



Benefits of patient pathways in rheumatoid arthritis care

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Rheumatoid arthritis is a painful, inflammatory, chronic condition that often results in irreversible joint damage. This article uses the condition to highlight the benefits of patient pathways and illustrate how they can be developed.

Rheumatoid arthritis (RA) is associated with a significant social and economic burden. Each year it is responsible for 1.9 million GP consultations and 45,887 hospital admissions (Office for Health Economics, 2001; Department of Health, 2000). Around 40,000 adults in the UK are estimated to have RA and the condition accounts for more than nine million lost working days per year, representing an annual production loss of £833m (Department for Work and Pensions, 2005). Women are almost three times as likely as men to contract the disease, with the risk of onset increasing with age (Arthritis Research Campaign, 2005; Dieppe, 1985). The precise aetiology of the disease remains unclear but genetic and environmental factors are thought to play a prominent part.

The principal aims of treatment are to control pain and to reduce swelling and long-term joint damage. Failure to achieve this can have a devastating impact on an individual's quality of life as persistent disease activity is associated with poorer disease outcomes and shorter life expectancy (Mikuls et al, 2002; Pincus and Callahan, 1993). In recent years it has been recognised that management strategies should be aggressive, comprising both prompt interventions and proactive management (British Society for Rheumatology, 2005; Emery et al, 2002).

This therapeutic urgency means that, in keeping with many other chronic diseases, RA management would benefit from efficient, tailored, nurse-driven care. The aim of this article is to explain how such care strategies can be implemented through nurse-led patient pathways and demonstrates the vital elements for successful pathway delivery.

Patient pathways

Patient pathways are a way of setting out the expected step-by-step process that a patient is likely to experience in their healthcare 'journey'. Events

such as assessments, consultations, treatments, lifestyle changes, disease education and hospital visits are mapped on a timeline, an approach that essentially explains exactly what is likely to happen at each stage of the care continuum.

The planning of a patient pathway makes the whole disease process simple for patients and carers to comprehend. It also allows health professionals, patients and carers to agree short and long-term goals that allow them to tailor care according to the individual's disease process and circumstances.

Patient pathways should be an essential tool for patients with RA. As in many other chronic diseases, the success of RA management largely depends on the transparency of the process and the clarity of the treatment options. This enables the patient to become an informed and active participant in the decision-making processes. Clearly if the patient recognises the goals, treatment options and likely obstacles from the outset this will improve the likelihood that the care will be successful.

Patient referral plan

Patient pathways are becoming an integral part of the modern NHS. In October 2005 the DH issued a discussion document to promote the advantages of an 18-week patient referral plan. This pathway, which covers the period from referral to initial treatment, was successfully piloted throughout 2005 and is set to become a universal NHS access target by December 2008.

The principles of planning healthcare provision around transparent patient journeys have also been supported by the NHS Modernisation Agency. The agency noted that by following a patient's healthcare journey, one can clearly demonstrate the difference between targeted standards and guidelines, and the reality of unnecessary waits and inappropriate referral pathways (NHS Modernisation Agency and DH, 2005a).

There are important healthcare agendas that support a greater decision-making partnership between patients and providers. These include:

- Creating transparency and equity of care – helping patients to understand why some treatments have not been offered (for example if they are excluded by treatment-specific NICE criteria);
- Improving patient self-management – building upon the principles of encouraging informed decision-making and allowing patients to consider

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treatment options with family and friends (DH, 2003; 2001);

- Reducing unnecessary risks – developing process clarity for practitioners who may not have specific expertise but provide additional non-specialist care interventions (DH, 2005a).

Nurse-led pathways

The ultimate RA pathway should help patients gain access to the most appropriate evidence-based care as and when it is needed. As an advocate of the patient, the nurse has a pivotal role in developing a pathway that achieves this principal criterion. It is therefore vital that the nurse spends time understanding the unique, individual needs of the patient and that these requirements form an integral part of the treatment negotiations. These include:

- Overall knowledge of the disease;
- Likely outcome if the disease is untreated;
- Cultural beliefs about the condition and its treatment options;
- Prior knowledge and expectations concerning treatment efficacy;
- Associated treatment risks;
- Treatment side-effect profile;
- Tolerability alongside concurrent medications
- Fears surrounding drug administration (such as needle phobia);
- Physical ability to take the medication (for example patient dexterity);
- Route of administration;
- Beliefs of significant others.

In order to meet these needs as fully as possible, several key elements must be satisfied.

Underlying health beliefs

Nurses will need to gain an insight into a patient's perceptions of their disease, as these beliefs can profoundly affect any health-related patient decisions. Patients will compare the information they are given with their own underlying health beliefs. As a result, if the discrepancy between the two stances is substantial, the patient may become dissatisfied with their management plan and will be unlikely to comply (Donovan and Blake, 2000).

Consider the following patients, who have just been told that they have RA.

Patient A

'My joint pain appeared overnight but I just need to wait a few weeks and it will quickly go away again. It's probably related to the stress I've been under with my job.

'I've already made a decision to take some time off work and seek some complementary therapies to regain my immune system balance. I don't take prescription drugs – they are dangerous and damage your immune system.'

Patient B

'I have been worrying for so long about what was happening to me. All sorts of things have been running through my head. Now I have a name for my condition I just feel relieved.

'I want you to tell me as much as you can about the disease and the available treatments. I just want to know as much as possible so that I know what to expect and what to do.'

These markedly different reactions to the diagnosis of RA arise from the patients' contrasting health beliefs and coping styles. Patient B is clearly relieved to have been given a definitive diagnosis and now wants as much information as possible, while Patient A is in denial over having the condition and also has some views about conventional medicines. Patient A

BOX 1. BENEFITS OF THE PATIENT PATHWAY APPROACH

The benefits of delivering a successful patient pathway are numerous and varied. A successful patient pathway should:

- Increase patient concordance;
- Improve the agreed long-term outcomes;
- Achieve a transparent and informed consent process;
- Reduce the potential for litigation;
- Increase patient awareness of ongoing issues and allow goal sharing between patients, partners and family members;
- Improve the patient-provider relationship;
- Increase patient motivation and self-management principles;
- Enable patients to feel in control of their disease;
- Enable patients to make important healthcare decisions;
- Reduce the likelihood of unnecessary hospital admissions;
- Increase patient/carer satisfaction;
- Allow a streamlined and transparent process that guides all practitioners throughout the continuous care pathway;
- Improve communication between primary care, secondary care and community-based health professionals;
- Minimise delays in the delivery of essential healthcare services;
- Improve care coordination.

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- For related articles on this subject and links to relevant websites see www.nursingtimes.net

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BOX 2. STEP-BY-STEP GUIDE TO DEVELOPING A SUCCESSFUL PATIENT PATHWAY

Scope current service issues	<ul style="list-style-type: none"> Do the management have a process-mapping project under way? Find out more about it. Review key documents in process-mapping and seek local expert support if available. Work with the full multiprofessional team.
Seek management and clinical manager support	<ul style="list-style-type: none"> Collate any evidence you might have about the current service provision and patient pathways. Seek consent to undertake a scoping exercise of the patient support elements of public and patient liaison groups.
Process mapping	<ul style="list-style-type: none"> Full guidance is available from www.modern.nhs.uk. Clinicians, managers and patients should review the results and plan agreed referral points and points of patient contact/care.
Developing individual patient pathways	<ul style="list-style-type: none"> The agreed pathway should be based upon guidelines and standards. However, it must also be tailored according to the patient's individual nursing support/management needs. Some of this work will be supported by clinical management plans, monitoring regimes and local treatment policies.
Nurse consultation with the patient	<ul style="list-style-type: none"> Review patient knowledge of their disease, treatments and current healthcare needs. Discuss treatment options and key standard points of care as agreed with the multiprofessional team. Discuss clinical management plans, identify any individual-specific needs and negotiate the next few steps of the journey. Document planned next steps in notes and on patient-held records using clear, agreed time frames. Support discussions with patient information leaflets and additional resources as appropriate (for example video).

will need an additional level of support to enable effective management of the condition and coming to terms with the diagnosis. Patient A may also be resistant to taking conventional medications or may simply need more time to understand the beneficial role of treatment in reducing long-term damage. The pathway should therefore be adapted accordingly.

Patient empowerment

Healthcare professionals play a small yet vital part in supporting individuals with chronic conditions. Most of the time patients manage their condition independently within their own home-based environment, with the support of friends and family. Any management pathway should therefore provide the necessary resources to empower patients to manage their condition themselves.

Patient empowerment is the key to good practice. Provided with the vital tools of information and education, the majority of patients will make informed choices and develop their own self-management expertise. They therefore become an 'active participant' in their own healthcare.

The best sources of patient information are factual and concise. They include:

- Professionally endorsed information leaflets and websites (such as the Arthritis Research Campaign at www.arc.org.uk);
- Websites of patient groups (such as the National Rheumatoid Arthritis Society at www.rheumatoid.org.uk);
- Dedicated telephone advice lines;
- Peer-reviewed journals (depending on intellectual capabilities).

To empower patients nurses must provide:

- Open, honest and factual consultations;
- Adequate clinic facilities/time to explore issues;
- Best-practice treatment options;
- Guidance on potential risks and benefits;
- A clear opportunity for the patient to voice their own opinions;
- Tailored information to alleviate specific patient issues/concerns (for example education leaflets, website forums, self-help group details, dedicated advice lines).

Effective communication

Effective nurse-patient communication is vital if the patient is to fully 'buy-in' to their chosen pathway. The first encounter with the patient may set the

pattern for the therapeutic relationship. If we 'lose' the patient at the beginning, it may take some time before an effective working relationship can be established (Ryan et al, 2003).

Part of setting the right level of support at the beginning of the therapeutic relationship is to ensure that information is provided in a way that the patient fully understands. In some cases, individuals may have no prior knowledge of the condition, whereas others may have memories of a relative with a similar disease.

For those who have researched the condition via the internet, it is important to ascertain whether the chosen websites have provided accurate, credible and up-to-date information. If not, guidance should be promptly provided in order to correct any misunderstandings.

Continual improvement

Trust between nurse and patient will usually take time to develop. Nurses should always be open to the patient's viewpoint, because if an individual believes that their opinions are not being respected they can express their disillusionment by choosing not to take their medication or not attend their next consultation, for example. Such a reaction, of course, may have an adverse effect on their long-term prognosis.

A patient pathway must be able to evolve because the patient's needs may vary along the way. A good patient pathway will always take into account evolving issues that may arise from changes in the patient's condition, personal needs or treatment options.

Case study

Betty Baker (not her real name) lives alone in a small terraced house near to her frail mother whose care she supports. She works part time in a local department store and apart from a diagnosis of RA she is otherwise healthy. She attends the local district hospital for routine follow-up appointments but has no planned patient pathway. Her RA is well controlled on sulphasalazine.

When Mrs Baker recently moved into the area her care was transferred from another specialist unit and she has therefore not been part of the hospital's structured patient education programme. She is unaware of our nurse telephone advice line and has not had information about treatment options and monitoring programmes.

Following a chest infection that was treated with antibiotics she has had increasingly painful joints. Infections are known to cause flare-ups in RA. However, Mrs Baker was unaware of this and did not seek help as she thought that she must simply 'struggle on'.

Eventually she attended her surgery where

blood tests were taken and revealed high levels of CRP (C-reactive protein) and raised ALT (alanine aminotransferase). Her GP stopped her sulphasalazine and prescribed a one-week course of oral steroids and tramadol for the pain. He referred her for urgent review by the rheumatologist and respite care was organised for her mother.

After two weeks Mrs Baker's functional abilities had deteriorated and she was taking NSAIDs to supplement her tramadol. Poorly controlled pain and poor appetite had led to weight loss and general fatigue. She was admitted to hospital by her GP.

This hospital stay triggered inclusion in a patient education programme for people who have RA, which provided information to allow Mrs Baker to make some informed decisions about her treatment and agree a pathway for her care. She commenced treatment with methotrexate and naproxen and is now booked into the nurse clinic for assessment and support.

It can be seen from this case study that the healthcare Mrs Baker received could have been much improved. The development of a patient pathway at the outset of service provision would have significantly enhanced her healthcare experience. It would have enabled Mrs Baker to identify early that she was experiencing a flare-up of her RA and she would then have been able to receive advice via the patient helpline and/or attend the rapid-access RA clinic. This may have prevented her hospital admission.

Conclusions

Although negotiating an appropriate, tailored pathway requires an initial, additional investment of time, it has the potential to bring about numerous, long-term benefits in patients with chronic RA. These include (DH, 2005b):

- An improved patient experience;
- An informed and concordant patient;
- Simplicity, clarity and transparency of the healthcare process;
- Treatments that are safe, efficacious and well-tolerated;
- Efficient multidisciplinary working;
- Cost-effective care provision;
- Improved long-term prognosis;
- Risk reduction.

About 12,000 new cases of RA are being diagnosed in the UK every year (Symmons et al, 1994). As patient advocates, nurses are uniquely placed to help individuals manage their condition and make informed treatment decisions. It is imperative that patients are involved in their own pathway planning, and that all consultations are open and transparent. This will enable them to voice their anxieties and preferences, and ensure that their evidence-based pathway respects their needs. ■

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