Patient Delays In Seeking Help At The Onset Of Rheumatoid Arthritis: The Problem, Its Causes And Potential Solutions

KEYWORDS

Rheumatoid arthritis; help-seeking; patient decision-making; illness perceptions; early intervention

ABSTRACT

Rheumatoid arthritis (RA) is a chronic inflammatory disease for which early treatment is vital to limit long term joint damage. However, people often delay in seeking medical help at the onset of RA symptoms. The early interpretation of symptoms and the process of making sense of symptoms impacts on both help-seeking decision-making and self-management. Furthermore, the general public’s perceptions and knowledge of RA may also affect the way that symptoms are interpreted. Examining the psychology behind early symptom interpretation, the barriers to help-seeking behaviour and investigating the public understandings of RA, can help us understand how decisions are made and guide us in developing interventions which encourage people to seek help promptly at the onset of RA.
INTRODUCTION

Rheumatoid arthritis (RA) is an incurable disease which affects approximately 1% of the population.\[1\] The disease is characterised by polyarticular swelling and tenderness (the small joints of the hands and feet are most often affected), stiffness and fatigue. These symptoms are driven by chronic inflammation of the synovium which, in the long term, causes irreversible joint damage and consequent disability.

The diagnosis of RA includes a clinical assessment of swollen and tender joints, and the determination of autoantibody status which may include tests for rheumatoid factor (RF) and anti–citrullinated protein antibody (ACPA).\[2\] Auto-antibodies are predictive of progressive joint destruction and have been found to be present in the blood of patients with RA for many years before the clinical manifestation of symptoms. This suggests a potential preclinical phase which may be amenable to preventive treatment.\[3,4\]

Once RA symptoms have developed, early treatment is essential to reduce the risk of irreversible joint damage. The first three months following the onset of symptoms are considered to be a key therapeutic window during which disease modifying anti-rheumatic drug (DMARD) treatment is particularly effective at controlling symptoms and limiting subsequent joint damage.\[5-8\] Policy makers, clinicians and researchers are working towards ensuring that patients are treated promptly when the symptoms of RA begin.\[9\]

Despite increased recognition of the benefits of early treatment there remains considerable patient delay between symptom onset and the initiation of treatment.\[10-16\] Delays can

n.leeson@futuremedicine.com

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occur at multiple points in the patient’s journey to treatment (see figure 1). These include patient delay (delay on the part of the patient in seeking medical advice at symptom onset), primary care delay (delays by the primary health care professional in recognising the symptoms and making an appropriate referral to a rheumatologist), and finally delay in secondary care (where delays may include diagnosis delay and delays in initiating treatment).

Figure 1: Patient pathway from RA symptom onset to receiving treatment: outline of phases where delay can occur.

In the UK, patient delay between the onset of symptoms and seeking help from a healthcare professional was found to be a median of twelve weeks. [11] Delay attributed to primary care services were a median of two weeks and delays related to secondary care were a median of 3 weeks. Therefore, patient delay was the largest contributor to patients not receiving timely treatment. Long delays in patients seeking help at the onset of symptoms have also been reported in other UK studies. [16,17] Conversely, in the Netherlands, patient
delay is much shorter (median delay is less than 2 months), and it is delay on the part of the initial assessing healthcare professional (GP or family physician) which is the largest contributor to patients not being seen quickly.[6]

An exploration of delay in the diagnosis of RA across 10 rheumatology centres in seven European countries reported marked variations in patient delay both between and within countries.[18] Berlin (Germany) and Vienna (Austria) had the shortest patient delay, with patients delaying for a median of 2 weeks before seeking help. Patients in Stockholm (Sweden) and Warsaw (Poland) waited a median of 4 weeks before seeking help, while in Lund (Sweden), Umeå (Sweden), Prague (Czech Republic) and Zurich (Switzerland) median patient delay was 8 weeks. The longest patient delays were recorded in Birmingham (UK) and in Heraklion (Crete) which had median patient delays of 12 and 22 weeks respectively. Difference in health systems, access to healthcare, health literacy and cultural factors may in part explain differences in the level of patient delay observed internationally, although it is clear from this study that delay is not limited to a single country or health care system. Understanding patient barriers to seeking help at RA onset will allow interventions to be developed that encourage and facilitate rapid help seeking behaviour, and will allow us to understand why patients in some counties delay for longer than their counterparts in other parts of the world.
PATIENT BARRIERS TO SEEKING HELP AT RHEUMATOID ARTHRITIS ONSET

At the beginning of an illness the first physical indications that a person has to suggest that they are unwell is the presence of a symptom(s). A patient experiencing the first symptom(s) of RA would be required to engage in a number of psychological processes before deciding how to act. Firstly, as an individual becomes aware of symptoms, they begin to cognitively direct their attention towards the symptoms’ characteristics for example its intensity, location or duration of the symptom. As characteristics are evaluated and interpreted, meaning is given to the processes of symptom emergence. Once a personal interpretation of the symptoms has been developed a person can then use this information to decide how to act, for example seeking medical attention, or not seeking help. Qualitative research has been pivotal in understanding the way that symptoms are perceived, evaluated and acted upon at the onset of RA.[19-22]

A meta-synthesis of qualitative studies [23] identified five constructs which acted as drivers of and barriers to help seeking at the onset of RA:

1. The early RA symptom experience
2. Making sense of early symptom experience and prototypes of RA
3. Minimising the impact of symptoms
4. Speaking to others, gathering information and seeking alternative treatments
5. Accessing health services and attitudes towards healthcare professionals

The nature of symptom onset and the way that individuals interpreted these symptoms were important factors in decisions to seek help.[23] When the onset of symptoms was
acute, with severe symptoms appearing rapidly, people indicated that they interpreted the
symptoms as significant and in need of rapid medical attention. However, this type of rapid
onset only occurs in a minority of patients.[24] In most cases, RA onset is slow and insidious,
with symptom often being described as vague and transitory.[25-27] When symptom onset
is slow, this may lead to incorrect interpretations of symptoms, and cause greater delays in
seeking help. Research has found that older people are more likely to attribute mild
symptoms to the “normal” aging processes, and are more likely to accept their presence
without seeking help.[28] This is because when faced with a new symptom people consider
the impact of symptoms, identify possible causes, estimate how long symptoms may last
and consider whether symptoms can be controlled.[29] Unfortunately, these thoughts
about symptoms at the onset of RA maybe unlikely to lead people to suspect RA as a
possible cause of symptoms nor appreciate that early treatment is necessary for their
condition to improve long term outcomes. Following diagnosis some have suggested that
they had little knowledge of RA before they were diagnosed, often believing RA to be a mild
condition caused by wear and tear which affected the elderly.[21,22] These misperceptions
made correct symptom interpretation unlikely, and often lead to delays in seeking medical
attention.

Behaviours which enable people to cope with symptoms were often described at symptom
onset. Coping behaviours, which are used to help people to manage stressful situations are
used by patients managing new symptoms and include self-managing through limiting daily
activities, using over-the-counter medicines and trying alternative or traditional remedies.
Recent research has found that patients often use over-the-counter medicines from

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pharmacies before seeking help. They develop regimens and use ‘trial and error’ methods of
taking medicines to minimise the impact of symptoms.[30] Further research exploring how
community pharmacies are used to manage the early symptoms of RA, and how
pharmacists advise and intervene in cases of suspected RA is vital.

Seeking information about symptoms and about whether to seek medical attention was
important to help people to feel reassured that the action they had chosen was correct.
Family and friends were often used as “lay consultants”, from whom advice and validation
were sought. For some, social interactions at the onset of symptoms encouraged rapid help-
seeking behaviour, with concerned friends and family persuading the individual to seek help
sooner than they may have done without the encouragement. However, social interactions
could also lead to delay as some were advised to take other courses of action (e.g.
alternative medicines, religious consultation etc) or were advised that symptoms were
unimportant.[19] A study of patient delay in people with arthralgia found that consulting a
family member about symptoms was more common in patients who went on to be
diagnosed with arthritis.[31] That study also found that family and friends were more likely
to encourage younger patients to seek help.

In the UK, primary care services are usually the first point of contact for people experiencing
health concerns or illness. To see a rheumatologist, patients are usually referred by a
General Practitioner (GP), therefore, at the onset of RA, patients need to be encouraged to
consult their GP quickly.[32] Access to primary care services and attitudes towards GPs were
identified as drivers of rapid help seeking, but also as barriers to seeking help.[23] Where
access was restricted (through limited surgery opening hours) or a patient described a poor relationship with or difficulty communicating with their GP, delays in seeking help were reported. A large survey of access to primary care service in England found that younger people, people from black and minority ethnic (BME) groups and those in full time employment had lower levels of satisfaction with primary care services and were reported to use services less. Patients registered with small practices had higher levels of satisfaction.

This summary of the current research exploring the drivers and barriers to help-seeking behaviour at the onset of RA highlights the role of psychology (the broad study of cognition, emotion and behaviour) in understanding how people respond to the early symptoms of RA. Psychologists have also developed models to explain health and illness behaviour, which can help us to understand the relationships between drivers and barrier, and can provide a template for predicting behaviour. These are described in more detail later in this paper.
Psychological theories, including the health belief model and theory of planned behaviour, provide a framework for understanding the way that people perceive and react to a health threat.[34-36] These theories examine the cognitions (thoughts, beliefs and perceptions) and decision-making processes which predict future health-related behaviours. Different psychological theories suggest that different sets of cognitions are important in predicting behaviour. For example, the health belief model suggests that perceptions such as perceived susceptibility and severity are helpful in predicting behaviour, while the theory of reasoned action emphasises the role of perceived behavioural control, and intentions to act as being important in predicting behaviour. These models are particularly useful in understanding why people choose to engage in unhealthy behaviours or in health protective behaviours. The self-regulation model (SRM, also referred to as the Common Sense Model) differs from other psychological models because it specifically represents the thoughts and emotional processes a person may face when presented with the threat of new symptoms or an illness.[37,38] When applied to help-seeking behaviour, the SRM suggests that when a person is faced with a new symptom they will attempt to understand and assign meaning to their experiences. The SRM proposes that five key concepts, known as illness representations, are explored when new symptoms are encountered. The five key concepts described by this model are: illness identity, illness cause, illness timeline, illness consequences and illness controllability. Illness representations are important for understanding outcomes and behaviour throughout the course of RA. For example, in people with RA, perceptions about the consequences of disease are associated with clinical
depression,[39] concerns about illness and consequences are associated with lower health related quality of life [40] and disease activity scores are correlated with the perceived consequences of illness and higher illness identity scores[41].

Table 1 illustrates how these illness cognitions may influence help-seeking behaviour. It is argued that these representations direct how people interpret and respond to symptoms,[42] and consequently influence whether help is sought or another course of self-management is undertaken. It is also proposed that when symptoms correspond with pre-existing ideas and representations of a particular illness, a person will recognise that they are ill and in need of medical attention.[43]

Table 1. Categories of illness representation, their descriptions, and examples of beliefs associated with these representations in relation to RA

<table>
<thead>
<tr>
<th>Representation</th>
<th>Description</th>
<th>Example of beliefs associated with this representation</th>
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<tbody>
<tr>
<td>Cause</td>
<td>Beliefs related to the perceived cause of symptoms</td>
<td>Symptoms are caused by physical exertion</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Symptoms are a normal part of the aging process</td>
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<tr>
<td></td>
<td></td>
<td>Symptoms are caused by hormonal changes</td>
</tr>
<tr>
<td>Timeline</td>
<td>Beliefs related to how long the symptom will last</td>
<td>Symptoms will be short-term and self-resolving</td>
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<td></td>
<td></td>
<td>Symptoms will last for the rest of my life</td>
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<tr>
<td></td>
<td></td>
<td>Symptoms will come and go over time (palindromic)</td>
</tr>
<tr>
<td>Control (and curability)</td>
<td>Ability to personally control symptoms, and the perception that seeking help will result in the control of symptoms</td>
<td>Symptoms can be controlled through self-management (such as diet, over the counter medicines or rest)</td>
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<tr>
<td></td>
<td></td>
<td>Symptoms can be controlled through herbal remedies</td>
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<td></td>
<td></td>
<td>Symptoms cannot be controlled by medicines prescribed by a doctor</td>
</tr>
<tr>
<td>Identity</td>
<td>Characteristics of the symptoms experience</td>
<td>Symptoms will emerge slowly</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Symptoms will grow in intensity</td>
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These representations are cognitively processed alongside emotional reactions such as fear and worry about the illness.

Research has shown that illness representations play an important role in decisions to seek help when new symptoms emerge.[44,45] For example, Cameron and colleagues found that an increase in the perceived severity of disease was negatively correlated with the period between symptom onset and seeking help.[44] Therefore, as perceptions of symptom severity grew, the more likely an individual would be to seek help. This study also found that when a person’s self-care strategy failed they were more likely to seek help. This supports the SRM proposition that people continually appraise symptoms, respond, and then appraise the outcome. When the outcome fails, new appraisals and coping strategies are implemented. As summarised by Cameron and colleagues, “As an illness episode unfolds and coping procedures are executed and appraised, the illness representation is increasingly elaborated. The more complex the representation, the more varied and active are the coping procedures. When this process results in a judgment that a symptom is serious, disruptive of ongoing activities, and difficult to control, the person is likely to seek medical care. In summary, symptoms initiate the decision process and play a continuing role.

<table>
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<tr>
<th>Consequences</th>
<th>Symptoms will be concentrated in the joints of my fingers</th>
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<td>The consequences of the symptoms</td>
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<td></td>
<td>Symptoms will prevent engagement with usual daily activities</td>
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<td></td>
<td>Symptoms may be life threatening</td>
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<tr>
<td></td>
<td>Symptoms will stop me from working</td>
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Symptoms will be concentrated in the joints of my fingers

The consequences of the symptoms

Symptoms will prevent engagement with usual daily activities
Symptoms may be life threatening
Symptoms will stop me from working

As an illness episode unfolds and coping procedures are executed and appraised, the illness representation is increasingly elaborated. The more complex the representation, the more varied and active are the coping procedures. When this process results in a judgment that a symptom is serious, disruptive of ongoing activities, and difficult to control, the person is likely to seek medical care. In summary, symptoms initiate the decision process and play a continuing role.
... throughout the illness episode as targets for coping and as points of reference for appraising coping outcomes.”[44]

Furthermore, a study of the content of consultations where patients presented to primary healthcare services for the first time found that 95% of discussions could be mapped on to perceptions of control, identify, consequences, timeline and cause.[46] This further highlights that the SRM is a useful framework for exploring how and why people access health services at the onset of new symptoms.

Some theorists argue that elderly individuals have a greater amount of “life experience” to draw on when interpreting new symptoms, and deciding if the symptoms are trivial or require medical attention. For example, Mora and colleagues propose that elderly individuals should be able to draw on personal experiences of illness and interpret whether an illness timeline is short (acute), long-term or chronic, severe or mild, novel or an expected part of the aging processes.[47] Therefore, theoretically older people should be able to make more coherent and informed decisions on whether to seek help.
SOCIAL REPRESENTATIONS AND PUBLIC PERCEPTIONS OF RA

Perceptions about illness which do not concur with the lived experience or medical understandings of illness are known as misperceptions. The misperceptions a society has about RA may cause members of public to view RA as a trivial condition or a normal part of aging. Indeed misperceptions can cause those diagnosed with RA to face stigmatization by their peers.[48] Therefore cultural and societal beliefs about RA can affect a person’s reaction to their first signs of this illness. Also, at an individual level, exploring the way that members of the public (without RA) may respond to the first symptoms of RA, could help us understand the processes involved in the construction of personal evaluations of symptoms and the help-seeking decision making process.[49,50]

Pre-existing ideas about illness are often referred to as prototypical illness beliefs, and are held by people who have no personal experience of the illness in question to draw from.[51] These prototype models of illness are influenced by cultural understandings of illness and knowledge (often derived from media, family and peers).[52] The prototypes of some illnesses may be better formed than the prototypes held for others, for example, the knowledge surrounding the symptoms of and how to manage a condition like the flu, maybe more complete, robust and reliable than the prototypical beliefs held about a condition such as RA. Similar to illness representations, prototypes may indicate how long a person expects a particular illness to last, how severe they perceived it to be, the symptoms they would expect to experience, their understanding of whether it can be controlled, who is more susceptible to the illness and what the consequence of having such an illness maybe
(similar in structure to illness perceptions). \[51\] The core difference between illness perceptions and prototypical beliefs are that illness perceptions are derived from personal experience of illness by those who are ill (usually diagnosed with that illness).

Prototypical models can be unhelpful if they do not concur with actual illness experience or medical models of illness, and may mislead people into believing that the symptoms of conditions such as RA do not require them to seek medical attention.

Studies investigating prototypical beliefs about RA have examined the knowledge that members of the public have about RA. In Australia, researchers conducted 2038 telephone interviews with members of the public (25% were reported to have RA or another type of arthritis; 81% knew someone with arthritis). \[53\] When asked what types of arthritis they could name, only 35% of respondents mentioned osteoarthritis and 44% named RA. Overall, a third of respondents could not name any form of arthritis. Male respondents and those in younger age groups (18-29) were more likely just to mention general arthritis or could not name any form of arthritis at all. In contrast, female respondents, those in older age groups and those with a higher level of either education or income, were more likely to name RA.

No direct comparisons were made between those with arthritis and the rest of the respondents for knowledge of arthritis types. When asked whom they thought was most at risk of developing arthritis, a third of participants thought it was mainly old people whereas only 20% indicated that people of all ages could develop arthritis. Those with RA or another type of arthritis were slightly more accurate when indicating who was most at risk.
In the US, a survey of 300 members of the public found that only 22% of people could name osteoarthritis as a form of arthritis, and that only 13% of people could name RA.[54] Furthermore, 28% of people surveyed thought that arthritis was a natural part of growing older, and almost half of the sample believed that arthritis could be caused by poor diet and/or cold and wet climates. A survey of US college students found that RA was perceived to be less severe and to be more curable that other chronic illness such as AIDS and multiple sclerosis.[55] Similarly, college students in New Zealand perceived RA to be a non-life threatening disease and were unsure of whether RA could be cured.[49] This research highlights that knowledge about arthritic conditions in general is poor and that knowledge about RA in particular is poor in comparison to other conditions.

In Europe, the public’s knowledge of rheumatic disease, including RA, also appears to be poor.[56,57] A survey including 17 true or false statements about rheumatic diseases, was sent to members of the public in the Netherlands,[57] and in Portugal.[56] In the Netherlands, members of the public correctly answered 48% of statements on rheumatic diseases, while in Portugal this figure was 62%. A more detailed comparison between the individual knowledge items showed some interesting differences and similarities between the two countries. Only 17% of the Dutch sample correctly believed that about one in twenty Dutch people is being treated for a rheumatic disease, whereas 84% of Portuguese sample believe the same for the Portuguese people. Thirty-three percent of people in the Netherlands and 47% in Portugal believed that people could die from the consequences of rheumatic diseases. Sixty percent of the Dutch sample and 89% of the Portuguese sample
correctly believed that “Rheumatoid arthritis is a rheumatic disease in which the joints are affected with inflammations”.

A UK survey of people with RA and those without, found that 30% of participants with arthritis incorrectly believed that arthritis only occurred in cold weather compared to 16% of the subsample of participants who had a friend or relative with arthritis and 23% of participants who did not have arthritis and did not know anyone with arthritis. In addition, 36% of arthritis patients incorrectly linked it solely to damp environments compared to 25% of those who knew someone with arthritis and 33% of those who did not have arthritis nor did they know someone with arthritis. Interestingly, 78% of the subsample of participants with arthritis further believed it to be a non-fatal disease, compared to 60% of the participants who had a friend or relative with arthritis and 50% of the participants who did not have arthritis and did not know anyone with arthritis. Seventy-three per cent of the participants aged 65 or older believed that the disease would progressively get worse compared to 50% of the under 35s. The authors of this survey concluded that factors such as age and experience might affect knowledge about arthritis, something which the findings of the Australian study support. Research with older people experiencing joint problems shows that they are able to distinguish between symptoms which are normal for their particular joint problems (what they would call normal aches and pains), and the symptoms of more serious problems such as RA. Interviews with older people revealed that they were able to distinguish between ‘wear and tear-type’ joint pain and other joint pain that they did not consider to be normal for their age (for which they were more likely to seek help). This indicates that older people do use their previous experiences to make decisions, to interpret perceived symptoms, and make decisions to seek help. More recently,
studies of previous experience and knowledge have focused on health literacy, which in the context of help-seeking behaviour represents one’s ability to understand and use information, and draw on previously acquired knowledge and skills to make informed decisions on whether to seek medical treatment.[60]

THE ROLE OF HEALTH LITERACY IN REDUCING PATIENT DELAY

Health literacy refers to the ability of a person to obtain, interpret and understand health information and use it to their advantage[61] and is defined by the World Health Organisation as: “the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand and use information in ways which promote and maintain good health”. [62]

Low levels of health literacy are associated with lower levels of health knowledge, poorer self-management skills, less use of preventive services and a great risk of hospitalisation.[63] In a US study of community-dwelling older adults, low health literacy was independently associated with poorer physical and mental health.[63] Research on the impact of health literacy in information seeking found that people with low levels of health literacy were less engaged with health information-seeking behaviour, specifically not going beyond what their GP told them.[64] Participants with intermediate levels of health literacy were more likely to obtain information about arthritis from newspapers and television, and from within their social network. Those with high health literacy levels obtained information about arthritis from the internet and specialist health sources. Furthermore, these participants were often providers of health information within their social network. People with a
chronic disease such as RA and low health literacy may have problems communicating with health care professionals and have a lack of knowledge about their disease and medication.[65] These findings suggest that health literacy may have an important impact on health outcomes in established disease.

The associations between the general public’s health literacy levels, their knowledge of RA, the likelihood that they will seek information and seek help when first experiencing the symptoms of RA remain unclear. This needs to be addressed if we want to develop successful interventions to address the delay in GP consultation with early onset RA symptoms.

THE DEVELOPMENT OF INTERVENTIONS TO ADDRESS PATIENT DELAY AT RA ONSET

There is some evidence that careful structured information may change the public’s perception of RA. A recent study provided participants with different types of written information prior to being questioned about RA. One third of participants received information about RA which emphasized the consequences of RA and highlighted a number of possible causes, including smoking and drinking coffee, one third of participants received information which emphasized that RA could be treated and discussed infection as a possible cause and the remaining participants received no information other than the name of the disease (RA).[50] Those participants in the latter group were significantly more likely to attribute RA to aging, heredity, injury and overwork, and were significantly more likely to think of it as a disease which could be personally controlled or controlled by treatment. Those participants receiving the other types of information gave answers which indicated...
that providing information about RA and its causes had a (short-term) effect on what people believed the causes and impact of RA to be. However, the attribution to aging was made by a high percentage of participants in all three groups, regardless of the information provided.

This study found that people without RA draw on the generalized representation of RA, particularly in relation to aging and that they do fully utilize information about RA when it is provided. Interventions aimed at increasing the awareness of RA in the general population should therefore provide the public with accurate information about RA in a format that is appropriate to their level of health literacy.

Research has further shown that the terminology used when providing medical information will have an impact on public perceptions of an illness. Young and colleagues found that in cases of newly defined medical conditions using a medical term rather than a lay term led participants to perceive the illness to be more severe and less common. Participants also felt that the medical term described the disease better than the lay term.[66] Their study highlights the influence of medical language in communication and suggests that this might impact on the public perception of the illness in areas such as advertising and press releases. It seems clear that the language used in any intervention (such as public health campaigns on television or in newspapers) should be carefully checked for its impact on the public perception.

An additional factor which impacts on the public perception of an illness is the frequency with which it is reported in the media. In a series of experimental studies, Young and colleagues found that participants considered infectious diseases, which received repetitive
media attention, to be more severe and more ‘disease-like’ than comparable diseases which received less media attention. [67] Van der Wardt and colleagues investigated the quantity and the quality of information on health conditions provided by the mass media (specifically nine newspapers and four Dutch TV channels) in the Netherlands over a one year period (in the early 1990s). [68] They concluded that the amount of attention given to a disease by the media was influenced by its fatality rate, not its prevalence. They further concluded that more frequent and more accurate coverage of chronic diseases and in particular rheumatic diseases was needed to do justice to the impact of these diseases on the general public.

When developing an effective intervention to make the public more aware of the early symptoms of RA, we should consider the information we present, the language we use and how the campaign makes use of the media.

To date, there have been very few campaigns targeting RA in the UK. The S Factor campaign was developed by the Rheumatology Futures Research Group, National Rheumatoid Arthritis Society and Arthritis Research UK and launched in 2011. [69] The primary communication strategy in this campaign was a poster highlighting the most common symptoms of RA: swelling, stiffness and squeeze (pain when the joints are put under pressure). No data are yet available regarding the impact of this campaign.

FUTURE PERSPECTIVE
There have been calls for evidenced based tailored interventions to promote rapid help-seeking and promote public understandings of RA.[9] Future research aims to map the causes of delay and drivers of help seeking behaviour on to different demographic groups to inform the development of tailored health promotion interventions.[51] The development of a robust evidence base is vital to inform the content of such interventions and the impact of such interventions needs to be rigorously assessed from a health economic perspective.

Research exploring help-seeking behaviour at the onset a myocardial infarction (MI) has employed a number of experiential methods to explore the role illness perceptions and prototypes in patient delay at symptom onset. These methods include the comparison of the perceptions people hold about the symptoms of MI before onset and the symptoms they actually experienced; mismatched prototypes and experience cause longer delays in seeking help.[70,71] Research has also identified symptom clusters which represent the illness experience of people who have experienced an MI.[72] This research has contributed to an evidence base used to inform interventions to reduce patient delay at MI onset. A similar research base is urgently needed in the field of RA to inform future public health interventions. In the future, once interventions have been developed, they must be implemented and their effectiveness in reducing patient delay tested.

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 have been identified to explain patient delay, for example by highlighting that although initial symptoms may be mild, rapid help seeking is still necessary to allow early treatment to limit long term damage. The effectiveness and cost effectiveness of these help-seeking 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 (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 intervention strategies.

Finally, ongoing research is focusing on the identification of people at risk of RA before symptoms are experienced with the aim of implementing preventive therapies.[3] Healthcare professionals may thus be required to intervene even earlier, before symptoms become apparent. It will be important that clinical services can access those at risk effectively, and that once individuals at risk are identified that the consequences, severity of RA, and risks associated with RA can be effectively communicated.
Reference List


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