



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