

Delays in help seeking at the onset of the symptoms of rheumatoid arthritis: a systematic synthesis of qualitative literature

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ABSTRACT

Objective

To conduct a systematic review to identify drivers of, and barriers to, help seeking behaviour in people with new onset RA.

Methods

Qualitative peer-reviewed publications discussing primary data on the drivers of, and barriers to, seeking help at RA onset in adults were included. One thousand and fifty-eight abstracts were searched. Fifty-three articles were read to identify relevant publications which were assessed for quality and subjected to analysis informed by thematic and grounded theory frameworks.

Results

Twenty-one publications were included in the final analysis. Several interacting themes were identified. These included the early experience of RA symptoms; making sense of early symptom experience and prototypes of RA; minimising the impact of symptoms; speaking to others, gathering information and seeking alternative treatments; and issues related to accessing health services and attitudes towards healthcare professionals. Many people suggested that they had little knowledge of RA before diagnosis, often believing RA to be a mild condition caused by wear and tear which affected the elderly. These misperceptions made correct symptom interpretation unlikely. Instead, RA symptoms were attributed to causes such as injuries. Normalising and ignoring the presence of symptoms helped people to cope and delay for longer. However, when symptoms impacted on daily activities these coping mechanisms became inadequate and help was sought.

Conclusions

Individual interpretations of symptoms are both drivers of and barriers to help seeking. Interpretations are informed by symptom onset, sources of information and coping mechanisms.

Targeted public health interventions are required to inform symptom interpretation and reduce delays.

BACKGROUND

Irreversible joint damage occurs during the early stages of rheumatoid arthritis (RA). The first three months following clinical disease onset represent a therapeutic window during which drug treatment is particularly effective at controlling synovitis and limiting joint damage.[1-3] Despite increased recognition of the benefits of early treatment there remains considerable delay between symptom onset and the initiation of treatment.[4-10] Delays can occur at several levels including delay on the part of the patient in seeking medical advice at symptom onset, delay in obtaining an appointment with a healthcare professional and delays in referral to a rheumatologist, diagnosis and commencement of disease modifying therapy. In the UK, the median delay between onset and assessment by a Rheumatologist is 23 weeks, most of which is attributed to patient delay in seeking help (median 12 weeks).[5] In countries such as the UK, many patients miss the therapeutic window because they delay in seeking help for their symptoms.

Evidence from other conditions shows that personal understandings of illness and the way that symptoms are interpreted influence help-seeking behavior.[11-13] For example, following an acute myocardial infarction, those with a mismatch between expected and experienced symptoms delayed for longer.[14] Pre-existing ideas, or prototypical illness beliefs, are held by people without personal experience of the illness to draw on and are influenced by factors such as knowledge of the disease and cultural understandings of illness in general. The prototypes of some illnesses may be better formed than those of others, but generally prototypes influence how long a person expects an illness to last, how severe they perceive it to be, the symptoms they expect to experience, their understanding of whether it can be controlled, who is most susceptible and what its consequence may be. Prototypes can

be unhelpful if they are inaccurate and lead people to believe that the symptoms of conditions such as RA do not require medical attention.

To date there have been no systematic reviews of help seeking behaviour in RA, however, syntheses of the qualitative literature regarding help seeking in other conditions have been illuminating.[15] This review synthesised the literature regarding the drivers of and barriers to help seeking behaviour in people with a new onset of RA.

METHOD

Inclusion criteria

Qualitative studies using an interpretative paradigm to analyse and report data on the drivers of and barriers to help seeking behaviour in adults (>18 years) at RA onset was included. Patient delay was defined as the period from the onset of symptoms to the time that help was sought from a healthcare professional who could prescribe disease modifying treatment. The search was restricted to English language peer reviewed publications.

Search strategy

The following databases were searched using the combinations of search terms in table 1:

EMBASE Classic+EMBASE (1947- November 2010); HMIC Health Management Information Consortium (2010); CAB Abstracts (1973 – November 2010); Ovid MEDLINE(R) (1950 - October 2010) and PsycINFO (1806 - November 2010).

In addition, the reference lists of relevant articles and the online abstracts from European League Against Rheumatism (2002 to 2010) and the American College of Rheumatology (2006 to 2010) conferences were searched. Combined, these search strategies identified 1058 peer reviewed publications (excluding duplicates). The abstracts of all publications were read by RS and 53 potentially relevant full text publications were selected for detailed analysis. Where multiple publications of the same data reporting identical findings were identified, one exemplar publication was selected. Examples of papers excluded were those describing symptoms experienced at RA onset without linking these to help seeking behaviours,[16, 17] and papers that sampled people with “arthritis” or “inflammatory arthritis” in general, or people across multiple illnesses, without specifying the themes or quotations attributed to RA.[18, 19]

Analysis

Selected publications were critically assessed for quality using established criteria.[20-23] A tension exists between inclusiveness and quality of data in qualitative synthesis. Like other published syntheses [15] we opted for an inclusive strategy, reviewing all studies that contributed relevant data, but we have included information about methodologies and quality indicators in the supplementary table. Publications were analysed using an approach informed by thematic and grounded theory frameworks to systematically identify shared concepts and themes.[24, 25] The results/findings section of each article was subjected to initial coding by RS and KR. Initial coding described the emerging concepts in the relevant sections of each article, and then generated new conceptual understandings derived from interpretations of the data. The initial codes were categorised and labelled with an overarching descriptor. Concepts shared across studies, and their inter-relationships, were identified. Core themes were identified and summarised. Themes were checked again by RS who re-read the articles, modified themes and incorporated illustrative quotations.

RESULTS

Twenty-one publications were included in the final analysis (see supplementary table). Concepts such as early symptoms disrupting functional roles and a slow symptom onset were relevant to multiple themes. Illustrative quotations are shown (table 2).

The early RA symptom experience

At the onset of RA, the severity, intensity and duration of symptoms such as pain, stiffness, joint swelling and fatigue influenced whether people sought help.[26, 32, 40, 43] When symptoms appeared rapidly, people reported being fearful and usually everyday tasks were dramatically affected,[31, 41] often resulting in prompt help seeking.[40, 43, 45] Interestingly, some who sought help following what they described as a rapid symptom onset, retrospectively recalled mild symptoms of RA which they had ignored or misattributed.[43]

When the onset of symptoms was slow, vague or transitory,[40, 43] people found it difficult to pinpoint when their relevant symptoms first began.[33] As symptoms increased in severity and duration people's explanations for their symptoms changed to match their symptom experience.[45] Changes in symptoms, experience (e.g. the intensity of pain) and explanations helped people to determine when help should be sought.[26, 33, 36]

While few people recognised their symptoms as indicative of RA, those that did suggested that they sought help when pain spread to multiple joints. Often when people initially sought help, it was not usually for an explanation of the cause of their escalating symptoms or to receive a diagnosis, but instead for symptom relief.[27, 32, 33]

Making sense of early symptom experience and prototypes of RA

Many reported little or no knowledge of RA prior to diagnosis,[26, 28, 29, 33, 45] with some suggesting that, if they had had more knowledge, they would have sought help earlier.[27]

People felt they had a lack of knowledge about the significance of musculoskeletal symptoms, different types of arthritis and in particular RA, the need for early intervention in RA, treatments for RA (beyond analgesics), rheumatology services, their own risk of RA and causes of RA.[26, 27, 29, 33] Furthermore, it was felt that the public had a greater awareness of conditions such as cancer and heart disease, and did not perceive joint symptoms to be indicative of a serious disease.[27, 35]

Some were uncertain about whether an illness really existed, and what action, if any, should be taken.[38, 42, 46] A slow symptom onset caused uncertainty and some found it difficult to understand the cause of their symptoms.[40, 43] Often prototypes were based on inaccurate understandings of RA, such as the belief that RA affected the elderly or was caused by “wear and tear”. [27, 33, 45] This resulted in people experiencing symptoms which did not match their prototypes of RA making correct symptom interpretation and prompt help seeking unlikely. Changes in the character and duration of symptoms

frequently led to some causal explanations becoming invalid; alternative explanations for symptoms were then sought.

Causal beliefs associated with RA symptoms included stressful life-events, child birth, work,[32, 37, 40, 41, 44, 46] an injury or “over-doing it”.[26, 27, 32, 33, 38-43, 45, 46]

Attributing symptoms to external factors often meant that people believed their symptoms to be temporary, and not requiring medical attention.[27, 33, 45] Internal attributions were less likely. A few people, with pre-existing illnesses, thought that the emergence of new symptoms was the result of their pre-existing condition (e.g. osteoarthritis). However, few had suspected RA as a cause, and some suggested that since they had no family history of arthritis, they had discounted it as an explanation for their symptoms.[27, 33]

Minimising the impact of symptoms

Normalising symptoms led some to explain away their early symptoms.[29] People described symptoms as normal “aches and pains”,[33] or “normal” (for someone of their age, gender, life circumstance etc). Ignoring symptoms allowed some to continue with normal daily activities. However, when daily activities were disrupted, symptoms could no longer be ignored and perceptions changed.[27, 31, 35, 36] For some, other life events meant that they did not prioritise their symptoms.[33] Some people did not want to think about themselves as being unhealthy.[33, 45] Denial was also described by those who did not want to deal with the stress of a possible chronic illness or an additional morbidity for those with pre-existing conditions.[33] For others, ignoring and denying the presence of

symptoms was driven by a fear of symptoms becoming more intense and permanent, and fears of medical treatments.[26, 40, 43]

Many studies described disruption to normal roles and daily activities as driving help seeking behaviour. [26, 29, 40, 43, 46] As the severity of symptoms increased and impacted on activities, the likelihood of consultation also increased. [33, 46] Often this disruption was initially managed through a process of adaptation and accommodation. However, when the anticipated or real level of disruption became a concern, or previous strategies for dealing with symptoms failed, help was sought.[26, 34]

Speaking to others, gathering information and seeking alternative treatments

Family and friends were often used as 'lay consultants', and advice and validation were frequently sought before seeking medical attention.[39, 43] For example, some men noted that their partners were often drivers of their decision to seek help.[45, 46] Lay consultants also advised on symptom control, possible cures and occasionally that symptoms may be indicative of RA.[27, 33, 45] In some instances this advice caused people to delay for longer, for example when it was suggested that symptoms represented a curse or that alternative medicines should be used.[27] Interestingly, knowing someone with RA did not necessarily trigger symptom recognition nor encourage help-seeking behaviours.[26]

Some commented that they felt isolated because their problems were not taken seriously.[40] Some people intentionally hid their symptoms from family and friends,[45, 46]

and feared being labelled as a “moaner” and receiving a lack of empathy.[33, 35] The “invisibility” of many RA symptoms made nondisclosure easier. However, in some circumstances lay consultants were persuaded to disclose information, without the questioner revealing that they were experiencing health difficulties.[39]

People sought information at the onset of symptoms and prior to seeking help, particularly when their symptoms flared up or were disruptive to daily activities.[26, 29, 40, 43]

Information was gathered in an attempt to validate symptoms and in some cases self-diagnose.[30] In some cases people with similar experiences or symptoms were sought online.[30] This helped people decide whether to seek help or to self-manage their condition.[26] Knowing where to seek appropriate information was difficult; some were unaware of available resources.[30]

Behavioural responses to symptoms included no action, self-treatment (such as changing footwear), engaging in activities and self-medication (including over the counter medicines and alternative medicines).[26, 27, 33, 37, 39] When the onset of RA was slow, people were more likely to use alternative therapies to self-manage.[43] Some sought help from alternative practitioners and other healthcare professionals (e.g. chiropodists or physiotherapists) before consulting the General Practitioner.[32] Cultural background may have influenced the type and extent of use of complementary and alternative management strategies including dietary manipulation, heat, physical therapies, traditional medicines, and prayer.[27][35]

Accessing health services and attitudes towards healthcare professionals

For some there were physical barriers to accessing health services (e.g. living in a rural area).[36] However, thoughts and attitudes about healthcare professionals and health services were important arbiters of both delay and help seeking. Negative attitudes towards healthcare professionals, including a lack of confidence in a General Practitioner's competence and knowledge, created a barrier to seeking help.[26, 33, 42, 45] Some feared that healthcare professionals would blame symptoms on a lifestyle factor (e.g. excess weight or alcohol consumption), dismiss symptoms and make them feel guilty or like a "hypochondriac".[33] Others delayed in seeking help because they did not want to waste the healthcare professional's time.[27, 33] Conversely, a minority held a proactive approach towards health services leading to rapid help seeking.[33]

Previous exposure to health services may influence help seeking behaviour,[29] for example, people with multiple conditions are likely to have greater experience of health services, a relationship with a healthcare professional, and may have been advised to return if new symptoms emerged.[33] Extra contact with healthcare professionals appeared to create a sense of approachability and made help seeking more prompt.[28]

DISCUSSION

Symptom interpretation was central to decisions to seek help at the onset of RA. Many people had little knowledge of RA, and the initial symptoms they experienced did not match their expectations. This review identified that many held the prototypical view that RA was a non-severe condition of the elderly, caused by “wear and tear”, and interpreted their initial symptoms as indicative of injury or overuse. Although delays in help seeking are common, the studies included in this review all captured patients who had eventually presented to a health care professional and were diagnosed with RA. Clearly in all these patients any initial barriers to presentation were eventually overcome. Themes identified in this review inform our understanding of the interplay between factors discouraging and promoting help seeking.

A qualitative review of help-seeking in people with cancer also found symptom interpretation to be important and, like in RA, the sudden appearance of symptoms induced fear and lead to rapid help seeking.[15] Whilst pain was a driver of help seeking behaviour in people with cancer,[15] in RA it was usually when pain interfered with functional ability that help was sought. It is possible that, in addition to the intensity of pain, its site indicates whether the pain is perceived as indicative of a serious underlying condition; for example with joint pain being perceived as less concerning than abdominal or chest pain. Research should explore this further through a range of methods including qualitative studies exploring perceptions of joint pain, and vignette studies using short scenarios about individuals experiencing pain in specified areas and circumstances.

Decisions to seek help are influenced by factors beyond understandings of illness. Good relationships with healthcare professionals were a driver of help seeking behaviour, but anticipated negative communication or attitudes contributed towards patient delay. This highlights a wider issue about healthcare professionals communication styles; healthcare professionals should consider how previous encounters may affect patients' future help seeking behaviour.

Information was sought from a number of sources including significant others and the internet. By providing all members of the community with insights into RA, significant others may thus be able to relay health promotion messages to people experiencing RA symptoms. However, we do not fully understand the role of social influences and significant others in decisions to seek help, and it is important that qualitative research is used to explore this. Furthermore, sources of information on the internet and elsewhere need to be investigated not only for accuracy, reliability and their encouragement of appropriate help seeking behaviour but also for the accessibility of this information for its intended target audience. In addition, the advice given to people complaining of joint problems by professionals such as chiropractors or community pharmacists also must be explored.

In some countries including the UK, only half of patients present to a health care professional within 12 weeks of the onset of symptoms attributable to their RA.[5] However in other countries including Austria, Germany and the Netherlands delay on the part of the patient is shorter.[2, 50] Understanding the reasons for shorter delays, where these are

present, and the possible impacts of public health campaigns addressing RA and the structure of healthcare systems in these countries, will provide important information regarding drivers of help seeking and how these can be modified.

A limitation of the literature in this area is that few studies reported findings from developing countries or populations from a non-white background. Therefore, our findings do not provide detailed insights into the understandings of inflammatory joint symptom in these populations. The illness beliefs of people from different cultural backgrounds have been shown to influence illness behaviours such as adherence.[48, 49] Furthermore, no studies focused on male help seeking behaviour, and the proportion of males in studies sampling both genders was small. The lack of insight into male help seeking behaviour is a limitation, especially, as a stereotype suggested in one study is that males delay for longer, and have poorer help seeking tendencies. Future research should redress these gaps in our understanding.

Our future research aims to map the causes of delay and drivers of help seeking on to different demographic groups to inform the development of tailored health promotion interventions (see study website for further details).[51] The key challenge facing the development of interventions in this area is that appropriate help seeking must be encouraged, in particular rapid help seeking in the context of a new onset of symptoms indicative of RA (e.g. small joint involvement, symmetric joint involvement, swelling and morning stiffness), without promoting rapid help seeking in the context of other causes of

musculoskeletal symptoms where self-management may be more appropriate or urgent assessment is not necessary (e.g. mechanical low back pain, osteoarthritis, fibromyalgia. Strategies to promote help seeking in RA patients should specifically address issues which explain delay for example highlighting that although initial symptoms may be mild that rapid help seeking is still necessary to allow early treatment to limit long term damage. The effectiveness and cost effectiveness of these interventions will need to be assessed longitudinally. As awareness of RA is raised, it is possible that there will be an increase in both appropriate and inappropriate help seeking from General Practitioners (e.g. seeking help where self-management would have been more appropriate) and data regarding this will need to be captured in any assessment of public health interventions strategies.

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We declare that we have no conflicts of interest to declare.

EXCLUSIVE LICENCE

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Table 1. Search terms

Arthrit* OR Rheumat* OR Synovitis	AND	Seek help OR sought help
		Seek medical OR sought medical
		Seek consultation OR sought consultation
		Seek health* OR sought health*
		help seeking behaviour OR help seeking behavior
		health care seeking
		help seek* OR medical seek* OR professional seek* OR treatment seek*
		symptom interpretation OR symptom recognition OR symptom perception
		Delay OR delayed diagnosis OR procrastinate
		Symptom onset OR early detection

Table 2. Quotations

<p>The early RA symptom experience</p>	<p><i>“Well, I probably had it for a year, but I didn't realize what I had. I used to go skiing, and once in a while my feet would hurt, like a big toe or something. I would think that, well, maybe the boots were too tight or the socks were too tightThen one day, all of a sudden my joints all swelled up. All over. And they were so tender and horrible. My legs swelled up and my hands were so sore I couldn't touch anything. When my feet swelled up, I finally went to a doctor.” ([43] pp292)</i></p> <p><i>“Instead of getting better.....it gradually got worse..... and I started wondering if it might be arthritis.” ([39] pp232)</i></p> <p><i>“My thumb just swelled up and a couple of my fingers just kind of puffed out. When I first noticed it, I just thought it was from sailing. I would get better for a while then it came back after a month or two and didn't go away.” ([43], pp292)</i></p>
<p>Making sense of early symptom experience and prototypes of RA</p>	<p><i>“You see when you have chest pain you automatically think either indigestion or heart and you go quickly to see the GPs (general practitioners). People have fear of heart attacks or cancer. With the joints you tend to put explanation. If they ache you automatically think that you are either tired or done too much.” ([27] pp1009)</i></p> <p><i>“Diseases related to internal organs directly influence eating and sleeping and even influence the life span. Disease of the arms and legs do not cause serious effects on lifestyle.” ([35] pp1798)</i></p> <p><i>“I heard about it. I thought it was if you were getting on a bit, fifty or older.... I knew some get fingers twisted.” ([33] pp1579)</i></p> <p><i>“Well at first I thought I'd broken, chipped the bone in the finger, with it being a knuckle. I thought, I bet I've banged it, really, because I do bang my hands a lot sometimes and I thought I'd chipped it and I thought, "oh it'll go off". It was months, really, before I got round to going to the doctor because we got married in the July and I didn't go and see the doctor before the end of August, beginning of September. I just thought it was one of those things that would clear up. It never dawned on me it would end up like this.” ([45] pp 171)</i></p> <p><i>“.....aware of swelling to fingers of the right hand..... waited two weeks to see if condition improved.” ([32] pp257)</i></p>

<p>Minimising the impact of symptoms</p>	<p><i>"Instead of getting better..... it gradually got worse..... and I started wondering if it might be arthritis." ([39] pp 232).</i></p> <p><i>"I ignored all these things. Ill's for other people not for me." (pp 1579[33])</i></p> <p><i>"When I noticed it was preventing me doing thing and it interfered in my sleep, it woke me during the night, then I thought, gosh, this is not right, something needs to be done about this" ([27] pp 1008)</i></p> <p><i>"I'd had a bad toe for twelve months. It kept swelling up and was ever so sore and painful. And then all of a sudden I noticed that I couldn't do simple thing like wringing out a face cloth or a dish cloth. I kept thinking 'this isn't right', and then joints started to ache" ([37]pp79)</i></p>
<p>Speaking to others, gathering information and seeking alternative treatments</p>	<p><i>"Friends and family would say 'what's the matter with you?' You were fine and fit. This is not normal. Why don't you seek help from a priest? They said 'Look. We think someone has put a curse on you" ([27] pp1009)</i></p> <p><i>"If you complain too much about arthritic pain, people will think that you are a hypochondriac...even my husband believes that I exaggerated my pain because he thinks that arthritic pain is not so serious" ([35]pp1798)</i></p> <p><i>"I think the hardest part was that I would tell people about this and they would . . . blow it off. . . so I had a tendency to kind of keep it to myself" ([39] pp233)</i></p>
<p>Accessing health services and attitudes towards healthcare professionals</p>	<p><i>'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" (pp. 1579[33])</i></p> <p><i>"Most males, it's an effort just to get them to go to the doctor" ([28]pp 648)</i></p>

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