



The key symptoms of axSpA such as pain, fatigue, and stiffness can combine to have a profound impact on a patient's ability to maintain a healthy social life (Doward et al. 2003; Hamilton-West and Quine 2009). Qualitative data capturing the perspectives of patients living with axSpA indicate that relationships with friends, family, and work colleagues can all become strained and participation in social events can become difficult (Doward et al. 2003; Hamilton-West and Quine 2009). Patients often report difficulties in their marital relationships, their relationships with other family members, and concerns regarding family planning (Doward et al. 2003; Hamilton-West and Quine 2009; Ward 1999).

A social support network is a crucial aspect of axSpA treatment and preservation of social function is one of the primary goals of axSpA treatment detailed in current ASAS-EULAR recommendations (Heijde et al. 2017). Indeed, a recent study found that having satisfactory social relationships was more important and contributed more to well-being in patients with AS than in a control population who did not have the disease (Genderen et al. 2018). However, supporting social participation, particularly in aspects such as intimate relationships and leisure activities, is often of lower priority than clinical factors when treating individuals with axSpA; this represents an important unmet need that needs to be addressed.

8.1 Impact of axSpA on Relationships

Almost half of the participants reported worsened relationships with work colleagues, and one-third reported worsened relationships with friends (Table 8.1). Due to the importance placed upon maintenance of social participation in current treatment recommendations (Heijde et al. 2017), this could have important implications for participants' quality of life and also the success of overall disease management.

Table 8.1 Impact of axSpA on participants' relationships since disease onset (N = 1,037–2,649)

Relationships	Comparison with before disease onset										N
	Much better		Better		Same		Worse		Much worse		
	n	%	n	%	n	%	n	%	n	%	
Work colleagues	12	1.2	59	5.7	502	48.4	294	28.4	170	16.4	1,037
Friends	52	2.0	162	6.1	1,487	56.4	664	25.2	274	10.4	2,639
Spouse	109	4.6	203	8.6	1,330	56.3	482	20.4	237	10.0	2,361
Family	71	2.7	249	9.4	1,705	64.4	489	18.5	135	5.1	2,649
Neighbors	36	1.5	96	4.1	1,794	76.0	311	13.2	123	5.2	2,360

axSpA axial spondyloarthritis

Although the precise reasons for these worsened relationships were not collected in the IMAS European survey, previous qualitative studies in patients with axSpA have captured anecdotal reports that physical changes were 'off-putting at meetings' and that 'bullying and harassment... by an intimidating workplace' was experienced (Hamilton-West and Quine 2009). The worsened relationships with work colleagues may also be a result of actual or perceived problems with presenteeism and/or absenteeism (as discussed in Chap. 10). For example, patients with axSpA may be unable to perform certain aspects of their work due to fatigue or loss of mobility and colleagues may feel unhappy that they are having to take on extra work as a result (or be worried that this may happen in future). Furthermore, an association between presenteeism and poor relationships with colleagues has been reported (Boonen et al. 2015), including conflicts with colleagues and employers during painful episodes that affect speed or quality of work (Bagcivan et al. 2015).

Worsened relationships with friends may be due to patients with axSpA being unable to participate in certain social events, concerns about dependence on other people, or a lack of understanding of how axSpA affects individuals (Hamilton-West and Quine 2009). Patients with axSpA who have a worse health state have been reported to be more likely to have reduced productivity, both within and outside the workplace, and to miss family, social, and leisure activities more often than those with a better health state (Osterhaus and Purcaru 2014). Patients with AS have also reported logistical problems, such as with scheduling activities/having to change plans due to the unpredictable fluctuating nature of the disease or inability to stay at a friend's house due to an unsuitable mattress (Mengshoel 2008). Nevertheless, some IMAS participants reported that relationships changed for the better, with one out of 10 participants improving their relationships with their spouse or family.

Table 8.2 Effect of axSpA on levels of social activities in participants (N = 2,515–2,685)

Social activities	Comparison with before disease onset										N
	Much more		More		Same		Less		Much less		
	n	%	n	%	n	%	n	%	n	%	
Sports	138	5.1	348	12.9	481	17.8	709	26.2	1,029	38.0	2,705
Travel/excursions	39	1.5	166	6.2	941	35.0	804	29.9	735	27.4	2,685
Intimate relations	28	1.1	51	2.0	1,017	40.4	835	33.2	584	23.2	2,515
Cinemas/theaters/museums	29	1.1	107	4.0	1,188	44.4	722	27.0	631	23.6	2,677
Bars/restaurants	55	2.1	107	4.0	1,166	43.6	727	27.2	618	23.1	2,673

axSpA axial spondyloarthritis

8.2 Impact of axSpA on Social Activities

Participants reported that axSpA had the greatest impact on their ability to socialize through sports, with two-thirds of respondents participating in sports less than before (Table 8.2). Conversely, after disease onset, one-fifth of participants socialized more through sports, and were perhaps motivated by the dual benefit to their physical and social health gained through sporting activities.

axSpA had an overall negative impact on social activities, with approximately half of participants reporting that they were traveling, engaging in intimate relations, going to the cinema, or visiting museums and bars less or much less than before (Table 8.2).

As missing social events has previously been associated with a worse health state in axSpA (Osterhaus and Purcaru 2014), and as patients with AS have reported having to stay at home during episodes of pain (Bagcivan et al. 2015), it is possible that the negative impact on social participation found in the IMAS survey could be explained by the high disease activity and physical limitations experienced by participants (Chap. 6).

Engaging in social activities has been associated with a higher satisfaction with life in patients with AS, although this aspect has typically not been prioritized by HCPs involved in managing the disease (Genderen et al. 2018). This concept, along with the data reported from the IMAS survey, highlights the importance of supporting patients with axSpA to maintain their social roles.

8.3 Patient Organizations Provide an Important Support Network

Approximately 70% of IMAS participants were recruited through patient organizations, and the majority of countries participating in IMAS had at least one of these groups.

Patient organizations play an integral role in providing patients and their families with the tools and resources they need to face the challenges of living with a serious and chronic disease such as axSpA. Support is offered in several different ways, including patient education, disease-specific group physiotherapy, disease-adapted sport, legal advice, and scientific research. Such materials are usually offered freely through online channels, extending access to as wide an audience as possible.

There is increasing appreciation of the key role played by patient organizations in offering support to patients (Strand and Singh 2017), with evidence to suggest that joining a support group can improve some of the signs and symptoms of axSpA (Barlow et al. 1992).

The majority of survey participants reported that they were not members of a patient organization (in response to a question asking ‘Are you a member of any Spondylitis Support Group or Association?’; Fig. 8.1), which is somewhat surprising given that most participants were recruited for the survey through these groups. However, much of the support and information provided is freely available to people who are not full members through websites and social media. The ability of patient organizations to encourage large numbers of patients to participate in the IMAS survey, even though many were not members, suggests that patients are accessing freely available material and engaging with these services regardless of membership. The nature of patient organizations varies across Europe and they may be a particularly useful source of information where patients have limited access to specialist rheumatology centers.

In a previously reported analysis of the subset of patients from Spain included in IMAS, membership of a patient organization was linked with greater engagement in physical activities considered beneficial for axSpA and lower likelihood of smoking (Garrido-Cumbrera et al. 2020). Despite being older and having longer disease duration, membership was also linked with lower BASDAI, lower Functional Limitation Index, and less risk of psychological distress compared with

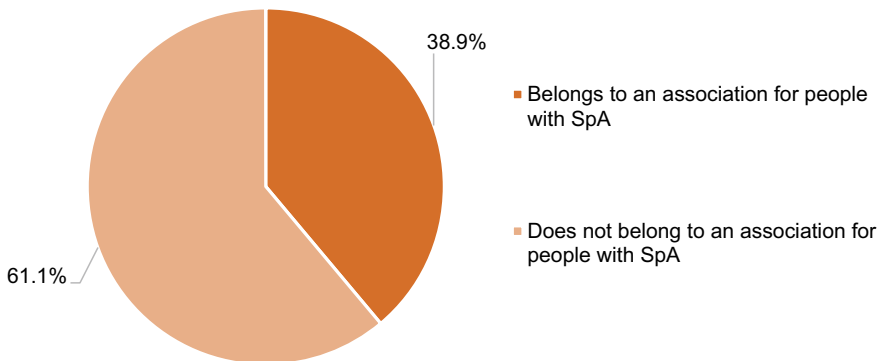


Fig. 8.1 Membership of patient organizations among participants (N = 2,846). SpA spondyloarthritis

non-members, but conversely (like in the overall IMAS population) higher Spinal Stiffness Index scores, potentially reflecting the older age of those who were members.

8.4 Conclusions

- Substantial proportions of participants reported worsened relationships with work colleagues, spouses, family, and friends.
- axSpA had a significant impact on participants' ability to participate in social activities, particularly those of a sporting nature and travel.
- Patient organizations recruited 70% of the participants to the IMAS survey; these groups offer an important support network and reach audiences beyond their membership, for example by providing freely accessible educational material.
- The results serve to highlight the significant impact of axSpA on the social lives of individuals with the disease.
- Maximizing health-related quality of life through preservation of social engagement is recognized in treatment guidelines as a key goal of axSpA management.

References

- Bagcivan G, Cinar FI, Cinar M, Oflaz F, Uzun S, Pay S. Living with pain in ankylosing spondylitis: a qualitative study. *Contemp Nurse*. 2015;51:135–47.
- Barlow JH, Macey SJ, Struthers G. Psychosocial factors and self-help in ankylosing spondylitis patients. *Clin Rheumatol*. 1992;11:220–5.
- Boonen A, Boone C, Albert A, Mielants H. Understanding limitations in at-work productivity in patients with active ankylosing spondylitis: the role of work-related contextual factors. *J Rheumatol*. 2015;42:93–100.
- Doward LC, Spoorenberg A, Cook SA, et al. Development of the ASQoL: a quality of life instrument specific to ankylosing spondylitis. *Ann Rheum Dis*. 2003;62:20–6.
- Garrido-Cumbrera M, Chacón-García J, Navarro-Compán V, et al. Does belonging to a patient association is of help for patients with axial spondyloarthritis? Results from the Atlas Survey. *Curr Rheumatol Rep*. 2020;22:22.
- Hamilton-West KE, Quine L. Living with ankylosing spondylitis: the patient's perspective. *J Health Psychol*. 2009;14:820–30.
- Mengshoel AM. Living with a fluctuating illness of ankylosing spondylitis: a qualitative study. *Arthritis Rheum*. 2008;59:1439–44.
- Osterhaus JT, Purcaru O. Discriminant validity, responsiveness and reliability of the arthritis-specific Work Productivity Survey assessing workplace and household productivity in patients with psoriatic arthritis. *Arthritis Res Ther*. 2014;16:R140.
- Strand V, Singh JA. Patient burden of axial spondyloarthritis. *J Clin Rheumatol*. 2017;23:383–91.

- van der Heijde D, Ramiro S, Landewe R, et al. 2016 update of the ASAS-EULAR management recommendations for axial spondyloarthritis. *Ann Rheum Dis*. 2017;76:978–91.
- van Genderen S, Plasqui G, van der Heijde D, et al. Social role participation and satisfaction with life: a study among patients with ankylosing spondylitis and population controls. *Arthritis Care Res (hoboken)*. 2018;70:600–7.
- Ward MM. Health-related quality of life in ankylosing spondylitis: a survey of 175 patients. *Arthritis Care Res*. 1999;12:247–55.

Open Access This chapter is licensed under the terms of the Creative Commons Attribution 4.0 International License (<http://creativecommons.org/licenses/by/4.0/>), which permits use, sharing, adaptation, distribution and reproduction in any medium or format, as long as you give appropriate credit to the original author(s) and the source, provide a link to the Creative Commons license and indicate if changes were made.

The images or other third party material in this chapter are included in the chapter's Creative Commons license, unless indicated otherwise in a credit line to the material. If material is not included in the chapter's Creative Commons license and your intended use is not permitted by statutory regulation or exceeds the permitted use, you will need to obtain permission directly from the copyright holder.

