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## THE EUROPEAN MAP OF AXIAL SPONDYLOARTHRITIS (EMAS) – LIVING WITH THE CONDITION

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**Aim.** The European Map of Axial Spondyloarthritis (EMAS) aims to describe how patients diagnosed with axSpA experience the disease from a physical, psychological, and everyday life perspective and how they are managed within the healthcare systems.

**Methods.** EMAS employed a cross-sectional survey adapted from the Spanish Atlas of Axial Spondyloarthritis 2017, and containing 120 items on socio-demographics, diagnosis, comorbidities, psychological distress (General Health Questionnaire- GHQ-12), healthcare utilization, pharmacological treatments, disease activity (BASDAI), physical activity and limitations, productivity loss, and patient perspective. Patients from Austria, Belgium, France, Germany, Italy, Netherlands, Norway, Russia, Slovenia, Sweden, Switzerland and UK were included. Data from Spain was retrospectively added. A scientific steering committee, formed by 9 leading axSpA experts was selected to validate the results.

**Results.** 2,846 axSpA patients participated in the survey: mean age was 44 years, 61.3% were female, 67.9% were married and 79.2% were HLA-B27 positive. Almost half were university educated (48.1%), working (51.5%) and members of a patient support group (38.9%). Participants reported a diagnostic delay of 7.2 years with a disease duration of 16.8 years. Active disease (BASDAI  $\geq 4$ ) was detected in 70.9%, while 33.5% had received biological therapy. High GHQ-12 ( $\geq 3$ ) was observed in 57.1%, and patients reported diagnosed anxiety (37.2%) or depression (33.3%).

**Conclusion.** In this sample of non-selected patients, long diagnostic delay and high patient burden, including self-reported active disease and psychological distress, indicate important unmet needs in axSpA. As the first snapshot of issues relevant to European axSpA patients and disease management, EMAS results may contribute to increasing disease awareness and improving the standard of care.

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## ACTIVATION OF NLRP3 INFLAMMASOMES IN PERIPHERAL BLOOD MONONUCLEAR CELLS OF PATIENTS WITH ANKYLOSING SPONDYLITIS

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**Objective.** NLRP3 inflammasome is a molecular platform triggering activation of inflammatory cytokines including interleukin-1 $\beta$  (IL-1 $\beta$ ). This study aimed to assess the expression of NLRP3 inflammasome complex and pro-inflammatory cytokines in patients with ankylosing spondylitis (AS).

**Methods.** Peripheral blood mononuclear cells (PBMCs) and serum from 23 male patients and gender-matched 30 healthy controls were consecutively collected. The mRNA expression for target genes including NLRP3, caspase-1, IL-1 $\beta$ , IL-17A, and IL-23 from PBMCs were evaluated by quantitative real-time polymerase chain reaction (qRT-PCR). Clinical information related with AS patients were collected including Bath Ankylosing Spondylitis Disease Activity Index (BASDAI), peripheral arthritis, enthesitis, and extraarticular manifestations. Statistical analyses were performed using Spearman's correlation coefficient and Mann-Whitney *t* test.

**Results.** Higher mRNA expression of NLRP3, caspase-1, IL-1 $\beta$ , IL-17A, and IL-23 in AS was noted than those in controls ( $p=0.010$ ,  $p=0.029$ ,  $p=0.005$ ,  $p=0.046$ , and  $p=0.002$ , respectively). Patients treated with biological diseases modifying antirheumatic drugs (bDMARDs) showed significantly lower caspase-1, IL-1 $\beta$ , and IL-17A mRNA levels than those without bDMARDs, but not in IL-23 and NLRP3. NLRP3 mRNA levels were significantly associated with IL-23, IL-17A, caspase-1, and IL-1 $\beta$  ( $p<0.05$  of all). These gene expression was not associated with disease duration and BASDAI score ( $p>0.05$  of all).

**Conclusion.** This study suggests that inflammatory response by activation of NLRP3 inflammasome might be involved in the pathogenesis of AS.

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## ASSESSING FUNCTIONAL DISABILITY AND GENERAL HEALTH SITUATION IN PATIENTS WITH ANKYLOSING SPONDYLITIS BY ASAS HEALTH INDEX

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**Introduction/Aim.** Ankylosing Spondylitis can cause physical dysfunction and reduce patients health quality and thus can cause disability. Ankylosing Spondylitis Quality of Life (ASQoL) index is widely used to assess patients with ankylosing spondylitis. ASAS health index and environmental factors index are easy to use and show us the disease from patients perspective. We aimed to assess general health status, dysfunctions by using ASAS health index and environment factors and other doctor and patient related scales.

**Materials and Methods.** 94 patients covered ASAS diagnostic criteria were included. ASAS Health index (ASAS-HI), Bath ankylosing spondylitis disease activity index (BASDAI), Bath ankylosing spondylitis functional index (BASFI), patient related health assessment questionnaire (HAQ) and ankylosing spondylitis quality of life (ASQoL) questionnaires were filled by participants.

**Results.** 45 of 91 (%50) patients were male, mean age was 35.6 (10.6) and average disease duration was 25.7 (40.5) months. %50 of patients BASDAI score was more than 4 (0-10) and had active disease. When ASAS health index result was evaluated, 29 patients (%33) had normal function and 32 patients had (%36.4) moderate dysfunction and 27 patient (%30.7) had severe dysfunction. When compared with BASDAI results disease activity and ASAS health index results showed positive relation ( $p=0.00$ ). ASAS health index results showed positive correlations with BASFI, BASDAI, spinal pain, HAQ. (respectively  $r:0.5, 0.6, 0.5, 0.6$ ).

**Discussion.** ASAS health index and environmental factor index results showed positive correlations with BASFI, BASDAI, spinal pain and HAQ. Although ASQoL is only used to assess health quality, ASAS health index and environmental factor index are used to assess general health status, functional disability degrees, pain levels, social participation and emotional and sexual function status.

**Conclusion.** ASAS health index is a easy, fast and reliable scale in patients with axial spondyloarthritis.

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## EMPOWERING ANKYLOSING SPONDYLITIS (AS) PATIENTS THROUGH AN ONLINE PERSONAL HEALTH SYSTEM

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**Introduction.** Patient empowerment integrates multiple concepts that allow a patient to self-manage his disease, which are accessing to health information, education, bi-directional communication between patients and healthcare professionals, self-care support, chronic disease management support and shared decision making.

**Methods.** In order to evaluate whether an online personal health platform improves AS patients' health and enhances their effectiveness in managing their health, an online personal health platform is developed for AS patients in Turkey within the scope of European Commission supported PALANTE project. Share them with healthcare professionals, messaging module which allows patients to ask questions to healthcare professionals without getting any appointment, exercise module which allows patients to follow the exercise plan specified by physical therapist, videos module which allows patients to learn how to do exercises correctly.

The system has been used by 131 patients and 3 healthcare professionals in Turkey. In order to evaluate the success of the system, a questionnaire was sent to the patients after they used the system for 6 months.

**Results.** Questions are categorized in three groups as communication, educational, and informational features. For each group, same set of questions were asked to patients. Using the functionalities enabled me to accomplish my healthcare tasks more quickly; Communication 70%, educational 74%, Informational 67%. Using the functionalities enhanced my effectiveness in managing my health; Communication 66%, educational 73%, Informational 66%. I found the ... functionalities useful for managing my health; Communication 67%, educational 76%, Informational 73%. I want this service to continue; Communication 86%, educational 83%, Informational 83%.

**Conclusion.** As it can be seen from the table, majority of patients reacted positively and want the services to continue. Patients found educational features, which contains videos module that allows patients to do their daily exercises correctly without consulting physical therapist, as the most useful functionality of the system. Consequently, the system improved AS patients' health and enhanced their effectiveness in managing their health.