Editorial

Is it ever appropriate to discharge patients with rheumatoid arthritis?

Once upon a time there was a British rheumatologist who thought that he ran a very good outpatient service. When it came to determining when and whether to follow-up a patient, he made a judgement based on two factors:

(i) How bad the patient's ongoing musculoskeletal problem was, and

(ii) The availability of clinic slots.

Now this rheumatologist had been lucky, because when his post started a few years ago, it was a brand new job. Consequently, he was able to slot patients in for review very flexibly. However, his workload had built up; each year added another 50–80 patients with inflammatory arthritis that needed specialist supervision. Available review slots were becoming more distant, even though he tried to discharge as many patients as he could. When he audited his new patient attendances he confirmed that most non-inflammatory joint problems were dealt with on a 'one-stop' basis and it was patients with inflammatory joint disease who required follow-up. He tried to resist over-booking clinics, but there was pressure to maintain the throughput of new patients, and some review patients were not well and needed to be seen frequently. The rheumatologist felt increasingly uncomfortable about the quality of service he was able to provide, and his ability to cope with what seemed an ever increasing clinical workload. This was made worse by a growing body of patients who seemed to find it easier to see him than their primary care physician in an emergency.

As if this was not bad enough, he now found that new pressures were emerging:

(i) Payment by results. This system of healthcare financing ensured that his hospital, received money for each outpatient attendance. The local purchaser, or Primary Care Trust (PCT), was under pressure from government to keep patients in the community, and did not want to pay for follow-up appointments if these could be avoided, as its budget did not cover all its expenditure. It was requesting that his department came into line with another rheumatology department that had a much lower new to follow-up ratio. To achieve this he would have to stop seeing half of his follow-up patient cohort altogether. As only 8% of his follow-up patients had non-inflammatory joint disease this meant, effectively, that he would have to discharge most of his patients with RA, even though he was seeing a fair proportion of these once a year—the recommended minimum in his national guidelines.

(ii) Practice-based commissioning. One or two local primary care physicians (PCPs) who labelled themselves as 'dynamic' (though the rheumatologist felt 'aggressive' might be more appropriate) had murmured that they felt too many patients were being followed up inappropriately in rheumatology, and that they could provide just as good a service at a much lower cost. After all, they said, diabetes management was increasingly being done in primary care. They were also threatening to contract with alternative suppliers—either from their own numbers (PCPs with a special interest) or from private providers, both individuals and private hospitals. There did not seem to be any clinical reason for this, merely a suggestion that it would save money by avoiding paying the tariff.

(iii) Unfortunately, some academic colleagues were not helping our rheumatologist. They were publishing evidence that a flexible service where patients could attend simply when they perceived they had a problem had many advantages over traditional regular follow-up. As follow-up would be on demand it only seemed likely to be less frequent than a traditional service. Needless to say, the PCTs, Hospital Trusts and 'dynamic' PCPs were all quoting this sort of literature liberally in their arguments. In some cases, the expected reductions in caseload, usually from enforced quotas, had resulted in a failure to replace retiring consultants.

You may sympathize with our rheumatologist. If you work in the UK you may feel that you are that rheumatologist; if not, you are probably astonished by the whole scenario. Given the follow-up workload for most rheumatologists comprises inflammatory arthritis, and largely RA [1], a relevant and topical question is 'Is it ever appropriate to discharge a patient with RA from specialist supervision?' Indeed, given the financial pressures in the National Health Service, UK, it is a necessary question.

We have, therefore, examined current practice and research in inflammatory joint disease.

(i) Does RA go into remission?

With early detection and aggressive interventions, the management of RA has never been better. However, early inflammatory arthritis clinics have identified that spontaneous drug-free remission is rare [2]. In the pre-biologics era, two studies estimated that 5–7% of early RA patients will go into sustained remission with or without disease-modifying anti-rheumatic drug (DMARD) therapy [3, 4]. It has also been argued that patients with self-limiting disease might have a separate disease entity from 'true' RA [5]. It may be that, having become established, RA is always persistent and requires ongoing aggressive treatment. With the advent of combinations of conventional and biological drugs, it has been suggested that up to 20% of patients may go into sustained remission, and this should be achievable in current clinical practice [6]. The Tight Control of Rheumatoid Arthritis (TICORA) study demonstrated that in the short-term, substantially higher rates of remission could be achieved with close monitoring of disease activity and rapid interventions [7]. Even tolerating low levels of disease activity is not as satisfactory as aiming for remission in terms of functional abilities on HAQ scores [8] or X-ray progression [9]. Recent studies have demonstrated that even in patients fulfilling remission criteria, MRI can demonstrate ongoing active synovitis [10] and X-rays may still show progression [11]. As yet we cannot easily predict which patients will go into sustained remission—or which may have multiple drug side-effects—although there are some pointers such as anti-CCP antibody status [12].

What can we conclude from this? The evidence to date suggests that spontaneous remission in RA is rare, if it occurs at all. As a consequence, patients need ongoing disease-modifying drugs. We should be aiming to get patients into remission with these regimes, because even low, sub-clinical disease activity can be associated with disease progression. All of these require careful supervision and assessment. Most of our patients will require drug regimes that generalists would not be qualified to monitor for either efficacy or toxicity. On these grounds alone, no RA patient should lose touch with a secondary care team.

(ii) Is quality of care for rheumatology as good in the community?

Data from the Norfolk Arthritis Register, a primary care-based register, have shown that (a) inflammatory polyarthritis is...
(b) severe disability can be predicted easily in the community in early disease and (c) most patients have a HAQ score of $>1$ after $1$ yr [13]. Tight and aggressive control has also been shown to be effective in a variety of reports, especially in early disease [14–16]. In established disease, tight control does influence outcome [7]. For both recent onset and established disease, aggressive therapy and regular monitoring is required.

A number of studies from Canada have addressed the quality of care of RA in the community. It was found that in community-treated patients, demand for care was high with five primary care and six rheumatology visits per annum [17]. Although this does not directly parallel practice in the UK, it shows that RA patients in the community do demand regular, ongoing care. A further study has compared community with hospital care and found better clinical outcomes in the hospital population [18]. Another survey of prevalent cases has shown that access to a rheumatologist increased the use of DMARDs 31-fold [19]. These data raise the concerns that RA in the community is not benign and is likely to be undertreated by non-experts, providing evidence that all RA should be treated in conjunction with secondary care.

(iii) Is it cheaper in the community?

Much of the push towards community care in the UK is based on the premise that it is cheaper. A UK study of PCPs with a specialist interest in dermatology showed that they were more expensive than consultants [20]. Furthermore, there is evidence that the presence of PCPs with a special interest may merely unmask unmet need and result in an increase in referrals to specialist care [21]. In an American study of 249 patients with RA followed over a 5-yr period, there was no difference in cost between those either followed-up or not by a rheumatologist [22]. An economic analysis from the British Rheumatoidcide Outcome Study Group compared hospital care (with protocols to determine interventions for active disease) with shared care (annual hospital review, with PCP disease monitoring between) [23]. Hospital care was cheaper over 3 yrs than shared care (£4450 vs £4540, £6571 vs £6704) with similar gains in quality-adjusted life years (QALYs) (1.60 vs 1.67). Treatment interventions were similar in the two groups, with the hospital care group frequently deviating from protocols. It is likely that if the study was repeated now, more aggressive interventions in the hospital arm would lead to higher QALYs. Even if this is not the case, it should be remembered that the shared-care arm still had an annual hospital-based review, so that care was by no means exclusively in the community. In an American cost analysis of quality of care [24], it was found that care that included specialists was of a higher clinical and economic quality.

A further proposal is to move specialists ‘into the community’, placing them in PCP surgeries and removing them from a traditional hospital setting. Some so-called community rheumatology posts have been established but there is a widespread concern that it may divorce specialists from their multidisciplinary teams, colleagues in other relevant specialties and from investigative facilities. Furthermore, the Roland report on Outpatient Services and Primary Care concluded that the tactic was largely ineffective, and where hospital-based outpatient provision was satisfactory, moving to the community would decrease effectiveness and efficiency of the service [25]. The report also challenged the concept that community care is cheaper, and found examples where this is frequently not the case. The supposition that transferring care to the community will not increase overall demand is also met with scepticism. It highlighted other areas of concern. Transferring minor surgery to primary care was associated with reductions in quality and safety. Financial incentives designed to discourage outpatient referral were effective, but risked reducing necessary referrals. These conclusions have significant consequences for future rheumatology services, and the Roland report needs to be considered in any reconfiguration.

In conclusion, we have no evidence that care provided in the community is cheaper than hospital care, and the opposite may be true. Given concerns about the quality of care, we find no sound argument for moving care out of hospitals.

(iv) Can PCPs access the multidisciplinary team?

In a Canadian study looking at the management of RA in primary and secondary care, it was found that rates of referral to members of the multi-disciplinary team were lower amongst primary care physicians [26]. An American study has demonstrated that access to healthcare is more geared towards acute services and that RA and osteoarthritis are neglected [27]. Data from the UK are sparse, but in the experience of the three authors of this editorial, access to and use of a multidisciplinary team (as opposed to access to disparate individual elements, such as physiotherapy) by primary care is poor. Community physiotherapy may be provided by individuals who are not in touch with modern developments and may not always possess the expertise to address the problems of musculoskeletal disease.

(v) Should patients be followed up ‘on demand’?

The traditional model of follow-up is to see RA patients on a regular basis, with frequency determined by disease activity and clinic availability. This approach has been challenged, particularly with long-term follow-up studies from Bristol, UK. A group of patients randomized to patient-initiated follow-up as opposed to regular clinics has now been followed up for 6 yrs [28–30]. Patients randomized to this group requested fewer appointments, found direct access more satisfactory, and had a third fewer appointments. However, this approach did not appeal to everybody. Of 302 patients approached, only 209 agreed to be randomized. Patients not wanting to participate were significantly older and more disabled.

In order for this model to work, safety nets are required to contact patients who have not been in touch with the service for some time (which the Bristol unit has in place), and patients need to be able to identify active disease quickly. Data from Birmingham, UK indicate that in early disease, patients can delay access to both primary and secondary care as they fail to recognize the disease [31]. Additionally, many studies, including one from the Bristol group, have shown that patient self-assessment can differ from physician assessment of disease considerably [32–35]. This would seem to indicate that an ‘on demand’ service might miss some patients who consider their disease well controlled and who need access to changes in DMARD therapy. However, the flexibility for patients has much to commend it, retains contact with secondary care and might be built into some services for those patients for whom this style of follow-up is suitable. It is particularly suitable for the management of acute flares and may well be layered over a regular, less-frequent review. However, from the viewpoint of a Primary Care Trust that is endeavouring to ‘cap’ follow-up appointments, a patient-initiated follow-up system is anathema, as it removes all control from the primary care refererrer.

(vi) Is clinical research still worthwhile in the UK?

The development of the British Society for Rheumatology/Arthritis Research Campaign (arc) Clinical Trials Unit was designed to facilitate the development of clinically based research. Many trials have been conducted in the UK on a multi-centre basis; much valuable information has emerged from collaborative organizations such as the Early Rheumatoid Arthritis Network (ERAN) and from large registers (for instance, the Chingford Study). These have expanded the UK research base out of teaching centres, thus including and maintaining the research interests of many specialists who would otherwise not have the opportunity. Dismantling large swathes of specialist provision would undermine this; indeed it would set back inflammatory...
Conclusion

A review of current practice and evidence indicates that patients with RA, irrespective of perceived disease activity, should still be monitored by a multidisciplinary specialist service. Some patients could be managed using open access. However, a minimum of annual review of all patients is a pragmatic and safe way to monitor disease. Wholesale transfer of care out of the hands of specialists into primary care has no evidence for cost saving, and raises grave concerns about the impact on quality of care. Changes in service provision must also take into account the needs of rheumatology service providers elsewhere in the world who have been subjected to the same pressures as a cancer service. We are not aware that any rheumatology services in the country are not a benign disease: predicting functional disability one year after presentation. J Rheumatol 1996;23:1326–31.

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References