Concise Report

Delay in presentation to primary care physicians is the main reason why patients with rheumatoid arthritis are seen late by rheumatologists

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Objectives. To study the delay from the time of symptom onset to assessment by a Rheumatologist in patients with rheumatoid arthritis (RA) and to determine the contributions of patient and physician dependent factors to this delay.
Methods. Data were collected from 169 consecutive patients with RA at the time of assessment by Rheumatologists working in hospitals serving an inner city population in Birmingham, UK. Dates were recorded for: (i) onset of inflammatory joint symptoms; (ii) initial assessment in primary care; and (iii) referral from primary to secondary care. (iv) initial assessment by a rheumatologist in secondary care.
Results. The median delay from the onset of symptoms to a patient being assessed in secondary care was 23 weeks (IQR 12–54 weeks). The median delay before the patient was assessed in primary care was 12 weeks (IQR 4–28 weeks). For 96 patients (57%) more than half of the overall delay in assessment in secondary care was accounted for by a delay in assessment in primary care.
Conclusions. Patient dependent factors, leading to a delay in consulting primary care physicians, are the principal reasons for the delay in patients with RA being seen by Rheumatologists in our population. A considerable body of evidence demonstrates that the earlier that therapy is introduced the better the clinical outcome. Consequently it is important to understand why some patients with RA delay in seeking medical advice, in order to allow effective interventions to reduce this delay.

KEY WORDS: Rheumatoid arthritis, early arthritis, diagnosis, delay.

Introduction

The window within which Rheumatologists aim to treat patients with newly presenting rheumatoid arthritis (RA) has been narrowing since the 1980s [1]. Increasing numbers of drugs are becoming available, which are relatively safe and highly effective at controlling synovitis, especially when given early in disease [2,3]. In addition, we are now able to predict with a high degree of specificity, which patients with very early synovitis will develop RA [4–6]. Consequently, we can now intervene in a useful and targeted way in patients with early synovitis [7].

In order to intervene early, Rheumatologists need to see patients early. In the 1980s the median delay from symptom onset to referral from primary to secondary care for patients with RA was over 20 months in a teaching hospital in Glasgow, UK [8]. This delay is dependent on two factors; the time taken for patients with symptoms to consult their General Practitioner (GP) (patient-dependent factors) and the time taken for GPs to refer to Rheumatologists (physician-dependent factors). Over the last 20 years the education of GPs and the shortening of out-patient waiting times for the patients with new onset synovitis have led to dramatic reductions in physician delays. Between 1994 and 1997 the median time from symptom onset to GP referral was 4 months and from GP referral to hospital clinic appointment was 1 month, in Glasgow, UK [8]. However, the length of time from the onset of symptoms to the patients first presenting to their GPs has not been adequately addressed. As part of an audit addressing the delay in patients with RA presenting to Rheumatologists, we captured data on the length of time patients with RA waited before consulting their GP.

Method

We surveyed consecutive patients in whom the assessing Rheumatologist made a diagnosis of RA and who were seen for initial assessment in Rheumatology clinics of Sandwell and West Birmingham Hospital NHS Trust between January 2004 and June 2006. All patients were assessed by a consultant Rheumatologist. The NHS Trust in which this survey was conducted serves an ethnically diverse inner city population of approximately 400 000. The Rheumatology department operates a rapid access early arthritis clinic in which patients who are referred with symptoms of less than 12 weeks duration are seen within 2 weeks of referral. This clinic has been actively promoted to local GPs for several years through local meetings and regular newsletters.

Data were collected during the clinic visit from all the patients in whom a pragmatic clinical diagnosis of RA was made. Patients were not required to fulfil ARA classification criteria for RA to be included. However, data on the number of ARA classification criteria that each patient fulfilled were collected [9]. Patients in whom the GP had made a diagnosis of RA and had commenced a disease-modifying anti-rheumatic drug (DMARD) were excluded (only one such patient was seen over the 30 month period).

To establish the reasons for the delay in assessment by a Rheumatologist we captured information on delay at the following levels: (i) from the onset of symptoms to a patient being assessed in primary care (the onset of symptoms was defined as the time the patient first developed new symptoms which the assessing Rheumatologist later ascribed to inflammatory arthritis); (ii) from the initial assessment in primary care to a referral to secondary care being made; and (iii) from the referral to secondary care to the patient being seen in secondary care. In addition the patient's gender and age were recorded. Data on the rheumatoid factor status were subsequently extracted from the clinical notes. The data presented in this manuscript were collected as part of a clinical audit. The protocol for this audit was reviewed and approved by the Chairman of the Local Research Ethics Committee (Sandwell and West Birmingham Research Ethics Committee).

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Data are presented as the median values and interquartile range (IQR). Numerical variables were compared using the Mann–Whitney test. Spearman's test was used to assess the correlation between variables.

Results

We captured data from 169 patients. Out of them, 105 were female (62%). The median age was 58 years (IQR 47–69 yrs). Rheumatoid factor had not been measured in one patient and was positive in 123 patients (73%). 168 patients fulfilled ARA classification criteria for RA and one did not (fulfilling only 3 of the 7 list criteria).

The median delay from the onset of symptoms to a patient being assessed in secondary care was 23 weeks (IQR 12–54 weeks) (Fig. 1). Only 30% of patients were seen in secondary care within 12 weeks of the onset of inflammatory joint symptoms. The median delay before the patient was assessed in primary care was 12 weeks (IQR 4–28 weeks) (Fig. 1). Delays in referral to secondary care after the patient had been seen in primary care (median 2 weeks, IQR <1 to 10 weeks) and in the patient being seen in secondary care after referral from primary care (median 3 weeks, IQR 2–8 weeks) accounted for a much smaller proportion of the delay (Fig. 1). For 96 patients (57%) more than half of the overall delay in assessment in secondary care was accounted for by a delay in assessment in primary care. There was no correlation between patient age and the time to assessment in primary care (Spearman rho = –0.08) and no difference between men and women in the time to assessment in primary care. There was a greater delay from symptom onset to assessment in primary care in patients who were rheumatoid factor positive [median delay 13 weeks (IQR 4–52 weeks)] compared with patients who were rheumatoid factor negative [median delay 4 weeks (IQR 3–14 weeks)] ($P=0.011$).

Discussion

A considerable body of evidence supports the concept that the earlier that DMARD therapy is initiated in patients with RA the better the outcome is likely to be. The diagnosis of RA and the initiation of DMARDs usually occur in a hospital-based setting. Consequently it is important to establish those factors that explain the delay between the onset of inflammatory joint symptoms and a patient being seen in secondary care. Several studies have looked at the lag time between the onset of symptoms and access to Rheumatology care in patients with RA [8,10].
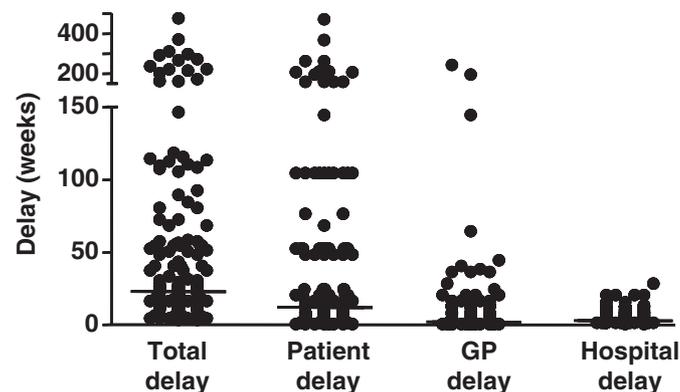

FIG. 1. The delay in assessment of patients with rheumatoid arthritis in secondary care. Total delay (weeks from the onset of symptoms to assessment in secondary care) is composed of patient delay (weeks from the onset of symptoms to assessment in primary care), GP delay (weeks from assessment in primary care to referral to secondary care) and hospital delay (weeks from referral from primary care to assessment in secondary care). Median values are shown (horizontal lines).

Irvine *et al.* [8] identified that the main delay occurred between the onset of symptoms and referral from primary care. Those factors that explain why GPs may delay in referring appropriate patients to secondary care have been studied [11]. However, the delay from the onset of symptoms to the referral to secondary care is composed of two elements: firstly a delay on the patient's behalf in seeking medical advice and secondly a delay on the GP's behalf in referring the patient. In our study the majority of the delay was accounted for by the delay before the patient was assessed in primary care. There are clearly two potential components to this. The first is the delay before a patient seeks an appointment with a GP and the second the delay whilst the patient is waiting for this appointment. We did not specifically collect data on these two components. However, given the short waiting times for assessment in primary care in the UK it is highly likely that the majority of the delay before the patient was assessed in primary care was as a result of a delay in the patient seeking medical advice. There were no statistically significant relationships between this delay and patient gender and age. Surprisingly, rheumatoid factor positivity was associated with a greater delay from symptom onset to assessment in primary care. It is widely recognized that RA patients who are seropositive for rheumatoid factor have worse prognosis disease than those who are seronegative. Bukhari *et al.* [12] have reported that rheumatoid factor positivity is associated with the presence of erosions at initial assessment and the rate of progression of erosive damage. However, the relationship between rheumatoid factor status and disease activity at initial presentation is less clear with some studies having reported no correlation [13]. The explanation for the relationship between rheumatoid factor status and delay in assessment in primary care is unclear. However, this relationship was not being tested as an a priori hypothesis; consequently this result should be interpreted with caution.

Few other studies have addressed delay at the level of the patient presenting to primary care. In a study conducted in Ostfold County, Norway, the median delay on the part of the patient was 4 weeks (range 1–28 weeks) [14]. This is dramatically shorter than in our patient population. This difference may relate to socioeconomic and cultural differences in the populations studied and differences in public health campaigns that have operated in these countries. Interestingly the median GP delay was longer in the Norwegian study (8 weeks) than in our study (2 weeks) and this may relate to the education that has been provided to GPs locally in Birmingham as well as nationally in the UK.

Our study has several limitations. The data were collected as part of an audit of the delay in presentation to secondary care and not as part of a study to examine the causes of each component of the delay. Consequently data were not collected about a number of variables, including socioeconomic status, educational level and occupation, which may have had an impact on at least one of these levels of delay. The retrospective nature of the data collection meant that we were reliant upon accurate documentation at the time of data collection. The date of referral to secondary care and the date the patient was seen in secondary care could be recorded with absolute accuracy. However, we were dependent upon patient memory for the date of symptom onset and the date of initial presentation to primary care. Patients with an insidious onset of symptoms and patients with longer symptom duration frequently find it difficult to be precise about the date of onset of symptoms and often approximate these. This is likely to explain why patient delays of 52 weeks and 104 weeks, equating to an estimated duration of 1 and 2 years, are overrepresented in (Fig. 1). In addition, we were dependent upon the clinical judgement of the consultant Rheumatologist in determining when symptoms, which could be ascribed to a new onset of inflammatory arthritis, began. However, these limitations are inevitable in any study of the phase of disease before a patient has made contact with a health care professional.

In conclusion, in an inner city area in the UK the majority of the delay in assessing patients with RA in secondary care lay at the level of the patient seeking medical advice. Reducing this delay is essential to allow the early assessment of patients with synovitis and the early institution of DMARD therapy in appropriate patients. This delay can only be reduced if the reasons that underlie patients' decision making processes when determining whether to seek medical advice are understood. We are currently investigating this with the aim of devising education programmes that should reduce this delay in the future. With the development of increasingly more effective therapies for RA this will be an important public health measure.

Rheumatology key messages

- Patients with RA frequently delay for prolonged periods before seeking medical advice.
- Understanding the reasons for this delay is essential to facilitate a rapid diagnosis of RA being made.

Acknowledgements

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