Spondylitis Disease Activity Index; GHQ-12, General Health Questionnaire 12.

who reported pain and stiffness across all body regions compared with men, with the numerically largest differences seen in the lumbar region (75.2% vs. 50.0%) and sacroiliac joints (67.9% vs. 35.6%). Overall, the most commonly reported comorbid disorders or diseases experienced by patients were anxiety (42.5%) and depression (41.2%), and 23.2% and 20.2% of patients reported comorbid psoriatic arthritis and fibromyalgia, respectively (Figure 4B). axSpA extraarticular manifestations of uveitis and psoriasis affected 23.7% and 20.2% of patients, respectively. Waking up during the night or early in the morning because of pain and the inability to go to sleep within 30 minutes were the top quality-of-sleep concerns identified on the quality-of-sleep scale (Figure 4C). Additionally, patients who had moderate or high disease activity as measured by a BASDAI score of

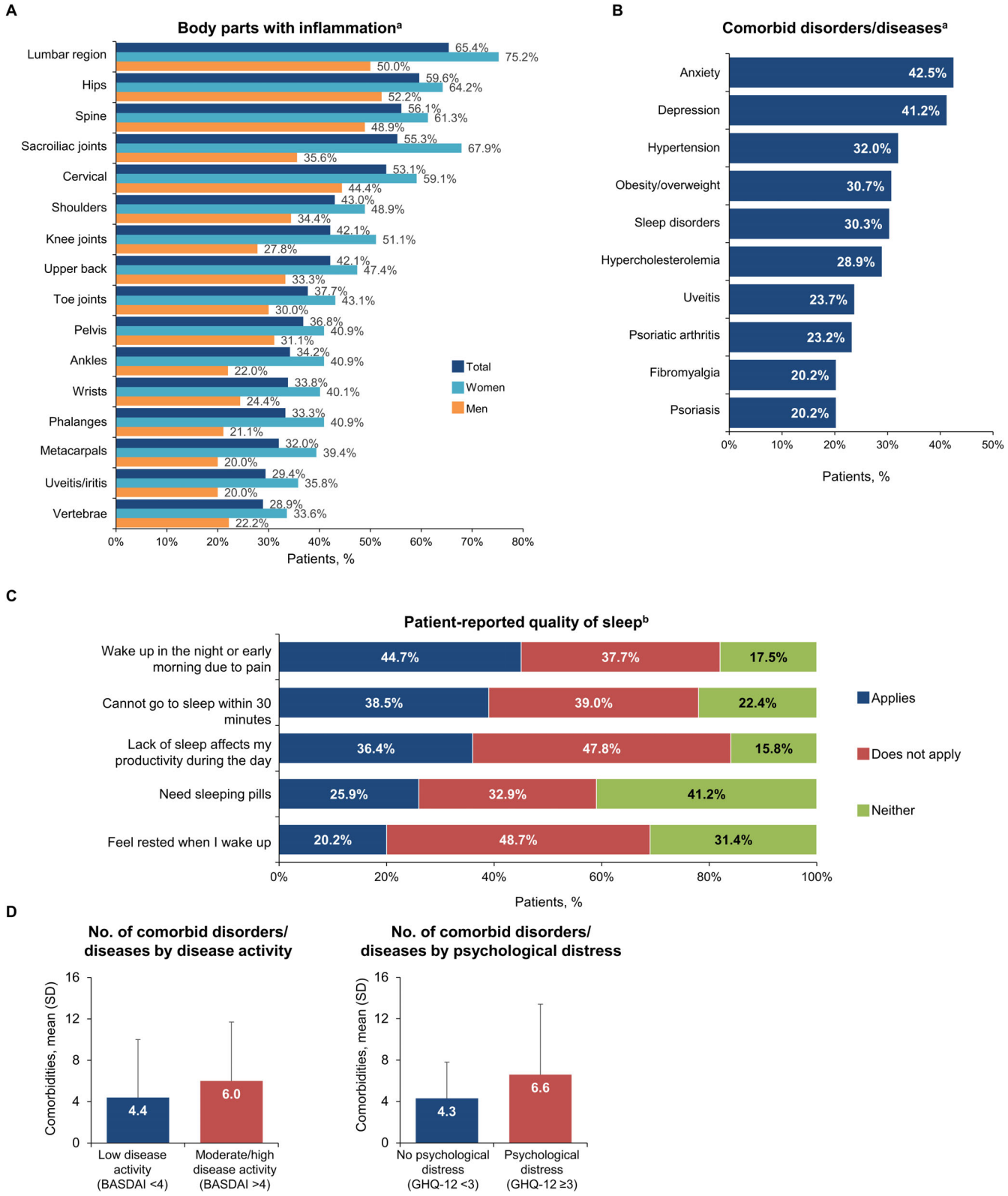

Figure 4. Key symptoms and comorbid disorders or diseases among patients with axSpA. **A**, Body parts with inflammation. **B**, Comorbid disorders or diseases. **C**, Patient-reported quality of sleep. **D**, Number of comorbid disorders or diseases by disease activity and psychological distress. [a]Includes those reported in more than 20% of patients. [b]Quality of sleep scale was scored 1 to 7: does not apply (scores 1-2), neither (scores 3-5), and applies (scores 5-7). axSpA, axial spondyloarthritis; BASDAI, Bath Ankylosing Spondylitis Disease Activity Index; GHQ-12, General Health Questionnaire 12.

4 or higher and who reported psychological distress as measured by a GHQ-12 score of 3 or higher had a higher mean number of comorbid disorders or diseases (6.0 and 6.6, respectively) compared with those without active disease (BASDAI score ≥4) or psychological distress (4.4 and 4.3, respectively) (Figure 4D).

The burden of axSpA on patients' daily lives. Nearly all patients (93.0%) agreed that axSpA pain sometimes disrupted their normal activities, that they had problems running (88.2%), and that they found it hard to stand for long periods (86.0%) based on responses to the ASAS-HI questionnaire (Figure 5A). axSpA led to a high degree of impairment in daily activities for patients as measured by ASAS-HI scores of 6 or higher (81.6%) and Global Limitation Index scores higher than 36 (53%) (Figure 5A and B). Higher proportions of patients reported the need to make adaptations to their lives due to their disease, including the purchase of customized or comfortable shoes (64.9%), adaptation of their workplace (58.3%), and loss of a hobby (57.0%) (Figure 5C). Patients also reported that axSpA had a substantial impact on their personal lives, with 49.1% responding that they felt guilty about the impact their disease had on close family or friends, 43.0% responding that they felt that axSpA affected their sex lives, and 39.9% responding that they had to avoid making commitments because of their disease (Figure 5D).

axSpA-related impact on the working life of patients. A total of 53.9% of patients with axSpA were employed (61.1% men and 49.6% women), 14.0% were retired, and 8.8% were unemployed at the time of survey completion (Figure 6A). Among those patients who were currently employed, the top work-related issues they reported experiencing within the past 12 months were missed work for doctor appointments (41.8%), difficulty sitting or standing for long hours (41.0%), and taking sick leave (31.1%) (Figure 6B). Survey patients also reported that they believed axSpA had an influence on employment and work choice, with 59.2% agreeing that their disease did have a negative impact on their ability to find a job and 46.5% responding that their current or past work choice was determined by their disease (Figure 6C).

DISCUSSION

This survey study of a large cohort of US patients with axSpA demonstrates the substantial impact this disease has on the daily function of patients, including both physical and psychological burden. The mean diagnostic delay in this cohort was long, and high proportions of patients reported visiting multiple HCPs and receiving a misdiagnosis prior to receiving a diagnosis of axSpA. The diagnostic delay was also longer in women compared with men. The findings presented in this study indicate the ongoing unmet needs in axSpA.

The results from this survey study are consistent with findings from previous studies and corroborate the ongoing substantial diagnostic delays in axSpA as well as the difference observed between sexes. Previous reports have found the overall mean diagnostic delays from symptom onset to diagnosis to be between 6.6 and 7.6 years (8,14,21), with some as high as 12 years (6), and a mean delay higher in women compared with men (8.8 vs. 6.5 years) (8). In a similar cross-sectional survey study with the European Map of axSpA (EMAS) questionnaire, the mean diagnostic delay was determined to be 7.4 years, and patients in that European cohort reported visiting an average of two HCPs prior to diagnosis (14). Comparable findings were described in a cross-sectional survey study of patients with a diagnosis of AS associated with SAA, with a mean diagnostic delay of 8.2 years, and patients in that cohort reported consulting an average of 2.2 physicians for back pain, joint pain, or inflammatory problems (22). The delays for this US cohort are marginally longer than those commonly reported, with a mean delay in diagnosis for the overall cohort of 8.8 years and a higher delay of 11.2 years for women compared with 5.2 years for men. The differences in diagnostic delays have been attributed to differential disease presentation between men and women, including reports of genetic and immunologic differences, as well as a higher frequency of peripheral symptoms and/or presence of central sensitization or fibromyalgia in women, which may mask IBP or make differentiation of axSpA from other immunologic conditions more difficult (21,23–25).

Men and women also experienced differences in the diagnostic journey and management of disease, including differences in health care–seeking behavior, diagnostic coding, and treatment patterns, that may favor earlier detection of IBP and diagnosis of axSpA in men versus women (26–28). Along their journey to diagnosis, more than one half of patients in this US cohort (64.5%) received a misdiagnosis. Patients had a mean of 5.6 comorbid disorders or diseases, which may, in part, impact the time to diagnosis and contribute to differences seen between sexes and overall high rates of misdiagnosis. Furthermore, patients in this study reported seeing an average of three different HCPs prior to receiving their diagnosis of axSpA, mainly primary care providers, general practitioners, and family doctors, with women reporting more visits with HCP specialists than men. The results could also reflect the different behaviors in the US health care system, for example, the lack of universal health care coverage (29), treatment affordability and accessibility (30,31), access to medical care (32), and inadequate focus of education on axSpA outside rheumatology specialists (3,33), all of which may influence a patient's access or likelihood to visit an HCP and the timeliness of an accurate diagnosis.

axSpA has a substantial impact on the lives of patients, and several studies have demonstrated impaired functional disability associated with this disease (9,34). Similarly, most patients in this US cohort had moderate or high disease activity, with a BASDAI

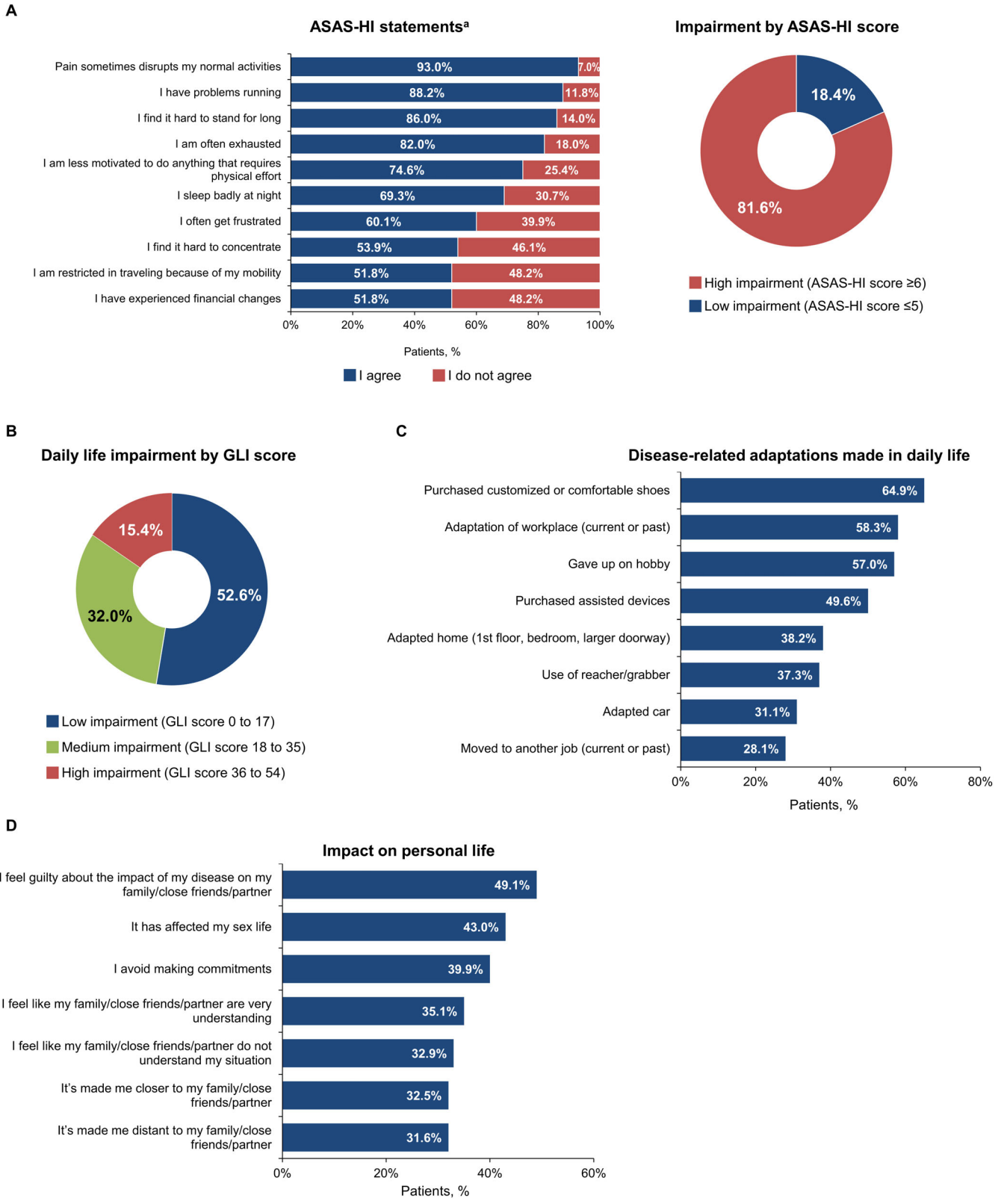

Figure 5. Impact of axSpA on daily lives of patients. **A**, ASAS-HI statements and impairment by ASAS-HI score. **B**, Daily life impairment by GLI score. **C**, Disease-related adaptations made in daily life. **D**, Impact on personal life. [a]ASAS-HI statements presented if more than 50% of patients responded in agreement. ASAS-HI, Assessment of SpondyloArthritis international Society Health Index; axSpA, axial spondyloarthritis; GLI, Global Limitation Index.

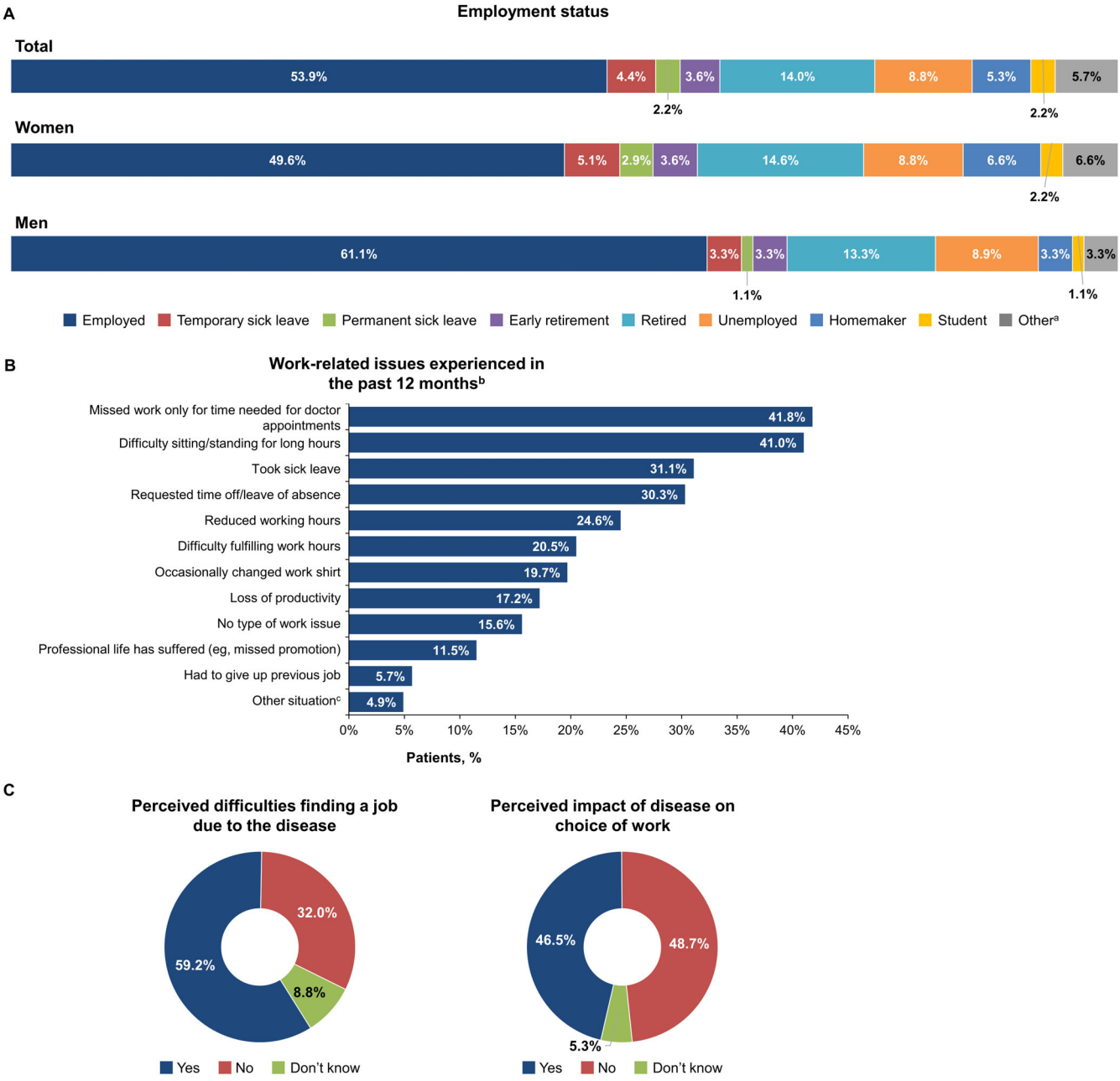

Figure 6. Patient-reported impact of axSpA on working life. **A**, Employment status. **B**, Work-related issues experienced in the past 12 months. **C**, Perceived difficulties finding a job due to the disease and perceived impact of disease on choice of work. [a]"Other" comprised the following: do not know, self-employed, disabled, independent contractor, or computer work. [b]Among those employed (n = 122). [c]"Other situation" comprised remote work due to pain, missed office days or work, or unspecified. axSpA, axial spondyloarthritis.

score of 4 or higher. In an SAA survey study of patients, 41.9% of respondents reported that their disease had a high impact on physical function as measured by the Evaluation of Ankylosing Spondylitis Quality of Life, and women were significantly more likely than men to report a high physical disease burden (50.3% vs. 39.2%) (22). A pooled analysis in a systemic literature review that assessed disease activity in radiographic axSpA and nr-axSpA found active disease, with an overall mean BASDAI score of 4.6 across 39 studies (34), and comparable disease activity was reported in a retrospective US cohort study, with a mean BASDAI score of 4.5 in patients with axSpA (21). Furthermore, prior studies outside the US have reported high BASDAI scores; a prospective observational study across seven countries demonstrated a mean BASDAI score of 5.0 (35), and a comparable high mean BASDAI score of 5.5 was reported in the EMAS questionnaire survey study described previously (14). Patients in

this study who completed the IMAS survey reported experiencing high levels of active disease, as seen by a mean BASDAI score of 5.8, and most patients (78.9%) had moderate or high disease activity (BASDAI score ≥4), and more than one half of patients reported moderate or severe spinal stiffness in multiple regions on the spinal stiffness scale.

Additionally, the negative impact that axSpA can have on mental health has been reported in other studies and is corroborated with the findings presented in this US cohort (15,36,37). In line with prior studies, a high proportion of patients in this US cohort reported psychological distress (GHQ-12 score ≥3; 57.0%), depression (42.5%), and anxiety (41.2%). In a similar study using the EMAS survey, in which approximately one third of patients had a diagnosis of depression or anxiety, 60.7% of patients reported psychological distress as measured by the GHQ-12, and factors associated the most with the risk of mental health disorders were moderate or high disease activity (BASDAI score ≥4; odds ratio, 2.80) and patient-reported depression (odds ratio, 2.42) and anxiety (odds ratio, 2.39) (15). Another cross-sectional study in axSpA reported that patients who were at high risk for depression and anxiety, assessed with the Hospital Anxiety and Depression Scale depression and anxiety subscales, had higher BASDAI, Bath Ankylosing Spondylitis Functional Index, and Ankylosing Spondylitis Quality of Life questionnaire (ASQoL) scores and found that BASDAI and ASQoL scores were associated with the risk of depression (37). Furthermore, in the US cohort who completed the IMAS survey, the psychological distress reported was also increased among patients with moderate or high disease activity as assessed with BASDAI (61.7%) compared with patients with low disease activity. Of note, the proportions of patients with high or moderate disease activity and those who reported psychological distress were comparable between women and men in this study, which is contrary to prior studies in which women reported a higher degree of disease activity and were at higher risk for psychological distress (15). Taken together, these findings substantiate the considerable physical and psychological burden experienced by patients with axSpA. Evidence presented in this study of the relation between active disease and impact on mental health wellness may provide useful insights into treatment response and patient unmet needs, as well as indicate the importance of additional patient-reported indices and scales to capture a comprehensive patient experience.

Findings from this study also demonstrated substantial impairment in QOL in patients with axSpA. Nearly all patients had a high degree of impairment in their daily lives as assessed by the ASAS-HI. The QOL impairment in this study cohort is comparable to that in other similar studies (38–40), as evidenced by an overall mean (SD) ASAS-HI score of 9.5 (4.4) and the large proportion of patients (81.6%) who experienced a high degree of impairment, with ASAS-HI scores of 6 or higher. The impact that axSpA has on daily activities was further corroborated in our study, with specific questions regarding disease-related adaptations that patients made and the impact that axSpA had on their personal lives.

This is one of the first studies in the US to provide details of how patients adapt to their disease and how axSpA specifically affects interpersonal relationships. High proportions of patients in this US cohort reported that axSpA had a negative impact on the personal, social, and work aspects of their lives. More than one half of patients in this study made adaptations to their workplace and daily activities because of axSpA, and nearly one half of patients expressed feelings of guilt about how their disease impacted their loved ones, that it affected their sex lives, and that they avoided making commitments because of their feelings about their disease. These findings indicate the specific ways in which axSpA impacts daily activities and relationships, which may in turn affect the mental health status of patients. Moreover, they can help further improve our understanding of the disease burden and inadequate satisfaction experienced by patients.

This study is also unique in highlighting the impact of axSpA on work life compared with the general population (41–43). Patients who were employed reported missed work due to doctor appointments (41.8%), difficulty sitting or standing for long hours (41.0%), and the need to take sick leave due to their disease (31.1%) as the top three work-related issues experienced within the 12 months prior to survey completion. A considerable proportion of patients reported that their disease negatively impacted their ability to find a job and affected their choice of work. A cross-sectional study of patients with axSpA in the ArthritisPower registry cohort demonstrated that 40% of patients were not employed owing entirely or partially to axSpA, that employed patients had lower disease activity and better overall health compared with those who were not employed, and that participants who were employed experienced work productivity impairment (52.7%), as measured by the Work Productivity and Activity questionnaire (WPAI), over a 3-month period because of their disease (42). Similar impacts on work productivity were reported in a retrospective analysis of patients with AS and nr-axSpA in a US-based registry that reported that all patients experienced 26.5% reduction in presenteeism, 28.1% work productivity loss, and 30.7% impairment in daily activities as measured by the WPAI (43). These results may indicate the specific impact that axSpA can have on patients' work lives and may influence treatment decisions and goals if HCPs are more aware of the specific ways work life may be improved.

The findings presented in this study should be interpreted with our acknowledgment of the limitations inherent to survey studies, including patient recall of events, sample generalizability, and the use of nonvalidated tools. All data presented here are self-reported, and answers are based on patients' perceptions and attitudes; therefore, recall bias may impact the accuracy of findings and could lead to an underestimation or overestimation of outcomes. No corroboration was performed to confirm diagnosis, and no clinician-reported assessments were used to validate

survey responses. However, the aim of this study was to provide an understanding of the patient experience, and direct feedback was essential. Selection bias was also a potential limitation of this study because the patient population was recruited solely online (eg, people registered with SAA). The population surveyed was predominantly female, which is consistent with online survey studies irrespective of research field, and contributes to the limited data on axSpA in women because it has historically been seen as a disease that predominantly affects men. Furthermore, most respondents had high BASDAI scores, and a large proportion completed higher education, which may not be representative of the overall axSpA population in the US. This patient selection may impact generalizability to underrepresented populations of patients with axSpA, including those who do not have internet access readily available or who may not be involved in the organizations used for recruitment of this survey. Additionally, scales and indices that are not validated were used to assess functional limitations in daily activities and spinal stiffness because of the concerns expressed by patients that established indices may not have captured all aspects of their disease during the development of the survey. These scales and indices were internally validated with appropriate Cronbach α values and applied in similar published reports (14) and offer novel outcomes that more closely represent how patients feel about their disease.

In conclusion, our study highlighted high disease burden in patients with axSpA with both physical and psychological impairment based on a self-reported survey. This study further demonstrated that significant delays in diagnosis remain an issue in patients with axSpA, particularly in women. The thorough assessment of the impact of axSpA provided by the IMAS survey indicates the crucial need to improve early and accurate diagnosis and increase awareness of this disease. Increased incorporation of patients' perspectives into routine clinical practice can facilitate shared decision-making with providers, which may have a positive impact on treatment adherence and outcomes. This can also improve comprehensive disease management, with mental health referrals and encouragement of patients to participate in support groups, and can adequately address the impact axSpA has on all aspects of patients' lives.

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