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letters to the editor

Safety monitoring for disease-modifying anti-rheumatic drugs in primary and secondary care: adherence to local and national guidelines and patients' views

Sir, We were aware that our safety-monitoring requirement for disease-modifying anti-rheumatic drugs (DMARDs) had grown enormously (from 10% of RA patients in 1984 to 80% in 1994), without additional resources, and may no longer have met the patients' needs. We therefore undertook a survey to describe adherence to recommended monitoring intervals for DMARDs in primary and secondary care, to examine patients' views and experiences of DMARD information and monitoring systems and their preferences for change. A questionnaire was sent to the 1838 adult patients prescribed DMARD therapy for a variety of diagnoses from one hospital, addressing these questions.

Response rate was 1251/1838 (68%) after two mailings. Methotrexate and sulphasalazine were by far the most common drugs to be taken (536 and 351, respectively), with smaller numbers taking leflunomide (86) or myocrisin (73), and fewer than 40 each taking hydroxychloroquine, azathioprine, penicillamine and cyclosporin. The majority of patients had a diagnosis of RA, and the sex ratio was 3 female to 1 male. Over 80% of patients could recall being given information about their DMARD therapy and similar numbers could describe appropriate potential adverse reactions; 73% specifically recalled being given an information leaflet about their medication; 88.8% felt the level of information given was 'about right', with 1.9% describing the information as 'too much' and 9.4% 'too little'. Those feeling they had received too little information were less likely to recall receiving a leaflet (P < 0.0001), but were no more or less likely to identify appropriate potential adverse effects. The most common sources of information were a hospital doctor, a nurse or the GP, with perhaps surprisingly few recalling being given information by a pharmacist.

A total of 121 patients (10.9%) appeared to fall outside local recommended monitoring intervals. More patients describing themselves as having monitoring supervised in hospital were non-adherent to guidelines (13.4 vs 6.1%, odds ratio 2.52, 95% confidence interval 1.57, 4.06, P < 0.0001). All patients taking leflunomide were within recommended guideline intervals, whereas the drug with the highest rate of non-adherence was penicillamine. This may reflect small numbers, or, given that penicillamine therapy is rarely initiated these days, complacency with treatment taken for many years.

Usually, 60.3% of patients were monitored in hospital; 448 (37.2%) were monitored at the GP surgery and 30 (2.5%) somewhere else, for example at their place of work (one patient is a GP and two others work in hospitals) or at home. Patients were asked where, if they had the choice, they would prefer to have their blood tests for monitoring taken; 39.2% chose hospital monitoring, 56.2% the GP surgery and 3.9% somewhere else. Interestingly, only 17 patients (3.9%) would choose to change from primary care to hospital monitoring, whereas 240 (34%) of those monitored in hospital would prefer to have their monitoring undertaken at the GP surgery. It should be noted that the majority of patients have monitoring initiated in the nurse-run clinic at the hospital, so that those patients monitored in primary care have some experience of the hospital monitoring service, whereas few of those monitored in hospital will have direct knowledge of primary care monitoring. A variety of reasons were given for the patients' choices. Those choosing hospital monitoring were likely to cite specialist knowledge, friendly staff and a rapid route for sorting out any problems among reasons for their choice, whereas convenient access, friendly staff and a reduced need for time off work were reasons for preferring monitoring at the GP surgery.

We asked patients whose responsibility they thought it should be to organize monitoring appointments. Opinions were fairly evenly split between the responsibility lying with the rheumatologist (42.4%) and the patient themselves (40.7%), with fewer attributing responsibility to their GP and very few to a nurse. This was surprising given the central role of nurses in DMARD monitoring.

This study demonstrates that large numbers of patients are currently prescribed DMARDs, generating a high workload. Adherence to monitoring intervals recommended by local guidelines is higher than previously found [1, 2], but there is room for improvement. We have not studied the actions taken in response to monitoring results received, but can demonstrate that those supervising monitoring in the majority of these patients are in a position to identify safety problems. It is of interest that adherence rates are higher in primary than secondary care. It is possible that patients who have no regular monitoring arrangements would be more likely to identify themselves as hospital patients rather than primary care, or it may be the case that primary care systems of call-and-recall, as used for immunizations and cervical smear testing, are more efficient than those in hospital. Monitoring in primary care was at least as safe and acceptable to patients as secondary care-based services, and many patients see themselves as responsible for organizing their own care.

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