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Concise report

Services provided for axial spondyloarthritis patients by rheumatologists in India: a survey

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Abstract

Objective We sought to evaluate the current knowledge and attitudes of Indian rheumatologists concerning axial spondyloarthritis (axSpA) with respect to recent terminology for diagnosis, management strategies and additional services.

Methods The survey was designed for spondyloarthritis care given by rheumatologists in the Indian health-care context. The structured survey consisted of a combination of multiple-choice and open-ended questions. An anonymous Web-based questionnaire was sent to 710 members of the Indian Rheumatology Association, and descriptive analysis of responses was done.

Results The survey respondents were from government and private health-care facilities and gave a response rate of 19% (133 of 710). About 49% of respondents were using the terminology axSpA for a new diagnosis of spondyloarthritis (SpA). BASDAI was used routinely as the main disease monitoring tool by most respondents (76.2%). Same-day MRI was available to 42.9% (51 of 119) respondents. Selective cyclooxygenase-2 inhibitors were the preferred first NSAID for 50% of respondents, and SSZ was the most preferred DMARD for peripheral arthritis. Financial constraints were the most common factor that affected the initiation of biologics and also the most common reason for stopping biological therapies. Nearly 65% (80 of 122) of respondents did not have a multidisciplinary team available in clinical practice, and only 15% of respondents had access to patient support groups.

Conclusion For a new diagnosis, the terminology of axSpA is not fully accepted by Indian rheumatologists. The axSpA management given by Indian rheumatologists is in agreement with recent guidelines, however, there is a significant lack of accessibility to multidisciplinary care and patient support groups in India.

Key words: axial spondyloarthritis, ankylosing spondylitis, service provision, India, survey, biologic therapy, multidisciplinary team

CLINICAL SCIENCE

Key messages

- Axial spondyloarthritis terminology is not widely used by rheumatologists in India for new diagnosis.
- The management of axial spondyloarthritis patients given by Indian rheumatologists is in agreement with current international guidelines.
- For the majority of axial spondyloarthritis patients in India, there remains a significant deficit of multidisciplinary care and patient support groups.

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Introduction

The concept of axial spondyloarthritis (axSpA) is an ever-evolving phenomenon. In the last two decades, there have been extraordinary advances in the understanding of the pathophysiology, epidemiology and management of spondyloarthritis spectrum disorders. This knowledge progression has resulted in much-required refinement of older terms like Ankylosing

spondylitis (AS) into newer and clinically relevant subgroups of radiographic axSpA and non-radiographic axSpA [1]. The shift from previous modified New York criteria and AS terminology to the use of 2009 assessment of spondyloarthritis international society (ASAS) criteria for classification was meant to increase early diagnosis of axSpA with the use of inflammatory markers (ESR and CRP) and MRI changes in SI joints and vertebrae [1]. On the management front, identification of pathogenic cytokine pathways involving TNF-α, IL23/12 and IL17 has led to the introduction of very effective anti-cytokine therapies, which have become standard of care for patients who cannot tolerate or are resistant to NSAIDs [2]. Likewise, multiple studies have shown the significance of physical therapy as an essential adjuvant to drug therapy in axSpA management [3]. There have been no studies from India evaluating awareness among rheumatologists about changes in terminology and management concepts in axSpA. There are also inadequate data regarding the status of allied health care for spondyloarthritis in India.

With this background, an anonymized Web-based survey of rheumatologists was done to evaluate the current status of axSpA care in India. We also aimed to identify the issues encountered by an Indian rheumatologist in daily practice while treating axSpA patients.

Methods

During the 2017 annual conference of the Indian Rheumatology Association (IRA), in a spondyloarthritis special interest group meeting, it was decided to initiate an Internet-based survey of current practices of Indian rheumatologists. Given that there was no previous validated questionnaire available from India in the subject matter, a new Web-based survey was constructed. The questions were developed in the context of spondyloarthritis care given in the Indian health-care scenario. The structured questionnaire was developed by all four authors, who are rheumatologists from India. A pilot online survey was done of 34 rheumatologists in January 2018. After the internal validation by checking the consistency of responses and revision of questions, the survey format was finalized. The survey was distributed through Google Docs, and survey links were emailed to 710 members of the IRA. Six weeks (from the first week of March 2018 to the second week of April 2018) were given to complete the survey. The survey was made completely anonymized by changing required settings in Google forms such that no respondent information, including email address, was visible to investigators. No ethical approval was required for the survey, according to the Indian Council of Medical Research guidance [4]. Descriptive statistical analysis was done by Microsoft Excel (v.16.41), and results were expressed as a percentages or as the median [interquartile range (IQR)].

The survey consisted of a total of 34 questions (32 multiple choice questions and 2 free text questions). The questions were grouped into 5 domains: demography (6 questions), clinical assessment (4 questions), diagnosis/imagining (5 questions), treatment (10 questions) and additional services (9 questions). The final survey template is provided as Supplementary Data S1, available at *Rheumatology Advances in Practice* online. Given that many respondents did not answer all survey questions, the result analysis was done according to responses available for each question.

Results

Demography

The survey response rate was 19% (133 of 710). The respondents were from teaching tertiary care hospitals (30.1%), government hospitals (5.3%), private clinics (24.8%), private multi-speciality hospitals (21.1%) and corporate hospitals (24.8%). About 83% (110 of 133) of respondents were consultants and 17.3% (23 of 133) rheumatology trainees or fellows. Axial spondyloarthritis terminology was used by 48.9% (58 of 133) respondents for a new diagnosis of spondyloarthritis (Table 1). SpA was still the preferred terminology for 43.6% of respondents for a new diagnosis. Non-radiographic axSpA patients comprised <25% of total SpA patients in the clinical practice of 49% (60 of 122) of respondents. Approximately 10 (5–20) [median (IQR)] patients with axSpA visited rheumatology clinics per week. Three-monthly reviews were the most common (63.9%) follow-up duration, whereas 19.5% of clinicians were reviewing patients monthly.

Clinical assessment

Seventy-four per cent (90 of 122) of rheumatologists were using disease monitoring and assessment tools in routine clinical practice, of which 76.2% (93 of 122) were using BASDAI routinely. In clinics, 23%, 27.9% and 24.6% of clinicians were carrying out ankylosing spondylitis disease activity score (ASDAS)-ESR, ASDAS-CRP and BASMI, respectively.

Diagnosis and imaging

Nearly 52% (63 of 122) of respondents would prefer X-ray of the SI joints as the first radiological investigation, whereas 34.4% (42 of 122) would prefer both X-ray and MRI of the SI joints and 13.6% (17 of 122) would only do MRI (Table 1). Same-day MRI was available to 42.9% (51 of 119), whereas 36.1% (43 of 119) would obtain MRI within a week (Table 1). When asked about satisfaction with MRI arrangements on a Linkert scale (0–10), where 0 was unsatisfactory and 10 satisfactory, the response was 7 (5–9) [median (IQR)].

Treatment

For 50% (61 of 122) of the respondents, selective cyclooxygenase-2 inhibitors were the preferred first NSAID (Table 1). Only 2.5% (3 of 122) were using DMARDs for pure axSpA, and sulfasalazine (SSZ) was the preferred

Table 1 Salient survey responses

Response	*n* (%)
Terminology preferred for new diagnosis (responses = 133)	
SpA	58 (43.6)
Axial spondyloarthritis (axSpA)	65 (48.9)
AS	6 (4.5)
Spondyloarthritis	3 (2.2)
Seronegative spondyloarthritis	1 (0.8)
Imaging ordered for new axSpA patients (responses = 122)	
X-ray	63 (51.6)
MRI	17 (13.9)
Both	42 (34.5)
Waiting time to get MRI for axSpA patients (responses = 119)	
Same day	51 (42.9)
Within a week	43 (36.1)
2 weeks	6 (5)
1 month	15 (12.6)
3 months	4 (3.4)
Preferred first NSAID in axSpA patients (responses = 122)*	
Cyclooxygenase-2 inhibitors	61 (50)
Indomethacin	31 (25.4)
Naproxen	12 (98)
Aceclofenac	4 (3.3)
Variable	14 (11.5)

*Given that rheumatologists named more than one drug, values overlap. axSpA: axial spondyloarthritis.

choice. For 91% (111 of 122), SSZ was the preferred DMARD for peripheral arthritis. Of all patients, 10% (3–23) [median (IQR)] axSpA patients were on TNF inhibitor (TNFi) therapy. No data on IL17 inhibitor therapy was obtained.

With respect to TNFi biosimilar usage, 61.2% of prescribers were completely confident, 27.3% were very confident and 11.6% were not very confident. For 42.1% of prescribers, the ability to prescribe TNFi therapy was restricted, and the most common cause (95.9%) for this was the financial constraints of the patients. Financial constraints of the patients were also the most common reason (84.9%) for stopping TNFi therapy. Disease remission and non-efficacy were a cause for stopping TNFi therapy in 9.2% and 1.7%, respectively. Tuberculosis or other infections resulted in stoppage of therapy in only 4.2% of patients. About 19% (23 of 121) practitioners were comfortable with prescribing TNFi therapy in non-radiographic axSpA without MRI changes.

Additional services

About 34.7% (42 of 121) of respondents had accessibility to a multidisciplinary team in the clinic, of whom 85% (36 of 42) had physiotherapy accessibility and 33.3% (14 of 42) had a nurse specialist in the multidisciplinary team (Table 2). With respect to non-pharmacological guidance, 29.7% (33 of 111) advise hydrotherapy, 19.8% (22 of 111) give advice on driving and 71.1% (80 of 111) have a patient education programme.

Patient queries outside the clinic were also answered, and 57.1% (64 of 112) of respondents provided

Table 2 Status of allied services

Allied services	*n* (%)
Multidisciplinary team (responses = 121)	
Yes	42 (34.7)
No	79 (65.3)
Members of multidisciplinary team (responses = 42)	
Physiotherapist	36 (85.0)
Rheumatology nurse specialist	14 (33.3)
Occupational therapist	11 (26.19)
Musculoskeletal radiologist	18 (42.8)

telephone support, 42.9% (48 of 112) responded to SMS or WhatsApp messages and 40.2% (45 of 112) gave email advice. Sixty-two per cent (68 of 109) of clinicians responded within 24 h. Only 15.7% (19 of 121) of respondents had access to patient support groups to refer patients. The patient database was maintained by 35.8% (43 of 120), and 45.9% (56 of 122) of respondents had access to clinical trials for new therapies. Rheumatologists highlighted the financial constraints of patients and misconceptions about therapies among others as the main challenges in daily practice. A few salient points suggested by survey participants to improve patient care are listed in Table 3.

Discussion

The classification of axSpA into radiographic axSpA (AS) and non-radiographic axSpA (no radiographic changes in SI joints and vertebrae) is now being used in clinical trials and management guidelines of various societies across the world [5]. It is therefore imperative that treating clinicians are up to date with the latest terminologies.

Our survey shows that around half of the participating Indian rheumatologists are now using axSpA terminology for a new diagnosis, but others are still using terms such as SpA and AS. This discrepancy in diagnostic terminology might result in confusion in patients and other allied health-care workers [6]. Around 25% of patients (median) from respondents' clinical practices have non-radiographic axSpA which is similar to previous studies from India and internationally [7, 8]. The average time of patient review is 1–3 months, which is also similar to other countries [9]. BASDAI remains the most commonly used disease monitoring tool; two-thirds of survey respondents are doing it regularly on follow-up, whereas only one-quarter are doing ASDAS ESR or CRP. This could be because of the ease of carrying out BASDAI compared with ASAS tools, which require inflammatory markers that might not be available at every clinic visit [10].

Advancement in MRI technology has been the main reason for the increase in diagnostic accuracy in axSpA. Valid use of MRI in appropriate clinical scenarios results in early diagnosis, well before the development of irreversible radiographic deformities. It was heartening to know that ~75% of respondents can obtain MRI within a week, which might help in early diagnosis. Most of the respondents were happy with the MRI arrangements. Accessibility to MRI in Indian rheumatology practice is much better than in other countries [9], but the average cost of MRI is about 10 times higher than a pelvic radiograph, which is an out-of-pocket expense to the patients in the absence of universal health insurance. This reflects the fact that health care in India is decentralized, however inequitable for resources. Only 2.5% of respondents are using DMARDs for axSpA, and SSZ remains the preferred therapy for peripheral arthritis. This is according to current management guidelines [5]. Financial constraints of patients remain the most common cause of delay in starting biologics. Reassuringly, in only 4.2% of patients, TB or other infections were the reason for stopping TNFi, which reaffirms the safety of TNFi in India [11].

Although TNFi therapy has been approved in non-radiographic SpA with or without MRI changes [5], the use of TNFi in MRI-negative axSpA patients is still a matter of discussion [12]. This dilemma is also reflected in our survey, where only 19% of respondents will advise TNFi for non-radiographic axSpA with no MRI changes. About 90% of the respondents are confident in using TNFi biosimilars, which negates safety and efficacy issues with biosimilars in the Indian context [13]. Our survey confirms that the axSpA management given by Indian rheumatologists is in agreement with the latest published guidelines around the world.

Care by a multidisciplinary team comprising a physiotherapist, nurse specialists, an occupational therapist and a rehabilitation specialist is an important component of optimal axSpA care [14]. On looking at the current Indian health-care scenario, it can be assumed that deficient multidisciplinary team care remains a worrying aspect of axSpA care in India [15]. This is also reflected in our survey, where ~65% of respondents do not have access to the services of a multidisciplinary team.

As a part of the continuity of care, a helpline for patients in rheumatology clinics can play a significant

Table 3 Main challenges and suggestions to improve care

Main challenges faced by rheumatologists in management of axSpA patients in daily clinical practice:
Financial constraints of patients
Inability to obtain early MRI
Lack of awareness in patients and other health professionals about axSpA
Delayed referral
Misconception about NSAIDs as pain killers in both patients and primary care doctors
Rheumatologists' suggestions to improve axSpA patient care:
Access to low-cost effective therapies
Formation of patient support groups
Access to multidisciplinary team, especially rheumatology nurses
Increasing awareness of general practitioners, physicians and orthopaedics in axSpA
Indian spondyloarthritis registry

axSpA: axial spondyloarthritis.

part in optimizing care [9]. Usually, in other health-care systems, these helplines are run by nurse practitioners. In the Indian scenario, there is a significant lack of rheumatology nurse practitioners (Table 2). The results of our survey show that this responsibility eventually comes to treating rheumatologists, who are responding to patient queries by telephone, SMS, WhatsApp or email. The lack of a dedicated patient helpline might increase the workload of a busy clinician, implying a need to train nurse practitioners in rheumatology [16]. A patient support group can play important role in enhancing patient education, allaying anxiety about the disease and fears about therapy. Important examples are successful patient support groups such as the National Axial Spondyloarthritis Society (NASS) in the UK and the Spondylitis Association of America (SAA) in the USA. In our survey, only 15% of carers in India have access to patient support groups, meaning that many patients are unsupported for non-clinical advice.

In our survey, financial constraints of patients were the main challenges faced by practitioners in daily practice. In India, universal health insurance is not available and most private health insurance policies do not cover rheumatological treatments. A sizeable number of rheumatology patients are getting treatment in government hospitals, where specialist rheumatology care is absent except for a few tertiary care teaching centres [17]. This means that most of the axSpA patients are being cared for by non-specialists, which leads to delayed diagnosis, inadequate management and poor disease outcomes [15, 18]. Rheumatologists participating in the survey expressed the need for increasing awareness of SpA spectrum diseases in primary care doctors and other speciality medical professionals.

The low response rate (19%) is the biggest limitation of our survey. However, it has been recognized previously that Internet-based surveys on average have a 20–30% response rate but nonetheless remain an important part of understanding practices of a study population [19]. A recent international survey performed to assess the perceptions and attitudes of rheumatologists towards classification criteria of axSpA had a response rate of 6% [20]. Another issue with our survey was that not all respondents replied to all survey questions; however, each question was analysed separately according to the responses received, thus reducing the impact on the overall results. We think that our survey will help in understanding axSpA care in India, with recognition of deficiencies that are affecting optimal patient care. The results also remain valuable information for future studies seeking trends of axSpA care in India.

Conclusion

To our knowledge, ours is the first survey that aspires to evaluate care given by Indian rheumatologists for axSpA. The survey results show that axSpA terminology is still not widely used for new diagnosis by rheumatologists in India. The management practices of axSpA of Indian rheumatologists are according to the current international management guidelines, but biologic use is restricted because of the financial constraints of the patients. Patient care for axSpA in India remains uneven, in that imaging services including MRI are easily accessible but multidisciplinary team services and patient support groups are lacking.

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Data availability statement

The data underlying this article will be shared at reasonable request to the corresponding author.

Supplementary data

Supplementary data are available at *Rheumatology Advances in Practice* online.

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