Delayed diagnosis and treatment of rheumatoid arthritis in Sarawak General Hospital

Sharifah Aishah Wan, MBBS(Mal), MRCP (UK)¹, Cheng Lay Teh, MD(UKM), MRCP(UK)¹, Yaw Kiet Cheong, MD(UNIMAS), MRCP(UK)¹, Ahmad Tirmizi Jobli, MMed(Rad)(UKM)²

¹Department of Rheumatology, Sarawak General Hospital, Kuching, Sarawak, Malaysia, ²Faculty of Medicine and Health Sciences, UNIMAS

ABSTRACT

Introduction: Rheumatoid arthritis (RA) is an autoimmune systemic inflammatory disorder characterised by symmetrical polyarthritis which leads to damage of joints if untreated. Early diagnosis and treatment of RA to achieve tight control of the disease will improve outcome and prevent disability.

Objective: We aimed to examine the delays in the diagnosis of RA in patients presenting to the Rheumatology Unit, Sarawak General Hospital (SGH).

Methods: Data on demographics and various delays were collected from the medical records from January 2015 until March 2018. Patient delay is defined as from the time onset of symptom to the first primary care presentation. Primary care delay is defined as from the first primary care presentation to referral to rheumatology. Rheumatology delay is defined as from rheumatology referral to appointment at the rheumatology clinic. Disease modifying anti-rheumatic drugs (DMARDS) delay is defined as from the rheumatology clinic appointment to starting DMARDS. Total delay is from symptom onset to starting DMARDS.

Results: There were 84 new patients diagnosed with rheumatoid arthritis, out of which 66 were females (78.6%). The mean age was 54.1 ± 12.0 years. Only 19 patients (22.6%) were treated with DMARDS within 12 weeks of symptom onset. The median time for patient delay was four weeks (Interquartile range (IQR) 2-20 weeks), while the median time primary care delay was 11 weeks (IQR 4-24 weeks). The median time for rheumatology delay was zero weeks (IQR 0-1 week) and the DMARDS delay was zero week (IQR 0). The median time from symptom onset to DMARDS initiation was 23.5 weeks (IQR 13.25-51 weeks).

Conclusion: The delays in the diagnosis of rheumatoid arthritis were mainly from the patient and primary care.

KEY WORDS:

Rheumatoid arthritis, delay, diagnosis

INTRODUCTION

Rheumatoid arthritis (RA) is an autoimmune systemic inflammatory disorder characterised by symmetrical polyarthritis which leads to joint damage and disability if untreated. The estimated prevalence of RA is 0.5-1%.¹

Early diagnosis and treatment of RA with disease modifying anti-rheumatic drugs (DMARDS) will improve the outcome and eventually prevent disability. There is a 'window of opportunity' where treating the disease at an early phase may halt the inflammatory process and prevent progression to damage of the joints. The evidence for treatment at this 'window of opportunity' period is increasing, and many physicians are advocating early diagnosis and treatment.²⁻⁵ Patients need to be treated into remission, or at least low disease activity state to ensure an optimal outcome. The association between disease activity and radiological progression to damage in joints is already highlighted by various groups.^{6,7} Therefore, it is imperative that patients suffering from RA are diagnosed and treated early, and the treatment targeted to tight control of the disease to prevent irreversible damage of the joints. Rheumatologists are well aware of the importance of an early diagnosis, but there is a need to improve the awareness of the primary care practitioners as patients present first to them.⁸

Diagnosis and treatment delays in RA occur at various levels. Musculoskeletal symptoms are varied, and the diagnosis may not be obvious at the onset. Patients may present late when the onset of disease is insidious with mild to moderate symptoms, which may not interfere with their daily activities. When patients do present to the primary care providers, possible reasons in the delay to a referral to rheumatology may be due to the attending doctor being unsure of the diagnosis, wait for results of blood tests or adopting the 'wait and see' approach. There may also be delays in being seen by the rheumatologists due to limited access to rheumatology services and limited clinic slots. Therefore, it is important to pinpoint these delays to enable steps to be taken to address them and shorten the time of diagnosis and commencement of treatment.

Kumar et al., examined the delays that occurred in RA diagnosis and treatment in Birmingham, UK and found that the median delay from symptom onset to secondary care was 23 weeks. Only 30% of patients was seen in secondary care within three months of symptom onset. Patient dependent factors, leading to delay in consulting primary care physicians, are the main reason for the delay.⁹ Jamal et al., studied the delays in RA diagnosis and treatment in Toronto, Canada and found that 22% of patients received treatment within three months.¹⁰

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Patient characteristics	Number of patients (%)	
Gender		
Female	66 (78.6%)	
Male	18 (21.4%)	
Ethnicity		
Malays	31 (36.9%)	
Chinese	16 (19%)	
Iban	25 (29.8%)	
Bidayuh	11(13.1%)	
Kadazan	1 (1.2%)	
Rheumatoid factor		
Positive	66 (78.6%)	
Negative	18 (21.4%)	
Smoking history		
Non smoker	69 (82.1%)	
Ex-smoker	6 (7.1%)	
Current smoker	9 (10.7%)	

Table I: Patient demography

Table II: The types of delay in the	e diagnosis of rheumatoid arthritis
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Type of delay	Median (weeks)	Minimum (weeks)	Maximum (weeks)	Interquartile range (weeks)
Patient: from symptom onset to first primary care presentation	4	0	512	2-20
Primary care: from first primary care presentation to rheumatology referral	11	0	324	4-24
Rheumatology: from rheumatology referral to rheumatology clinic appointment	0	0	8	0-1
DMARDS: from rheumatology clinic appointment to initiation of DMARDS	0	0	16	0
Total delay: from symptom onset to initiation of DMARDS	23.5	4	516	13.25-51

In a study conducted at the Sarawak General Hospital (SGH) in 2008, found that the mean disease duration was 5.4 years (\pm 5.69) and a mean duration of delay in diagnosis and treatment of 42.9 \pm 60.1 months.¹² In another study conducted in selected government rheumatology centres in Peninsular Malaysia in 2008, found that patients had mean age of 49.6 \pm 11.8 years, and 74.3% were diagnosed within two years of the onset of symptoms.¹³ So far there are no studies looking into the various delays that occur in RA diagnosis and treatment in Malaysia. Our objective is to examine the delays in the diagnosis of RA in patients presenting to Rheumatology Unit, SGH.

MATERIALS AND METHODS

Data was collected from the medical records of consecutive patients newly diagnosed with RA who presented to the SGH from January 2015 until March 2018. The data collection was part of a clinical audit.

The government-based health system in Malaysia is such that all patients will be seen in the primary care and then referred to a specialist who is based in the government/public funded hospital. Alternatively, patients can seek treatment in private health clinics or hospitals. All patients in this study were given 'standard of care' management and data collection is from review of case notes. The date of referral to a rheumatologist was gathered from the referral letter. Data on demography, joint involvement and rheumatoid factor status were collected from the notes. Joint radiographs were also performed as standard of care. All patients were diagnosed with RA based on the 2010 RA classification criteria.¹⁴ Patients who have been treated for RA in a different centre, either government or private practice were excluded.

The definition of terms of the various types of delays:

- 1) Patient delay: from symptom onset until presentation to primary care;
- 2) Primary care delay: from presentation to primary care to a rheumatology referral;
- 3) Rheumatology delay: from rheumatology referral to being seen in rheumatology clinic;
- 4) DMARDS delay: From rheumatology clinic assessment to starting DMARDS; and
- 5) Total delay: From symptom onset until starting DMARDS.

Statistical analysis was done using SPSS version 21 (IBM Corp). Data regarding the delays were presented as the median values and interquartile range (IQR).

RESULTS

There were 84 patients (66 female patients; 78.6%) and all fulfilled the 2010 RA classification criteria. The mean age was 54.1 ± 12.0 years. The demographics data are presented in Table I.

The various type of delays is presented in Table II. Only 19 patients (22.6%) were treated with DMARDS within 12 weeks of symptom onset. The median delay before a patient was assessed in primary care was four weeks (IQR 2-20 weeks), while the median delay for referral to a rheumatologist by a

primary care doctor was 11 weeks (IQR 4-24 weeks). The median delay to being assessed in the rheumatology clinic was zero weeks (IQR 0-1 week). The DMARDS delay (from rheumatology clinic appointment to initiation of DMARDS) was zero week (IQR 0). The median delay between symptom onset to DMARDS initiation was 23.5 weeks (IQR 13.25-51 weeks).

We analysed the associations between gender, ethnicity and rheumatoid factor seropositivity with the delays in diagnosis and treatment. There was no statistically significant difference in all the above.

DISCUSSION

This study showed that the main delay in RA diagnosis was from the patients and the primary care. This rheumatology unit has an early arthritis programme in which early arthritis referrals from the primary care will be seen within one to two weeks. Referrals are made to the rheumatologists on call who will set the date of rheumatology appointment. Table II shows that early arthritis patients were usually seen within the same week. However, one patient defaulted the early appointment was given appointment only eight weeks later. DMARDS were usually started within the same week provided the baseline blood investigation results were available. One patient was started on DMARDS only 16 weeks later by the rheumatologist as he was initially treated as acute gout when he presented with monoarthritis of the knee. Diagnosis was revised to RA when he subsequently developed symmetrical polyarthritis.

Other studies done in cities in Europe and North America with good access to rheumatology services which examined the delays in RA diagnosis and treatment showed similar trends in which the delays were mostly from the patient and primary care.^{9-10,15-22} Less developed countries or countries with different health care systems may face additional challenges, which include a lack of access to rheumatology services and a generally low level of awareness among healthcare professionals and the public.²³⁻²⁷

It is important to understand where and why the delays occur so that steps can be taken to reduce them. Robinson et al., examined the delays that occurred in RA diagnosis and the factors influencing them²⁸ and reported the factors that influenced the decision for patients to present to primary care, a primary care practitioner's decision to refer to a rheumatologist and a eventually the rheumatologist assigning a rheumatology clinic appointment.

Patient delay in presenting to the primary care is a significant 'reason of delay' in RA diagnosis and treatment. Sheppard et al., performed a qualitative study on 24 RA patients and the factors that influenced their decision to present to primary care.²⁹ The factors were among four main themes: the severity of the symptoms and how they affect the daily activities, symptom evaluation and whether they are able to explain the symptoms, patients' knowledge of RA and the available therapy, and finally experience and attitudes of patients towards health care providers. Stack et al also examined the factors that

influence help-seeking behaviours were early experience of symptoms, minimising the impact of symptoms, speaking to others about their symptoms, gathering information and utilising alternative treatments, attitudes towards healthcare professionals and issues relating to health services.³⁰

There is also the delay in the primary care setting in which the primary care practitioner waits to refer to a rheumatologist. Suter et al., conducted a qualitative study involving 19 primary care practitioners to examine the factors influencing their decision to refer patients to rheumatology.³¹ They identified the following factors: patient clinical characteristics, patient preferences, rheumatology access, clinical and administrative leadership which emphasized quality care and timeliness, physician confidence and expectations and interpersonal relationship. Having a good rapport between the primary care practitioners and rheumatologists will facilitate referrals. Robinson et al reported clinical characteristics such as increased C-reactive protein (CRP) and increased swollen joint counts would more likely result in an urgent appointment request from the primary care practitioner.³² Comorbid health problems, access issues and management priorities were also important factors in referrals to a rheumatologist.²⁸ Patient gender may play a role but findings are contradictory. Some studies reported this increased the primary care delay, some reported this shortened the delay while others reported no influence on the delay.28 Palm et al.,³³ and Lard et al.,³⁴ stated that women with rheumatoid arthritis were referred later than men in the Leiden University EAC and the district of Ostfold respectively. It is not clear why women were referred later but one factor suggested was that more women consult their primary care practitioners for benign musculoskeletal symptoms, which may make it more difficult for the primary care practitioners to diagnose early rheumatoid arthritis in women. Men may also be more demanding of medical aid due to socioeconomic reasons. However, Feldman et al.,¹⁶ found women had a shorter time to rheumatology consultation compared to men. Robinson et al.,³² found no difference in time to assessment between men and women.

Rheumatology delays occur when a patient with RA is seen late in the rheumatology clinic. This is usually due to the lack of available clinic slots, especially in a centre with few rheumatologists. Rheumatologists have long since known that RA patients who were diagnosed and treated early will achieve better outcome, and most rheumatology centres have addressed this issue with the formation of early arthritis clinics.^{4.5}

Studies have examined the strategies to reduce the delays in RA diagnosis and treatment. Villeneueve et al., performed a systematic literature review to identify strategies to reduce the delays.³⁵ Strategies to reduce patient delays were community case-finding strategies (using a questionnaire and autoantibody testing) and websites. These strategies had variable outcomes and the websites were of variable quality. Strategies to reduce primary care delay included primary care education, patient self-administered questionnaire and a guideline for early referral to rheumatology. Strategies to reduce rheumatology delays are formation of a triage system,

triage clinics, rapid access systems and early arthritis clinics. These early access systems have good evidence in that they reduce delay in RA diagnosis and treatment.

Primary care education should be re-enforced, focusing on recognizing clinical features of inflammatory arthritis. Visser et al., produced a prediction model for diagnosis of inflammatory arthritis which included seven variables: symptom duration at first visit, early morning stiffness for more than one hour, arthritis of more than three joints, bilateral compression pain in the metatarsophalangeal joints, rheumatoid factor positivity, anti-cyclic citrullinated peptide antibody (Anti-CCP) positivity, and the presence of erosions of the hands/feet.³⁶ Emery et al., recommended a rapid referral criteria to rheumatology early arthritis clinics for the primary care practitioners: the involvement of more than swollen joints, involvement of three metacarpophalangeal/metatarsophalangeal joints and early morning stiffness for more than 30 minutes.³⁷ Ten Bricnk et al., developed a clinical rule consisting of clinical characteristics tailored for primary care practitioners to refer inflammatory arthritis cases that were less clear and needed further investigations.³⁸ This rule was not applicable to patients with obvious inflammatory arthritis who were referred to the early arthritis clinic straightaway, but meant for those who did not have obvious inflammatory arthritis and warranted further investigations or referral to secondary care. The clinical rule inflammatory arthritis risk calculator consists of the male gender, age >60, symptom duration, morning stiffness >60 min, number of patient-reported painful joints, patient-reported joint swelling, and difficulty making a fist.

Rapid access systems and early arthritis clinics have been established to reduce the waiting time for rheumatology assessment. This strategy has been shown to be effective.³⁵ A variation of this system is an immediate access system, where a rheumatologist has a brief initial assessment with the patient and triages the patient to an early arthritis clinic, a normal clinic slot or continuation in primary care. This strategy has also been shown to be effective in reducing the rheumatology waiting time with good diagnostic accuracy.^{39,40}

Our Rheumatology unit in SGH is one of two providing rheumatology services in Sarawak serving not only the population residing in Kuching district, but also populations in nearby districts. These patients may need to travel quite far to get treatment for their rheumatological conditions. Patients may first visit several primary care practitioners who are easier to access, adding delay to referral to a rheumatologist. Primary care practitioner delay may be related to the uncertainty in the diagnosis or waiting for results of investigations. Referrals from primary care are triaged by the rheumatologist and symptoms suggestive of inflammatory arthritis are given appointments within 1 to 2 weeks. Most patients attend the appointment, but some patients may not be able to make the journey in time due to logistic reasons. Our unit conducts regular education programmes for primary care practitioners, in addition to a programme called Practical and Essential Approach to Rheumato Logical Symptoms (PEARLS) organised by the Malaysian Society of Rheumatology. Triaging referrals from

primary care to reduce the delay in RA diagnosis is appropriate in our practice. We hope to further reduce delays in the primary care by conducting continuous education programmes on inflammatory arthritis.

The limitation of this study may be an inaccurate patient recall regarding the onset of symptoms and the date of their first visit to the primary care practitioner. Since this was a retrospective study, another limitation was insufficient data from the medical records. We also examined the home-based primary care cards of patients However, if the patient had gone to a private primary care practitioner this data would not have been captured. We did not collect data on the other reasons such as socioeconomic factors, home distance from the hospital or clinic, nor the reason for primary care delay for example waiting for rheumatoid factor results. These factors and how they affected the outcome of the delay in diagnosis may be interesting. A prospective study will be able to address these factors.

CONCLUSION

The delays in the diagnosis of rheumatoid arthritis were mainly from the patient and primary care.

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ETHICAL APPROVAL

This study was registered under the National Medical Research Registry (NMRR-18-710-41474)

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