



Implementation of Patient-Initiated Review in Rheumatoid Arthritis

Keywords:

Patient-initiated, rheumatoid arthritis, nurse-led care, follow-up, telephone helpline, chronic illness

Duration of project:

August 2002 – August 2004

Report received for publication: June 2005

Project leader:

Dr Sarah Hewlett, arc Senior Lecturer and Honorary Consultant Nurse

Project team:

Sue Tipler, Rheumatology Nurse Specialist; Denise Pope, Project Nurse; Professor John Kirwan, Professor of Rheumatology; Wendy Harrison, Clinic Administrator, Rheumatology; Anne Brooks, Senior Secretary, Rheumatology; Margaret Upcott, Patient Project Partner; Bob Noddings, Patient Project Partner.

Contact details:

Sarah.Hewlett@bristol.ac.uk

Summary of project

Rheumatoid arthritis (RA) is a chronic illness with unpredictable daily symptoms and an uncertain long-term outcome that is traditionally managed by regular medical review initiated by the hospital rheumatologist. However, appointments do not always coincide with patient need, and an unwieldy system makes it difficult to respond to requests for an urgent appointment within a reasonable time-frame. This project implemented recently published research into patient-initiated review, which replaces rheumatologist-initiated review in RA. The system is supported by three nurse-led initiatives: an education session, a helpline and a specialist nurse review.

Background

RA is a chronic, lifetime disease with unpredictable, repeated flares of synovitis and joint pain, leading to joint destruction, disability, pain and fatigue while unpredictability disrupts life plans, increasing psychological distress and helplessness (Perry, 1991, Newman et al., 1996). Stress is put on relationships as roles and dependency change (Ryan, 1996). Drug interventions include anti-inflammatory drugs and disease modifying anti-rheumatic drugs. Whilst interventions by the multidisciplinary team aim to reduce pain, swelling and deformity, preserve function and maximize coping and self-management, patients need the skills to manage their condition and its consequences upon their lives.

Traditionally, patients are managed by routine medical reviews, initiated by the hospital rheumatologist every 3-6 months. The aim is to assess inflammatory activity, efficacy and side-effects of drugs, and offer interventions to reduce or prevent disability or to increase self-management. As the appointment date is determined up to 6 months in advance, patients often attend for medical review when they are well, but because of the volume of RA patients under routine follow-up appointments, urgent requests for help in times of increased disease activity are difficult to accommodate. Therefore a patient experiencing a flare of their RA may have to wait several months for an urgent appointment, while at the same time, 35% of routine medical reviews are deemed unnecessary by the rheumatologists (Hehir et al, 2001).

Research evidence for an innovative service

A 6 year randomised controlled (RCT) trial undertaken by this team, tested patient-initiated review against traditional, regular reviews initiated by rheumatologists (Hewlett et al, 2005). In the new system, appointments were initiated by the patient (or GP) via a telephone helpline run by the Rheumatology Nurse Specialists (RNS). This system replaced the regular reviews initiated by the rheumatologists every 3-6 months. The telephone helpline was also used for advice, and the decision on need for a medical appointment was made collaboratively between the patient and the RNS. Medical reviews were then provided within 10 working days. Occupational therapy or physiotherapy reviews were also made via the helpline, or the nurse could suggest a review in the nurse-led clinic. The RCT showed that patient-initiated-reviews reduced unnecessary medical reviews and made more efficient use of limited resources, whilst maintaining the patient's physical and psychological status. The data also showed that patients and GPs had more confidence and satisfaction in such a system, compared to routine follow-up.

Empowering and facilitating the patient's ability to self-manage are prime nursing functions and are known to be associated with improved outcome in RA, while patient involvement is a government objective (Ryan, 1999; Lorig et al, 1993; Department of Health, 2001). The development of rheumatology nurse specialists and consultant nurses, nurse-led telephone helplines, and an RCT of nurse-led management indicate the potential for nurse-led care in RA (Phelan et al, 1992; McCabe et al, 2000; Hill et al, 1994). Giving the patient a role in managing their own condition through the ability to request their own specialist reviews, might improve psychological status.

Given the evidence that patient initiated review reduces medical visits and costs, has no negative health impacts, and improves satisfaction and confidence, it was decided to implement it fully as the normal clinical service for patients with RA in the Bristol Royal Infirmary Rheumatology Centre. It was anticipated that most of the 1000 RA patients could stop routine medical reviews and enter the new system of Direct Access (DA). The RCT included a medical review every 24 months, and would be replaced by an RNS review for any patient who does not request an appointment within 24 months. It was intended to enrol approximately 400 patients with well-established RA during the project, after which the smaller number of patients becoming eligible to enter the DA system as they reach two years disease duration, would be manageable within existing RNS resources.

Implementation would clearly involve major changes in the working practices of the nurses, the rheumatologists, and the administrative support staff, as well as collaboration with hospital managers and IT department. It was thought unlikely that this major project could be implemented without dedicated manpower, therefore an application was made to the Foundation of Nursing Studies to second a rheumatology nurse for 2 years (1.5 days/week) in order to manage the implementation.

Project management

The implementation of Direct Access (DA) was managed by a steering committee, comprising the project leader, the RNS, the project nurse, a consultant rheumatologist, the clinic co-ordinator, the senior secretary, and two patients from the two arms of the RCT. When appropriate, other team members were invited to the steering meetings to address specific issues (e.g. IT manager to assist with a new computer booking system for 24 month reviews, hospital manager to discuss waiting lists). Meetings were held monthly initially, reducing in frequency as the implementation project progressed, and the project manager and project nurse met as necessary on a weekly basis. All team members were invited to contribute to all meetings, and were always asked whether they were experiencing or expecting any major difficulties in their areas.

Implementation

Implementation of the project had four aspects: a) setting up the system for the clinics; b) designing a patient education session to prepare patients for using patient-initiated review, c) establishing the helpline and d) establishing the format of patient review by the RNS for patients who have not had a medical review within 24 months. It took 3 months organisation before patients could be approached.

Setting up the clinic system

The RCT managed 100 DA patients on one clinic list/fortnight. Initially, the 70 control patients from the recent RCT were enrolled into DA, entering the system very rapidly as a large group, therefore we immediately converted a second clinic list to DA, giving one clinic list/week. Other patients from this consultant were then enrolled as they came up for a routine follow-up

appointment, until the bulk of his patients were in the DA system. After this, we approached patients from the second, and finally third consultants.

All patients considered suitable for the DA system were approached at the end of their routine medical consultation. The rheumatologist would discuss the new system with the patient, and then record this in their notes. The clinic co-ordinator would then enter the patient as a DA patient on the computer system with their next appointment on the 2-year pending list. The patient is given an initial information sheet explaining the system, and booked into one of the DA patient education sessions over the coming 2-3 weeks. The clinic co-ordinator offers the opportunity for the patient to further discuss Direct Access with the rheumatology nursing staff in clinic. An information sheet and guidelines on managing RA are enclosed with the consultant's GP letter.

Initially, 2-3 slots on a clinic list were converted to DA at a time. Further slots were converted as it became apparent that the existing DA slots were being utilised to capacity (i.e. it became harder to meet the 10 working day deadline). This staged approach worked efficiently, increasing DA slots until the first consultant had two DA clinic lists/week. At this point it appeared that the majority of his eligible RA patients were enrolled, and enrolment started afresh with the next consultant.

During the implementation, it was discovered that medical staff annual holidays and public holidays had a major effect on the ability to provide appointments within 10 working days. Overcoming this required that clinic planning be done 2-3 months ahead to ensure sufficient clinic times for both routine and DA patients were available. In addition, it was also recognised that 'new patient' appointment times needed to be protected within the DA clinics.

Designing a patient education session

The steering committee felt that patients joining DA would benefit from a specific educational intervention before entering the system. Based on 20 years experience of running patient self-management programmes in RA, and in consultation with the steering group patients, a 90 minute nurse-led education session was designed. The key objectives of this session were, that patients would:

- understand how DA operates and what they can expect
- understand when and how to request an appointment
- be able to use the telephone help line
- feel confident about using the DA system of care

In addition, an overview on the role of the RNS is given, and a short session on recognising and managing an inflammatory flare of RA.

At the end of the session, patients take home a full DA information leaflet, a business card with the details of the helpline, and a prompt card on how to use the helpline and the message to leave (to keep beside their phone). It

was felt important to provide this prompt card as some patients who are older feel anxious about using answerphones and we had experienced some patients simply saying 'please call me' without leaving a name.

The education session is delivered to groups of 5-8 patients, and is open to partners or friends as desired. It is offered on two days a week, usually at lunchtime and held in the patient education room attached to the Rheumatology Centre. On occasions an early evening session is held for those patients who work full-time. If a patient declines to attend a session, they are contacted by the project nurse who explains this session is a pre-requisite for joining DA, or given a clinic appointment with the RNS, who goes through the information on a one-to-one basis.

Both steering group patients attended the first pilot education session to provide evaluation and feedback. Following their advice some minor changes were made to the overhead presentations, and to the supportive literature. Each year, at least one patient project partner attends a session to help with quality assurance.

Establishing the helpline

Using information from published research and expert guidance (McCabe et al, 2000; RCN 1999, Telephone Helpline Association, 1995), the project nurse and steering committee agreed a protocol for managing the helpline. The RCT data showed that the helpline nurse changed the outcome of the helpline calls in 26% of cases (Mitchell et al, 2004), therefore it was felt essential that the point of contact be clinical and not clerical. It was agreed that the most recent clinic letter could immediately be obtained from the NHS secretaries to help the RNS with helpline queries (patient's notes would take 1-3 days).

In order to manage the workload, it was agreed that the helpline would be permanently connected to an answerphone (voicemail) and the calls checked and returned each morning and evening, from Monday to Friday. As the unit does not have an in-patient ward, there is no facility for out of hours response, although other units may wish to consider this. The answerphone system enables the RNS to plan sessions when she will return calls, allowing her to provide concentrated attention rather than constant interruptions to her working day, or to consult with an appropriate member of the multi-disciplinary team before returning the call. The RNS records the nature of the call, actions taken and advice given. The record sheet is photocopied for the patient's notes, so that it is available to the rheumatologist who subsequently sees the patient in clinic. The helpline is situated in the RNS office in order that there is privacy and quiet, and medical and secretarial staff situated nearby. With 420 patients on DA, the calls account for approximately 2 clinic sessions for the RNS.

Establishing the format of patient review by the RNS

All patients who do not request a medical appointment over 24 months are recalled for an RNS review in clinic. In order to ensure that such patients are identified, patients joining the DA system, are given a 2 year

'pending' appointment. This is cancelled and re-booked each time a patient attends a DA clinic (i.e. the 2 year clock is re-set from the latest appointment).

The aims of the 24 month review by the RNS are to check that the patient's RA is well controlled, review health status, and function; review medication, monitoring and side-effects; ensure the patient is managing their inflammatory flares; refer the patient to other members of the multi-disciplinary team as appropriate; support the patient in managing and coping with their chronic illness; and check that the patient understands the DA system. The project nurse worked with the RNS to design the format of the review, which was then discussed with all members of the multi-disciplinary team. The resulting review form guides the consultation, but the RNS uses her judgement to move beyond the specified format as necessary. One hour is allowed for each appointment with the RNS.

Audit

Helpline calls over 6 months were audited (n=382). The bulk of these related to inflammatory flares of arthritis (45%), drugs (32%) and general advice (24%), but many patients had more than one question. Only 62% of the calls resulted in an appointment with the rheumatologist, the others either being given an appointment with the GP, OT, RNS or Physiotherapist (2-4%) or deciding in collaboration with the RNS, that they did not need an appointment (26%). Clearly the helpline is being used for more than just a request to have an appointment with a rheumatologist, and it would not be appropriate for this to be run by a clerical member of the team.

RNS review appointments at 24 months were audited (n=30). The RNS made no referrals for 16/30 patients, 7 were referred to the rheumatologist, 5 were referred to the physiotherapist, 5 to Xray, 4 to OT, 4 to the podiatrist, and one to the patient self-management programme. Only 3 of 30 patients needed a reminder about accessing the DA system more readily. Compared to 30 consecutive RA patients reviewed by the other RNS during their regular outpatient visits, the data do not suggest that DA patients coming back for a 2 year review are in greater need than those being regularly reviewed.

Waiting times for 40 consecutive requests for DA appointments were audited and only 5 were found to be outside the target of 10 working days. Of these, two patients chose a later day for their own convenience, and one was due to cancelled clinics during the Christmas period.

Implementation of DA in other units

The implementation of a DA system can present many challenges. Some team members may be resistant as the system requires many professionals to change their practices, and could challenge their beliefs about the need for routine review. It could also challenge the beliefs of patients about easy access to the system in times of need, when their previous experience has been that such access is difficult to organise and is accompanied by a large delay.

In this project, the appointment of a project nurse was the

key element in engendering a sense of ownership, teamwork and commitment, and in reducing the workload of implementation for the rest of the team which would otherwise have disrupted their working schedule. The involvement of patient partners was also crucial for their practical, common sense approach, and their ability to liaise with our Patient Advisory Group and to contribute articles to the patient newsletter.

It should be acknowledged that all hospitals run their departments differently, and implementation will need to be considered not only in the light of the published RCT evidence and this report, but also in the light of their own particular practices. For example, all the Bristol Royal Infirmary clinics are held on site, whereas other units may run clinics in smaller outlying hospitals. This will raise issues of where a helpline should be situated and how it can be manned, for example, the helpline might be more efficiently run (in terms of staff time and expertise) if it is based at the main hospital, but this may cause difficulties with accessing the patients notes/letters if they are from a peripheral clinic.

Conclusion

A new service of patient-initiated review in RA has been implemented over a two year period. Implementation of this new service expands and strengthens the role of the rheumatology nurse specialist by providing new nurse-led services for patients with chronic illness and incorporated major changes in the working practices of clinic administrative staff, medical staff and the way in which patients have had their outpatient review appointments managed since diagnosis. This required sensitive collaboration between doctors, nurses, the multi-disciplinary team, the administrative team and hospital management, and vital input from patient partners. By the end of the project, 420 patients had been successfully enrolled into an efficient system that is appreciated by patients, GPs and staff, and that allows patients to drive their own care, supported by specialist nurses. This patient-led service, supported by specialist nurses, might be appropriate for other long-term conditions where there is a tradition of hospital follow-up, fluctuating symptoms and a need for patient self-management (e.g. inflammatory bowel disease, neurological disorders).

References

Department of Health (2001) *The Expert Patient: a new approach to chronic disease management for the 21st century*. London: HMSO.

Hehir, M. et al. (2001). What happens in rheumatoid arthritis outpatient clinics? *Rheumatology*. Vol. 40. suppl 1. pp 146.

Hewlett, S. et al. (2005) Patient-initiated outpatient follow-up in rheumatoid arthritis: six year randomised controlled trial. *British Medical Journal*. Vol. 33. pp 171-175.

Hill, J et al. (1994) An evaluation of the effectiveness, safety and acceptability of a nurse practitioner in a rheumatology outpatient clinic. *British Journal of Rheumatology*. Vol. 33. pp 283-288.

Lorig, K., Mazonson, P., Holman, H. (1993) Evidence suggesting that health education for self-management in patients with chronic arthritis has sustained health benefits while reducing health care costs. *Arthritis and Rheumatism*. Vol. 36. pp 439-446.

McCabe, C. et al. (2000) Rheumatology telephone helplines – an activity analysis. *Rheumatology*. Vol. 39. pp 1390-1395.

Mitchell, K. et al. (2004) Patient-initiated review: Specific helpline support is required. *Rheumatology*. Vol. 43. Suppl. 2. pp 149.

Newman, S. et al. (Eds) (1996) Chapter 5 in *Understanding rheumatoid arthritis*. London: Routledge.

Perry, E. (1991) Living with rheumatoid arthritis. *Nursing Times*. Vol. 87. No. 37. pp 58-59.

Phelan, M.J.I. et al. (1992) A profile of the rheumatology nurse specialist in the United Kingdom. *British Journal of Rheumatology*. Vol. 31. No. 12. pp 858-859.

Royal College of Nursing. (1999) *Nurse telephone consultation services: information and good practice*. London: RCN.

Ryan, S. (1996) Living with rheumatoid arthritis: a phenomenological exploration. *Nursing Standard*. Vol. 10. pp 45-48.

Ryan, S. (1999) Rheumatology: psychological issues. *Professional Nurse*. Vol. 14. pp 509-512.

Telephone Helpline Guidelines Group. (1995) *Telephone Helplines – Guidelines for good practice:4. (2nd ed.)*. Windsor Print Production.

Further Reading

A copy of the full project report can be downloaded from the Foundation of Nursing Studies website: www.fons.org/ahcp/completedprojects/arthritis.asp

Acknowledgements

To the Foundation of Nursing Studies for supporting the implementation and dissemination of this project including funding for the project nurse time.

To Arthritis Research Campaign for funding Dr Hewlett's academic post.

To the United Bristol Healthcare Trust for encouraging all members of the multi-disciplinary team and the administrative support staff in rheumatology to participate in this project, by making their time available.

To the Freemasons' Grand Charity for supporting the dissemination of this project.

How to reference this report

Hewlett, S. (2005) Implementation of patient-initiated review in rheumatoid arthritis. In Shaw, T. and Sanders, K. (Eds) *Foundation of Nursing Studies Dissemination Series*. Vol.3. No. 3.

The Foundation of Nursing Studies Dissemination Series

ISSN 1478-4106
 Editors: Theresa Shaw and Kate Sanders
 32 Buckingham Palace Road
 London SW1W 0RE
 Tel: 020 7233 5750
 Fax: 020 7233 5759
www.fons.org
 Reg. Charity No 1071117