

HOPES AND FEARS OF PATIENTS WITH AXIAL SPONDYLOARTHRITIS IN SPAIN. THE VALUE OF PATIENT OPINION: RESULTS FROM THE SPANISH ATLAS

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Background: Not much attention has been paid to listening to the opinions of patients in most scientific studies on Spondyloarthritis, despite their opinions playing an increasingly important role in decision-making alongside clinical and public health criteria.

Objectives: To assess the opinions of patients with Axial Spondyloarthritis (ax-SpA) using qualitative information.

Methods: A sample of 680 patients diagnosed with ax-SpA was interviewed during 2016 as part of the Spanish Atlas, which aims to promote early referral and improve healthcare and the use of effective treatments in patients with ax-SpA. The Atlas is a CEADE initiative (Spanish Coordinator of Patients with ax-SpA in Spain) developed by the University of Seville and Max Weber Institute in collaboration with GRESSER (Spanish Rheumatology Society spondyloarthritis study group). Responses to qualitative items about patients' hopes and fears for their disease and their personal aims regarding their treatment were analysed.

Results: 53% were females, mean age 46 years and 77.1% were HLA-B27+. The five main hopes of patients are: stopping the disease, dream of a cure, elimination of pain, improve their quality of life and live without limitations. Additionally, patients has expectations on the medical research outcomes. Thus, 81% of patients hope that the research will make possible to find the cause and a cure for ax-SpA, developing more efficient biologic therapies (11%), and finding new techniques or medication (8%).

The following stand out among drug treatment-related concerns: having more effective treatments (32%), sustaining the results of biologic therapies (29%), being able to start on biologics (8%), the public health system funding non-drug treatments for AS (8%), eliminating secondary effects (15%), reducing prices (4%), and correct use (4%).

With respect to their fears, patients stated that their main concern was mobility loss (31%), followed by loss of independence (23%), disability (22%), stiffness (12%), structural damage (3%), organ damage (3%), other illnesses and diseases related (3%), physical decline (3%), and sight loss (1%).

Patients who expressed fear regarding their disease listed their greatest concern was that they would not overcome or tolerate pain (56%), followed by the fear that the disease would develop (32%), along with apprehension about flare-ups (7%), and tiredness (5%).

With respect to patients' personal objectives in terms of their treatments, they highlighted the wish that their treatment would, first, help them to reduce and eliminate pain, increasing their in mobility, improved quality of life, the avoidance of structural damage and the disease eventually being cured.

Conclusions: Analysis of patient opinion using qualitative information has enabled the identification of important concerns for patients such as discovering the cause of the disease, reducing pain and structural damage, loss of self-sufficiency and disability.

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