

'I just thought it was normal aches and pains': a qualitative study of decision-making processes in patients with early rheumatoid arthritis

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Objective. Effective treatment can only be given during the early stages of RA if patients are seen early. However, many patients delay for prolonged periods before seeking medical advice. This study explores factors influencing the decision to seek medical advice in RA patients.

Methods. In-depth, semi-structured interviews were carried out with 24 patients. Purposive sampling ensured a cross-section in terms of time to presentation, gender, age and ethnic background. Interview transcripts were analysed and themes identified using established methods.

Results. Four main themes influenced the decision to seek medical advice: (i) symptom experience: the severity of symptoms and their impact on functional ability; (ii) symptom evaluation: the patient's explanation for their symptoms and recognition of their significance; (iii) knowledge of RA and available therapies; and (iv) experience of and attitudes towards health care providers. A significant and rapid impact of the disease on functional ability characterized those presenting early. Many developed an explanation for their symptoms that related to preceding activities. Recognition that this explanation was inadequate to explain symptom progression frequently prompted a consultation. Only one patient sought advice because she thought that she might have RA.

Conclusions. Symptom evaluation is a key factor influencing how quickly medical advice is sought in other diseases. In contrast to the situation with many cancers where there is widespread association of symptoms and signs with the eventual diagnosis, this was not the case in RA. Our findings should inform strategies to reduce delays in help-seeking in people with early RA.

KEY WORDS: Rheumatoid arthritis, Early arthritis, Delay, Presentation, Primary care.

Introduction

Highly effective interventions are available to control disease progression and improve long-term outcomes in RA [1–3]. A delay in the introduction of DMARDs is associated with worse disease control [1]. Unfortunately, there is often a delay between patients developing the symptoms of inflammatory arthritis and being seen by a specialist in secondary care [4–6]. Delays occur at several levels: the time taken for patients with symptoms to consult their GP (patient-dependent factors); the time taken for GPs to refer to rheumatologists (primary care-dependent factors) and the time taken for patients, once referred, to be seen in secondary care (secondary care-dependent factors). Research from North America has addressed primary care-dependent factors [7]. In the UK, delay due to primary care-dependent factors has reduced significantly over the last 20 yrs [4]. A recent study from our group, demonstrated that the most common reasons for delay in a cohort of patients seen in secondary care were patient-dependent factors [5]. Most patients with RA did not present to their GP until over 3 months after the onset of their symptoms. This observation has been confirmed in a separate UK study [8]. Understanding the reasons for this delay is important if interventions at a population level to facilitate early presentation are to be effective.

One potential approach to addressing this issue would be to identify reasons which we, as researchers, felt were important and to assess their prevalence in a quantitative study. However, this approach carries a real risk that reasons for delay that individuals with a new onset of synovitis feel are important are ignored. Only by listening to what such individuals have to say in a structured way using qualitative methods can the full spectrum of reasons for delay be captured [9]. Qualitative methods can be used to

understand people's experiences and interpretations of events and are useful to explore the reasons underlying people's behaviour [9]. Using a qualitative approach we aimed to explore people's beliefs, feelings and actions at the onset of their RA to gain insights into the factors that influenced their decision to consult their GP.

Methods

The study was carried out at Sandwell and West Birmingham Hospitals NHS Trust, which serves an ethnically diverse inner city population in Birmingham, UK. Ethical approval was obtained and all participants gave written informed consent.

Participant selection and recruitment

Participants were sampled from a database of patients who had been diagnosed with RA in the preceding 14 months in which the length of time from the onset of symptoms to assessment by the GP (as documented by the managing consultant at the time of diagnosis) was recorded. In contrast to quantitative research, the sample size in studies using qualitative methodologies is dependent on the concept of thematic saturation with recruitment of participants continuing until no additional themes emerge from data [10]. To be able to understand the determinants of both delayed and rapid presentation, we aimed to recruit similar numbers of participants who had seen their GP within 3 months and who had seen their GP more than 6 months after their symptoms began. To maximize diversity and allow contrasts in opinions to be detected, participants were purposively sampled to ensure a cross-section in terms of gender, age and ethnic background.

Sixty-two patients were contacted by letter and invited to participate. Reminder letters were sent 2 weeks later if a reply had not been received. Twenty-five agreed to take part. One of these was later admitted to hospital on the day of her interview and so this interview was cancelled.

Data collection analysis and validation

Data was collected using face-to-face, in-depth, semi-structured interviews. The interviews were undertaken by J.S. and K.K. J.S. had had no previous clinical contact with any of the participants;

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K.K. had previously seen six in her capacity as rheumatology specialist nurse. To maximize participation, ensure that less mobile participants were represented and that the interview setting was as permissive as possible, interviews were carried out at the participant's home or in hospital away from a clinical setting according to the participant's preference. Furthermore, to facilitate a permissive environment, the researchers wore casual but smart clothes, adopted the stance of the 'naive' researcher and reiterated anonymity. All interviews were conducted in private and lasted between 30 min and an hour.

Open questions were asked to elicit the participant's experiences of inflammatory joint disease. Participants were encouraged to talk about their thoughts, understanding, feelings and actions between the time their symptoms began and when they sought medical advice. Written notes were taken on non-verbal cues during the interviews. One of the interviews took place in the participant's preferred language (Punjabi) with K.K. acting as interviewer and translator. All interviews were audio-taped and transcribed verbatim. Each transcript was verified by J.S. or K.K.

Analysis adhered to rigorous procedures that enabled themes to be generated from the data. After each interview, emerging themes were discussed within the research team for use in subsequent interviews. In this way, the content of interviews evolved with our understanding of the subject matter, following a grounded theory approach [11, 12].

On conclusion of the interviews the transcripts were repeatedly read, annotated and coded to identify emergent concepts. This was undertaken independently by J.S. and K.K. Any discrepancies in coding were resolved by discussion. Similar concepts brought up by different participants were studied in greater detail leading to the identification of key themes. In addition, cases that appeared to contradict the emerging explanations of the phenomena under study were studied in greater detail.

Validation was undertaken using member checking by providing the participant with a verbal summary of the areas covered and themes that they had identified in the interview. Participants were asked to comment on these. Participants were then asked whether they wanted written feedback about their interview. Twenty-one requested this and were sent a summary of their interview and the major themes as identified by the research team. Participants were asked to comment on the summary of the interview and the themes drawn from it. None of the participants disagreed with the summary or the themes that we identified.

The themes and issues raised during the interviews are exemplified in the quotations used in the following sections.

Results

Characteristics of the participants and those who declined to participate are shown in Table 1. More women than men declined to participate though the difference was not statistically significant. All participants fulfilled 1987 ARA criteria for RA [13].

At the end of the interviews thematic saturation was achieved. Analysis of the interview data identified four interlinking themes that influenced decision-making processes in early RA (Table 2). Not all participants gave evidence of every theme. However, there were common patterns across the interviews, which explained why participants did, or did not, consult their GP quickly. These themes will be discussed individually although there is overlap between them.

Symptom experience

Participants differed in their experiences of the onset of their symptoms of RA. Participants who went to their GP within days of symptom onset often recalled the precise time their symptoms began. This was either due to the severity of their symptoms (such as joint pain and stiffness), the impact of these symptoms on daily activities (such as dressing, typing or caring for relatives) or both.

TABLE 1. Demographic details of participants and those who declined to participate

Characteristic	Participants (n=24)	Non-participants (n=38)	P value*
Gender			
Male	14	15	0.15
Female	10	23	
Ethnicity			
White	21	34	0.44
Black	1	0	
South Asian	2	4	
Age < yrs			
30–39	1	3	0.08
40–49	7	2	
50–59	3	11	
60–69	7	14	
70+	6	8	
Time to present to primary care			
≤3 months	12	18	0.84
>6 months	12	20	

* χ^2 test.

For others, the onset of symptoms was more gradual and they were unable to pinpoint the day or even week that their symptoms began. The rapidity of onset of symptoms, and time taken until severe pain developed, influenced the time taken to seek help (Table 3, quotations 1 and 2). Participants who perceived their symptoms as rapidly progressive or who had symptoms severe enough to impact on their daily activities consulted more quickly.

Many participants talked about ignoring symptoms at first and trying to 'get on with things'. Some hoped that their symptoms would resolve. Others felt they had little choice but to ignore their symptoms because of other demands on them (Table 3, quotation 3). For example, being a single parent or difficulty getting time off from work made it difficult to find the time to consult the GP.

Many tried to control their symptoms themselves with over-the-counter medicines such as analgesics, anti-inflammatory medications and alternative methods such as drinking cider vinegar. If symptoms persisted or progressed despite these measures, then the participants often felt that they were unable to deal with the situation themselves and required outside help.

Symptom evaluation

A central theme to emerge from the interviews was the way in which symptoms were interpreted and evaluated by individuals. The significance an individual attached to a symptom influenced their behaviour in response to it.

Many participants commented that they thought their symptoms were just everyday 'aches and pains' or, for some, a progression of their existing OA. A failure to connect their symptoms with a new and potentially serious diagnosis meant that they delayed in seeking help.

At the onset of their symptoms many had their own, relatively innocuous, explanations for the cause of their symptoms (Table 4, quotations 1 and 2 and supplementary data quotations 1 and 2, available as supplementary data at *Rheumatology Online*). Having such an explanation meant that many participants felt it unnecessary to see the GP. Often participants acknowledged that they took the decision to consult when they no longer regarded their explanations as adequate to cover the persistence or evolution of their symptoms (Table 4, quotation 3).

Most participants said that they went to their GP looking for symptomatic relief rather than looking for an underlying diagnosis to be confirmed or refuted although there were three exceptions to this—one was specifically concerned about RA and two were concerned about cancer. One of the participants concluded that the pain could have been 'cancer of the bone'

TABLE 2. Factors influencing decision-making processes in patients with a new onset of RA

1.	Symptom experience: the severity of symptoms and their impact on the patient's functional ability.
2.	Symptom evaluation: the patient's explanation for their symptoms and understanding of their significance.
3.	Existing knowledge about RA and available therapies.
4.	The patient's experience of and attitudes towards their GP and the health care system.

TABLE 3. Symptom experience of patients with a new onset of RA

Quotations	
1.	'Pain was horrendous. Could not stand it. That is why I went to GP so quickly... oh it was severe.'
2.	'It came on very slow. Very slow. Biggest pain started in knee... I could go two or three weeks then I would have another joint. That went on for six months if not longer before I decided that I needed to go and see the doctor.'
3.	'I have to work, I have to pay a mortgage and there isn't anybody else but me to do it... and that is why I kept struggling on.'

while the second related her symptoms to those of her mother who had presented with bony metastases (supplementary data quotations 3 and 4, available as supplementary data at *Rheumatology Online*).

A number of people discussed not wanting to admit that there was a problem. In some cases, participants said that this was because they did not want to be ill (Table 4, quotation 4); in other cases, they felt that they already had enough other medical conditions to contend with.

Existing ideas and knowledge about RA

Many participants commented that before they were diagnosed by a rheumatologist they knew very little about RA, were unaware that there were different types of arthritis or that treatment other than analgesia was available. A number of them commented that they believed there was a much greater awareness about other medical conditions such as heart disease and cancer as a result of widespread advertising about these conditions.

Some of those who had heard of RA did not view it as a 'serious' diagnosis. Two participants talked of having a sense of relief when given the diagnosis as they were worried that it might have been cancer.

A theme running through the accounts was that many did not consider themselves to be susceptible to arthritis. A number of different reasons were cited for this: being too young, not having a family history of RA, already having OA and not being the 'type' to get unwell. A very common comment, made by participants throughout the age spectrum studied, was that they thought that arthritis only affected people older than them (Table 5, quotation 1).

In contrast to this, one individual who had a close relative with RA perceived RA as a debilitating and progressive condition and she presented very quickly to try to rule it out as soon as she developed symptoms (Table 5, quotation 2).

Experience of and attitudes towards health care

A major theme running through the interviews related to attitudes towards the health care system, health professionals in general, their own GPs and their perception of the possible benefits and disadvantages of seeking professional medical advice. Previous experiences of health care, either personally or in those close to them, played a large part in shaping these attitudes.

TABLE 4. Symptom evaluation by patients with a new onset of RA

Quotations	
1.	'I just thought it was part and parcel of being on my feet all day, walking, running, getting into the odd scrap, old sports injuries if you like, I just thought it was something to do with that... because thinking it could be anything to do with arthritis. So, I just left it at that.'
2.	'What didn't help was working in the building trade. We do a lot of physical things and work in all sorts of conditions. Everyone has shown symptoms of suffering from different types. Bricklayer has got big fat fingers, not rheumatoid arthritis. Just through job they are doing. One of those things, getting older. It never occurred to me it could be arthritis.'
3.	'To begin with I thought I had sprained my wrist, 'cos my wrist went as you normally do if you sprain it, it hurt and it became swollen a little bit, so I stuck a wrist strap on it and carried on. It did not get any better for a week and a half, but then the swelling started from the wrist into the back of the hand.... and that all swole up until it got quite large. Now, at that stage, I thought well I had better go up and see the doctor.'
4.	'I ignore all these things. Ill's for other people not for me.'

TABLE 5. Existing ideas and knowledge about RA in patients with a new onset of RA

Quotations	
1.	'I heard about it. I thought it was if you were getting on a bit, fifty or older.... I knew some get fingers twisted.'
2.	'I think because its been in the family and it was such a strong part of my growing up because my mum suffered from it from such an early age, was only late 30s early 40s at the onset, so I think really being the age group that was my first thing to think about really.'

TABLE 6. Experience of and attitudes towards health care and other factors influencing behaviour in patients with a new onset of RA

Quotations	
1.	'I don't like to go to the doctor and waste the doctor's time on things like colds and things like that which are not necessarily particularly treatable that you can deal with yourself. I don't have time, because I work, to go unnecessarily. I would prefer not to go if I can help it.'
2.	'If I'm not very well I get straight in touch with the doctor 'cos that's what he's told me like, if you get a cold, don't leave it 'cos the cold will turn and you'll have a chest infection, so don't leave it. And of course when I had the arthritis, I had the pain in my legs, I think it was about two, three days and I was up to the doctors to see what it was like.'
3.	'I didn't really take much notice. Because my wife was ill more than me then. Plus, we had planned a holiday and we had about three weeks off and that's when she really took ill and so I was looking after her and didn't really care much about myself.'

Many participants held the view that it was better to avoid going to the GP if it could be helped (Table 6, quotation 1). A number of reasons were cited for this: not wasting the GP's time; not wasting their own time; not using a valuable appointment that someone else might need more; not being a drain on the NHS; not wanting to appear to be a 'timewaster' or 'hypochondriac'.

Some participants commented that they would not go to their GP unless they felt that the GP would be able to help them. Those who already had chronic joint pain from OA, and one who believed that they were intolerant of analgesics, said that they did not go to the GP because they thought that all they would be offered was analgesia.

Many participants described putting off the decision to go to their GP until they felt that they had no other option available. Two participants commented that they felt that men in general were slower at seeking help for medical problems (supplementary data quotation 5, available as supplementary data at *Rheumatology Online*).

One participant delayed presenting as she was sure that her GP would attribute her joint symptoms to her weight, an attitude she had experienced in relation to other symptoms (supplementary data quotation 6, available as supplementary data at *Rheumatology* Online).

Two participants, who presented to their GPs early, provided explanations for their behaviour which differed significantly from those of other participants. One, with multiple comorbidities, had been extremely ill previously. He had been advised to consult his GP immediately when experiencing any new symptoms. He presented to his GP very soon after developing joint pain. This man believed that his previous experiences of ill health and his relationship with his GP had strongly influenced his decision to consult promptly (Table 6, quotation 2). Another early presenter took a very consumerist approach to health care. She strongly expressed the view that if an individual developed a new symptom they should go to their GP and insist on being investigated, regarding the GP as a resource to be utilized. She acknowledged that the majority of people took a different approach to this but said she could not understand why.

People who had prior experiences of hospital medicine, either through their own medical conditions or those of close relatives, felt greater confidence in approaching their GP for advice or to request a referral to secondary care. Two of the participants who delayed in consulting their GP had little prior experience of hospital medicine and attributed some of their delay to not understanding 'the system'.

Other factors influencing behaviour

Participants described an array of emotions triggered by their experiences at the time their symptoms began. Some said that the effect of their symptoms on their mood influenced their behaviour during this time (supplementary data quotation 7, available as supplementary data at *Rheumatology* Online).

Some participants found it helpful to talk to friends, family, neighbours or colleagues about their symptoms. These individuals frequently gave advice about how to control symptoms and whether to seek professional help. Others were reluctant to share their experiences and did not want any one else to know that they were having problems. Several felt as though people did not understand the severity of their symptoms and thought they were 'moaning'. One young participant was given the impression by her elder relatives that she was making a fuss as she was too young to be ill. As a result it took some time for her to present to her GP.

Partners were often the main confidantes. Many of the men commented that their wives encouraged them to seek help. Sometimes they ignored this advice, sometimes they took it and sometimes they said that they eventually 'gave in' to pressure and went to the doctor.

Other important life events occurring simultaneously sometimes overshadowed the onset of the arthritis. Such events sometimes made it difficult to find the time to go to the doctor or meant that, in relative terms, the participant viewed their symptoms as unimportant. One individual took very little notice of his own symptoms as he was focussing on his wife's illness (Table 6, quotation 3).

Discussion

Delay in seeking medical advice is a central determinant of delay in receiving appropriate therapy. The importance of understanding the reasons for delay have been widely appreciated by those seeking to improve the quality of care provided to patients with a number of diseases including ischaemic heart disease and various malignancies [14, 15]. However, despite considerable advances in identifying predictors of outcome once patients with early synovitis are seen in secondary care [16–19], the reasons for delay in presenting to primary care in the UK have largely been

overlooked. A qualitative study carried out by Bury in the 1970s explored the thoughts of patients with RA at around the time of disease onset and the emotional and social impact of their disease on them [20]. This study reported on data from interviews with 25 patients with a new onset of RA though the duration of delay in help seeking and the relationship between this and the patients' thoughts and beliefs was not directly addressed. However, despite the 30-yr gap between these interviews and those reported in our study, a period that has seen dramatic advances in the field of RA, a number of themes identified in the 1970s remain as significant obstacles to early presentation. Furthermore, we have identified a number of new themes not previously described in the context of RA in the UK population. A study, by Sakalys, carried out in the United States explored illness behaviour in RA patients prior to a diagnosis of RA being made [21]. That study did not have, as its primary aim, an exploration of why some patients delayed in consulting a physician and others did not. However, an analysis of the data from that study suggested that fatigue, pain, functional impairment and unexplained persistence of symptoms were the main determinants of consultation [21]. However, the Sakalys study [21] has the disadvantage that it included only women. Whilst our study did not identify fatigue as a determinant of consultation, it did identify a number of factors not identified by Sakalys, in particular a lack of knowledge of RA and experiences of and attitudes towards health care.

Our study provides important insights into the complex, multi-faceted and highly individual factors influencing the decision-making process in those with a new onset of RA in a contemporary setting. A number of recurring themes arose from our analysis. Major determinants of the time to presentation were the severity of the symptoms, the impact of these on the patient's daily life and the patient's interpretation and evaluation of their symptoms. The significance an individual attached to their symptoms, and whether they were seen as indicative of a serious underlying diagnosis, strongly influenced their response to them. Individuals who were concerned that something serious was wrong frequently presented quickly.

Musculoskeletal symptoms are extremely common in the community [22, 23] and many people with such symptoms never consult their GPs [24]. Indeed a previous study of people with OA reported that older people were likely to accept that joint pain was a normal and integral part of their biography [25]. In our study, patients throughout the age spectrum said that they felt they were too young to develop arthritis, an observation that may explain the lack of correlation between patient age and the extent of delay in presentation to the GP that we have reported previously [5]. Many of the participants in our study said that they had previously experienced joint pain that had either settled spontaneously or recurred intermittently and for which they had developed their own explanatory model. Not recognizing the symptoms of early RA as different from other conditions affecting the musculoskeletal system meant that many patients believed that the eventual outcome on this occasion would be similarly benign.

Parallels can be drawn with results from studies of help-seeking behaviour in other conditions. In a qualitative synthesis of 32 studies of patients with a variety of malignancies, important triggers for consultation were: (i) specific well-known symptoms (e.g. a lump); (ii) knowledge of cancer symptoms and awareness of risk; (iii) symptoms that worsened or persisted; (iv) new additional symptoms (e.g. pain); (v) severe symptoms that reached crisis point; (vi) symptoms that affected everyday life; and (vii) discussion of symptoms with friends and family [15]. The last five of these triggers are shared with participants in our study. However, the first two triggers did not emerge as important themes in our study and were identified in only one patient with RA. This reflects Bury's finding [20] that none of his 25 patients recognized their first signs or symptoms as indicating RA. At the onset of symptoms most of our patients developed their own explanatory models for their symptoms that were frequently based

on recent physical experiences. This has previously been reported [20, 26]. Factors have also been identified in patients with cancer, which can lead to a delay in the decision to consult [15]: (i) vague and mild symptoms attributed to a common ailment not needing urgent medical attention; (ii) absence of pain or lump; (iii) beliefs that symptoms will go away; (iv) intermittent symptoms; (v) no awareness of cancer symptoms or risk; and (vi) previous benign diagnosis for symptoms by the doctor. Many of these themes emerged from our interviews. In the oncological literature, fear of a potentially fatal incurable disease and of unpleasant treatments is, for some patients, a barrier to help-seeking behaviour [15]. This theme was not identified in our study, and this is almost certainly related to the fact that there was widespread lack of awareness of RA as a diagnostic entity at the time of symptom onset. A lack of knowledge of RA is likely to explain why many participants did not consider themselves to be susceptible to this condition before their diagnosis. The concept of arthritis being a disease that only affects the elderly would appear to have changed little over the last 30 yrs [20].

Beliefs about the appropriate use of the health service are common themes in other studies of patient delay. In a study of decision-making processes in patients with symptoms of acute myocardial infarction, 21 of 22 patients felt concern about wasting NHS time and resources [14]. This issue was not addressed in Bury's study [20] but was an important issue for our patients with RA. In addition, two male patients said that they viewed help-seeking as not masculine, a theme that appears in other studies [15, 27].

Several of the themes we have identified have also been observed to influence why GPs delay in referring patients to secondary care. In a qualitative study from the United States, primary care physicians stated that mild disease and slowly progressive disease were barriers to referral [7]. This may explain the relationship between the delay in presentation to the GP and the delay in referral by the GP that has been observed by Sandhu *et al.* [8]. In that study, patients who waited <6 weeks to see their GP after symptom onset were significantly more likely to wait < 12 weeks to be referred to a rheumatologist than those who waited > 6 weeks to see their GP.

Our study has a number of limitations. Only 39% of those approached agreed to participate. More women than men declined to participate and the result of this disparity was that only 42% of the participants were women. In addition, there was a trend towards older patients declining to participate, which meant that the age distribution of the population we studied was not entirely typical of the age distribution of a newly presenting RA population [28]. Nevertheless, we managed to capture a broad cross-section of patients in terms of age allowing us to identify themes across the age spectrum. In all cases, the interviews were conducted after a diagnosis of RA had been made and the time from diagnosis to interview was up to 14 months. Consequently, the responses given by the participants may have been influenced by events that occurred after they had first seen their GP. Finally, although saturation of themes was achieved in our study, further work is necessary to assess whether any new themes would be identified in specific groups, such as ethnic minorities, not well represented in our study.

In conclusion, patients at particular risk of delayed presentation to primary care included those with an insidious onset of mild symptoms that had little initial impact on functional ability. Lack of knowledge about RA often contributed to a delay in presentation; patients virtually never associated symptoms such as joint pain, stiffness and swelling with an underlying diagnosis that required prompt medical attention. This suggests that the rheumatological community has not effectively engaged the public in the recognition of a condition for which highly effective treatments are now available. We are in the process of developing a quantitative study in which the frequency of each component of the themes underlying delay is assessed as a relevant explanatory

factor in a much larger cohort of patients with newly presenting RA. This will allow us to understand the relationship between these themes and characteristics such as age, gender, ethnic origin and socioeconomic status and determine the generalizability of the themes we have identified. Only by understanding these explanatory factors in more detail can we design effective public health strategies to tackle this problem.

Rheumatology key messages

- Many patients with RA delay for prolonged periods of time before seeking the advice of a health care professional.
- A lack of knowledge about RA is an important determinant of this delay.

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Supplementary data

Supplementary data are available at *Rheumatology* Online.

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