Spondylitis Association of America™
35th Anniversary

FRI0200

Insight Into the Quality of Life of Patients With Ankylosing Spondylitis: Real-World Data From a US-Based Life Impact Survey

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BACKGROUND

- Ankylosing spondylitis (AS) is a chronic, inflammatory disease characterized by progressive spinal stiffness and fusion; this disease primarily involves structural changes in the sacroiliac joints[1-3]
- Early indicators of AS may not be discernible; hence, patients often suffer from chronic pain due to an "invisible" disease[4,5]
- Disease progression often results in functional limitation and impairment of quality of life (QoL)
- A survey of 592 patients with rheumatic diseases, including AS, indicated that up to 50% of patients were seldom or never queried on the impact of their disease on their QoL, and that normalization of QoL and symptom relief were the most important treatment attributes for these patients[6]

OBJECTIVE

- To assess patient-reported impact of AS on QoL in the physical, discomfort, social, and emotional domains among US patients with AS in a real-world setting

METHODS

Spondylitis Association of America (SAA) Life Impact Survey Data Source and Study Population

- Descriptive data on demographics and QoL were collected from a random sample of patients associated with SAA
  - SAA, founded in 1983, is a national nonprofit organization headquartered in Van Nuys, CA, USA, with an all-volunteer board of directors and an internationally recognized panel of experts on its medical and scientific advisory board
  - SAA creates and maintains programs and services directed at improving the lives of patients with ankylosing spondylitis and related diseases
  - Previous Life Impact Surveys were conducted by SAA in 2002 and 2011[7,8]
- Between July 7, 2017, and December 31, 2017, a total of 820 interviews were conducted with SAA contacts, including 720 completed via web survey (from 7750 emails) and 100 via follow-up over the phone (from 10,784 phone calls made to 5000 unique numbers)

Data Variables

- QoL metrics were based on the Evaluation of Ankylosing Spondylitis Quality of Life (EASi-QoL) questionnaire[9]
  - The EASi-QoL consists of 20 questions designed to evaluate the impact of AS on 4 QoL domains (scale, 0-80; higher score indicates more severe impact)
    - Physical function (6 questions; maximum score = 24)
    - Disease activity or discomfort (4 questions; maximum score = 16)
    - Emotional well-being (5 questions; maximum score = 20)
    - Social participation (5 questions; maximum score = 20)
  - Each question is scored 0 to 4 (0 = not limited at all, 1 = a little limited, 2 = moderately limited, 3 = very limited, and 4 = totally limited/unable to do)
  - A low impact of disease on QoL is reflected by total EASi-QoL score of 0 to 17, medium impact by 18 to 35, and high impact by ≥ 36
    - The top 2 levels of impairment (ie, "very limited" and "totally limited/unable to do") were considered as being high impact of disease for each individual question
- Participants were queried on the impact of AS on their QoL on the day of the survey with regard to the physical domain and during the previous week with regard to the discomfort, emotional, and social domains
- A 3:1 (male-to-female) weighting was performed to reflect the reported prevalence of spondyloarthritis in US adults, ie, the fact that men are 3 times more likely than women to have spondyloarthritis[10]

Data Analysis

- Categorical variables were presented as the count and percentage of respondents per category, and continuous variables were summarized with means
- The χ^2 test was used to test for differences in categorical variables between men and women; $P < 0.05$ was considered statistically significant

RESULTS

Baseline Demographics and Disease Characteristics

- Of 820 participants who completed the survey, 716 self-reported receiving a diagnosis of AS from their doctor and were included in this study
- Baseline demographics and disease characteristics are summarized in **Table 1**
  - The mean age of survey participants was 55.5 years; 46.9% were male
  - Participants were from all regions of the United States (Northeast, 20.3%; Southeast, 21.6%; Midwest, 18.3%; West, 27.2%; Southwest, 11.3%; Other, 1.3%)
  - The most common locations of pain reported were the lumbar spine (86.9%), neck (84.1%), and hip joint (80.2%)
  - The most frequently reported comorbidities were high blood pressure (35.9%), high cholesterol (26.7%), and depression (24.1%)
  - Approximately 30% of respondents reported a history of uveitis
- On average, participants first noticed disease symptoms 26.6 years prior to the completion of the survey and received an AS diagnosis ≈ 8.2 years later

Table 1. Baseline Demographics and Disease Characteristics of Respondents with AS

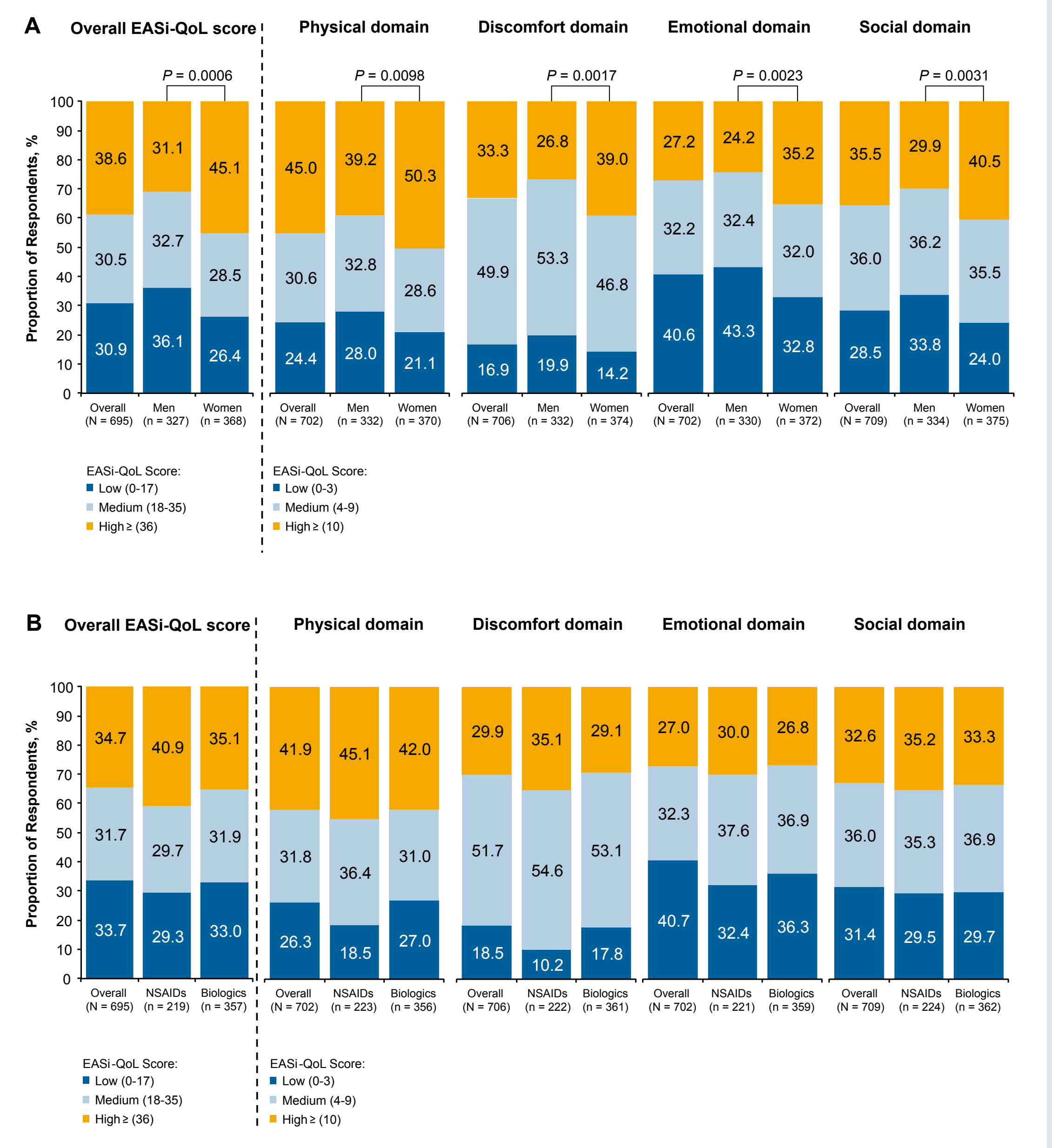
Characteristics	Overall (N = 716)
Age, mean, years	55.5
Age category, n (%)	
< 35 years	63 (8.8)
35 to < 55 years	239 (33.4)
≥ 55 years	412 (57.5)
Unsure/missing	2 (0.3)
Male, n (%)	336 (46.9)
Region, n (%)	
Northeast	145 (20.3)
Southeast	155 (21.6)
Midwest	131 (18.3)
West	195 (27.2)
Southwest	81 (11.3)
Other (out of country)	9 (1.3)
Locations of pain, n (%)	
Lumbar spine	622 (86.9)
Neck	602 (84.1)
Hip joint	574 (80.2)
Waist or sacrum or pelvis	505 (70.5)
Shoulders	496 (69.3)
Comorbidities, n (%)	
High blood pressure	253 (35.9)
High cholesterol	188 (26.7)
Depression	170 (24.1)
Fibromyalgia	98 (13.9)
Associated diseases, n (%)	
Uveitis	217 (30.3)
Crohn disease or ulcerative colitis	110 (15.6)
Other conditions, n (%)	
Acid reflux	364 (50.8)
Eye inflammation	332 (46.4)
Irritable bowel syndrome	239 (33.4)
Migraine	237 (33.1)
Balance issues	234 (32.7)
Mean time since development of symptoms associated with AS, years	26.6
Time since development of symptoms associated with AS, n (%)	
≤ 5 years ago	69 (9.6)
6 to < 20 years ago	216 (30.2)
≥ 20 years ago	431 (60.2)
Mean time since diagnosis of AS, years	18.4
Time since diagnosis of AS, n (%)	
≤ 5 years ago	162 (22.6)
6 to < 20 years ago	272 (38.0)
≥ 20 years ago	282 (39.4)

AS, ankylosing spondylitis.

Disease Impact on QoL

- Using the EASi-QoL survey, respondents reported the impact of AS on their QoL stratified by sex and current treatment (**Figure 1**)
  - The mean total EASi-QoL score was 28.9; overall, 33.7%, 31.7%, and 34.7% of respondents, respectively, reported low (EASi-QoL score, 0-17), medium (18-35), and high (≥ 36) impact of AS on QoL (weighted)
  - Of the 4 QoL domains evaluated, AS had the highest impact on physical function, with 41.9% of respondents overall (weighted) reporting high impact of AS on the physical domain (EASi-QoL score, ≥ 10)
  - When stratified by sex, women were significantly more likely than men to report a high impact of disease on the physical (50.3% vs 39.2%), discomfort (39.0% vs 26.8%), emotional (35.2% vs 24.2%), and social domains (40.5% vs 29.9%) (**Figure 1A**)
  - When stratified by nonsteroidal anti-inflammatory drugs (NSAIDs) vs biologic use, lower proportion of respondents on biologics reported high impact of AS on their QoL compared with respondents on NSAIDs (**Figure 1B**)

Figure 1. Impact of AS on QoL of Respondents With AS Stratified by **(A)** Sex and **(B)** Current Use of NSAIDs vs Biologics*

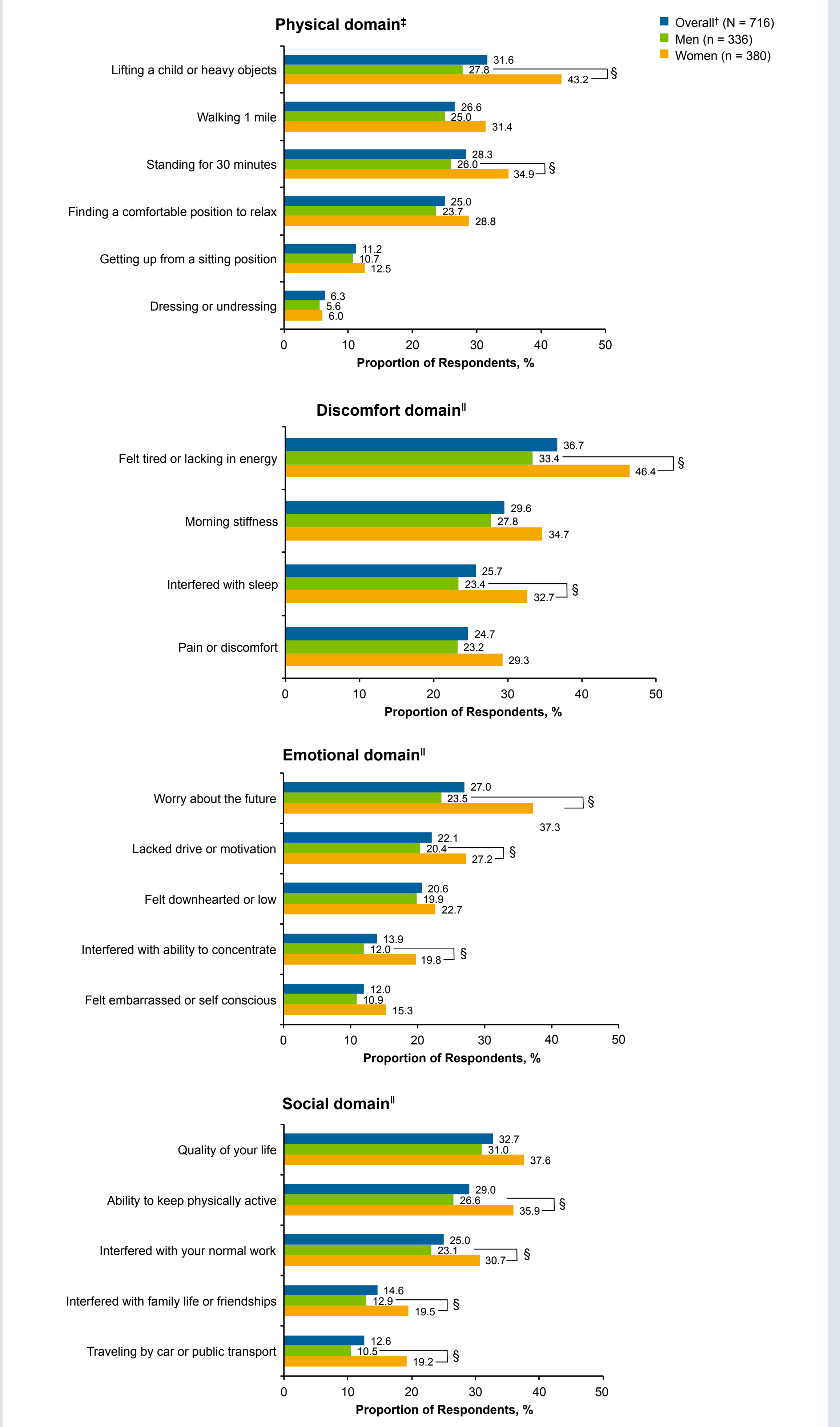


AS, ankylosing spondylitis; EASi-QoL, Evaluation of Ankylosing Spondylitis Quality of Life questionnaire; NSAID, nonsteroidal anti-inflammatory drug; QoL, quality of life.

* Data stratified by sex are reported as observed; data stratified by current NSAID vs biologic use are weighted 3:1 (male to female).

- The proportion of respondents (overall and stratified by sex) reporting high impact of AS (ie, the top 2 levels of impairment for each question) in the 4 QoL domains is shown in **Figure 2**
  - Women were significantly more likely than men to report high impact of AS in several aspects in all QoL domains, such as lifting a child or heavy objects (physical domain) or feeling tired or lacking in energy (discomfort domain)

Figure 2. Proportion of Respondents With AS Reporting the Top 2 Levels of Impairment by Their Disease Across 4 Domains of Disease Stratified by Sex*



AS, ankylosing spondylitis; QoL, quality of life.

* Respondents were "very limited" or "totally limited/unable to do" each activity as a result of their AS.

† Weighted 3:1 (male to female).

‡ For activities related to the physical domain, participants were queried on the impact of AS on their QoL on the day of survey participation.

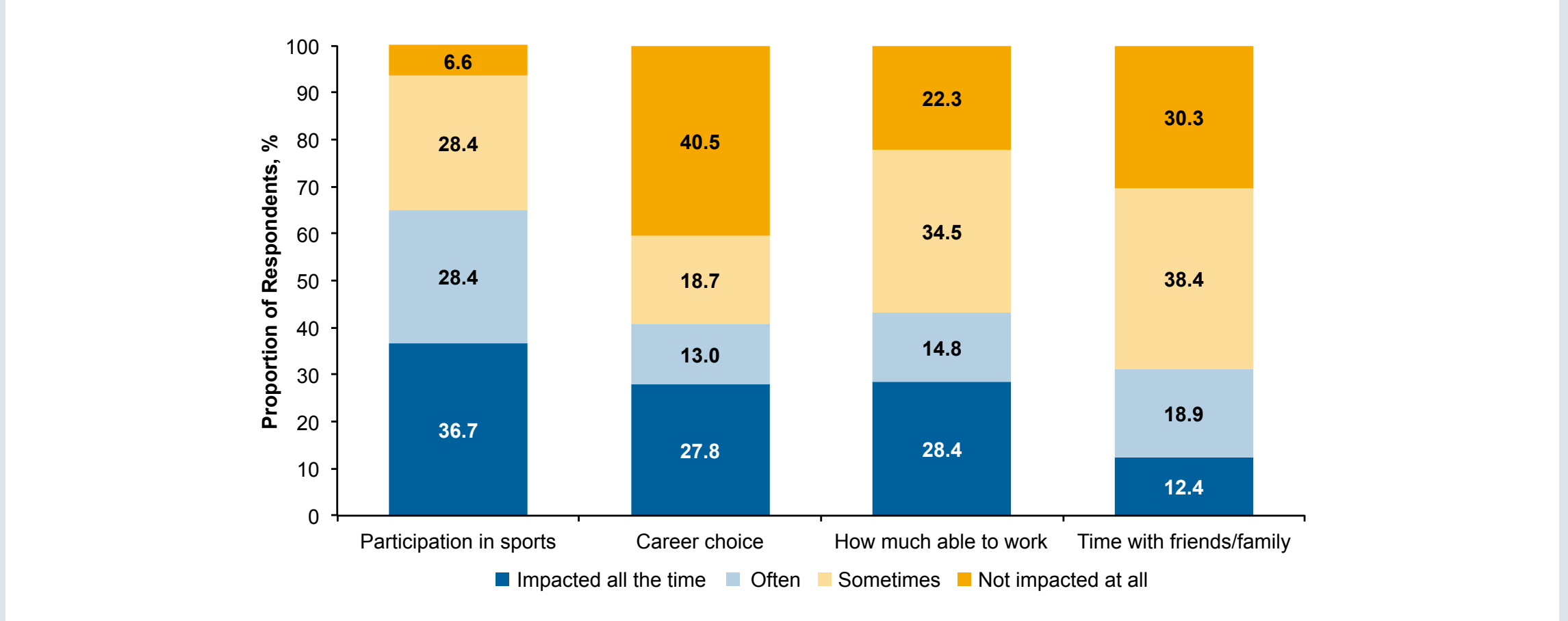
§ $P < 0.05$, male vs female.

‖ For activities related to the discomfort, emotional, and social domains, participants were queried on the impact of AS on their QoL during the previous week.

Disease Impact on Lifestyle

- The impact of AS on certain lifestyle characteristics is shown in **Figure 3**, including participation in sports, career choice, ability to work, and time with friends and family
  - Nearly two-thirds of respondents reported frequent ("all the time" and "often") impact of AS on participation in sports
  - In addition, ≈ 40% of respondents reported similar impact of AS on career choice and how much they were able to work

Figure 3. Patient-Reported Impact of AS on Lifestyle Characteristics (N = 716)*



AS, ankylosing spondylitis.

* Weighted 3:1 (male to female).

LIMITATIONS

- As with all survey-based studies, patient perspectives may be subject to the patients' bias and experience
- Physician-confirmed diagnosis and detailed treatment history were not available
- Only a small proportion of individuals contacted participated in this survey
- The participation rate was greater among female respondents compared with males

CONCLUSIONS

- Respondents with AS reported negative impacts in all QoL domains, with a mean overall EASi-QoL score of 28.9
- Sex differences were also revealed across several aspects of daily living, including lifting a child or heavy objects and worrying about the future
- Integrating subjective metrics of disease via patient-reported outcomes should be included along with clinical evaluation of AS progression

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DISCLOSURES

J. Rosenbaum receives research support from Alcon Research Institute, the Spondylitis Association of America (SAA), and Pfizer; consults for AbbVie, Gilead, Novartis, Regeneron, and UCB; holds stock in Novartis; and receives royalties from UpToDate. L. Pisenti is an employee of UCB, Inc. Y. Park is an employee of Novartis Pharmaceuticals Corporation. R. Howard is an employee of the SAA. The SAA Spondyloarthritis Life Impact Survey was funded by Novartis and UCB.

ACKNOWLEDGMENTS

- Support for third-party writing assistance for this poster, furnished by Kheng Bekdache, PhD, of Health Interactions, Inc, was provided by the Spondylitis Association of America.
- This study was conducted by the Spondylitis Association of America.

Presented at the European League Against Rheumatism Annual European Congress of Rheumatology; June 13-16, 2018; Amsterdam, The Netherlands.