Spondylitis Association of America™

"Rheum to Diagnosis": Uncovering Impediments to Accurate Diagnosis of Non-radiographic Axial Spondyloarthritis

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BACKGROUND

- In the US, there is up to a 14-year delay in axSpA diagnosis
- Timely detection of patients with nr-axSpA remains a major obstacle to appropriate care
- Impediments to timely diagnosis of nr-axSpA are inadequately understood
- This study aimed to characterize the journey to nr-axSpA diagnosis and factors contributing to diagnostic delay

OBJECTIVES

Primary

- To determine the impediments to diagnosis of nr-axSpA in the US

Secondary

- To determine the top 5 types of HCPs seen by patients before nr-axSpA diagnosis
- To determine the number of rheumatologists seen before nr-axSpA diagnosis

Exploratory

- To investigate if demographic factors determine delay in diagnosis

METHODS

- Mixed-methods study (Figure 1)
- Qualitative component (February 2020)
  - Convenience sampling method
  - 15 rheumatologists and 25 patients
  - Semistructured phone interviews
  - Grounded theory analytical approach
- Quantitative component (April-July 2020)
  - Overarching qualitative themes integrated into online, self-administered survey and subsequent analysis

Figure 1. Mixed-Methods Study

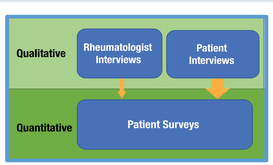


Table 1. Qualitative Interviews Sample

	Patients	Patients	Rheumatologists
Recruitment	SAA monthly newsletter	Back pain panel	SAA list
Screened	165	1425	26
Qualified	50	15	
Interviewed	24	1	15

Table 2. Quantitative Patient Interviews Sample

	Total	SAA sample	General sample
Responded	16,283	252	16,031
Ineligible[a]	16,097	164	15,933
Analyzed	**186**	**88**	**98**

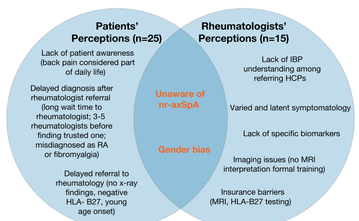
[a] Includes respondents who did not meet criteria for rheumatology-confirmed nr-axSpA (n=15,702), incomplete surveys (n=148), and unreliable surveys (gamers, flatliners, and surveys with implausible responses [n=247]).

- Patients recruited via SAA newsletter, social media channels, and back pain patient databases, and screened for eligibility.

RESULTS

Qualitative Phase Results

Figure 3. Qualitative Phase Results: Impediments to Diagnosis



IBP, inflammatory back pain; MRI, magnetic resonance imaging; RA, rheumatoid arthritis.

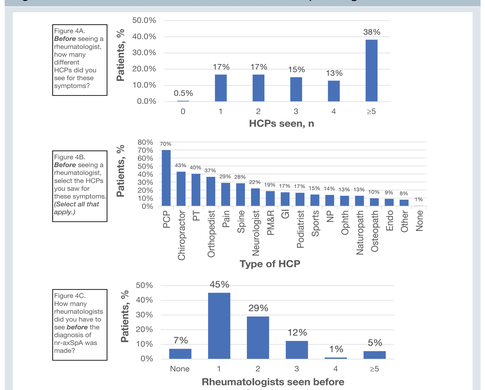
Quantitative Phase Results

- 51% saw ≥4 different HCPs before rheumatologist (**Figure 4**)
- 47% saw ≥2 rheumatologists before nr-axSpA diagnosis (**Figure 4**)
- Interval from symptom onset to nr-axSpA diagnosis: ≤2 years (49%) to ≥11 years (23%) (**Figure 5**)
- Issues perceived as leading barriers to timely diagnosis (**Table 4**)
  - Symptoms are a consequence of activity or age
  - HCPs minimize, overlook, or misinterpret signs of inflammatory disease
  - Missed diagnoses due to young age, female sex

Table 3. Demographic Characteristics for Quantitative Analysis (N=186)

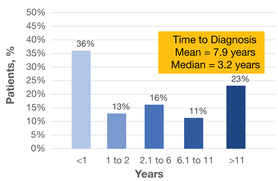
Sex	
Female	67%
Male	33%
Mean age (range), years	43.0 (18-73)
Race/ethnicity	
Asian	4%
Black	4%
LatinX	6%
White	81%
Multiracial	3%
Other	1%
Education	
High school or less	8%
Trade/technical school	8%
Some college or associate degree	26%
Bachelors degree	39%
Advanced degree	23%
Work status (prior to pandemic)	
Student	2%
Full time	59%
Part time	11%
Stay-at-home parent	4%
Retired	9%
On disability	10%
Unemployed	5%

Figure 4. Interactions With HCPs Prior to nr-axSpA Diagnosis[a]



[a] Percentages may not total 100 due to rounding.

Figure 5. Time From Symptom Onset to nr-axSpA Diagnosis[a]



[a] Data missing for 1% of respondents.

Table 4. Translation of Qualitative Themes to Quantitative Results

Themes from qualitative interviews Patients (n=25) and rheumatologists (n=15)	Quantitative survey findings Patients (n=186)
Patients feel back pain is normal or age related and does not require prompt medical care	64%: joint pains due to activity or injury 29%: pain due to aging 23%: symptoms are growing pains due to young age
Clinicians often minimize persistent symptoms, especially if they occur in young and/or female patients	38%: HCP thought symptoms were "in my head" 25%: told nr-axSpA is a "man's disease" [*female respondents only*]
Physicians, including rheumatologists, do not know enough about nr-axSpA or inflammatory back disease	53%: HCPs attributed symptoms to activity or injury 25%: initially misdiagnosed
Specific biomarkers to facilitate diagnosis are currently lacking	36%: normal x-rays or MRI were barriers 38%: negative HLA-B27 status contributed to delayed diagnosis [*HLA-B27–negative respondents only*]
Delayed referral to rheumatologist	32%: medical professionals did not know to refer to rheumatologist 25%: limited access to rheumatologists 11%: requested referral to rheumatologist but denied
Seeing a rheumatologist does not necessarily lead to a prompt diagnosis	48%: saw ≥2 rheumatologists before nr-axSpA diagnosis 22%: received conflicting diagnoses from rheumatologists 16%: rheumatologists were unaware of nr-axSpA

CONCLUSIONS

- Both patients and clinicians may be unfamiliar with IBP and nr-axSpA and may not realize that nr-axSpA can occur in young people and females and that patients with nr-axSpA can have normal x-rays
- Patients with nr-axSpA often see multiple HCPs before receiving diagnosis
- Disease recognition by non-rheumatology HCPs is key for early referral
- Education on cardinal features, epidemiology, burden, and benefits of timely nr-axSpA diagnosis is warranted for HCPs who commonly manage back pain

LIMITATIONS

- SAA-derived participants may be more knowledgeable about this condition and thus not representative of the general public

REFERENCES

1. Deodhar A, et al. *Arthritis Rheumatol.* 2016;68:1669-1676.

DISCLOSURES

Kiwalkar: Nothing to disclose,

Howard: Consulting/advisory board: Novartis
Stock: AbbVie, Amgen, Bristol Myers Squibb, GSK, Johnson & Johnson, Lilly, Merck, Novartis, Pfizer, Teva
Deodhar: Consulting/advisory boards: AbbVie, Amgen, Boehringer Ingelheim, Bristol Myers Squibb, Celgene, Eli Lilly, Galapagos, GSK, Janssen, Novartis, Pfizer, UCB
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ABBREVIATIONS

ASAS, Assessment in SpondyloArthritis international Society; Endo, endocrinologist; GI, gastroenterologist; HCP, healthcare provider; IBD, inflammatory bowel disease; IBP, inflammatory back pain; MRI, magnetic resonance imaging scan; NP, nurse practitioner; NSAID, nonsteroidal anti-inflammatory drug; Ophth, ophthalmologist; Pain, pain specialist; PCP, primary care physician; PM&R, physical medicine and rehabilitation specialist; PT, physical therapist; RA, rheumatoid arthritis; SAA, Spondylitis Association of America; Spine, spine specialist; Sports, sports medicine specialist.

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