General Practitioners' Perceptions of Their Ability to Identify and Refer Patients with Suspected Axial Spondyloarthritis: A Qualitative Study

Marloes van Onna, Simone Gorter, Aniek van Meerendonk, and Astrid van Tubergen

ABSTRACT. ***Objective.*** To explore the knowledge, beliefs, and experiences of general practitioners (GP) about inflammatory back pain (IBP) and axial spondyloarthritis (axSpA) and potential barriers for referral of patients suspected of having axSpA.

Methods. A qualitative study involving semistructured interviews with GP was conducted. Transcripts of the interviews were independently read and annotated by 2 readers. Illustrative themes were identified and a coding system to categorize the data was developed.

Results. Ten GP (all men; mean age 49 yrs) were interviewed. All could adequately describe "classic" ankylosing spondylitis (AS) and mentioned chronic back pain and/or stiffness as key features. All GP thought that AS is almost exclusively diagnosed in men. Six GP knew that there is a difference between mechanical back pain and IBP, but could recall only a limited number of variables indicative of IBP, such as awakening night pain (4 GP), insidious onset of back pain (1 GP), improvement with movement (1 GP), and (morning) stiffness (2 GP). Two GP mentioned peripheral arthritis as other SpA features, none mentioned dactylitis or enthesitis. GP awareness of associated extraarticular manifestations was low. Most GP expressed that (practical) referral measures would be useful.

Conclusion. GP are aware of "classic", but longterm features of axSpA. Knowledge about the disease spectrum and early detection is, however, limited. Addressing these issues in training programs may improve recognition of axSpA in primary care. This may ultimately contribute to earlier referral, diagnosis, and initiation of effective treatment in patients with axSpA. (J Rheumatol First Release April 1 2014; doi:10.3899/jrheum.131293)

Key Indexing Terms:
INFLAMMATORY BACK PAIN AXIAL SPONDYLOARTHRITIS PRIMARY CARE

Spondyloarthritis (SpA) comprises a group of interrelated inflammatory disorders with overlapping clinical features and shared genetic markers. The estimated prevalence of SpA in white populations is about 1%, similar to that of rheumatoid arthritis[1]. Symptom patterns and physical signs of SpA can be divided into predominantly axial involvement, with inflammatory back pain (IBP) as the most important clinical feature and predominantly peripheral involvement including peripheral arthritis, dactylitis, and enthesitis[2]. Extraarticular manifestations related to axial and peripheral SpA include psoriasis, anterior uveitis, and inflammatory bowel disease.

Axial SpA (axSpA) comprises a disease continuum, including both nonradiographic axSpA and ankylosing spondylitis (AS)[3]. Patients with nonradiographic axSpA have similar clinical characteristics, disease activity, and response to treatment as patients with established AS, emphasizing the need for early and correct diagnosis[4]. However, the diagnosis of axSpA is often delayed owing to the insidious onset, the heterogeneous clinical picture, and a limited knowledge about the manifestations belonging to axSpA by general practitioners (GP) or other referring physicians[5]. Offering tools for referral may be helpful in improving early diagnosis. Several initiatives have been performed to study the effect of referral strategies in primary care. The objectives of these referral programs were to identify patients with possible axSpA early, to make a correct diagnosis, and to provide the best possible care as early as possible[6]. However, limited knowledge of manifestations belonging to axSpA might prevent successful implementation of these referral strategies in the primary care setting.

From the Department of Medicine, Division of Rheumatology, Maastricht University Medical Center; The School for Public Health and Primary Care (CAPHRI), University of Maastricht, Maastricht, The Netherlands.

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M. van Onna, MD; S. Gorter, MD, PhD, Department of Medicine, Division of Rheumatology, Maastricht University Medical Center and CAPHRI, University of Maastricht; A. van Meerendonk, MD, Department of Medicine, Division of Rheumatology, Maastricht University Medical Center; A. van Tubergen, Department of Medicine, Division of Rheumatology, Maastricht University Medical Center and CAPHRI, University of Maastricht.

Address correspondence to Dr. M. van Onna, Department of Medicine, Division of Rheumatology, Maastricht University Medical Center and School for Public Health and Primary Care (CAPHRI), University of Maastricht, P. Debyelaan 25, 6202 AZ, Maastricht, The Netherlands. E-mail: m.van.onna@mumc.nl

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The aim of our qualitative study was to explore, using semistructured interviews, the knowledge, beliefs, and experiences of GP about IBP and axSpA, and the potential barriers for referral of patients suspected of having axSpA.

MATERIALS AND METHODS

Study design and participants. For this qualitative study, GP acquainted with the interviewers, without known specific interest or knowledge of musculoskeletal diseases and with various numbers of years of experience, were invited for a semistructured interview. A semistructured interview is a technique used to collect qualitative data about the topic of interest by combining open questions with the option to further explore particular answers[7]. The duration of 1 interview was about 1 h. The interviews took place in 2012 and all invited GP were working in the region of Limburg, The Netherlands. The study was approved by the ethics committee from the Maastricht University Medical Center. All participants provided written informed consent and thereby agreed to the presentation of the collected data and quotes in anonymized form.

Data collection. An interview guide that consisted of both open-ended and closed questions was developed to secure uniform data quality and comparability. A pilot interview was conducted to ensure that the questions were clear and addressed all important topics. Each interview was audiotaped and afterward fully transcribed. Each transcript was offered to the matching GP to review for validation.

The topics addressed in the interview included general questions: age, working experience in years as a GP, and specific medical interests. More substantial questions asked about the GP's (1) approach to patients presenting with chronic back pain, knowledge about symptoms indicative of mechanical back pain (MBP) or IBP, management of back pain, and motivating factors to refer a patient to a rheumatologist; (2) perceptions and knowledge about axSpA, including nonradiographic axSpA and AS, awareness about diagnostic delay, and knowledge of extraarticular manifestations of axSpA; (3) approach to patients already diagnosed with axSpA, and disease management; and (4) awareness of treatment options and opinion about the current standards of care for patients with axSpA.

Data analysis. The transcripts were independently analyzed by 2 readers. All transcripts were repeatedly read and annotated. A coding system based on the grounded theory approach was developed by defining categories and developing a taxonomy of the data[7]. The readers met regularly to discuss coding and interpretation of data. In case of disagreement, consensus was reached between the 2 readers after re-reading the specific passage of the transcript. While analyzing the data, illustrative quotes made by GP were collected.

RESULTS

Participant characteristics. Ten of 16 invited GP agreed to participate and were interviewed. All of the GP included were men and the mean age was 49 years (range 37–58 yrs; SD 6.4 yrs). The mean number of years of experience as a GP was 20 years (range 10–29 yrs; SD 6.0 yrs). Three GP had a specific interest in musculoskeletal disorders. When GP were asked to estimate the mean number of patients with AS registered in their practice, the range of answers was between 0 and > 10 patients (without further specification).

When analyzing the data, a number of themes and patterns were identified across the interviews. These themes and patterns are described below and exemplified in quotes (Table 1).

Ability to differentiate MBP from IBP. Four GP were not familiar with the terms MBP and IBP (quote 1). Six GP knew that there is a difference between MBP and IBP, but these GP could recall only a limited number of typical variables to differentiate MBP from IBP. Four of these 6 GP mentioned awakening night pain as a typical feature of IBP and considered it a relevant symptom that needed attention (quote 2). Two GP also mentioned insidious onset of back pain and improvement of back pain with movement as typical features of IBP. Morning stiffness was mentioned by 2 GP. Seven GP mentioned stiffness of the back as typical for AS but did not elaborate on the course of stiffness during the day.

Knowledge about the terms "classic" AS and axSpA and awareness about diagnostic delay. All GP were familiar with the term AS and mentioned back pain and/or stiffness of the back as prominent features of AS. Three GP also considered (severe) kyphosis as an important feature of AS. None of the GP could give an adequate description of the term axSpA.

When asked about the age at onset of first symptoms, all GP answered that symptoms first appear in early adulthood. All GP thought that AS is almost exclusively diagnosed in men. Two GP thought that the delay in diagnosis was less than 1 year. The remainder of GP answered that the delay in diagnosis was up to several years, without further specification. A few GP commented that this is probably due to a patients' and doctors' delay (quote 3).

Knowledge about associated clinical manifestations of axSpA. Most GP could describe only a limited number of clinical features belonging to axSpA. Two GP considered peripheral arthritis as belonging to the spectrum of axSpA; dactylitis and enthesitis were not mentioned at all. When asked about extraarticular manifestations of patients with axSpA, 5 GP mentioned anterior uveitis and 1 GP mentioned "eye complaints" (quote 4). Inflammatory bowel disease was mentioned by 2 GP and psoriasis by 3.

Use of diagnostic tests in the primary care setting. None of the GP would order an HLA-B27 test when a patient presented with chronic back pain. A few GP commented that this test should only be ordered by the rheumatologist (quote 5). Most GP specifically commented that they would only order a conventional radiograph in case of chronic back pain. One GP mentioned that a normal pelvic radiograph in a patient presenting with back pain would be a motivating factor to refer this patient to a neurologist and not a rheumatologist (quote 6).

Perceptions about management of axSpA. A decrease in pain and stiffness of the back and maintaining function were judged as the most important treatment goals by the majority of the GP. The use of nonsteroidal antiinflammatory drugs (NSAID) was considered an adequate treatment option by all GP. Most GP also mentioned physical therapy or that the patient should do home-based exercises. Five GP indicated that antitumor necrosis factor (TNF)-α therapy can be

Table 1. Illustrative quotes made by general practitioners.

Number	Quote*
1	"I really do not know the difference between mechanical and inflammatory back pain. I do not see a lot of patients with a history of inflammatory back pain. (…)When a patient has back pain for a long period of time, I usually refer them to a rheumatologist. But it certainly would not surprise me if there are several undiagnosed patients with AS in my practice.
2	"If a patient presents with a history of back pain, I ask if he or she can still perform household chores and work-related duties. I ask if the pain is continuous or not and if there is night pain or pain when waking up. (…) When there are signs of awakening night pain, I tend to look more seriously at the symptoms. During the physical examination I check the range of motion and the stiffness of the back."
3	"I think that the time between first complaints and diagnosis of AS varies. There is a patient delay, but also a doctor delay. When there are family members with AS, you tend to look more seriously and will probably refer this patient to a rheumatologist at an early stage. But if this is not the case… How long it will take before a GP will refer a patient with chronic back pain? I do not know, months to years maybe?"
4	"Whether I can mention other symptoms associated with AS? Eye complaints probably, but I do not think it is very typical. Conjunctivitis maybe? Psoriasis also, but that is not really inflammation, but it belongs to another group of autoimmune disorders. It is not really clear to me."
5	"If the HLA-B27 test is positive or negative, it will not solve the diagnostic problem. When the test is positive, you think, "OK, maybe...", but what to do when the test is negative? In case of a negative test result, that does not mean that the patient does not have AS. I still have to refer the patient to the rheumatologist."
6	"When a patient presents with a history of low back pain and there are no abnormalities on the radiograph, I will refer this patient to the neurologist. It is very unlikely that I refer this patient to the rheumatologist. Provided that low back pain is the only symptom."
7	"I want to know more about how to recognize AS. Are there specific tools or diagnostic tests you can use as a GP to make a diagnosis of AS more or less likely? If so, I will perform those tests and consult a rheumatologist or I will refer the patient. I also want to know more about how you treat patients with AS. What are the results?"
8	"I think that I miss the diagnosis frequently. Yes, too many times. The reason for this? Probably due to lack of knowledge."

*Quotes were translated from Dutch. AS: ankylosing spondylitis; GP: general practitioners.

prescribed to patients with axSpA. Four GP were aware of the fact that an increased risk of (serious) infections is an important side effect of anti-TNF-α therapy.

Preferences for educational programs about axSpA. Most GP expressed that (practical) referral measures to decrease the delay in diagnosis would be useful in clinical practice (quote 7). Most GP also wanted to know more about the treatment options, including anti-TNF-α therapy. One GP revealed that he recently did educational training that focused on axSpA. At the end of this training he realized that there were probably several undiagnosed patients in his practice (quote 8).

DISCUSSION

Our study demonstrated that there are several inconsistencies in the perceptions of GP about diagnosis and management of axSpA, including AS. Most GP could provide an adequate description about "classic" AS and were aware of the fact that there is a substantial delay in diagnosis. GP also knew that there is a difference between MBP and IBP, but were unable to explain how to differentiate one from the other. Knowledge about the disease spectrum of axSpA and associated extraarticular manifestations was limited. All GP were aware of the benefits of physiotherapy and NSAID, and half of the GP knew that anti-TNF-α therapy can be prescribed in patients with axSpA.

Chronic back pain is a common symptom in the general population and it is estimated that in 5% of these cases axSpA is the underlying disease[8]. In about 75% of the patients with axSpA, the chronic back pain has an inflammatory character. Several criteria sets to define IBP have been proposed, consisting of several measures to differentiate IBP from MBP. Single variables were insufficiently predictive in defining IBP, because they are also frequently present in patients without an inflammatory cause of their back pain[9]. Overall, the IBP criteria sets have a comparable sensitivity and specificity of about 75% to 80%[9,10,11]. IBP has been tested as a single referral measure and as part of a composite referral strategy in several studies[5,12,13,14]. When patients were referred by GP because of IBP alone, axSpA was diagnosed in 16% to 33% of the referred patients[5,12,13]. However, when patients were referred because of IBP in combination with other variables, such as HLA-B27 or sacroiliitis on imaging, axSpA was diagnosed in 35% to 56% of the referred patients[5,12,14].

Knowledge of important features associated with axSpA is essential before a referral strategy can successfully be implemented in the primary care setting. Six GP in our study could recall only a few items indicative of IBP and 4 GP were not familiar with the terms MBP and IBP. This was also observed in a study by Jois, *et al*[15]. Only 5% of GP in their study could identify all variables indicative of IBP when a list of prespecified response choices was presented to them. Further, studies have shown that the degree of agreement between referring physicians (including GP) and rheumatologists when evaluating IBP in patients with suspected axSpA is poor (kappa values between 0.04–0.20)[5,16]. Educating GP about the full range of variables indicative of IBP therefore seems to be the first step before IBP can successfully be used in a referral tool. The term "axial spondyloarthritis" will also increasingly be used in correspondence from rheumatologists to GP. It is, therefore, important to make GP familiar with this new terminology.

In our study, GP could recall only a limited number of extraarticular manifestations associated with axSpA. In some cases, GP mentioned "eye complaints" or "skin problems". Dactylitis and enthesitis were not mentioned at all by the GP in our study. Jois, *et al* also investigated the recognition of extraarticular manifestations of SpA by GP[15]. Psoriasis, inflammatory bowel disease, and uveitis were recognized as an extraarticular manifestation by 96%, 68%, and 60%, respectively, of GP, which is a higher proportion than in our small-sized study[15]. However, in our study open-ended questions were used, which probably resulted in lower response rates than the survey used in the study of Jois, *et al*[15]. All GP in our study also indicated that AS is almost exclusively diagnosed in men. Several studies that included patients with undifferentiated and nonradiographic axSpA, however, demonstrated that the sex ratio is more equally distributed[17,18,19]. Male sex has, however, been found to be a risk factor for developing radiographic sacroiliitis[20,21]. Further, patients with radiographic sacroiliitis have, in general, higher inflammatory markers than patients with nonradiographic axSpA[4,22]. Increasing awareness among GP that axSpA is equally present in females and males, and making them aware of the "SpA concept", which includes axial, but also peripheral and extraarticular manifestations, will likely facilitate referral and timely diagnosis.

Half of the GP in our study were aware that the therapeutic armamentarium in patients with axSpA is broadened with the introduction of anti-TNF-α therapy. When GP were asked about the side effects of anti-TNF-α therapy, 6 GP were not aware of the higher risk of (serious) infections. Collaboration and co-management with the rheumatologist is essential in managing patients with axSpA. Therefore, education about anti-TNF therapy and its side effects is an important step to maintain and improve the general health status of a patient with axSpA.

In general, the level of knowledge about axSpA was low. None of the GP could provide a specific reason for this lack of knowledge. Possible explanations are relatively low attention to this topic in medical school or at continuous medical education, and the large emphasis on a nonspecific cause of chronic back pain[23].

There were limitations in our study that need to be addressed. The design of the study was qualitative and the number of GP included was small. Further, only male and experienced GP were included. Several female GP were asked, but they declined to participate. Logistically, it was extremely difficult to include recently qualified GP, because in the Netherlands almost none of them have their own practices. We cannot rule out that selection bias or knowledge bias occurred. This may limit reproducibility of results and the ability to generalize them to a wider population. However, the main goal of this study was not to extrapolate the current findings to all GP, but to explore the level of knowledge and awareness that probably need attention in future educational programs. Further, theoretical saturation was reached with this number of GP.

Most GP were familiar with "classic" but longterm features of axSpA. Knowledge about variables indicative of IBP and awareness about the full range of SpA features, including the associated extraarticular manifestations, was limited. The disease spectrum and management of axSpA have changed substantially over the last few years. Educating GP about the leading presenting symptoms of axSpA and providing information about extraarticular disease manifestations and management of axSpA will be important in the successful referral of patients with suspected axSpA by GP. This may ultimately contribute to earlier initiation of effective treatment and the improvement of quality of life.

REFERENCES

1. Stolwijk C, Boonen A, van Tubergen A, Reveille JD. Epidemiology of spondyloarthritis. Rheum Dis Clin North Am 2012;38:441-76.
2. Rudwaleit M, Khan MA, Sieper J. The challenge of diagnosis and classification in early ankylosing spondylitis: do we need new criteria? Arthritis Rheum 2005;52:1000-8.
3. Rudwaleit M, van der Heijde D, Landewé R, Listing J, Brandt J, Braun J, et al. The development of Assessment of Spondyloarthritis international society classification criteria for axial spondyloarthritis (part II): validation and final selection. Ann Rheum Dis 2009;68:777-83.
4. Rudwaleit M, Haibel H, Baraliakos X, Listing J, Märker-Hermann E, Zeidler H, et al. The early disease stage in axial spondylarthritis: results from the German Spondyloarthritis Inception Cohort. Arthritis Rheum 2009;60:717-27.
5. Poddubnyy D, Vahldiek J, Spiller I, Buss B, Listing J, Rudwaleit M, et al. Evaluation of 2 screening strategies for early identification of patients with axial spondyloarthritis in primary care. J Rheumatol 2011;38:2452-60.
6. Rudwaleit M, Sieper J. Referral strategies for early diagnosis of axial spondyloarthritis. Nat Rev Rheumatol 2012;8:262-8.
7. Pope C, Mays N. Qualitative research in health care. Ames, Iowa, USA: Blackwell Publishing; 2006.
8. Underwood MR, Dawes P. Inflammatory back pain in primary care.

Br J Rheumatol 1995;34:1074-7.
9. Sieper J, van der Heijde D, Landewé R, Brandt J, Burgos-Vagas R, Collantes-Estevez E, et al. New criteria for inflammatory back pain in patients with chronic back pain: a real patient exercise by experts from the Assessment of SpondyloArthritis international Society (ASAS). Ann Rheum Dis 2009;68:784-8.
10. Rudwaleit M, Metter A, Listing J, Sieper J, Braun J. Inflammatory back pain in ankylosing spondylitis: a reassessment of the clinical history for application as classification and diagnostic criteria. Arthritis Rheum 2006;54:569-78.
11. Calin A, Porta J, Fries JF, Schurman DJ. Clinical history as a screening test for ankylosing spondylitis. JAMA 1977;237:2613-4.
12. Brandt HC, Spiller I, Song IH, Vahldiek JL, Rudwaleit M, Sieper J. Performance of referral recommendations in patients with chronic back pain and suspected axial spondyloarthritis. Ann Rheum Dis 2007;66:1479–84.
13. Hermann J, Giessauf H, Schaffler G, Ofner P, Graninger W. Early spondyloarthritis: usefulness of clinical screening. Rheumatology 2009;48:812–6.
14. Sieper J, Srinivasan S, Zamani O, Mielants H, Choquette D, Pavelka K, et al. Comparison of two referral strategies for diagnosis of axial spondyloarthritis: the Recognising and Diagnosing Ankylosing Spondylitis Reliably (RADAR) study. Ann Rheum Dis 2013;72:1621-7.
15. Jois RN, Macgregor AJ, Gaffney K. Recognition of inflammatory back pain and ankylosing spondylitis in primary care. Rheumatology 2008;47:1364-6.
16. López-González R, Hernández-Sanz A, Almodóvar-González R, Gobbo M. Are spondyloarthropathies adequately referred from primary care to specialized care? Reumatol Clin 2013;9:90-3.
17. Heuft-Dorenbosch LH, Landewé R, Weijers R, Houben H, van der Linden S, Jacobs P, et al. Performance of various criteria sets in patients with inflammatory back pain of short duration; the Maastricht early spondyloarthritis clinic. Ann Rheum Dis 2007;66:92-8.
18. van den Berg R, de Hooge M, Rudwaleit M, Sieper J, van Gaalen F, Reijnierse M, et al. ASAS modification of the Berlin algorithm for diagnosing axial spondyloarthritis: results from the SPondyloArthritis Caught Early (SPACE)-cohort and from the Assessment of SpondyloArthritis international Society (ASAS)-cohort. Ann Rheum Dis 2013;72:1646-53.
19. Dougados M, d'Agostino MA, Benessiano J, Berenbaum F, Breban M, Claudepierre P, et al. The DESIR cohort: a 10-year follow-up of early inflammatory back pain in France: study design and baseline characteristics of the 708 recruited patients. Joint Bone Spine 2011;78:598-603.
20. Van Tubergen A, Weber U. Diagnosis and classification in spondyloarthritis: identifying a chameleon. Nat Rev Rheumatol 2012;8:253-61.
21. Feldtkeller E, Bruckel J, Khan MA. Scientific contributions of ankylosing spondylitis patient advocacy groups. Curr Opin Rheumatol 2000;12:239-47.
22. Kiltz U, Baraliakos X, Karakostas P, Igelmann M, Kalthoff L, Klink C, et al. Do patients with non-radiographic axial spondylarthritis differ from patients with ankylosing spondylitis? Arthritis Care Res 2012;64:1415-22.
23. Balagué F, Mannion AF, Pellisé F, Cedraschi C. Non-specific low back pain. Lancet 2012;379:482-91.