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The 1st National Clinical audit for Rheumatoid and Early Inflammatory Arthritis: findings and implications for nursing practice

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Abstract

The first national audit for rheumatoid and early inflammatory arthritis has benchmarked care for the first three months of follow up activity from first presentation to a rheumatology service. Access to care, management of early RA and support for self care were measured against NICE quality standards and impact of early arthritis and experience of care were measured using patient reported outcome and experience measures. The results demonstrate delays in referral and accessing specialist care and the need for service improvement in treating to target, suppression of high levels of disease activity and support for self-care. Improvements in patient -reported outcomes within three months and high levels of overall satisfaction were reported but these results were affected by low response rates. Here we present a summary of the national data from the audit and discuss the implications for nursing practice.

Overview of the audit

Rheumatoid arthritis (RA) is the most common form of inflammatory arthritis affecting more than half a million people in the UK (REF). Rapid access to specialist care and early treatment with disease modifying anti-rheumatic drugs (DMARDs) has been shown to be crucial to slow the progression of structural damage and improve the long term outcomes of disease and overall quality of life (Emery et al, 2002). Quality standards were developed by the National Institute of Clinical Excellence (NICE, 2009) to inform the best practice management of RA and are summarized in Box 1. The first national clinical audit for rheumatoid and early inflammatory arthritis has benchmarked care given to adults with newly diagnosed inflammatory arthritis against these standards.

Patients ages 16 or over who presented for the first time in a rheumatology outpatients were recruited between 1st February 2014 to 31st January 2015. Clinician data was collected at organizational and patient level from the first outpatient appointment up to three months of follow up. This included the patient demographics; history; diagnosis; treatment; disease activity; response to treatment and support available to the patient. Patient data were collected at the first outpatient appointment and at three months including the impact on patients' everyday lives and ability to work, along with patient outcome and experience measures.

Almost all (97%) NHS rheumatology providers in England and Wales participated in the audit and data from 6,354 patients were available for analysis at the end of the first year. Scotland and Northern Ireland were invited to take part but declined at this time.

The first annual report was published in January 2016 and is available to read in full on line: http://www.rheumatology.org.uk/resources/audits/national_ra_audit/annual_report.aspx Here we present a summary of the main findings and discuss the implications for nursing practice.

Results

Access to care

NICE Quality Standard (QS) 1 states that people with persistent synovitis (swelling) affecting the small joints of the hands or feet, or more than one joint, should be referred to a rheumatology service within 3 working days of presentation to their GP. However, in the first national audit just 17% of patients were referred within this time frame. Whilst there was substantial variation within NHS regions across England and Wales, the average wait was 34 days nationally and one quarter of patients waited for more than three months.

People have often waited a while before making an appointment to see their GP or nurse practitioner as the onset of RA is often gradual and signs and symptoms may fluctuate. When RA or inflammatory arthritis is suspected early referral is important and should not be delayed by diagnostics undertaken in primary care. It is useful to obtain baseline blood tests including full blood count, urea and electrolytes, liver function, inflammatory markers, such as C-reactive protein, and rheumatoid factor but simultaneous referral is recommended. None of these tests if negative rule out a clinical diagnosis of RA and a positive rheumatoid factor is present in about one in every 20 people without RA. Rheumatoid factor may be negative whilst anti-CCP antibodies are more sensitive in early disease but this more expensive laboratory test is not required if a clinical diagnosis has been made and rheumatoid factor is positive.

Historically treatment was offered incrementally and non-steroidal anti-inflammatory drugs were trialed first, leading to progression of disease in the early stages of care affecting function and quality of life. The treatment pyramid has been inverted in light of substantial evidence that early immune suppression with DMARDs improves outcomes; NSAIDs may offer symptom relief along with simple analgesia. Hence a reduction in pain and stiffness should not delay referral as persistent synovitis (swelling) in the joints leads to irreversible erosive change.

NICE QS 2 states that people with suspected persistent synovitis (swelling) should be assessed in a rheumatology service within three weeks of referral. In the first national audit only 38% were seen in a rheumatology department within three weeks of referral. The average waiting time nationally was four weeks and three-quarters of patients were seen within seven weeks representing a significant delay in accessing specialist care for the majority of patients. There are a number of potentially modifiable factors that affect achievement of this standard. In 12% of referral letters there was no mention of suspected inflammatory arthritis in the referral meaning that there would be no reason for the referral

to be prioritized at triage if indeed this is under clinician control. This would also mean that there would be no reason to book the patient into an Early Arthritis Clinic. Early Arthritis Clinics were available in just over half of all participating trusts and were associated with a statistically significant improved ability to meet this standard.

Implications for nursing practice

Nurses work on the front line of patient care and are well placed to raise public awareness of RA in order to promote recognition of the signs and symptoms of inflammatory arthritis and the importance of early presentation to facilitate access to specialist care. One of the ways in which this can be done is through publicizing the Inflammatory Arthritis public awareness campaign:

Inflammatory Arthritis? Have you got the 'S' factor?

- Stiffness – Early morning joint stiffness lasting more than 30 minutes
- Swelling – Persistent swelling of one joint or more, especially hand joints
- Squeezing – Squeezing the joints is painful in inflammatory arthritis

This campaign was developed by the Rheumatology Futures Project Group and endorsed and supported by Arthritis Research UK, the National Rheumatoid Arthritis Society, Royal College of GPs and the Primary Care Rheumatology Society. There are posters available to download for display in general practice, pharmacies and other public places to raise awareness of the message that if you have any of the symptoms highlighted in the poster suggesting inflammatory arthritis, to seek help from your GP without delay:

http://www.rheumatology.org.uk/about_bsr/press_releases/bsr_archive/bsr_news_archive/nras_s_factor_awareness_campaign.aspx

GPs and nurse practitioners able to make referrals to specialist care need to ensure that referral letters contain sufficient information to indicate that inflammatory arthritis is suspected. Rapid referral is advocated in the event of any clinical suspicion of RA, which the evidence suggests may be supported by the presence of any of the following (Emery et al, 2002):

- 3 swollen joints
- Involvement of the metacarpal or metatarsal joints / squeeze test positive
- Morning stiffness of 30 minutes

Management of early RA

NICE QS 3 states that people with newly diagnosed RA should be offered short-term glucocorticoids and a combination of DMARDs by a rheumatology service within six weeks of referral. This standard and QS 5 are more specific to RA, hence the analysis was applied to those patients with a confirmed diagnosis of RA at baseline or follow up (n=2,936). Intramuscular or intra-articular steroids glucocorticoids were widely used in early management of RA with 76% of patients treated at the point of working diagnosis rising to 82% over the first 6 weeks. Whilst steroids work quickly to settle disease activity, DMARDs

are slow acting in nature and often take three months to be effective. Just 53% of patients commenced a DMARD within 6 weeks but only 36% commenced combination DMARDs during the first 3 months.

The reasons for variation here are likely to be complex. Treating to target allows for mono or sequential use of DMARDs with rapid titration of treatment linked to severity of disease presentation. Baseline investigations such as blood tests and chest x-ray may be required prior to initiation of DMARD therapy and the safe initiation of treatment is dependent upon patient education addressing the risk-benefit ratio of DMARDs and the need for blood monitoring. Engagement in a shared decision making process may mean that patients express a preference for one treatment over another but they may also elect to delay a decision to start treatment. Education about RA and its management is normally undertaken by specialist nurses and usually requires the availability of a dedicated appointment unless a 'one stop' approach is available within an early arthritis clinic.

NICE QS 5 recommends that people who have active RA should be offered monthly treatment escalation until disease is controlled to an agreed low disease activity target. Nationally 90% of patients were reported to have agreed a target with their clinician although only about 25% of patients met this within the first 3 months of presentation. Factors affecting achievement of this standard include the way in which the DAS-28 score is presented within a consultation and the extent to which the patient is included in the discussion about treating to target. As with NICE QS 3, the slow acting nature of DMARDs mean that in order to treat to target regular review is required for dose titration and rescue therapy with parenteral steroids.

Implications for nursing practice

Nurses working in rheumatology need to reflect on the way services are configured and examine staffing levels to see how performance against these standards can be improved. Higher specialist nurse numbers per head of population were significantly associated with the initiation of DMARDs within six weeks of referral (odds ratio 1.58; 95% CI 1.00-2.50) 1.58; and combination DMARDs at baseline or follow up (2.01; 1.21 -3.33). The availability of nurse led clinics creates capacity for consultants to see new patients quickly and for patients to be treated to target with regular review. A multi-centre randomized controlled trial in the UK has shown nurse led care to be both non-inferior and cost effective in comparison with rheumatologist care in providing follow up care (Ndosi et al, 2013). Furthermore, there is evidence that access to a specialist nurse for education improves knowledge of RA and its management and nurse led care has been shown to improve patient –preferred outcomes, symptom control; communication; continuity of care and satisfaction with care (van Eijk-Hustings et al, 2011). Local trust level data is available to view within the national report and can be used to support a business case for specialist nursing; successful examples of this have been noted since audit data collection started.

Support for self care

Clinicians reported that 59% of people with RA had been offered structured educational and self-management activities within one month of diagnosis (NICE QS 4). This may take the

form of one to one sessions with a specialist nurse; the provision of education materials; referral to the National Rheumatoid Arthritis Society (NRAS) or formal group education. In contrast, achievement of NICE QS 6 was much better; with 96% of patients with RA experiencing disease flares or possible drug related side effects able to receive advice within one working day of contacting the rheumatology service. This is usually provided in the form of a rheumatology advice line that is normally staffed by specialist nurses.

NICE QS 7 states that people with RA should have a comprehensive annual review that is coordinated by the rheumatology service. This standard was measured by the analysis of the organizational forms, which indicated that 82% of trusts reported that they provided comprehensive review. This standard was designed to measure quality of care for people with RA diagnosed one year so within the three months time frame the extent or quality of the annual review process was not assessed. Comprehensive annual review as defined by NICE (2009) should include assessment of disease activity and damage; measurement of functional ability and impact on quality of life including work; checking for the development of comorbidities, such as cardiovascular disease; osteoporosis and depression; assessing for complications of RA such as vasculitis, lung or eye disease; symptom control including pain management.

Annual review is also an important opportunity to offer education and support for self care and to facilitate referrals to the multidisciplinary team where appropriate to improve mobility, function and pain. In the audit, 75% of trusts reported patients had access to specialist physiotherapy; 77% to specialist occupational therapy and 55% to specialist podiatry services. There was variation in access to services across England and Wales and the provision of specialist podiatry in particular was low and patchy indicating room for improvement.

Implications for nursing practice

There is clearly the potential to improve educational provision and support self-management for people with RA, certainly in the early stages of adjusting to a diagnosis of inflammatory arthritis. There is a need to examine the capacity at service level for specialist nurses and allied health professionals to provide patient education which supports self-care, in addition to facilitating shared decision making in relation to treating to target and extended scope practice. Advice lines staffed by specialist nurses make a powerful contribution to supporting and empowering people with long term conditions and their carers, but it can also be useful for patients to access peer support. NRAS offer the opportunity to speak to a matched trained volunteer with RA about living with RA (<http://www.nras.org.uk/speak-to-someone-else-with-ra>).

Whilst responsibility for coordinating annual review is allocated to the rheumatology service, nurses working in primary and secondary care contribute many of the required elements. People with established RA are at approximately 1.5 fold increased risk of cardiovascular disease, which is thought to be linked to systemic inflammation, and EULAR guidelines recommend systematic assessment and modification of risk factors (Peters et al, 2010). Practice nurses are often best placed to assess risk, monitor for hypertension and hyperlipidaemia but whilst the 2016/17 Quality and Outcomes Framework states that

patients with RA should be reviewed annually, the components of this are not specified. Awareness of the increased cardiovascular risk associated with RA appears variable and a study in primary care has shown that patients with diabetes were twelve times more likely to receive vascular screening (Monk, Muller, Mallen and Hider, 2013). The JBS3 risk calculator now incorporates the appropriate multiplier for the presence of RA, as does QRISK-2 calculator.

Impact of early arthritis

Within the audit we measured two validated outcome measures: the Disease Activity Score (DAS-28) and the Rheumatoid Arthritis Impact of Disease (RAID score). The DAS-28 assesses disease activity in RA incorporating swollen and tender joint, inflammatory markers and patient reported overall well being (REF). This systematic assessment of disease activity is considered best practice to monitor response to treatment and becomes mandatory later in the patient journey to demonstrate eligibility for biologic therapy in severe disease. A DAS-28 greater than 5.1 defines high disease activity with scores between 3.2 -5.1 moderate disease activity, less than 3.2 low disease activity and less than 2.6 considered remission. A reduction in DAS-28 of > 1.2 is considered to be a clinically meaningful response.

The mean DAS-28 score at baseline nationally was 5.0 (SD 1.4) representing high disease activity although the range of scores reflected patients presenting with disease ranging from very mild to very severe. Within the first three months of care, 62% of patients achieved a reduction in DAS by 1.2.

The RAID score is a patient reported outcome measure in which patients are asked to rate their pain; function; fatigue; sleep; physical and emotional well being and coping on a scale ranging from 0 (best) to 10 (worst). The mean RAID score at baseline was 5.6 (SD 2.0) although again there was a wide range of scores consistent with different levels of disease severity. Evaluation of a second RAID score was planned at follow up for patients with a confirmed diagnosis of RA but was obtained in 21%. At follow up, the mean improvement in the RAID score was 2.4 (SD 3), which is just below the defined minimum clinically important difference of 3 points.

The audit also collected information about the affect the disease was having (if any) on peoples' working lives during the first three months following referral. Over 70% of people recruited were of working age (< 66 years) and one in eight patients (12%) reported needing frequent time off work or were not working because of their arthritis. A further 16% had occasionally needed time off. The audit also asked patients if they recalled ever being asked by their rheumatology team about their work. Response rates were low but where data was available only 42% of respondents reported they had been asked about their work and 19% said it had not been discussed. This highlights that many people with arthritis struggle to work in the early stages of receiving treatment and help is not being signposted.

Implications for nursing practice

DMARDs are slow acting in nature and once titrated up to a therapeutic dose can take up to 3 months to demonstrate their effectiveness. In the interim period, greater improvements in

disease control can be achieved through treatment with intra-muscular or intra-articular steroid therapy. It is important that patients are encouraged to contact their rheumatology advice line if they are struggling in between scheduled because flares are unpredictable.

The work data suggests that asking patients about the impact of RA on work is vital in the first 3 months in order to provide and signpost support to prevent work instability translating into long-term difficulties or job loss. Occupational therapists, Disability Employment Advisors and organisations such as Remploy offer support for work retention ranging from work -based assessments to negotiation around work modification.

Experience of care

Patients diagnosed with RA were asked to complete a confidential patient reported experience measure (PREM) about their experience of care, which was developed by the Commissioning for Quality in RA group. As with RAID score, the response rate was low (21%) which is a cause for concern. Of the respondents, 78% felt that overall they had a good experience of care for their arthritis; 17% left the question unanswered; 3% neither agreed nor disagreed and 1% disagreed. The PREM comprises a number of detailed questions about different aspects of care, the results of which were fed back to individual trusts to inform service improvement activities. Clinicians working in rheumatology services participating in the audit have been asked to look at ways to increase the capture of follow up data by flagging patient records and there are plans to simplify data collection in the next audit cycle.

Conclusion & future directions

The first national RA audit highlights important areas for service improvement ranging from raising public awareness of the signs and symptoms of early inflammatory arthritis to improving rapid access to, and experience of, specialist care to facilitate enhanced patient outcomes. Nurses working in a variety of settings can make an important contribution to raising standards of care, working with patients and public, GPs, rheumatologists and the multi-disciplinary team to promote awareness and provide high quality shared care. The second annual report is due to be published this summer and will enable us to see what progress has been made towards improving care. This will be available to download from the British Society for Rheumatology website (http://www.rheumatology.org.uk/resources/audits/national_ra_audit).

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Box 1**NICE Quality Standards for RA**

1. People with suspected persistent synovitis affecting the small joints of the hands or feet, or more than one joint, are referred to a rheumatology service within 3 working days of presentation.
2. People with suspected persistent synovitis are assessed in a rheumatology service within 3 weeks of referral.
3. People with newly diagnosed rheumatoid arthritis are offered short-term glucocorticoids and a combination of disease-modifying anti-rheumatic drugs by a rheumatology service within 6 weeks of referral.
4. People with rheumatoid arthritis are offered educational and self-management activities within 1 month of diagnosis.
5. People who have active rheumatoid arthritis are offered monthly treatment escalation until the disease is controlled to an agreed low disease activity target.
6. People with rheumatoid arthritis and disease flares or possible drug related side effects receive advice within 1 working day of contacting the rheumatology service.
7. People with rheumatoid arthritis have a comprehensive annual review that is coordinated by the rheumatology service.