Rheumatology Advance Access published March 18, 2011

RHEUMATOLOGY

Original article

doi:10.1093/rheumatology/ker013

Services for people with ankylosing spondylitis in the UK—a survey of rheumatologists and patients

Louise Hamilton[1], Annie Gilbert[2], Jane Skerrett[2], Sally Dickinson[2] and Karl Gaffney[1]

Abstract

Objective. To investigate the services offered to patients with AS in the UK in 2010.

Methods. Two thousand non-health-care professional members of the National Ankylosing Spondylitis Society (NASS) were sent a questionnaire asking about their experiences surrounding diagnosis, treatment and access to therapies (response rate 40%). A separate questionnaire was sent to a consultant rheumatologist in every acute NHS trust in the UK, asking about services offered to patients with AS (response rate 68%).

Results. Overall, there was a mean diagnostic delay of 8.57 years. Almost one-third (32.2%) of patients were not reviewed in secondary care. Non-attendance was associated with increasing age and longer disease duration. Twenty per cent of patients were taking anti-TNF drugs, but 18.8% of departments reported that their ability to give anti-TNF therapy was restricted (64% reported primary-care trust rationing and 14% lack of staff). Almost all rheumatology departments had access to MRI, but 70.9% still used X-ray radiographs as their first-line investigation. A minority (5.6%) of patients reported they had never seen a physiotherapist, but less than one-third could self-refer for treatment during a flare.

Conclusion. This is the first study to explore the services available to people with AS in the UK. Almost one-third of patients are not seen in rheumatology departments and therefore may be under-treated. For those who are seen, access to anti-TNF drugs and other therapies remains an issue.

Key words: Ankylosing spondylitis, UK, Services, Patient, Rheumatology, Anti-TNF, National Ankylosing Spondylitis Society.

Introduction

AS is a chronic inflammatory disease involving the spine, peripheral joints and extra-articular systems. Although its prevalence is on a par with RA [1], it has been, for years, something of a Cinderella disease, with unanswered questions about epidemiology and natural history, and no effective treatment. An interval between symptom onset and diagnosis of 8–11 years has been reported previously [2, 3].

AS tends to present in early adulthood, and the personal and societal costs of the disease can be high. Almost one-third of patients are unable to work [4] and more suffer work instability. People with AS are also less likely to get married, more likely to get divorced and (for women) less likely to have children [5]. However—for health-care providers at least—AS was until recently an inexpensive disease. Treatment was limited to NSAIDs, physiotherapy and occasionally DMARDs for peripheral joint involvement. Patients were not infrequently discharged from secondary care, or disengaged themselves from follow-up, as nothing could be done.

While many unanswered questions remain, treatment has been revolutionized in the past decade with the introduction of anti-TNF drugs. These treatments have been shown to significantly improve measures of disease activity [6–8], reduce evidence of inflammation on MRI scanning [9] and improve work capacity [10]. They have been more widely available in the UK since May 2008, when the National Institute for Health and Clinical Excellence (NICE) approved treatment with etanercept and/or adalimumab

[1]Rheumatology Department, Norfolk and Norwich University Hospital, Norwich and [2]National Ankylosing Spondylitis Society, London, UK.

Submitted 28 September 2010; revised version accepted 12 January 2011.

Correspondence to: Louise Hamilton, Rheumatology Department, Norfolk and Norwich University Hospital, Colney Lane, Norwich, NR4 7UY, UK. E-mail: louise.hamilton@nnuh.nhs.uk

for patients with severe AS. However, anti-TNF therapy is expensive, with drug costs alone >£9000 per annum. In April 2010, the National Ankylosing Spondylitis Society (NASS), with endorsement from other groups including the British Society for Rheumatology (BSR), launched a document entitled 'Looking Ahead: best practice for the care of people with ankylosing spondylitis (AS)' [11]. This set out seven recommendations to optimize care in the UK for patients with AS, from diagnosis to treatment to long-term management. As part of this project we wanted to explore the services currently available for people with AS in the UK.

Methods

Rheumatology department survey

An e-mail was sent to a named consultant rheumatologist at all 171 acute trusts in England, Scotland, Wales and Northern Ireland in February 2010. Consultants with an interest in AS were preferentially included. The e-mail contained a link to a web-based survey (see supplementary data available at *Rheumatology* Online), which the consultant was asked to complete or forward to a colleague. Reminders were sent to non-responders. A total of 117 responses were received (response rate 68%). The project was discussed with the local research ethics committee (REC) chairperson who judged it to be service evaluation not requiring formal National Health Service Research Ethics Committee review.

NASS member survey

Two thousand AS patients (all members of NASS) were surveyed during February 2010. Questionnaires (see supplementary data available at *Rheumatology* Online) were distributed to all 1300 members with e-mail addresses (using a link to a web-based survey) and 700 members randomly selected from the remaining membership. At the time of sampling, NASS had 5683 UK-based non-health-care professional members. Eight hundred and seven completed questionnaires were received (response rate 40%). Of the total, 505 (63%) were completed electronically and 302 (37%) by postal survey.

Analysis

Electronic results were collated by Survey Monkey, and analysed on an excel spreadsheet along with postal responses. Statistical analysis was carried out using Stata (StataCorp LP, College Station, TX, USA). Results are expressed as median (interquartile range) or *n* (%).

Results

Rheumatology department survey

Demographics

Surveys were returned from 117 departments throughout England, Scotland, Wales and Northern Ireland. All Strategic Health Authorities (SHAs) in England were represented. The vast majority [103 (92.0%)] of surveys were completed by consultants, 5 (4.5%) by specialist registrars, 2 (1.8%) by nurse specialists and 1 (0.9%) each by a physiotherapist and a department manager. Information about the hospitals is given in Table 1.

Table 1 Characteristics of the hospitals surveyed ($n = 117$)

Demographics	*n* (%)
Type of hospital	
Polyclinic	3 (2.6)
District general hospital	92 (78.6)
Tertiary referral centre	20 (14.9)
No answer	2 (1.7)
Teaching hospital	
Yes	71 (60.7)
No	43 (36.8)
No answer	3 (2.6)
Setting	
Inner city	20 (17.1)
Urban	41 (35.0)
Rural	12 (10.3)
Mixed	43 (36.8)
No comment	1 (0.8)
Catchment area	
100–199 999	8 (6.8)
200–499 999	75 (64.1)
500 000–1 million	25 (21.4)
>1 million	3 (2.6)
Do not know or no answer	6 (5.1)
Number of AS patients	
0–99	35 (29.9)
100–499	63 (53.8)
>500	4 (3.4)
Do not know or no answer	15 (12.8)

Clinic reviews

The majority of departments had a clinician with a special interest in AS [62 (53%)] and a multidisciplinary team with responsibility for AS patients [50 (61.5%)]. However, only one-third of units [38 (32.5%)] offered multidisciplinary clinics. Forty-eight (41.0%) ran dedicated AS or SpA clinics, with a positive correlation between a department having a specialist interest and running dedicated clinics (χ^2 $P < 0.001$). Forty units (35.4%) reported dedicated training for health-care professionals working in musculoskeletal triage, though general practitioners [104 (88.9%)] rather than musculoskeletal triage services [5 (4.6%)] were the main source of referrals.

Access to treatment, therapies and advice

Most departments offered hydrotherapy [67 (57.3%) on-site and 28 (23.9%) off-site]. Nearly half [57 (48.7%)] ran a patient education programme, and 53 (45.3%) an intensive treatment programme. Most [101 (86.3%)] offered access to NASS, with a sizeable minority offering specific advice on employment [50 (42.7%)] and driving [34 (29.1%)].

Almost all departments had patients with AS who were prescribed anti-TNF drugs [107 (91.4%) answered positively and the remainder failed to answer the question; no departments reported that they had no patients on anti-TNF]. However, the number of patients varied widely: between 3 and 200. Almost one-fifth [22 (18.8%)] of departments reported that their ability to give anti-TNF was restricted. Of those, 14 (64%) reported limits on patient numbers by the primary-care trust (PCT), 3 (14%) lack of staff and 1 (4%) both.

Ninety-six units (82%) had access to specialized orthopaedic spinal surgery. Of these, 52 (54.2%) referred to a surgeon in the same trust, and 48 (50%) to a tertiary centre.

Ninety-six (82%) departments reported that patients could self-refer if they flared, and 99 (84.6%) offered a patient advice line. For the majority [51 (55.4%)] this only operated in office hours, but 37 (40.2%) had a 24-h answering service. In four units (4.3%), the advice line was operational for <8 h each day or <5 days per week. Twenty-nine units (29.3%) aimed for a response to calls within the same working day, 57 (57.6%) by the end of the next working day and 12 (12.1%) by the end of the working week.

Imaging

Almost all [109 (93.1%)] departments had access to an MRI scanner onsite, and only one department (0.9%) reported being unable to access a scanner offsite. The average waiting time for MRI was never >3 months, and in most departments <1 month [8 (6.8%) 1–2 weeks, 62 (53.0%) 2–4 weeks and 41 (35.0%) 1–3 months]. Just under one-third [37 (31.6%)] of departments imaged the whole spine with MRI. In 83 (70.9%) departments, X-ray radiography was still the first-line investigation of choice in patients with suspected AS. Departments with a special interest in AS were not more likely to use MRI first line (Fisher's exact test $P = 0.1907$). A dedicated musculoskeletal radiologist was present in 92 (78.6%) of departments and of those all but one met the musculoskeletal radiologist(s) to discuss complex patients.

NASS member survey

Demographics

The demographic spread was as expected, with a male : female ratio approaching 3 : 1. Respondents tended to be older [5 (0.6%) aged <24 years, 212 (26.3%) 25–44 years, 407 (50.4%) 45–64 years and 180 (22.4%) >65 years] and had AS symptoms for a median [interquartile range (IQR)] of 27 (15–39) years. The median (IQR) disease duration was 17 (8–29) years. Reported country of residence was in proportion to NASS membership data. Gender balance between the electronic and postal response groups was similar [311 males (61.6%) *vs* 198 males (65.6%) respectively, Fisher's exact test $P = 0.1704$]. However, respondents to the electronic survey were significantly younger [165 (32.7%) were aged <45 years compared with 52 (17.2%) of those answering the postal survey, Fisher's exact test $P < 0.001$].

Diagnosis

The majority consulted a health-care professional within a year of developing symptoms (Fig. 1), but there was often a further significant delay between seeing a health-care professional and receiving a diagnosis of AS (Fig. 2).

There was a mean delay of 8.57 years between onset of symptoms and diagnosis [median (IQR) 6 (2–12) years]. In the majority of cases [561 (69.5%)], the final diagnosis of AS was made by a rheumatologist. General practitioners (GPs) diagnosed AS in 88 (10.9%) cases, and physiotherapists in 26 (3.2%). Diagnoses were also made by orthopaedic surgeons, opthalmologists and chiropractors.

Clinic reviews

Almost one-third of patients [260 (32.2%)] do not currently attend a clinic. Patients were less likely to see a

Fig. 1 Duration of symptoms before contacting a health-care professional. The delay between a patient first developing symptoms of AS and consulting a health-care professional ($n = 791$).

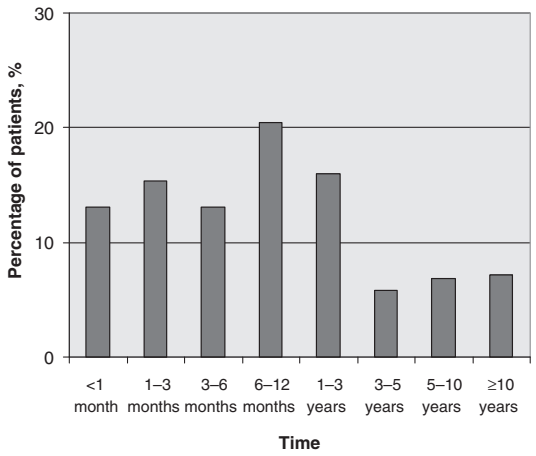


Fig. 2 Time between first contact with health-care professional and diagnosis of AS. The delay between a patient first consulting a health-care professional with symptoms of AS, and receiving a diagnosis ($n = 778$).

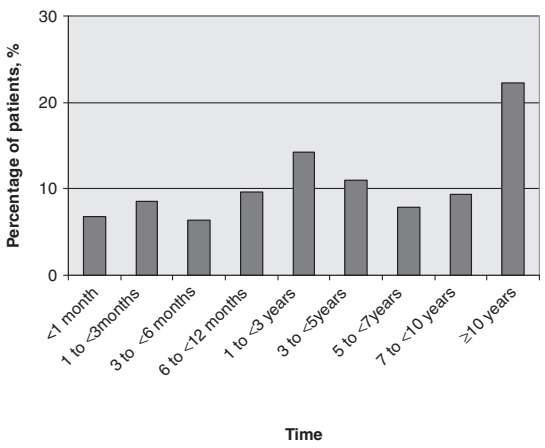


Table 2 Time since last consultation about AS

Time since last review	GP	Consultant	Specialist nurse	Physio therapist	OT
<1 month	120 (14.9)	81 (10.0)	45 (5.6)	126 (15.6)	11 (1.4)
1–6 months	165 (20.4)	244 (30.3)	103 (12.8)	113 (14.0)	19 (2.4)
6–12 months	73 (9.0)	105 (13)	30 (3.7)	59 (7.3)	18 (2.2)
>12 months ago	255 (31.6)	216 (26.8)	61 (7.6)	224 (27.8)	80 (9.9)
Never	29 (3.6)	22 (2.7)	214 (26.5)	45 (5.6)	264 (32.7)
No answer	165 (20.4)	139 (17.2)	354 (43.9)	240 (29.7)	414 (51.3)

The time elapsed since a patient last consulted each health-care professional specifically about AS. Results expressed as *n* (%). $N = 807$. OT = occupational therapist.

rheumatologist if they were >44 years (χ^2 $P < 0.001$) or had had AS for >20 years (χ^2 $P = 0.003$).

Access to therapies

Patients were asked when they had last seen certain health professionals (Table 2) and what services they had been offered since diagnosis. Not surprisingly, 606 (75%) had been directed towards NASS or other charity groups, with 553 (68.5%) patients being offered hydrotherapy. However, only 100 (12.4%) were invited to attend a patient education programme, 75 (9.3%) were offered driving advice and 52 (6.4%) employment advice.

Physiotherapy and hydrotherapy were organized through a number of routes, with 94 (11.7%) patients reporting that they had to organize their own physiotherapy privately. Reasons cited for this included lack of access to NHS treatment, long NHS waiting times and convenience. A minority of patients could self-refer in the event of a flare: 70 (8.7%) for physiotherapy only, 48 (6.0%) for hydrotherapy only and 106 (13.1%) for both. Nearly two-fifths [310 (38.4%)] could not self-refer and 228 (28.2%) did not know whether they could. Less than one-fifth [151 (18.7%)] have attended an intensive course of treatment for AS or pain (generally residential with daily sessions over a 2-week period), with 106 (74.1%) attendees finding the course very useful. A reduction in pain was experienced by 43 (20.3%), whereas 81 (38.2%) noted an improvement in quality of life.

Drug treatment

Figure 3 outlines the range of medications prescribed to patients since diagnosis.

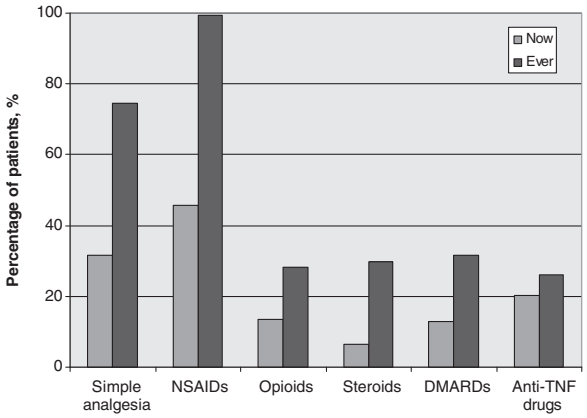
Surgery

One hundred and five (13%) patients underwent surgery for AS. Of those, 58 (36.2%) had surgery of the hip, 27 (16.9%) of the knee, 11 (6.9%) of the cervical spine and 29 (18.1%) of the dorsal/lumbar spine. Seventy (66.7%) operations were carried out in the NHS and 23 (21.9%) privately [13 (12.4%) patients underwent surgery but did not answer this question].

Advice and education

Of those patients attending outpatient clinics, 372 (68%) said they were able to contact their rheumatology department directly if they have a flare or other concerns.

Fig. 3 Drug treatment for AS. The percentage of patients who are currently treated and have ever been treated, with various classes of drug for AS ($n = 807$).



Sixty (11%) thought they were unable to do this, and 115 (21%) did not know whether they could. For most [286 (66.7%)] this contact is made by telephone during office hours. Eighty-six (20%) reported access to a 24-h answer phone service. Response times varied from the same working day [115 (23%)] to the end of the week [58 (11.6%)].

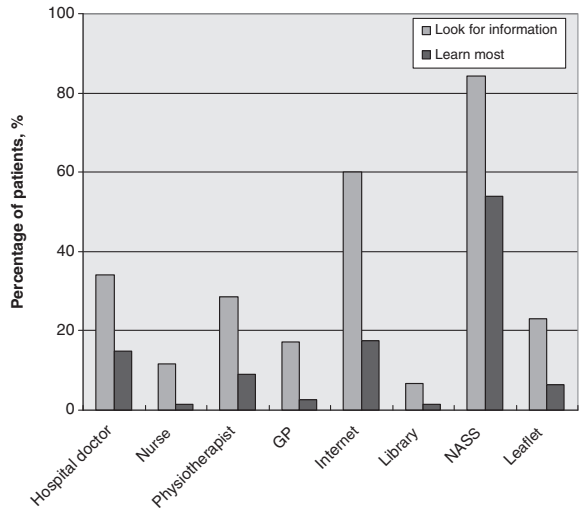
Only 118 (14.6%) patients had ever attended a patient education session about AS, with 86 (72.3%) of these sessions being held in the hospital. Those who attended such sessions found them useful: 73 (67.0%) rated the sessions as very useful and 35 (32.1%) quite useful. Despite the relatively low attendance at formal education sessions, 276 (34.2%) reported understanding a lot about AS and 368 (45.6%) quite a lot. Other sources of information are shown in Fig. 4.

There was no gender difference in where patients looked for information, but younger patients were more likely to use the Internet and less likely to seek advice from their doctor (χ^2 $P < 0.001$).

Discussion

This is the first study to explore the services available to patients with AS throughout the UK. There are inevitable

FIG. 4 Sources of patient information. The percentage of patients who report using each source to look for information about AS, and the source from which they learn most ($n = 807$).



limitations in using a questionnaire, but the response rate from both patients and clinicians was good and the sample reflected both the demographics of NASS membership and the breadth of rheumatology departments in the UK. Although similar questions were posed to patients and to departments, we are unable to correlate these directly as we have no way of knowing which patient attends which, or indeed any, department. Additionally, there will be some discrepancy between reports of services offered to patients now and services offered historically to a cohort of patients with a median disease duration of 17 years.

Looking Ahead Recommendation 1:

Back pain assessment pathways should include a system for the recognition of inflammatory back pain.

Looking Ahead Recommendation 2:

People with suspected AS should be referred to a rheumatologist.

The publication of the Musculoskeletal Services Framework document [12] in 2006 promoted the development of Clinical Assessment and Treatment Services (CATS) to triage musculoskeletal referrals to secondary care. While this was aimed primarily at reducing inappropriate orthopaedic referrals, it seems inevitable that some patients with inflammatory back pain would be seen by these services. The great majority of departments surveyed reported that their main source of AS referrals remains GPs. However, it is not clear if this is because GPs are identifying patients with inflammatory back pain and bypassing triage clinics, or because patients are not being diagnosed by CATS. The experience of patients was that it was rheumatologists, much more than GPs or physiotherapists, who made the diagnosis of AS.

The overwhelming majority of patients in this study have at one time been referred to a rheumatologist. Despite this, the mean diagnostic delay remains considerable at 8.57 years. A majority (62.1%) of patients reported contacting a health-care practitioner within a year of developing symptoms, so it seems that much of the delay in diagnosis occurs once patients have entered the health-care system. Failure on the part of primary-care clinicians to recognize symptoms plays a part in this [13], although delay is also likely at the level of secondary care.

Looking Ahead Recommendation 3:

The diagnosis of early AS/axial SpA should be made without waiting for X-ray changes: MRI is the investigation of choice.

Part of the historical diagnostic delay in secondary care can be attributed to the limitations in imaging and over-reliance on the modified New York criteria, for which sacroiliitis on plain radiographs is a prerequisite [14]. As it is well recognized that radiographic changes may take several years to manifest and that MRI is the best imaging modality in early disease [15], it was surprising to find that in 70.9% of departments X-ray radiography is still the first-line investigation of choice in patients with suspected AS. Lack of availability of MRI scanning should not be a factor in this, as on-site access to MRI scanners was near universal, with waiting lists for the majority of <1 month. The choice of MRI as a first-line investigation was not influenced by whether departments reported having a clinician with a special interest in AS, which suggests that knowledge of recent advances in diagnosis is not an issue. It seems likely that radiographs are still routinely performed at baseline as eligibility for anti-TNF treatment in the UK depends on a patient meeting the modified New York criteria. However, this requirement is likely to change in the future, and it is important that patients meeting more recent classification criteria {e.g. Assessment of SpondyloArthritis international Society (ASAS) [16]} are identified.

Looking Ahead Recommendation 4:

People with AS should have access to all appropriate specialists and treatments.

The high non-response rate to the question patients were asked about their last contact with a therapist (Table 2) poses difficulties in interpretation. It may be that these patients could not recall ever seeing a therapist, in which case the 5.6% who reported never seeing a physiotherapist and the 32.7% who reported never seeing an occupational therapist might actually be underestimates.

Physiotherapy is a mainstay of treatment in AS, improving symptoms and spinal mobility [17]. It is reassuring that the great majority of patients in this study have seen a

physiotherapist at some stage. However, the fact that a minority have been seen in the past year suggests that patients are largely managing their own disease through home exercise programmes (and some may not even be doing this—we did not ask patients whether they performed regular exercise). It is important that patients are able to access therapies during a flare, but less than one-third in this study could self-refer for physiotherapy or hydrotherapy. Others made arrangements for physiotherapy privately because they felt NHS availability was limited.

Occupational therapy is not mentioned in the ASAS/EULAR guidelines [18], and there is little published evidence for it. However, occupational therapists are well placed to advice patients on driving and occupational support—something that less than one-tenth of patients had received. Close to half of departments currently offer an intensive treatment programme, though less than one-fifth of patients report attending. Almost all found it 'very useful' or 'quite useful', but this is not translated into symptomatic benefit, with only one-fifth reporting a subsequent reduction in pain, and less than two-fifths an improvement in quality of life.

Only one-sixth of patients reported ever attending an educational session on AS, although almost all of those found it useful. Despite this apparent lack of formal education on AS, most patients felt they had a good understanding of the condition, with NASS and the Internet particularly important sources of information. There might be an argument, therefore, for replacing the formal education sessions, which nearly half of departments offer, with novel media such as podcasts or online videos. This would be particularly relevant for younger patients.

The Arthritis and Musculoskeletal Alliance (ARMA) standards of care for inflammatory arthritis [19] recommend that patients should have access to ongoing support with self-management (e.g. via a nurse-led advice line) and direct specialist advice in the event of a flare. Most departments offered an advice line, and allowed patients to self-refer in the event of a flare, which is encouraging. However, nearly one-third of patients attending a clinic were unaware that self-referral was a possibility, which suggests an unmet educational need.

Looking Ahead Recommendation 5:

People with AS should be made aware of the availability of anti-TNF therapy and offered treatment if eligible.

One-fifth of patients were currently prescribed anti-TNF drugs, with a discontinuation rate of 23.3%. This figure is less than that identified by the British Society for Rheumatology (BSR) biologics registry for AS patients (69% drug survival at 2 years) [20], but we do not know how long individual patients in this study have been taking the drug. In a separate question, 37.9% of patients reported that they had been assessed for anti-TNF treatment, with 79.9% of these subsequently being offered treatment. We assume that the discrepancy in numbers between those being offered the drug and those taking it is due to eligible patients declining treatment, but we cannot exclude memory bias. Although previous studies have looked at patients' reasons for choosing one anti-TNF drug over another [21], there is no information on the numbers and motivations of those declining treatment altogether.

A study in 2005 by Barkham *et al*. [22] showed that of 246 patients with AS in secondary care, 64% would meet criteria (since adopted by NICE) for anti-TNF therapy. This suggests that the 38% of patients assessed for treatment here is the tip of an iceberg. One would assume that the appropriateness of starting biologics is considered at each clinic visit for patients who are seen in outpatients. A far harder task is to reach those who are no longer seen in secondary care, especially those who are not members of NASS and therefore may be unaware of developments in treatment. The involvement of GPs in identifying and re-referring these patients will be crucial.

A further issue is the apparent rationing of anti-TNF treatment, with 18.8% of departments reporting that their ability to give anti-TNF was restricted. This is despite NICE guidance issued in May 2008, which approved the use of etanercept and adalimumab for patients meeting certain criteria. Of those units reporting restrictions, 64% reported limits on patient numbers imposed by the PCT and 14% a lack of staff in rheumatology departments. A recurring theme in free-text comments was the idea that, even in centres with no overt rationing, anti-TNF therapy is restricted by the need to meet modified New York criteria.

Looking Ahead Recommendation 6:

People with severe spinal deformity should have access to expert surgical assessment and treatment.

Patients may need spinal surgery to correct severe kyphotic deformities (e.g. where the visual field is restricted below the horizon), or complications of ankylosis (e.g. fractures and spinal stenosis). The evidence for surgery is only level IV in quality, and there remains controversy surrounding the most appropriate techniques.

In this study, the percentage of patients reporting surgery to the cervical spine was higher than in previous series (1.4 *vs* 0.5%) [23]. The increase in neck surgery perhaps reflects a growing willingness on the part of surgeons and patients to undertake what was previously seen as a high-risk procedure. The Looking Ahead document recommends that patients with severe spinal deformity should be offered spinal surgery in a specialist unit. While 86.5% of units have access to spinal surgery, the majority refers to a surgeon within their own trust. As the number of AS patients having surgery remains small, it may be that the operative experience needed by individual surgeons to maintain competence is lacking in many centres, and surgery would be better concentrated in super-specialist units.

Looking Ahead Recommendation 7:

People with AS should be followed up regularly and have ready access to expert reassessment.

Nearly one-third of patients reported that they are not currently attending a clinic. Patients who are not followed up long term tend to be older, with longer disease duration. We did not explore the reasons for patients no longer being seen, but with recent therapeutic advances some of them may be significantly under-treated. Both access to drugs and therapies, and evaluation of comorbidities such as cardiovascular risk, should be addressed in this population.

Conclusion

This is the first study to explore the services available to people with AS in the UK. Despite increasing awareness of the condition, diagnostic delay remains a concern. Access to anti-TNF therapy is also a problem, with fewer hospital patients assessed for anti-TNF than are likely to be eligible and drug rationing in almost one-fifth of rheumatology departments. Nearly one-third of people with AS in this survey are not currently seen in secondary care. While many members of this lost tribe may be well, others could be sub-optimally treated and at risk of treatable complications such as cardiovascular disease. We hope that the publication of the Looking Ahead document will raise the profile of AS in the UK, encourage patients to return to the fold and give rheumatology departments a framework for service development.

Rheumatology key messages

- Nearly one-third of AS patients in the UK are not seen in secondary care.
- Diagnostic delay remains a problem.
- Despite NICE approval, anti-TNF drugs continue to be rationed.

Acknowledgements

Dr Patrick Musonda helped with statistical analysis. Karly Graham helped with data collection. Alan Brooksby helped with electronic survey design

Funding: This work was supported by an educational grant from MSD and the secondment of A.G. A.G. is an employee of MSD, but was seconded to the NASS under a binding legal agreement preventing MSD from having any oversight of her work.

Disclosure statement: K.G. has received research funding from MSD, Pfizer and Abbott Pharmaceuticals. L.H. has received research funding from Pfizer and travel assistance from Pfizer and Schering Plough (now MSD). A.G. is an employee of MSD, but was seconded to the NASS under a binding legal agreement preventing MSD from having any oversight of her work. All other authors have declared no conflicts of interest.

Supplementary data

Supplementary data are available at *Rheumatology* Online.

References

1 Braun J, Bollow M, Remlinger G *et al*. Prevalence of spondyloarthropathies in HLA-B27 positive and negative blood donors. Arthritis Rheum 1998;41:58–67.

2 Feldtkeller E, Khan MA, van der Heijde D, van der Linden S, Braun J. Age at disease onset and diagnosis delay in HLA-B27 negative vs. positive patients with ankylosing spondylitis. Rheumatol Int 2003;23:61–6.

3 Khan MA. Ankylosing spondylitis: introductory comments on its diagnosis and treatment. Ann Rheum Dis 2002; 61(Suppl. III):iii3–7.

4 Barlow JH, Wright CC, Williams B, Keat A. Work disability among people with ankylosing spondylitis. Arthritis Rheum 2001;45:424–9.

5 Ward MM, Reveille JD, Learch TJ, Davis JC Jr, Weisman MH. Impact of ankylosing spondylitis on work and family life: comparisons with the US population. Arthr Care Res 2008;59:497–503.

6 Davis JC Jr, Van der Heijde D, Braun J *et al*. Recombinant human tumor necrosis factor receptor (etanercept) for treating ankylosing spondylitis: a randomized, controlled trial. Arthritis Rheum 2003;48:3230–6.

7 Van der Heijde D, Dijkmans B, Geusens P *et al*. Efficacy and safety of infliximab in patients with ankylosing spondylitis: results of a randomized, placebo-controlled trial (ASSERT). Arthritis Rheum 2005;52:582–91.

8 Van der Heijde D, Kivitz A, Schiff MH *et al*. Efficacy and safety of adalimumab in patients with ankylosing spondylitis: results of a multicenter, randomized, double-blind, placebo-controlled trial. Arthritis Rheum 2006;54:2136–46.

9 Sieper J, Baraliakos X, Listing J *et al*. Persistent reduction of spinal inflammation as assessed by magnetic resonance imaging in patients with ankylosing spondylitis after 2 years of treatment with the anti-tumour necrosis factor agent infliximab. Rheumatology 2005;44:1525–30.

10 Keat AC, Gaffney JK, Gilbert AK, Harris C, Leeder J. Influence of biologic therapy on return to work in people with work disability due to ankylosing spondylitis. Rheumatology 2008;47:481–3.

11 National Ankylosing Spondylitis Society. Looking Ahead: best practice for the care of people with ankylosing spondylitis (AS). London: NASS, 2010.

12 The Department of Health. Musculoskeletal Services Framework. London: DOH, 2006.

13 Jois RN, Macgregor AJ, Gaffney K. Recognition of inflammatory back pain and ankylosing spondylitis in primary care. Rheumatology 2008;47:1364–6.

14 Van der Linden S, Valkenburg HA, Cats A. Evaluation of diagnostic criteria for ankylosing spondylitis. A proposal for modification of the New York criteria. Arthritis Rheum 1984;27:361–8.

15 Weber U, Lambert RG, Ostergaard M, Hodler J, Pedersen SJ, Maksymowych WP. The diagnostic utility of MRI in spondyloarthritis: an international multicentre evaluation of 187 subjects (the MORPHO study). Arthritis

Rheum. Advance Access published May 23, 2010, doi 10.1002/art.27571.

16 Rudwaleit M, van der Heijde D, Landewé R *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.

17 Dagfinrud H, Kvien TK, Hagen KB. Physiotherapy interventions for ankylosing spondylitis. Cochrane Database Syst Rev 2008(1):CD002822.

18 Zochling J, van der Heijde D, Burgos-Vargas R *et al*. ASAS/EULAR recommendations for the management of ankylosing spondylitis. Ann Rheum Dis 2006;65:442–52.

19 Arthritis and Musculoskeletal Alliance (ARMA). Standards of care for people with inflammatory arthritis. London: ARMA, 2004.

20 Lord P, Lunt M, Watson KD, Symmons DP, Hyrich KL. Drug discontinuation due to inefficacy in ankylosing spondylitis patients treated with anti-TNF drugs: results from the British Society for Rheumatology Biologics Register (BSRBR). *In Program and abstracts of the American College of Rheumatology (ACR) 71st Annual Meeting, November 6–11, 2007*. MA: Boston.

21 Scarpato S, Antivalle M, Favalli EG *et al*. Patient preferences in the choice of anti-TNF therapies in rheumatoid arthritis. Results from a questionnaire survey (RIVIERA study) Rheumatology 2010;49:289–94.

22 Barkham N, Kong KO, Tennant A *et al*. The unmet need for anti-tumour necrosis factor (anti-TNF) therapy in ankylosing spondylitis. Rheumatology 2005;44:1277–81.

23 Koh W, Garrett SL, Calin A. Cervical spine surgery in ankylosing spondylitis: is the outcome good? Clin Rheumatol 1997;16:466–70.