Accessibility and quality of secondary care rheumatology services for people with inflammatory arthritis: a regional survey

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ABSTRACT – Secondary care rheumatology services for patients with inflammatory arthritis (IA) in the West Midlands were audited using Arthritis and Musculoskeletal Alliance (ARMA) standards of care. Questionnaires were analysed from 1,715 patients in 11 rheumatology departments. ARMA standards recommend full multidisciplinary team assessment; referral rates to nurse specialists (52.3%), physiotherapists (48.7%) and occupational therapists (36.5%) were, however, lower than expected. Attendance at existing hospital-led education groups was rare (8.9%), awareness of existing helplines was moderate (59.2%) but the proportion of patients reporting satisfaction with advice about their disease was high (80.5%). Significant variations were found between departments. For patients with IA <2 years (n=236), 84.5% were seen by a rheumatologist within the ARMA standard of 12 weeks of referral; diagnosis of a type of IA was made at the first rheumatology appointment in 66.4%; 82.8% of rheumatoid arthritis patients had commenced disease-modifying drugs, although time to commencement varied across departments. This study raises issues regarding provision of rheumatology services, prioritisation of patient referral and patient education.

KEY WORDS: inflammatory arthritis, referral, regional audit, standards of care

Introduction

Inflammatory arthritis (IA) is an umbrella term for a number of diseases, principally rheumatoid arthritis (RA), psoriatic arthritis and ankylosing spondylitis. Inflammatory arthritis has a huge impact on patients' lives and imposes a heavy financial burden on both the NHS and national productivity.[1,2] There has historically been great variation in provision of services for people with IA in the UK.[3] With major advances in therapy, however, there is a pressing need to evaluate, optimise and integrate services for these individuals.[4] The Arthritis and Musculoskeletal Alliance (ARMA) published standards of care for people with IA in 2004[3] and these have been supported by the RA guidelines from the British Society for Rheumatology.[5,6] Moreover, a Musculoskeletal Services Framework has now been published by the Department of Health,[7] which re-enforces the same principles of fast access to an array of services.

The ARMA standards were developed by an expert working group including people with IA, representatives of user organisations, service providers and clinicians. Following a review of needs of people with IA, evidence-based standards were determined to meet those needs with appropriate provision of musculoskeletal services.[3] The standards include ensuring patients with IA are seen by a rheumatology specialist within 12 weeks of referral, with a developmental standard of six weeks (Standard 4). This is crucial since early, intensive treatment with disease-modifying anti-rheumatic drugs (DMARDs) improves outcome for some types of IA, especially RA.[8–10] Access to and full assessment by members of a rheumatology

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multidisciplinary team (MDT) is emphasised in Standards 5 and 10. Standards 6 and 11 highlight the importance of facilitating patient self-management via information, advice, education and support, for example via local nurse-led rheumatology helplines or education groups. Awareness of primary prevention issues in relation to IA, including advice on stopping smoking, is emphasised in Standard 1.

The West Midlands Rheumatology Services and Training Committee (WMRSTC) organises regional audits annually, coordinated by specialist registrars (SpRs) under consultant supervision. Collecting data from a number of departments facilitates assessment of relatively large numbers of patients, allows comparison between departments, and acts as a training opportunity for planning, undertaking, analysing, presenting and publishing quality audits.[11–14] Using this methodology, the study aimed to assess the accessibility and quality of secondary care rheumatology services for patients with IA regionally using relevant ARMA standards of care as audit tools.

Methods

All 15 rheumatology departments in the West Midlands region of the UK were invited to participate in the audit, coordinated by SpRs and undertaken over a two-week period in February 2005. Data were collected using a digitally formatted questionnaire offered to all patients attending follow-up appointments. The patient completed the first page while waiting to see the clinician who then completed the second page assisted by the patient and with reference to their medical notes. The clinician completed the second page only for patients diagnosed with IA in the preceding two years. This group of patients was selected to provide a picture of recent practice and minimise recall bias with better access to accurate information in the medical notes.

For all these patients information on the timeframe from symptom onset to seeing their general practitioner (GP), subsequent referral to a rheumatologist and commencement of treatment was recorded.

Data management and statistical analyses

Completed questionnaires were scanned optically (Formic, London, UK) onto an Access database (Microsoft, Redmond, WA, USA), which was transferred to a SPSS database. Data were analysed using χ^2-tests to compared categories across groups with Cohen's κ of agreement reported where relevant. Student's t-tests and analyses of variance were employed to test differences in interval data across groups. Multivariate analyses made use of logistic regressions with forward conditional entry; the Wald statistics, odds ratios (OR) and their confidence intervals (CI) are reported for these models, which describe the number (and strength) of independent (non-overlapping) predictors of the outcome in question.

Results

Demographics

Eleven rheumatology departments participated, including one unit without a SpR. A total of 1,877 completed questionnaires were collected and 1,715 were analysed (162 patients did not have arthritis).

Table 1 outlines patient demographics and diagnosis. There was a strong agreement between the self-reported diagnosis and the clinician's diagnosis of RA (Cohen's κ=0.66, p<0.001). Of those diagnosed with recent IA, 30.9% were smokers compared with 23.7% of the other patients (χ^2(1, n=1,715)=5.79, p<0.05).

Table 1. Patient demographics and diagnosis.

	All patients (n=1,715)	Recent IA (<2 years) (n=236)
Mean age (range)	59.0 (13-92)	56.7 (16-85)
Women (%)	68.2	67.8
	Diagnosis according to patient (%)	Diagnosis according to clinician (%)
Unanswered	2.6	3.4
Rheumatoid arthritis	62.2	69.1
Psoriatic arthritis	6.0	8.1
Ankylosing spondylitis	2.6	1.3
Juvenile idiopathic arthritis	0.3	0.4
>1 diagnosis	1.7	2.5
Other	12.1	9.3
Did not know diagnosis	12.6	NA
Arthritis related to connective tissue disease	NA	3.4
Spondyloarthritis	NA	6.4

IA = inflammatory arthritis; n = number; NA = not applicable.

Patient recall and overall satisfaction with disease advice

Table 2 outlines patient recall of referral to MDT members, advice, information and education for all patients and those with recent IA. The range across the different departments is also presented along with the significance of these differences. Those with recent IA were compared to the remaining sample. No significant differences were observed in demographics or in the self-reported diagnosis of arthritis types between the rheumatology departments. As highlighted in Table 2, significant differences were identified when the results of individual departments were compared on the referral and education variables, with the exception of smoking cessation advice. More of the recent IA patients had been referred to a hospital education

group and provided with an educational leaflet than others, but fewer recent IA patients had been referred to physiotherapy.

Timeframe of the inflammatory arthritis journey for follow-up patients diagnosed between February 2003 and January 2005

Table 3 outlines the timeframe of the IA journey for the recent patients; 38.3% of patients sought assessment from a GP within six weeks of symptom onset and 62.1% within 12 weeks. However, 22.4% took more than six months to report their symptoms to their GP.

After seeking GP assessment, 42.5% were referred within six weeks and 66.8% within 12 weeks. However, 14.0% of patients waited more than six months to be referred to rheumatology. In

Table 2. Patient recall of referrals and satisfaction for the full sample and those with recently diagnosed inflammatory arthritis (IA).

	All patients (n=1,715)			Recent IA (<2 years) (n=236)			
	Percentage (%)	Region range (%)	p value[a]	Percentage (%)	Region range (%)	p value[a]	p value[b]
Physiotherapy referral	48.7	33.6–84.8	p<0.001	38.6	18.5–63.6	p=0.09	p<0.001
Occupational therapy referral	36.5	22.1–73.4	p<0.001	38.1	14.3–66.7	p<0.001	p=0.57
Nurse specialist referral	52.3	31.8–79.7	p<0.001	57.2	35.7–90.5	p<0.01	p=0.11
Education group referral[c]	8.9	0.0–25.3	p<0.001	13.9	0.0–38.1	p<0.001	p<0.05
Patient group referral	6.2	0.0–32.9	p<0.001	7.2	0.0–21.7	p=0.22	p=0.48
Helpline awareness[d]	59.2	29.5–78.5	p<0.001	63.2	28.6–95.2	p<0.01	p=0.20
Education leaflet given	51.6	22.7–84.8	p<0.001	61.0	28.6–90.9	p<0.001	p<0.01
Satisfied with disease education	80.5	70.5–89.9	p<0.001	81.4	70.4–100.0	p=0.06	p=0.73
Advised to stop smoking[e]	48.5	37.0–66.7	p=0.23	41.1	0.0–66.7	p=0.61	p=0.17

[a]Referring to differences between departments across the region.
[b]Referring to differences between those with recent IA and others.
[c]Referring only to the seven departments who offered an education group (n=1,072).
[d]Referring only to the 10 departments who offered a specific helpline (n=1,523).
[e]Referring only to the 423 and 73 patients (respectively) who responded to this question and did not say they were non-smokers.
n = number.

Table 3. Timeframe of the inflammatory arthritis journey.

Timeframe	Symptom onset to GP consultation (n=214)		GP consultation to GP referral (n=214)		GP referral to rheumatology appointment (n=219)		Rheumatology appointment to diagnosis (n=223)		Diagnosis to DMARD initiation (n=170)	
	Percentage (%)	Cumulative percentage (%)	Percentage (%)	Cumulative percentage (%)	Percentage (%)	Cumulative percentage (%)	Percentage (%)	Cumulative percentage (%)	Percentage (%)	Cumulative percentage (%)
Same day	0.0	0.0	0.0	0.0	0.0	0.0	66.4	66.4	34.1	34.1
<6 weeks	38.3	38.3	42.5	42.5	53.4	53.4	16.6	83.0	41.2	75.3
6–12 weeks	23.8	62.1	24.3	66.8	31.1	84.5	5.4	88.3	12.9	88.2
3–6 months	15.4	77.6	19.2	86.0	13.7	98.2	4.5	92.8	6.5	94.7
6–12 months	12.1	89.7	7.5	93.5	1.8	100.0	4.5	97.3	4.1	98.8
>1 year	10.3	100.0	6.5	100.0	0.0	100.0	2.7	100.0	1.2	100.0

DMARD = disease-modifying anti-rheumatic drugs; GP = general practitioner; n = number.

total, 53.4% of patients were seen by a rheumatologist within six weeks of referral by their GP and 84.5% were seen within the ARMA standard of 12 weeks. A diagnosis of a type of IA was made on first clinic visit in 66.4% of patients, in 83.0% within six weeks and in 88.3% within 12 weeks. None of the above times differed across department or by diagnosis with RA, sex or age.

DMARD therapy had been commenced by 170 (72.0%) patients, 150 (88.2%) of these within 12 weeks of diagnosis. Of those with RA (n=163), 135 (82.8%) were on DMARDs, 122 (90.4%) starting treatment within 12 weeks of diagnosis. This time did not differ by sex or age. There were variations in time to start a DMARD across departments (Wald = 4.71, p<0.05), although the proportion of patients taking DMARDs did not differ significantly between departments.

Of referrals to the rheumatology department, 61.4% were prioritised by rheumatologists as 'urgent' or 'soon', the remainder being marked 'routine' or were without priority. Significant differences were observed in percentages of referrals prioritised as 'urgent' or 'soon' between departments ($\chi^2(30, n=223)=55.36$, p<0.01).

Predictors of the timeframe of the inflammatory arthritis journey (Fig 1)

Patients who waited <6 weeks to see their GP after symptom onset were more likely to have waited <12 weeks to be referred to rheumatology by their GP after the first consultation (83.1%) than those who waited >6 weeks (59.2%; Wald = 11.78, p<0.001; OR 3.40; 95% CI 1.69–6.83).

Patients prioritised as 'urgent' or 'soon' were more likely to wait <12 weeks for a rheumatology appointment (90.4%) than others (73.7%; Wald = 7.06, p<0.01; OR 3.34; 95% CI 1.49–7.48). Moreover, patients who waited <6 weeks to see their GP after the onset of symptoms were more likely to wait <12 weeks for a rheumatology appointment (91.9%) than those who waited >6 weeks to see their GP (78.4%; Wald = 4.20, p<0.05; OR 3.11; 95% CI 1.21–8.01).

Patients who waited <6 weeks for a rheumatology appointment were more likely to wait <6 weeks to be diagnosed (91.0%) than those who waited >6 weeks for a rheumatology appointment (71.6%; Wald = 10.85, p<0.001; OR 4.01; 95% CI 1.76–9.17).

Among the 170 patients who had commenced a DMARD by the time of the audit, those who waited <6 weeks to be diagnosed were more likely to wait <6 weeks from diagnosis to DMARD initiation (78.6%) than those who waited >6 weeks to be diagnosed (52.2%; Wald = 6.30, p<0.05; OR 3.37; 95% CI 1.33–8.55).

Discussion

The complex, often multi-system nature of inflammatory joint diseases and the variety of health professionals involved with care provision present challenges when assessing or developing appropriate services for patients. The ARMA standards of care provide a much-needed assessment tool and our study should facilitate discussion both within rheumatology MDTs and with healthcare commissioners on optimisation of secondary care treatment pathways, as well as indicating further areas for research.

The rheumatology MDT is a well-established service model; self-reported rates of referral to MDT members were surprisingly low in our study with under half of patients reporting having seen a physiotherapist or occupational therapist. Recall bias may influence these results, patients being less familiar with a professional's title (eg occupational therapist) than their name or job (eg help with devices like splints). Nevertheless a good understanding of the role of all members of the MDT and also awareness of when and how to access their services is essential for patient self-management. This paper demonstrates wide variations in referral patterns within rheumatology departments regionally and individual departments may therefore wish to critically review local practice particularly if their results are lower than the estimated average.

In view of the adverse effects of smoking on IA,[15,16] smoking cessation is an essential part of patient education; in our study less than half of smokers reported having been advised to stop.
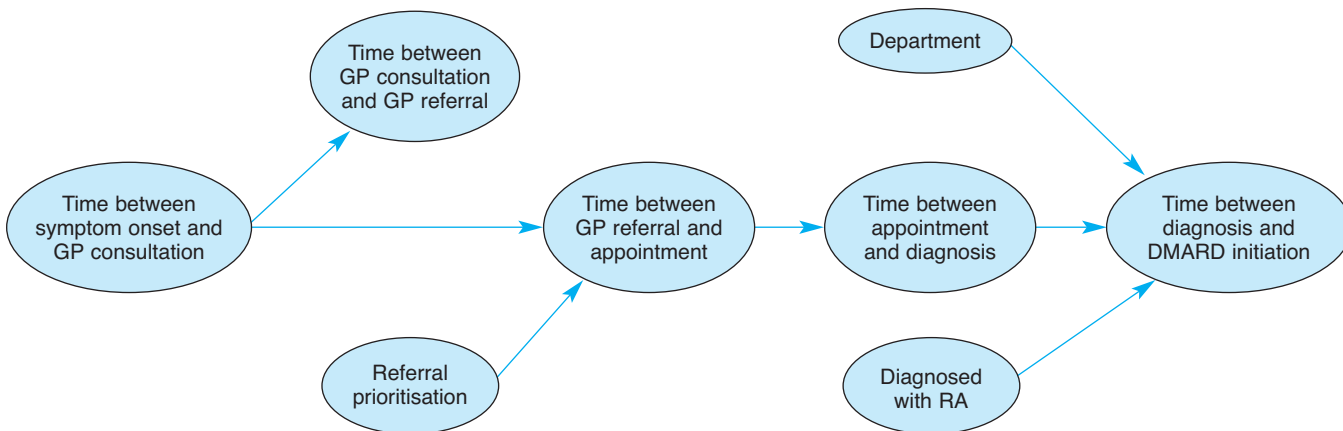

Fig 1. Predictors of the timeframe of the inflammatory arthritis journey for follow-up patients (arrows show effects with at least p<0.05). DMARD = disease-modifying anti-rheumatic drug; GP = general practitioner; RA = rheumatoid arthritis.

Although attendance at hospital-led education groups was very low the level of patient-reported satisfaction in relation to overall disease advice and education was high (>80%). This may reflect the part that each MDT member plays in educating patients and raises important questions relating to provision of optimal, appropriate and consistent disease education to the individual patient.

Early diagnosis and DMARD initiation is important to prevent joint destruction and subsequent loss of function in individuals with some types of IA including RA.[8–10] This requires prompt assessment by a rheumatologist; 84.5% of our patients met the ARMA standard of patients being seen within 12 weeks of referral. In addition, just over half were seen within six weeks, an ARMA developmental standard.[3] Recent reports suggest considerable variation nationally in the waiting times for rheumatology appointments for patients with RA,[17,18] possibly influenced by availability of early arthritis clinics. Referral prioritisation may require streamlining to meet ARMA's developmental standard in addition to increased resources. This study also suggests that greater awareness of the symptoms of IA among the general population is needed to ensure prompt GP consultation when relevant symptoms are experienced.

A diagnosis was made for two thirds of all recent IA patients at the first consultation. DMARDs are not indicated for all types of IA; the majority (82.8%) of RA patients were on DMARDs, 90.4% of these commencing promptly (within 12 weeks of diagnosis). Due to the study design, with the data collection for the recent IA patients concluding concurrently with the end of the study, a few patients may not have yet been given a diagnosis of type of IA or started a DMARD if indicated. This effect is, however, likely to be small as 96.6% of recent IA patients had a diagnosis (Table 1) and all were follow-up patients and therefore would have been seen at least twice in clinic. Time from diagnosis to commencement of DMARDs varied across departments and the reasons for this warrant further study.

Analysis of predictors of the timeframe of the patient's journey from symptom onset to DMARD commencement demonstrated that prompt appointment after referral was predictive of diagnosis at first appointment and prompt diagnosis (and the presence of RA) was predictive of early DMARD therapy in those who had commenced such treatment. The sum of the predictive relationships in this study suggests a core of fast-track patients who report swiftly to their GP, are seen quickly in rheumatology and then have a clear diagnosis and best practice treatment. Further research is required to investigate potential differences in patient demographics or the nature of onset of IA between these fast-track patients and those presenting and being treated later.

This study identified significant differences in service provision between rheumatology departments. Departments tended to have certain strengths and weakness in service provision rather than being classed as 'good' or 'bad' overall. Individual centre results have been provided to respective units in addition to overall and anonymised results of other centres; these have also been presented and discussed at regional meetings.

This study further highlights the value of regional audits allowing collection of sufficient data to make comparison between departments.[11–14] Other regions and medical specialties may consider adopting such a model that also provides an excellent training opportunity for SpRs. Combining different methodological approaches may improve the quality of the audit process; this audit experience has been shared with ARMA and hopefully facilitated the development and publication of ARMA audit tools.[19] National audits have been undertaken by some specialties, such as neurology,[20] and should be developed in rheumatology.

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