



Does Belonging to a Patient Association Is of Help for Patients with Axial Spondyloarthritis? Results from the Atlas Survey

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Abstract

Purpose of Review International guidelines for axial spondyloarthritis (axSpA) suggest that patients benefit from becoming members of patient associations. However, the scientific evidence for this is limited and unconvincing. The objective of this study was to evaluate the differences in sociodemographic characteristics, lifestyle habits, and patient-reported outcomes (PROs) between axSpA patients belonging to patient associations versus those who do not.

Recent Findings Out of 680 patients, 301 (44.3%) were members of a patient association. A significant proportion of association members were found to engage in physical activities considered appropriate to their condition (48.2% vs. 39.8%, $p = 0.03$), and smoked significantly less compared with their non-association counterparts (22.7% vs. 33.6%, $p = 0.02$). In addition, despite having longer disease duration, and receiving similar treatments, members of associations reported significantly lower disease activity (BASDAI 5.1 vs. 5.8; $p < 0.001$), less functional limitations (Functional Limitation Index 26.4 vs. 28.6; $p < 0.05$), and a lower risk of psychological distress (GHQ-12 4.9 vs. 6.5; $p < 0.001$).

Summary The results of this study suggest there are beneficial effects of belonging to a patient association for managing axSpA, since those member patients experience better lifestyle habits and PROs than those who do not so participate. Rheumatologists should encourage patients to enroll in patient associations for a holistic approach to managing their condition.

Keywords Axial spondyloarthritis · Ankylosing spondylitis · Patient association · Patient-reported outcomes · Non-pharmacological treatments

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Introduction

Patient associations are defined as non-profit organizations that are patient focused, and whereby patients and/or caregivers (the latter when patients are unable to represent themselves) represent a majority of the members in their governing bodies [1]. Patient associations have traditionally provided a supporting role for patients, but their activities are constantly developing and evolving. One of the emerging roles of the patient associations is as advocates for research, directly encouraging individual researchers to conduct patient-based research and lobbying government agencies to increase funding for the disease [2]. At present, their role in health policy is becoming more relevant. Regulatory agencies such as the FDA and EMA, health services, and health technology assessment agencies are creating patient advisory groups, as well as new opportunities for patient involvement [3].

One of the main purposes of patient associations is to provide peer support, bringing together people who have similar concerns so they can explore solutions to overcome shared challenges and feel supported by others who have had similar experiences and who may better understand each other's situation [4]. Research suggests that those patients who participate in support groups, whether face-to-face or online, are more satisfied and empowered, see their sense of self-efficacy and self-control increased, and are more confident to talk to their doctor about their illness [5]. Participation in peer support groups not only has benefits over perceived social support but also plays an important role in commitments, both to treatment and medical indications, as well as to recommendations for lifestyle changes such as physical exercise [6].

The objectives pursued by patient groups are usually to achieve better healthcare or social benefits. Given the enormous variety of chronic diseases and their associated disabilities, the collective needs of different patients groups are very diverse. However, there are commonalities among all of them. The International Alliance of Patients' Organizations (IAPO) carried out research encompassing 1200 patient group members from around the world and published a paper in which they reclaimed both a patient-centered approach to healthcare and active decision-making in health policies. This was the first global declaration on patient-centered healthcare generated and agreed upon by patients and patient organizations themselves [7]. Despite such efforts, research continues to reveal a lack of communication between patients with chronic diseases and healthcare professionals [8].

Of all chronic conditions, rheumatic diseases are one of the main causes of morbidity and disability in the world [9]. Rheumatic conditions include more than 150 diseases and syndromes and are usually strongly associated with pain. The course of rheumatic diseases is insidious with the intermittent appearance of symptoms not evident to third parties, such as pain and/or inflammation. This often leads to incomprehension from friends and family, which increases the psychological burden associated with these conditions [10]. For this reason, it is of great importance that patients dealing with rheumatic diseases belong to a peer support group with which to share their unique experiences.

Among rheumatic conditions, axial spondyloarthritis (axSpA) has been the focus of extensive research in the recent decades. AxSpA (including non-radiographic and radiographic axSpA—traditionally known as ankylosing spondylitis—AS) is a chronic inflammatory disease usually affecting the axial skeleton and involving the sacroiliac and spinal joints [11].

In addition, the 2006 ASAS/EULAR recommendations for disease management states that patient associations and self-help groups may be useful as a non-pharmacological treatment for AS [12, 13]. Similarly, the 2010 Update of the

ASAS/EULAR recommendations again stressed membership in patient associations and self-help groups as useful for the treatment of AS [14]. However, the scientific evidence upon which this recommendation was made was weak: on the one hand, the 2006 recommendations acknowledged that there were no studies that examined the impact of patient associations and self-help groups on pain or functional outcomes [12, 13], nor were any specifications made in this sense [14]. Most likely, due to this lack of evidence, the 2016 Update to the ASAS/EULAR recommendations makes no mention of patient associations. Here, the only aspects mentioned regarding non-pharmacological treatment were the importance of being educated about axSpA, regular exercise, and cessation of smoking [15••].

Scientific studies evaluating the positive effects of belonging to a patient association on axial spondyloarthritis are nearly non-existent [16]. At the beginning of the 1990s, a few studies demonstrated how membership in the UK National Axial Spondyloarthritis Society (NASS) and exercise could improve a patient's emotional state [16, 17•]. More recently, Song et al. [18•] analyzed data from a German survey that included over one thousand patients with AS to determine whether members felt better informed about their disease, smoked less, and had a better functional status compared with non-members.

Based on previous research, the hypothesis of the present study is that membership in a patient association correlates to a better overall health status in axSpA patients, both physically and psychologically. Therefore, the objective of this research is to determine the possible differences in sociodemographic characteristics, habits, and patient-reported outcomes (PROs) between those belonging to axSpA patient associations versus non-participants.

Methods

Survey

For this study, data from the survey of the Spanish Atlas of Axial Spondyloarthritis 2017 was analyzed. The methodology of this project has been previously published in detail in Garrido-Cumbrera et al. [19•, 20].

In summary, this was an initiative promoted by the Spanish Federation of Spondyloarthritis Associations (CEADE) and carried out by the Health & Territory Research (HTR) group of the University of Seville in collaboration with the Spanish Society of Rheumatology (SER) and Novartis.

First, a patient questionnaire was designed and disseminated among unselected individuals suffering from axSpA across the country. The questionnaire was developed over 4 months (from January to April 2016) and tested in a pilot group of 17 axSpA patients belonging to different age groups and with

varying educational levels. This allowed for completion of the questionnaire in its final version, which was comprised of 116 items and 4 open-ended qualitative questions assessing aspects related to axSpA: sociodemographic and disease characteristics, lifestyle habits, and patient-reported outcomes, among other areas. Patient inclusion criteria were as follows: at least 18 years of age, self-reported diagnosis of axSpA, and resident in Spain during the survey. In total, 838 patients with axSpA anonymously accessed the online questionnaire between May 1 and August 15, 2016. After validation and normalization of the information, the final sample consisted of 680 patients who responded to a majority of the questionnaire (minimum completion rate was at least 75%; see Fig. 1). A broader description of the cohort can be found in Garrido-Cumbrera et al. [19•, 20].

Variables

All indicators collected for the Atlas 2017 survey were patient-reported outcomes. A patient-reported outcome (PRO) is directly reported by the patient without interpretation of the patient’s response by a clinician or anyone else and pertains to the patient’s health, quality of life, or functional status associated with healthcare or treatment [21•]. This type of data ensures that the information collected concerns the patient and can be used to detect unmet needs that escape the eye of healthcare professionals or institutions. The following variables were considered for the present study (more detailed information can be found in the study by Garrido-Cumbrera et al. [19•, 20]):

Membership in a Patient Association The survey asked if they belonged to a specific patient association for AS or axSpA. To better facilitate their response, a list of patient associations included in the Spanish Federation of Spondyloarthritis Associations (CEADE) was provided.

Smoking Status Multiple smoking statuses were recorded through a list of pre-defined options and later classified into smokers, sporadic smokers, and non-smokers.

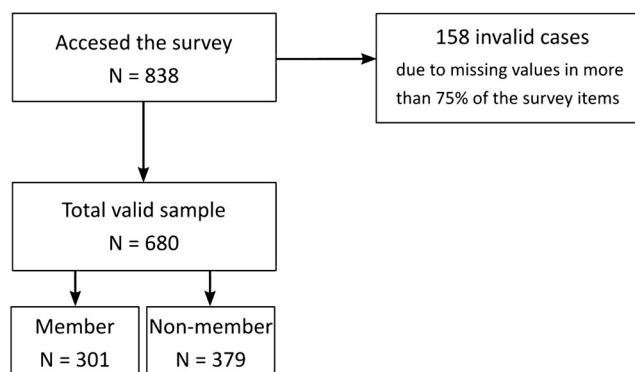


Fig. 1 Atlas 2017 sample selection flow chart

Physical Activities Participants reported on physical activities that previous studies recommended as beneficial for patients with axSpA. These included pilates [22, 23], yoga [24], swimming [23], aquatherapy [25], aquagym [26], and meditation [27]. Patients were asked about each of these activities in a dichotomous way (i.e., whether he/she does or does not perform each activity).

Any Beneficial Physical Activities A global dichotomous indicator (yes/no) was calculated to differentiate participants who performed at least one of the beneficial physical activities cited above from those who did not.

In addition, a range of supplementary indices were collected in the questionnaire to assess specific areas.

BASDAI The Bath Ankylosing Spondylitis Disease Activity Index (ranged from 0 to 10) was used to assess disease activity in patients with axSpA [28–30].

12-Item General Health Questionnaire Psychological distress was evaluated using Goldberg’s 12-Item General Health Questionnaire (GHQ-12) [31, 32]. As the GHQ-12 dichotomous score scale was utilized, the range was from 0 to 12. The cut-off point of 3 was established to define those patients at risk of psychological distress [33].

Spinal Stiffness Index This index was developed for the purpose of this study. Spinal Stiffness Index is based on the ASAS concept of spinal stiffness, which is defined by its intensity and duration upon awakening [12]. Therefore, one of the questionnaire sections distinguished between the three spinal regions: cervical, thoracic, and lumbar. The index resulted from adding unweighted degrees of spinal stiffness in these three regions on a scale of lesser to greater effect (from 3 to 12): where a value of 3 would imply no stiffness, between 4 and 6 light stiffness, between 7 and 9 moderate stiffness, and between 10 and 12 severe stiffness.

Functional Limitation Index This index, developed specifically for this study, was generated by adding, without weighting, the degree of self-reported functional limitations in 18 daily life activities (dressing/undressing, washing/personal grooming, taking a bath/shower, tying shoelaces, walking/getting around the house, going up or down the stairs, lying down/getting up from bed, going to the toilet, shopping, cooking, eating, housework/cleaning, walking down the street, using public transportation, driving, doing physical exercise, going to the doctor, and engaging in intimate relations), using a score of 0–3 (0—no limitation, 1—mild limitation, 2—moderate limitation, and 3—severe limitation), with a total result ranging between 0 and 54.

Statistics

This study used bivariate analysis through non-parametric Mann-Whitney and chi-squared tests to compare the variables (sociodemographic characteristics, lifestyle habits, and patient-reported outcomes) depending on whether or not respondents belonged to a Spanish axSpA patient association. The Mann-Whitney homogeneity test was used to make comparative analysis through rank differences, while the chi-squared test was used to determine whether there was a relationship between categorical variables by means of a contingency table. Statistical analysis was performed using SPSS version 25 and the significance level was set at 0.05.

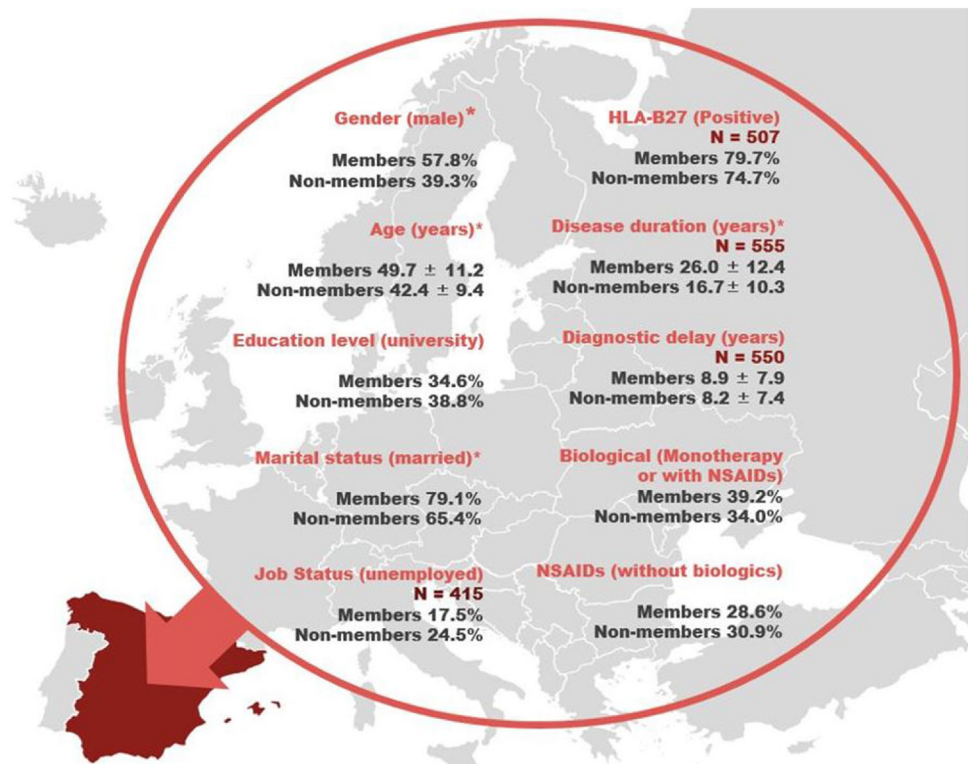
Results

Sociodemographic and Disease Characteristics

Of 680 patients, 301 (44.3%) were members of a patient association. The sample comprised a total of 30 different patient associations distributed across the country.

Figure 2 shows that association members were significantly older, experienced longer disease duration, and were to a higher percentage male. However, no differences in regard to treatment or delay in diagnosis were observed.

Fig. 2 Sociodemographic and disease characteristics among patients who are members of a patient association versus those who are not. The asterisk indicates that the association is significant at the 0.05 level. $N=680$ unless otherwise specified



* The association is significant at the 0.05 level

Note: $N=680$ unless otherwise specified

Lifestyle Habits

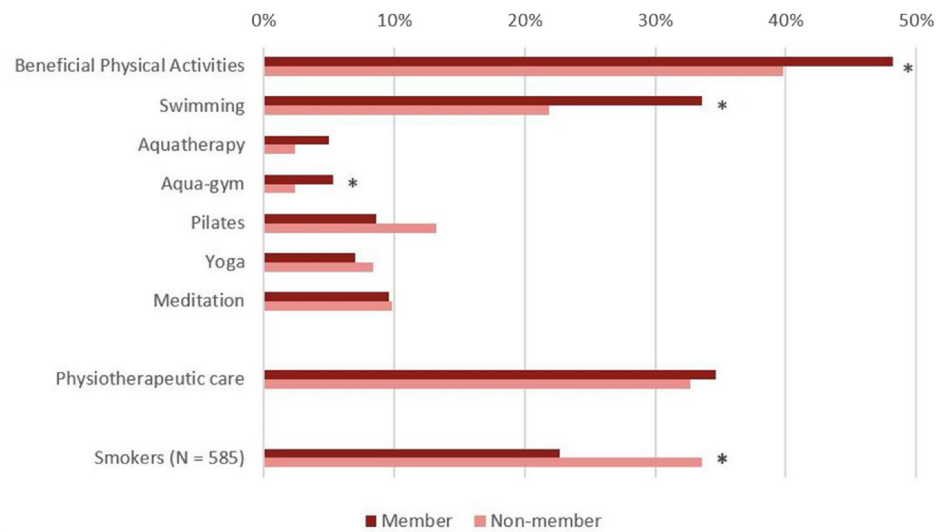
In regard to beneficial physical activities, the percentage of association respondents practicing these activities was significantly higher than that of non-participants (48.5% vs. 39.8%; $p=0.03$). Figure 3 presents the differences, by type, of beneficial physical activity. The analysis showed that physiotherapeutic care was a variable independent from association membership.

On the other hand, the proportion of patients who smoked was significantly lower among association members versus non-members (22.7% vs. 33.6%, $p=0.015$).

Patient-Reported Outcomes

Table 1 shows the results for the PROs in both groups. Self-reported disease activity was significantly lower among patients who were members of an association (BASDAI = 5.1 ± 2.1 vs. 5.8 ± 2.1 ; $p < 0.001$). Likewise, these patients were significantly less functionally impaired compared with their non-association counterparts (Functional Limitation Index = 26.4 ± 13.4 vs. 28.6 ± 12.9 ; $p = 0.038$, respectively). On the other hand, the mean Spinal Stiffness Index was significantly higher among those who were members versus non-members (7.7 ± 2.9 vs. 6.8 ± 2.6 , $p < 0.001$).

Fig. 3 Beneficial physical activities, physiotherapeutic care and smoking status between members and non-members of a patient association. The asterisk indicates that the association is significant at the 0.05 level. *N* = 680 unless otherwise specified



* The association is significant at the 0.05 level
 Note: *N* = 680 unless otherwise specified

Patients who were association members presented a lower risk of psychological distress than non-members (GHQ-12 = 4.9 ± 4.5 vs. 6.5 ± 4.4; *p* < 0.001).

Discussion

In this study, we explored the associations between sociodemographic indicators, physical health, and emotional states based on membership in a patient association, using a sample of 680 patients diagnosed with axSpA.

Support groups play an important role in helping patients maintain regular exercise. AS patients who attend support groups tend to better comply with exercise regimens and are less reliant on medical personnel to manage their health [16, 17]. The study showed how the patient association cohort, to a greater extent, engaged in beneficial physical activities indicated as healthy for the treatment of axSpA (e.g., swimming, aquatherapy and aquagym, pilates, yoga, and meditation). This may be due, as suggested by Feldtkeller et al. [34], to the important role played by patient associations in

disseminating non-pharmacological treatments and promoting beneficial activities, in many cases partially or totally financed by the associations themselves. Therefore, being a member of such an association should be understood as a factor that can promote healthy activities.

The impact of smoking on patients with axSpA has been analyzed in previous studies [35–37]. Its consumption is considered a risk factor for poor response to pharmacological therapy, disease progression, worsening functional capacity, and patient quality of life [38–40]. Our study showed that those who belong to patient associations tend to smoke less. This may be because they are better informed of the recommendations made by healthcare specialists regarding harmful habits related to their disease, and more specifically the negative impact of smoking.

The presence of psychological distress was measured by GHQ-12. Previous studies that evaluated the mental state of AS patients by this method demonstrated the impact of the disease on a patient’s emotional state [41, 42]. In our study, 57.7% of those belonging to a patient association reported psychological distress, while the figure for non-participants

Table 1 Patient-reported outcomes in association-participating patients versus non-participants

	Member (Mean ± SD or %)	Non-member (Mean ± SD or %)	<i>p</i> value
Disease activity (BASDAI) (<i>n</i> = 442)	5.1 ± 2.1	5.8 ± 2.1	0.001
Functional Limitation Index (<i>n</i> = 680)	26.4 ± 13.4	28.6 ± 12.9	0.038
- Moderate to severe	64.5%	68.3%	
Stiffness Index (<i>n</i> = 540)	7.7 ± 2.9	6.8 ± 2.6	< 0.001
- Moderate to severe	72.3%	68.8%	
Psychological distress (GHQ-12) (<i>n</i> = 474)	4.9 ± 4.5	6.5 ± 4.4	< 0.001

was considerably higher at 72.5% ($\text{GHQ} \geq 3$). This result reveals how belonging to an axSpA association can help lessen the psychological burden of the disease.

The Functional Limitation Index, a self-reported measure to assess functional status, showed how subjects who were members of a patient association experienced fewer functional limitations than non-participants. Although BASFI is commonly used in clinical studies of AS [43], only in that by Song et al. [15••] did the degree of functional limitation, as measured with BASFI, correlated to membership in a patient association, with members enjoying significantly better functional status.

The results of Atlas 2017 showed an average self-reported BASDAI of 5.5 ($n = 442$), which implies that the average degree of disease activity was high ($\text{BASDAI} \geq 4$), in line with previous studies on AS [39, 44, 45]. This analysis revealed that participants who were members of patient associations had significantly lower levels of disease activity than non-members. Previously, although the relationship between BASDAI and functional limitations had been analyzed in different AS studies [44, 46, 47], it had not been examined in the context of membership in an axSpA patient association.

The Spinal Stiffness Index showed a lower impact on non-association patients, which could reflect their older age and lower employment levels, which often translates to work incapacity.

These results support the recommendation to raise patient awareness of the advantages related to active membership in a support group [6]. These results also support the 2010 ASAS/EULAR recommendations, which regard associations as a useful non-pharmacological treatment for patients with axSpA. However, one must bear in mind that the Update to the ASAS/EULAR recommendations did not propose patient association membership as a useful non-pharmacological treatment for those with axSpA.

Finally, these results should serve as a basis for future research on the impact such associations have on the different facets of a patient's life, not only in terms of their physical and psychological health but also in raising their awareness to the benefits of healthy habits and lifestyle choices. Well-informed patients can make informed decisions regarding their own treatment and thus better cope with their disease.

Despite the benefits, only a small percentage of patients appear to be interested in actively participating in support groups [48]. Healthcare professionals should encourage patients to join patient associations in order to improve their physical and psychological state so as to improve their work capabilities, social interactions, and overall quality of life [49].

Patient organizations around the world are making a major contribution to the paradigm shift towards patient-centered care. Mobile health is a promising new technology that could support the role of patient associations by facilitating interactions between patients and patient advocates, promoting

patient-physician communication, and educating patients about the management of their disease [50, 51].

Limitations

The use of previously unvalidated scales or indices for assessing certain factors, such as functional limitations in daily activities and spinal stiffness, should be kept in mind. The reason for utilizing such scales or composite indices originated during the preliminary phase of the survey's development, when patients expressed their concern about not being able to report all aspects of their disease when other scales or indices were employed. In any case, a good Cronbach alpha value was obtained for the index chosen for our study, which testifies to the reliability of these methods.

The carrying out of various daily activities was not evaluated objectively or quantitatively, but through a questionnaire involving categorical answers. In addition, the cross-sectional design of this study does not allow for establishing a cause-effect relationship between patient association membership and specific outcomes (e.g., more exercise and less smoking). In other words, it is not possible to know with certainty whether those who smoke less have a greater tendency to become members of a patient association or whether those who do belong give up smoking because they are better informed and thus more aware of the harm that smoking causes to their health.

Conclusions

In this study, we show that members of axSpA patient associations engage in beneficial exercise on a more regular basis and smoke less compared with non-members. Both habits are essential components of non-pharmacological treatment in patients with axSpA. In addition, the results of this study suggest that membership in a patient association does improve disease management, since these axSpA patients experienced lower levels of disease activity, functional limitations, and psychological distress compared with non-members. Rheumatologists should encourage patients to enroll in patient association for a holistic approach to managing their condition.

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Compliance with Ethical Standards

Conflict of Interest Dr. Victoria Navarro-Compán has received unrelated honoraria or research grants from Abbvie, BMS, Lilly, MSD, Novartis, Pfizer, Roche, and UCB. Dr. Jordi Gratacós has received unrelated honoraria or research grants from Abbvie, BMS, Lilly, MSD, Novartis, Pfizer, Roche, and UCB. Dr. Eduardo Collantes has received unrelated honoraria or research grants from Abbvie, BMS, Lilly, MSD, Novartis, Pfizer, Roche, and UCB. Other authors declare that they have no conflicts of interest.

Human and Animal Rights and Informed Consent All patients agreed to their participation through informed consent. In this study, no clinical trial was conducted. As it was not an interventional study, no ethics committee approval was required.

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