

Impediments to Accurate Diagnosis of Non-radiographic Axial Spondyloarthritis (nr-axSpA): “Rheum to Diagnosis” Study: Interim Results

AUTHORS: Kiwalkar S¹, Howard R², Deodhar A¹

¹Oregon Health & Science University, Portland, Oregon

²Spondylitis Association of America, Van Nuys, California

BACKGROUND

In the US, there up to 14-year delay¹ in axial spondyloarthritis (axSpA) diagnosis, which is likely greater for nr-axSpA. Impediments to timely diagnosis of nr-axSpA are unknown. The objective of this qualitative study was to understand the patient experience and contributors to delayed nr-axSpA diagnosis.

METHOD

Nr-axSpA patients were recruited through announcement in the Spondylitis Association of America (SAA) monthly e-mail newsletter & from a national back pain panel. Interested patients (n=165) were screened for inclusion (Figure 1). First 25 to qualify were included. Out of 190 board-certified rheumatologists list from the SAA, 26 responded to an e-mail invitation. The first 15 available were included. We conducted semi-structured phone interviews with patients and rheumatologists. A grounded theory approach was used in the analysis.

RESULTS

Patients described: 1) a strong belief among healthcare providers (HCPs), including rheumatologists, that this is a “man’s disease”, leading to dismissed female complaints of back pain without x-ray evidence, requiring visits to multiple rheumatologists prior to accurate diagnosis; 2) need for “best care” including comprehensive treatment roadmap, alternatives to biologics, and holistic lifestyle management. Most study rheumatologists recognized inflammatory back pain (IBP) and conducted physical exams, ordered appropriate tests, but identified following barriers to optimal management: 1) availability of expert radiologists to read MRIs of sacroiliac joints; 2) navigating patients’ insurance for diagnostic investigations and unnecessary step therapy. There was agreement among study patients and rheumatologists that: 1) timely and accurate nr-axSpA diagnosis is prevented by lack of both, disease awareness and shared understanding among HCPs; 2) since chronic back pain is common, IBP is often unrecognized, resulting in missed referrals. A study limitation is participants’ association with SAA, resulting in disproportionately high knowledge of nr-axSpA diagnosis.

CONCLUSION

Patients desire treatment guidance beyond medication (diet, exercise recommendations, holistic lifestyle). Rheumatologists desire autonomy from insurers.

More widespread education on nr-axSpA is needed to improve awareness among all stakeholders. These 'qualitative' study results form the basis of the on-going 'quantitative' part of the study.

REFERENCE

¹Deodhar A et al. Arthritis Rheumatol 2016. July;68(7):1669–1676.

Figure 1: Screener for patient eligibility

