

RESEARCH ARTICLE

Qualitative Exploration of Illness Perceptions of Rheumatoid Arthritis in the General Public

Gwenda Simons^{1*†}, Anna Mason^{2†‡}, Marie Falahee¹, Kanta Kumar^{1,2,3}, Christian D. Mallen⁴, Karim Raza^{1,2§} & Rebecca J. Stack^{1,5§}

¹University of Birmingham, Birmingham, UK

²Sandwell and West Birmingham Hospitals NHS Trust, Birmingham, UK

³University of Manchester, Manchester, UK

⁴Keele University, Keele, UK

⁵Nottingham Trent University, Nottingham, UK

Abstract

Treating patients with rheumatoid arthritis (RA) within three months of symptom onset leads to significantly improved outcomes. However, many people delay seeking medical attention. In order to understand the reasons for this delay, it is important to have a thorough understanding of public perceptions about RA. The current study investigated these perceptions using the Self-Regulation Model (SRM) as a framework to explain how health behaviour is influenced by illness perceptions (prototypes) through qualitative interviews with 15 members of the public without RA. Interviews were audio-recorded, transcribed and analysed using framework analysis based on SRM illness perceptions. Both accurate and inaccurate perceptions about the identity, causes, consequences, controllability and timeline of RA were identified. This highlights opportunities to enhance public knowledge about RA. These findings further support the utility of exploring prototypical beliefs of illness, suggesting their potential role in influencing help-seeking behaviours and identifying probable drivers/barriers to early presentation. © 2016 The Authors Musculoskeletal Care Published by John Wiley & Sons Ltd.

Keywords

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

*Correspondence

Gwenda Simons, Rheumatology Research Group, Institute of Inflammation and Ageing (IIA), University of Birmingham, Queen Elizabeth Hospital, Birmingham, B15 2WB, UK. Tel: +44 (0) 121 371 3265.

Email: g.simons@bham.ac.uk

[†]Anna Mason is now at the Paediatric Department, Royal United Hospital, Bath, UK

[‡]First authors GS and AM have contributed equally to this work.

[§]Senior authors KR and RS have contributed equally to this work.

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Introduction

Rheumatoid arthritis (RA) is a systemic chronic inflammatory disease which primarily affects the peripheral joints. Its early symptoms are articular (e.g. joint stiffness, pain and swelling) and systemic (e.g. fatigue and mood disturbance). The sometimes non-specific nature of its

initial symptoms can make it difficult both for healthcare professionals and patients to identify the disease in its earliest phases (Stack et al., 2013a, 2014). The first three months following the clinical onset of RA represent a key therapeutic window during which drug treatment with disease-modifying anti-rheumatic drugs (DMARDs) is particularly effective at limiting long-term joint damage

(Nell *et al.*, 2004; Raza *et al.*, 2006; Scott *et al.*, 2011; van der Linden *et al.*, 2010). However, there are often considerable delays between symptom onset and the initiation of therapy (Feldman *et al.*, 2007; Kiely *et al.*, 2009; Kumar *et al.*, 2007; Mølbæk *et al.*, 2015). One important source of delay is the patients themselves (Villeneuve *et al.*, 2013). In the UK, people have been shown to delay for a median of 12 weeks at the onset of RA symptoms before seeking help from a healthcare professional, whereas across other European countries patient delay appears to vary between two and 22 weeks (Raza *et al.*, 2011). As a result of these delays, many patients miss the therapeutic window of opportunity (Kumar *et al.*, 2007; Mølbæk *et al.*, 2015).

Several models have been proposed to help to explain the underlying psychological processes which may lead to delayed help-seeking behaviour. One of these is the self-regulation model (SRM; also referred to as the common-sense model), which provides a framework through which to understand people's thoughts, emotions and behaviours in the context of the development of new symptoms (Leventhal *et al.*, 1983, 2005). The SRM proposes that individuals explore five key concepts, known as illness representations, when they experience new symptoms (Leventhal *et al.*, 1983, 2005): (1) Illness identity (the name or label given to the illness and the symptoms which people associate with it); (2) Illness cause (the perceived cause of the condition); (3) Illness consequences (beliefs about the consequences of the condition, including its physical and social impact); (4) Illness timeline (beliefs about how long the illness will last and its curability) and (5) Illness controllability (beliefs about whether the illness can be controlled and its symptoms alleviated).

'Prototypical illness beliefs' are the illness representations held by people who have no personal experience of the illness in question (Bishop and Converse, 1986). These beliefs are influenced by cultural societal understandings and knowledge about the illness, which is often derived from the media, family and peers (Shaw, 1992). The prototypes of some illnesses may be better formed than those of others. Knowledge surrounding the symptoms and management of common illnesses such as the flu may be more complete, robust and reliable than that held about rarer conditions such as RA (Leventhal *et al.*, 2005).

Illness representations have been shown to be useful for understanding outcomes and behaviours throughout the course of a patient's journey with RA (Hyphantis *et al.*, 2013; Sharpe *et al.*, 2001; van Os

et al., 2012), and may play an important role in decisions to seek help when new symptoms emerge (Berkanovic *et al.*, 1981; Cameron *et al.*, 1993). Cameron and colleagues (1993) found that the more severe a disease was perceived to be (identity), the shorter was the delay between symptom onset and seeking help.

The few studies that have investigated the prototypical beliefs about rheumatic disease held by the general public indicate that beliefs are often inaccurate (Badley and Wood, 1979; Severo *et al.*, 2010; van der Wardt *et al.*, 2000). Factors such as age and personal experience with joint problems may affect these beliefs (Badley and Wood, 1979). Indeed, research with older people experiencing musculoskeletal symptoms shows that they are able to distinguish between 'normal aches and pains', and the symptoms of more serious problems such as RA (Grime *et al.*, 2010; Mora *et al.*, 2002).

Illness representations or prototypical models that do not concur with the experiences of those suffering with the illness or with current medical understanding, are known as illness misperceptions (Stack *et al.*, 2013b). Illness misperceptions held about RA may include ideas that RA is a trivial condition or a normal part of ageing and may mislead people into believing that the symptoms of the condition do not require them to seek medical attention. Cultural beliefs and understanding may also affect the processes of symptom recognition and help-seeking (Kumar *et al.*, 2010). Investigating the prototypes of RA held by members of the public could help us to understand the processes involved in the help-seeking decision-making process (Treharne *et al.*, 2010). However, most research looking at the prototypical beliefs related to RA, especially in the UK, has been primarily focused on arthritis in general and is relatively dated, and thus might not reflect current perspectives (Severo *et al.*, 2010; van der Wardt *et al.*, 2000).

The current study investigated the (mis)perceptions and prototypical beliefs that members of the general public (without RA) had about RA and its symptoms through a series of qualitative interviews. In addition, the interviews explored their anticipated feelings, thoughts and behaviour if confronted with symptoms of RA (specifically, joint pain, joint stiffness and swelling). The use of qualitative interviews allows an in-depth exploration of the current perceptions of the general public about RA which in the future will be used to inform larger-scale quantitative studies. A novel aspect of the current study is that it systematically evaluated all five concepts of the SRM in relation to prototypical beliefs about RA.

Methods

Participants

Members of the general public, aged 18 years or over and without a diagnosis of inflammatory arthritis (including RA), registered with two inner-city practices from Primary Care Research Network Central England (PCRNCE) North Spoke, were invited to take part in an interview study looking at the public perception of long-term illnesses and seeking help. A Clinical Studies Officer (CSO) from PCRNCE North Spoke extracted names of potential participants from the patient list of participating practices, excluding participants with a diagnosis of inflammatory arthritis. Participants were purposively sampled from three age groups (18–40, 41–60 and over 61 years), with the largest group being the 41–60s, allowing the final sample to reflect demographically the age distribution for RA onset. The resulting lists were screened by the responsible general practitioner (GP) to exclude vulnerable patients whom they deemed unsuitable for the study. The CSO sent patients on the screened lists an invitation letter and participant information form on behalf of the GP practice and the researchers; these documents explained that the study was about the public perception of long-term illnesses and seeking help. Reminders were sent to non-responders after two weeks. Those interested in participating contacted GS directly to arrange an interview. A total of 416 patients were approached in several mailings, spread out over two months, and recruitment was ceased when data saturation was achieved. Data presented here came from a larger data set of 38 interviews with members of the public, of whom some knew people with RA and others did not (Simons *et al.*, 2015). As the current study focused on the RA prototypes of individuals with no personal experiences with RA, the analyses were restricted to those interviews in which the interviewee reported that they were not related to and did not personally know anyone with RA.

Interview procedure

The semi-structured interviews were conducted (by GS) in the general practices. The interview schedule was derived from previous research into barriers to help-seeking in patients with new-onset RA (Stack *et al.*, 2012) and was further informed by the literature

on prototypical illness beliefs (Bishop and Converse, 1986), illness perceptions (Cameron *et al.*, 1993) and the SRM. The interview schedule was developed with two patient research partners with RA, who modified some questions to reflect their personal experiences.

The interviews explored knowledge and perceptions about RA and its symptoms (e.g. '*what would you think if your fingers were swollen?*'). Participants were also asked what symptoms they associated with RA, OA and arthritis in general, and about their illness perceptions of RA (see Table 1 for the interview guide).

Analytical procedure

The interviews were audio-recorded and transcribed verbatim. The interview data were analysed using framework analysis (Gale *et al.*, 2013; Ritchie and Lewis, 2003; Smith & Firth, 2011), whereby the domains of the SRM were used to structure the data and their analysis. The framework method itself is not aligned to a particular epistemological or philosophical approach, but we used the SRM as a theoretical framework. RS and AM undertook initial blind coding on three transcripts, and areas of disagreement were discussed so that concordance in coding could be reached before AM coded the remaining transcripts. The codes were then grouped into the most frequently occurring categories. These categories were subsequently mapped onto the five SRM representations of illness [i.e. (1) Illness identity; (2) Illness cause; (3) Illness timeline; (4) Illness consequences and (5) Illness controllability] by AM, and then confirmed independently by RS and GS. Excerpts of the interview transcripts were also presented to patient research partners associated with the project, who provided feedback on the coding and analysis of the interview data. No substantial changes to the coding were needed as a result of this process.

Ethics

Ethical approval for the study was obtained from the South West – Bristol Research Ethics Committee (REC ref 12/SW/0195) and all participants gave written informed consent.

Results

Participants

Fifteen (12 females) of the 38 participants fitted the criteria for inclusion in the current study (i.e. aged over

Table 1. Interview guidelines**Introductory questions**

- Have you ever experienced problems with your joints?
 - If yes: when? What did you do? Who did you tell? How did you cope? How worried were you?
- How worried would you be now if you developed joint problems? What would worry you the most?
- What would you do in the future? (if you developed joint problems)
- How would having joint problems affect your life? OR How severe would a joint problem have to be to affect your life?

Specific symptoms**Swollen joints**

- What would you think if you noticed your fingers were swollen? What would you attribute swollen fingers to?
- Would swollen fingers worry you?
- What would you do about it?
- If your feet were swollen, would you feel differently or would your actions be different?
 - If different: Why do you think that is?
 - Would it worry you?

Joint stiffness in the morning

- What would you think if you woke one morning and found that your joints were stiff? What would you attribute it to?
- What would you do about it?
- What would you do if the stiff feeling did not disappear for over an hour?
- What would you do if this continued for a week/one month/six months/one year?
- At what point would you become worried or anxious about feeling stiff in the morning?

Painful joints

- What would you do if you experienced pain in one of your joints (e.g. in your fingers)?
- What would you do if you experienced pain in two joints (e.g. in more than one finger)?
- What would you do if you experienced pain in three or more joints (e.g. in lots of fingers on both hands)?
- If your feet were in pain, would you feel differently or would your actions be different?
- Would painful joints in your hands/feet/elsewhere worry you?

Knowledge of rheumatoid arthritis

- What do you understand about what may cause joint pain?
- What do you know about arthritis in general?
- What do you know about rheumatoid arthritis?
- What symptoms would you associate with rheumatoid arthritis?
- What symptoms would you associate with osteoarthritis?
- What would be the difference between rheumatoid arthritis and other joint problems?
- What do you know about what goes on in the joints with rheumatoid arthritis/osteoarthritis?
- Do you know anyone with rheumatoid arthritis?*

Illness perceptions about rheumatoid arthritis

- Is rheumatoid arthritis a serious condition?
- If you were told you had rheumatoid arthritis, how long do you think it would last?
- How would you know you had the condition – what signs would there be?

*(Continues)***Table 1.** (Continued)

- With whom do you associate arthritis/rheumatoid arthritis (i.e. who is the typical patient)?
- What would be the consequences of having rheumatoid arthritis for day-to-day living?
- What are the causes of rheumatoid arthritis?
- Do you think you would be able to control rheumatoid arthritis yourself?
- Would you need medical help?
- Do you think there are treatments available that would effectively treat rheumatoid arthritis?
- What kinds of treatment do you know?

*Answers to this question were used to identify whether participants fulfilled the inclusion criteria in the current analysis

18 years, no diagnosis of inflammatory arthritis and no family or friends with RA). Although none of the sub-sample of participants knew someone with RA, several participants indicated that either they or an acquaintance suffered from osteoarthritis (OA) or another non-inflammatory joint problem. All participants were white British and aged between 28 and 77 years (mean = 57.5; standard deviation = 15.3; see also Table 2).

Themes

The data presented reflect participants' prototypical understandings of RA organized around the five main SRM illness representations. Themes and subthemes are presented in Table 3. Illustrative quotations for each of these are presented below. Participants are identified by their participant number (*p*; e.g. *p01*).

Table 2. Participants' demographic details

Participant number	Age	Gender	Occupation
01	69	Male	Retired
02	60	Female	Healthcare-related job
03	59	Female	Not working owing to ill health
04	74	Female	Retired
05	67	Female	Retired
06	42	Female	Office worker
07	66	Female	Retired (medical background)
08	67	Female	Retired
09	28	Female	Office worker (medical background)
10	77	Male	Manual worker
11	60	Female	Retired
12	49	Male	Manual worker
13	44	Female	Office worker
14	70	Female	Retired
15	31	Female	Office worker

Table 3. Themes and subthemes

Theme title	Subthemes
1. Identity beliefs	Reported lack of knowledge Perceived symptoms of rheumatoid arthritis (RA) Underlying processes (wear and tear; inflammation) RA as a systemic disease or autoimmune disease
2. Illness cause	Natural part of the ageing process Result of specific (sports) activity or occupation or an injury to the joint Role of specific foods and diet Hereditary factor Different causes for symptoms in feet as opposed to hands
3. Illness consequences	Impact on mobility, resulting in restrictions for social activities Impact of symptoms on daily activities, the ability to work, driving Emotional consequences Loss of independence
4. Illness timeline	RA is lifelong No cure (might even shorten life expectancy) Disease progression
5. Illness controllability	Perceived lack of knowledge about the specific treatments available Specific medical treatments for the management of RA Symptomatic relief with analgesia, including anti-inflammatory medications Symptom management through physio- or hydrotherapy Symptom management through lifestyle changes Use of appliances to make coping with the consequences of RA easier Self-management (e.g. over-the-counter medication)

Theme 1: Identity beliefs

This theme focused on participants’ knowledge about RA and its symptoms. When asked directly, many participants expressed a lack of knowledge about the different types of arthritis, and about RA in particular. Many felt that very little was heard about RA and that the general public needed more information. For example, one participant highlighted that despite having been a nurse, she knew very little about RA, and thus questioned how non-medically trained people might know about it:

‘The fact that I don’t know much about it [RA], is, I suppose, worrying because, you know, what are people that are non-medically trained going to know about it? So, maybe, I just think if there was more education out there, maybe it would help people.’ (p09)

Other participants recognized that RA causes joint stiffness, restricted movement, deformity and disability. In terms of processes operating within the rheumatoid joint, many participants associated RA with ‘general joint wear and tear’. Furthermore, when participants were asked to describe the potential symptoms of RA, they often described symptoms typical of OA or osteoporosis instead:

‘Other than it’s a deterioration of the roughing of the bone surface, I think. And friction builds up between the joint.’ (p01)

Some participants talked about joint inflammation and identified that as the cause of joint pain. In some cases, a more systemic description of RA was given. Several participants further identified RA as an autoimmune disease, described by some as the body ‘damaging itself’:

‘What causes the pain in the joints? I presume that it’s something to do with inflammation as much as anything else. ...It’s usually joints that are inflamed, skin (can be) inflamed as well, but joints are inflamed. Joint inflammation, it does cause pain. I don’t know what it quite does to the nerve endings but it presumably irritates the nerve endings and that’s what causes the pain.’ (p11)

‘Rheumatoid arthritis. When I think about that, I think, and I’m probably quite wrong, it was like an autoimmune arthritis.’ (p09)

Theme 2: Causes of arthritis

This theme focused around participants’ descriptions of the potential causes of arthritis in general, and RA in particular. Many participants saw joint problems as a ‘natural’ or ‘common’ part of ageing and, as a result, felt that there was not much that could be done about its onset or progression. When asked specifically about the typical age that someone may develop RA, many participants associated RA with ‘older’ people, whereas some felt that it mainly affected younger people or indicated that its incidence was not age related:

‘Aches and pains are just something that you get as you get older.’ (p07)

‘I’d always assumed that it [RA] was, sort of, young or early middle-aged people that got it, I never thought about old people getting it.’ (p11)

Participants suggested that the joint symptoms associated with RA might be the result of being involved in certain activities, such as (over-) exercising, playing high-impact sports and/or specific occupations such as nursing and heavy industry:

‘Well, if you’ve got [a] very heavy industrial occupation, that can affect your joints. There’s a lot of occupations where they’re doing a lot of bending over, you know. That can affect back pain and eventually your joints, I should imagine.’ (p03)

Participants also mentioned the potential causal role of diet in the development of RA and suggested that specific foods might influence the chances of developing arthritis. Some participants suggested that arthritis, including RA, could occur following a fracture or dislocation of a joint. Several participants mentioned that arthritis in general can be hereditary, giving examples from their own family history. Others speculated about the possibility that genes play a role in the development of RA, although they were generally unsure about this:

‘I don’t know if there’s a genetic element to rheumatoid; I have no idea if it is or not.’ (p11)

Finally, when asked what they would think if the symptoms were to develop in their feet rather than hands, some participants suggested alternative causes, with foot symptoms being related, for example, to circulatory problems and ‘fluid retention’.

Theme 3: Consequences

This theme focused on the perceived consequences of being diagnosed with RA. Participants discussed the potential severity of the impact of (rheumatoid) arthritis on daily living, the types of limitations to activities that may occur and the social implications, including stigma and difficulty in managing social roles. Participants felt that the symptoms of RA would have an impact on mobility. The need for walking aids, such as sticks or frames, was commonly mentioned, with many having witnessed this in family or friends suffering with OA or some other form of arthritis/joint problem. Participants further felt that reduced mobility would restrict social and leisure activities, and could lead to potential isolation at home:

‘I think being able to get out of the house ... and I like to visit old churches and castles and get out into the countryside and have pub lunches; if I couldn’t do any of that....’ (p01)

In addition to mobility, a number of participants speculated how RA might cause difficulty with hand movements such as gripping, and highlighted the significant impact of that on daily activities. Many participants highlighted the effect that having RA would have on their ability to work, as a consequence, for example of, difficulties with writing, typing or standing for long periods. Several participants specifically mentioned that RA affecting the hands or feet could lead to difficulty in driving:

‘Because my hands are really sort of important for my work. ... I can’t work, can’t drive, can’t do anything without my hands. And so that would have a severely limiting effect on me.’ (p13)

Besides the physical limitations of having RA, many participants discussed potential emotional consequences, such as frustration and depression. These emotional consequences were often linked to issues such as the perceived pain, reduced mobility and the progressive nature of the condition:

‘I would be very, very upset ... because of walking. Because I do so much walking and if that was going to affect me then I think it could affect my mental health a bit.’ (p05)

The progressive decline in mobility and ability to self-care caused by RA was felt by a number of participants to lead eventually to a loss of independence and reliance on others for most daily tasks. Overall, it was felt that the symptoms of RA would have serious potential consequences for day-to-day activities and quality of life, although one participant mentioned that RA might vary in severity and thus have different effects on different people:

‘And I suppose ... there must be degrees of it. I don’t think it’s quite as black and white as you’ve either got it or you haven’t. I should think people sometimes have got degrees of it. And depending on the degrees of it ... it becomes serious.’ (p12)

Theme 4: Timeline

This theme relates to participants' perceptions about the duration of RA and their ideas about its curability and progression. When asked how long they thought the disease would last, many participants indicated that they thought it would be life-long, and at least one participant suggested that RA might in fact shorten life expectancy:

'Something that can affect people their whole life and that's something they've got to deal with their whole lives, and that they've got to, kind of, consider throughout their life.' (p09)

'And I don't know if this sounds right, if their life expectancy is, is less with rheumatoid arthritis? If it can be life threatening.' (p08)

Whereas some participants felt that RA would gradually progress, others felt that the pain associated with it might improve once bones had 'fused'. In general, participants who discussed the possible progression of the disease appeared to rely on their own experiences of non-inflammatory joint problems and expected progression to be similar in RA:

'I think it'll get worse, yeah. I don't think it'll get any better, you know.' (p08)

'It used to [be painful], but it's settled down now because I've got to the stage where the bones have all fused themselves together. So, I don't get the pain I used to get.' (p14, referring to progression of their own unspecified joint problems)

Theme 5: Control beliefs

This theme focused on how participants believed RA could be controlled. Participants proposed a number of self-management techniques, such as weight loss, dietary supplements or over-the-counter medications as well as discussing the potential need for prescribed therapies. When directly questioned about the treatment of RA, the majority of participants highlighted that they were not aware of specific treatments for RA. Participants recognized that RA itself could not be cured and, although many participants were uncertain of RA-specific medications used to manage the illness, some suggested steroids, 'autoimmune drugs' and

'(joint) injections' for RA management. Participants further believed that certain symptoms of RA – in particular, the pain – could be controlled to some extent:

'You have to put yourself in your doctor's hands. You know, you assume, be it right or wrong, that they know what they're talking about and that they steer you in the right direction.... I should imagine there are treatments, but just to ...what percentage they would help or whatever, I don't know. I hope there are some that can sort of alleviate some of the pain.' (p03)

'If you've got rheumatoid arthritis, you would be on steroids ... but that's about all [I know].' (p08)

Several participants mentioned the role of physiotherapy and hydrotherapy in managing arthritis and indicated that these might be an option for RA. Participants also mentioned a number of lifestyle changes, including changes in diet, which might help to control the symptoms. However, some were uncertain whether dietary changes would indeed help with controlling RA symptoms, especially without medical guidance. The potential benefit of taking 'supplements', such as cod liver oil and glucosamine, was commonly highlighted:

'I have my glucosamine and I have my cod liver oil, and I do my best, you know, and that's all you can do. ... I mean, you see articles about people saying diet helps and things, but they say diet helps anything. They say diet can cure cancer, so I, I've no idea how true that is.' (p11)

Another lifestyle adaptation which was mentioned was weight loss. Lastly, several participants indicated that they would use appliances at home or at work (e.g. special cutlery, chairs or grab rails) to help with day-to-day tasks if they were to suffer with RA. These were usually mentioned by those with experience of these appliances either for themselves or a family member with arthritis. Many felt that it was not a condition that could be entirely self-managed and that some form of medical advice was needed. However, although the need for medical input was recognized, many participants stated that they would put up with the symptoms for some time – for example, until they started to have an impact

on daily life. In addition, several participants indicated that they would initially try to control the symptoms themselves before consulting the GP – for example, using over-the-counter analgesics, such as paracetamol or ibuprofen, to help to relieve pain:

‘I suspect a lot of people don’t go to the GP about arthritis much, they’ll just go and get themselves some painkillers or, you know, some pain-killer ointment or rub it on – that’s what I seem to recall the old ladies... and gentlemen used to do.’ (p01)

Some participants said that they would discuss potential causes and management strategies with family or friends. Others said that they would use the internet or reference books to find out information about symptoms.

Discussion

The present study showed that members of the public often had a limited understanding of the nature of RA, which in turn may have an impact on the way that they react to initial symptoms and seek help, may influence the way that they would cope with having RA if they were to develop the disease, and may influence their attitude towards people with RA. We found that the SRM was a useful framework for understanding prototypical illness models and identifying commonly held perceptions among members of the public.

Overall, knowledge about the *identity* of RA was of variable accuracy. Although symptoms such as joint pain, stiffness and restricted movement were recognized as features of arthritis, the symptoms of RA were often confused with those of the more common condition, OA. Few participants correctly recognized the autoimmune or systemic nature of RA. Perceived *causes* of RA included over-exercising, physical occupations, diet and the ‘normal ageing process’; the role of genetic factors was mentioned by only a few participants. RA was correctly perceived by many participants to have potentially serious *consequences* for day-to-day activities and quality of life. Participants had a fair idea of the *timeline* of the disease and perceived RA to be a lifelong condition which could be symptomatically managed, but not cured. However, the perceptions regarding the *controllability* of RA varied and, although the need for medical input was acknowledged, there was a general lack of knowledge regarding specific medical treatments that could modulate

the disease’s natural course, as opposed to simply controlling its associated symptoms. Many participants expressed an intention to self-manage with over-the-counter analgesics for some time prior to consulting a GP.

Most research looking at knowledge and perceptions of RA among members of the general public is now relatively dated, especially in the UK (Badley and Wood, 1979), and may no longer reflect accurately changes in population structure, healthcare services and exposure of the population to health-related information (e.g. via the media). Furthermore, key concepts identified in the SRM and prototype models have not been fully studied in relation to RA. The present study has advanced the understanding of current perceptions and knowledge about RA held by members of the public with no personal experience of the condition.

Many of the comments made by the interviewees indicated that they were thinking of other types of arthritis and other causes of musculoskeletal symptoms when answering questions about RA. In fact, although none of the participants either had RA themselves or knew someone with the disease, many spoke about their experiences with joint problems in general, and with OA in particular, in response to many of the interview questions. It is clear that the prototypical beliefs about RA in our sample were often coloured by these experiences. This also reflects the general confusion at the level of the general public between RA and other forms of arthritis, including OA. For certain prototypical beliefs, such as the identity and controllability beliefs, this confusion between RA and OA may lead to illness misperceptions (e.g. regarding the appropriateness of self-management).

Some of these commonly held misperceptions about RA may further cause people to delay help-seeking when confronted with symptoms of new-onset RA. The lack of knowledge about the features of RA and misconceptions about the causes of RA and the association of the symptoms with ‘arthritis’ in general (particularly OA) and with ‘the natural ageing process’ mean that people would be unlikely to interpret the symptoms correctly if they were to experience them, or to seek appropriate help. In addition, the lack of awareness of treatments available for RA means that, even if symptoms are interpreted correctly, many would delay presentation while self-managing the symptoms. Without the knowledge that early treatment can improve outcome, many people will not understand the importance of early presentation to their healthcare provider.

Having this record of contemporary illness representations related to RA is important for understanding behaviour throughout the course of a patient's journey with RA. Understanding the common perceptions and misperceptions about RA and their effects on health-seeking behaviour is essential to help develop effective interventions to reduce the time between symptom onset and initial medical treatment. In addition to its importance in relation to decisions to seek help when symptoms first develop, it is likely that the correction of misperceptions will be an important part of supporting patients through their journey with RA and, for example, facilitating their adherence to necessary but potentially toxic immunosuppressive medications.

Conclusion

The present qualitative study has provided an indication of the current perceptions and understanding of RA symptoms by members of the public without a diagnosis of RA. Furthermore, the focus on RA and its symptoms, unlike in existing studies, which have examined arthritis in general, has proven to be beneficial as the current research has highlighted that people often confuse RA, OA and other joint-related conditions. The current research also demonstrated the suitability of the SRM as a framework for understanding people's knowledge and perceptions of RA. Future studies should quantify these perceptions of the identity, causes, consequences, timeline and controllability of RA in a larger, more representative sample. This will ultimately help to inform effective and appropriate public health interventions to improve the public understanding of RA and to reduce delays in help-seeking with the early symptoms of RA.

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REFERENCES

- Badley EM, Wood PH (1979). Attitudes of the public to arthritis. *Annals of the Rheumatic Diseases* 38: 97–100.
- Berkanovic E, Telesky C, Reeder S (1981). Structural and social psychological factors in the decision to seek medical care for symptoms. *Medical Care* 19: 693–709.
- Bishop GD, Converse SA (1986). Illness representations: A prototype approach. *Health Psychology* 5: 95–114.
- Cameron L, Leventhal EA, Leventhal H (1993). Symptom representations and affect as determinants of care seeking in a community-dwelling, adult sample population. *Health Psychology* 12: 171–9.
- Feldman D, Bernatsky S, Haggerty J, Leffondre K, Tousignant P, Roy Y, Xiao Y, Zummer M, Abrahamowicz M (2007). Delay in consultation with specialists for persons with suspected new-onset rheumatoid arthritis: A population-based study. *Arthritis and Rheumatism* 57: 1419–25.
- Gale NK, Heath G, Cameron E, Rashid S, Redwood S (2013). Using the framework method for the analysis of qualitative data in multi-disciplinary health research. *BMC Medical Research Methodology* 13: 117.
- Grime J, Richardson JC, Ong BN (2010). Perceptions of joint pain and feeling well in older people who reported being healthy: A qualitative study. *British Journal of General Practice* 60: 597–603.
- Hyphantis T, Kotsis K, Tsifetaki N, Creed F, Drosos AA, Carvalho AF, Voulgari PV (2013). The relationship between depressive symptoms, illness perceptions and quality of life in ankylosing spondylitis in comparison to rheumatoid arthritis. *Clinical Rheumatology* 32: 635–44.
- Kiely P, Williams R, Walsh D, Young A (2009). Contemporary patterns of care and disease activity outcome in early rheumatoid arthritis: The ERAN cohort. *Rheumatology* 48: 57–60.
- Kumar K, Daley E, Carruthers D, Situnayake D, Gordon C, Grindulis K, Buckley CD, Khattak F, Raza K (2007). Delay in presentation to primary care physicians is the main reason why patients with rheumatoid arthritis are seen late by rheumatologists. *Rheumatology* 46: 1438–40.
- Kumar K, Daley E, Khattak F, Buckley CD, Raza K (2010). The influence of ethnicity on the extent of, and reasons underlying, delay in general practitioner consultation in patients with RA. *Rheumatology* 49: 1005–12.
- Leventhal H, Halm E, Horkowitz C, Leventhal E, Ozakinci G (2005). Living with chronic illness: A contextualized, self-regulation approach. In Sutton S *et al.* (eds). *The*

- Sage Handbook of Health Psychology. Thousand Oaks, CA: Sage Publications.
- Leventhal H, Safer M, Panagis D (1983). The impact of communications on the self-regulation of health beliefs, decisions, and behavior. *Health Education Quarterly* 10: 3–29.
- Mølbæk K, Hørslev-Petersen K, Primdahl J (2015). Diagnostic delay in rheumatoid arthritis: A qualitative study of symptom interpretation before the first visit to the doctor. *Musculoskeletal Care*. DOI 10.1002/msc.1108.
- Mora PA, Robitaille C, Leventhal H, Swigar M, Leventhal EA (2002). Trait negative affect relates to prior-week symptoms, but not to reports of illness episodes, illness symptoms, and care seeking among older persons. *Psychosomatic Medicine* 64: 436–49.
- Nell V, Machold KP, Eberl G, Stamm T, Uffmann M, Smolen JS (2004). Benefit of very early referral and very early therapy with disease-modifying anti-rheumatic drugs in patients with early rheumatoid arthritis. *Rheumatology* 43: 906–14.
- Raza K, Buckley CE, Salmon M, Buckley CD (2006). Treating very early rheumatoid arthritis. *Best Practice and Research Clinical Rheumatology* 20: 849–63.
- Raza K, Stack R, Kumar K, Filer A, Detert J, Bastian H, Burmester GR, Sidiropoulos P, Kteniadaki E, Repa A, Saxne T, Turesson C, Mann H, Vencovsky J, Catrina A, Chatzidionysiou A, Hensvold A, Rantapää-Dahlqvist S, Binder A, Machold K, Kwiakowska B, Ciurea A, Tamborrini G, Kyburz D, Buckley CD (2011). Delays in assessment of patients with rheumatoid arthritis: Variations across Europe. *Annals of the Rheumatic Diseases* 70: 1822–5.
- Ritchie J, Lewis J (2003). *Qualitative Research Practice: A Guide for Social Science Students and Researchers*. London: Sage.
- Scott D, Hunter J, Deighton C, Scott D, Isenberg D (2011). Treatment of rheumatoid arthritis is good medicine. *BMJ* 343: d6962.
- Severo M, Gaio R, Lucas R, Barros H (2010). Assessment of the general public's knowledge about rheumatic diseases: Evidence from a Portuguese population-based survey. *BMC Musculoskeletal Disorders* 11: 211.
- Sharpe L, Sensky T, Allard S (2001). The course of depression in recent onset rheumatoid arthritis: The predictive role of disability, illness perceptions, pain and coping. *Journal of Psychosomatic Research* 51: 713–19.
- Shaw CM (1992). *Chronic illness: A media perspective*. WHO Regional Publications. European Series 44: 256–61.
- Simons G, Mallen CD, Kumar K, Stack RJ, Raza K (2015). A qualitative investigation of the barriers to help-seeking among members of the public presented with symptoms of new-onset rheumatoid arthritis. *Journal of Rheumatology* 42: 585–92.
- Smith J, Firth J (2011). Qualitative data analysis: The framework approach. *Nurse Researcher* 18: 52–62.
- Stack RJ, Shani M, Mallen CD, Raza K (2013a). Symptom complexes at the earliest phases of rheumatoid arthritis: A synthesis of the qualitative literature. *Arthritis Care Research* 65: 1916–26.
- Stack RJ, Shaw K, Mallen C, Herron-Marx S, Horne R, Raza K (2012). Delays in help seeking at the onset of the symptoms of rheumatoid arthritis: A systematic synthesis of qualitative literature. *Annals of the Rheumatic Diseases* 71: 493–7.
- Stack RJ, Simons G, Kumar K, Mallen CD, Raza K (2013b). Patient delays in seeking help at the onset of rheumatoid arthritis: The problem, its causes and potential solutions. *Aging Health* 9: 425–35.
- Stack RJ, van Tuyl LH, Sloots M, van de Stadt LA, Hoogland W, Maat B, Mallen CD, Tiwana R, Raza K, van Schaardenburg D (2014). Symptom complexes in patients with seropositive arthralgia and in patients newly diagnosed with rheumatoid arthritis: A qualitative exploration of symptom development. *Rheumatology* 53: 1646–53.
- Tretharne GJ, McGavock ZC, Tonks A, Kafka SA, Hale ED, Kitis GD (2010). Applying the common-sense model of illness perceptions to the general population's beliefs about rheumatoid arthritis. *Rheumatology* 49: 1139.
- van der Linden M, Le Cessie S, Raza K, van der Woude D, Knevel R, Huizinga T, van der Helm-van Mil AHM (2010). Long-term impact of delay in assessment of early arthritis patients. *Arthritis and Rheumatism* 62: 3537–46.
- van der Wardt EM, Taal E, Rasker JJ (2000). The general public's knowledge and perceptions about rheumatic diseases. *Annals of the Rheumatic Diseases* 59: 32–8.
- van Os S, Norton S, Hughes LD, Chilcot J (2012). Illness perceptions account for variation in positive outlook as well as psychological distress in rheumatoid arthritis. *Psychology, Health and Medicine* 17: 427–39.
- Villeneuve E, Nam JL, Bell MJ, Deighton CM, Felson DT, Hazes JM, McInnes IB, Silman AJ, Solomon DH, Thompson AE, White PH, Bykerk VP, Emery P (2013). A systematic literature review of strategies promoting early referral and reducing delays in the diagnosis and management of inflammatory arthritis. *Annals of the Rheumatic Diseases* 72: 13–22.