

Qualitative exploration of illness perceptions of rheumatoid arthritis in the general public

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1 **Title:** Qualitative exploration of illness perceptions of rheumatoid arthritis in the general public.

2 **Short title:** Illness perceptions of Rheumatoid Arthritis

3

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10

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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 behavior is influenced by illness perceptions (prototypes) through qualitative interviews with 15 members of the public without RA. Interviews were audio-recorded, transcribed and analyzed 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 behaviors and identifying probable drivers/barriers to early presentation.

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

1 Rheumatoid arthritis (RA) is a systemic chronic inflammatory disease which primarily
2 affects the peripheral joints. Its early symptoms are articular (e.g. joint stiffness, pain and
3 swelling) and systemic (e.g. fatigue and mood disturbance). The sometimes non-specific nature
4 of its initial symptoms can make it difficult for both health care professionals and patients to
5 identify the disease in its earliest phases (Stack et al., 2014; Stack, Shani, Mallen, & Raza,
6 2013). The first three months following the clinical onset of RA represent a key therapeutic
7 window during which drug treatment with disease-modifying anti-rheumatic drugs (DMARDs) is
8 particularly effective at limiting long-term joint damage (Nell et al., 2004; Raza, Buckley,
9 Salmon, & Buckley, 2006; Scott, Hunter, Deighton, Scott, & Isenberg, 2011; van der Linden et
10 al., 2010). However, there are often considerable delays between symptom onset and the
11 initiation of therapy (Feldman et al., 2007; Kiely, Williams, Walsh, & Young, 2009; Kumar et al.,
12 2007; Mølbæk, Hørslev-Petersen, & Primdahl, 2015). One important source of delay is the
13 patients themselves (Villeneuve et al., 2013). In the UK, people have been shown to delay for a
14 median of 12 weeks at the onset of RA symptoms before seeking help from a healthcare
15 professional, whereas across other European countries patient delay appears to vary between
16 two and 22 weeks (Raza et al., 2011). As a result of these delays, many patients miss the
17 therapeutic window of opportunity (Kumar et al., 2007; Mølbæk et al., 2015).

18 Several models have been proposed to help explain the underlying psychological
19 processes which may lead to delayed help seeking behavior. One of these is the self-regulation
20 model (SRM; also referred to as the common sense model) which provides a framework
21 through which to understand people's thoughts, emotions and behaviors in the context of the
22 development of new symptoms (Leventhal, Halm, Horkowitz, Leventhal, & Ozakinci, 2005;
23 Leventhal, Safer, & Panagis, 1983). The SRM proposes that individuals explore five key
24 concepts, known as illness representations, when they experience new symptoms (Leventhal et
25 al., 2005; Leventhal et al., 1983): (1) Illness identity (the name or label given to the illness and
26 the symptoms which people associate with it), (2) Illness cause (the perceived cause of the
27 condition), (3) Illness consequences (beliefs about the consequences of the condition including
28 its physical and social impact), (4) Illness timeline (beliefs about how long the illness will last

1 and its curability) and (5) Illness controllability (beliefs about whether the illness can be
2 controlled and its symptoms alleviated).

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

10 Illness representations have been shown to be useful for understanding outcomes and
11 behaviors throughout the course of a patient's journey with RA (Hyphantis et al., 2013; Sharpe,
12 Sensky, & Allard, 2001; van Os, Norton, Hughes, & Chilcot, 2012), and may play an important
13 role in decisions to seek help when new symptoms emerge (Berkanovic, Telesky, & Reeder,
14 1981; Cameron, Leventhal, & Leventhal, 1993). Cameron and colleagues found that the more
15 severe a disease was perceived to be (identity), the shorter the delay was between symptom
16 onset and seeking help (Cameron et al., 1993).

17 The few studies that have investigated the prototypical beliefs about rheumatic disease
18 held by the general public indicate that beliefs are often inaccurate (Badley & Wood, 1979;
19 Severo, Gaio, Lucas, & Barros, 2010; Van Der Wardt, Taal, & Rasker, 2000). Factors such as
20 age and personal experience with joint problems may affect these beliefs (Badley & Wood,
21 1979). Indeed, research with older people experiencing musculoskeletal symptoms shows that
22 they are able to distinguish between "normal aches and pains", and the symptoms of more
23 serious problems such as RA (Grime, Richardson, & Ong, 2010; Mora, Robitaille, Leventhal,
24 Swigar, & Leventhal, 2002).

25 Illness representations or prototypical models that do not concur with the experiences of
26 those suffering with the illness or with current medical understanding, are known as illness
27 misperceptions (Stack, Simons, Kumar, Mallen, & Raza, 2013). Illness misperceptions held
28 about RA may include ideas that RA is a trivial condition or a normal part of aging and may
29 mislead people into believing that the symptoms of the condition do not require them to seek

1 medical attention. Cultural beliefs and understanding may also affect the processes of symptom
2 recognition and help-seeking (Kumar, Daley, Khattak, Buckley, & Raza, 2010). Investigating the
3 prototypes of RA held by members of the public, could help us understand the processes
4 involved in the help-seeking decision-making process (Treharne et al., 2010). However most
5 research looking at the prototypical beliefs related to RA, especially in the UK, has been
6 primarily focused on arthritis in general and is relatively dated and thus might not reflect current
7 perspectives (Severo et al., 2010; Van Der Wardt et al., 2000).

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

16

17

1 **Methods**

2

3 **Participants**

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

25

26 **Interview procedure**

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

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

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

8

9 **Analysis procedure**

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

24

25 **Ethics**

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

28

29

1 Results

2 Participants

3 Fifteen (12 females) of the 38 participants fitted the criteria for inclusion in the current
4 paper (i.e. aged over 18, no diagnosis of inflammatory arthritis and no family or friends with RA).
5 Although none of the subsample of participants knew someone with RA, several participants did
6 indicate that either they, or an acquaintance, suffered from osteoarthritis (OA) or another non-
7 inflammatory joint problem. All participants were white British and aged between 28 and 77
8 years ($M = 57.5$, $SD = 15.3$; see also Table 2).

9

10 Themes

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

15

16 **Theme 1: Identity beliefs.** This theme focused on participants' knowledge about RA
17 and its symptoms. When asked directly, many participants expressed a lack of knowledge about
18 the different types of arthritis and about RA in particular. Many felt that very little was heard
19 about RA and that the general public needed more information. For example one participant
20 highlighted that despite having been a nurse, she knew very little about RA, and thus
21 questioned how non-medically trained people might know about it. Other participants
22 recognized that RA causes joint stiffness, restricted movement, deformity and disability.

23

24 *"The fact that I don't know much about it (RA), is I suppose, worrying, because, you*
25 *know, what are people that are non-medically trained going to know about it? So,*
26 *maybe, I just think if there was more education out there maybe it would help people".*

27 (p09)

28

1 In terms of processes operating within the rheumatoid joint, many participants
2 associated RA with 'general joint wear and tear'. Furthermore, when participants were asked to
3 describe the potential symptoms of RA, they often described symptoms typical of OA or
4 osteoporosis instead.

5

6 *"Other than it's a deterioration of the roughing of the bone surface I think. And friction*
7 *builds up between the joint."* (p01)

8

9 On the other hand, some participants talked about joint inflammation and identified that
10 as the cause of joint pain. In some cases a more systemic description of RA was given. Several
11 participants further identified RA as an auto-immune disease, described by several participants
12 as the body "damaging itself".

13

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

19

20 *"Rheumatoid arthritis. When I think about that, I think, and I'm probably quite wrong, it*
21 *was like an autoimmune arthritis."* (p09)

22

23 **Theme 2: Causes of arthritis.** This theme focused around participants' descriptions of
24 the potential causes of arthritis in general and RA in particular. Many participants saw joint
25 problems as a "natural" or "common" part of ageing and, as a result, felt that there was not
26 much that could be done about its onset or progression. When asked specifically about the
27 typical age that someone may develop RA, many participants associated RA with "older" people
28 whereas some felt that it mainly affected younger people or indicated that its incidence was not
29 age related.

1

2 *“Aches and pains are just something that you get as you get older. (p07)*3 *I’d always assumed that it (RA) was, sort of, young or early middle aged people that got*
4 *it, I never thought about old people getting it.” (p11)*

5

6 Participants suggested that the joint symptoms associated with RA might be the result
7 of being involved in certain activities, such as (over-) exercising, playing high impact sports
8 and/or specific occupations such as nursing and heavy industry. Participants also mentioned
9 the potential causal role of diet in the development of RA and suggested that specific foods
10 might influence the chances of developing arthritis. Some participants suggested that arthritis,
11 including RA, could occur following a fracture or dislocation of a joint.

12

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

16

17 Several participants mentioned that arthritis in general can be hereditary, giving
18 examples from their own family history. Others speculated about the possibility that genes play
19 a role in the development of RA, although they were generally unsure about this.

20

21 *“I don’t know if there’s a genetic element to rheumatoid, I have no idea if it is or not.”*
22 *(p11)*

23

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

27

28 **Theme 3: Consequences.** This theme focused on the perceived consequences of
29 being diagnosed with RA. Participants discussed the potential severity of the impact of

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

7

8 *“I think being able to get out of the house and I like to visit old churches and castles and*
9 *get out into the countryside and have pub lunches, if I couldn't do any of that,[...].” (p01)*

10

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

17

18 *“Because my hands are really sort of important for, my work. ... I can't work, can't*
19 *drive, can't do anything without my hands. And so that would have a severely limiting*
20 *effect on me.” (p13)*

21

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

26

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

29

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

6

7 *“And I suppose ... there must be degrees of it. I don't think it's quite as black and white*
8 *as you've either got it or you haven't. I should think people sometimes have got degrees*
9 *of it. And depending on the degrees of it, ... it becomes serious.”* (p12)

10

11 **Theme 4: Timeline.** This theme relates to participants' perceptions about the duration
12 of RA and their ideas about its curability and progression. When asked how long they thought
13 the disease would last many participants indicated that they thought it would be life-long and at
14 least one participant suggested that RA might in fact shorten life expectancy.

15

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

19

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

22

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

27

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

29

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

4
5 **Theme 5: Control beliefs.** This theme focused on how participants believed RA could
6 be controlled. Participants proposed a number of self-management techniques such as weight
7 loss, dietary supplements or over-the counter medications, as well as discussing the potential
8 need for prescribed therapies. When directly questioned about the treatment of RA, the majority
9 of participants highlighted that they were not aware of specific treatments for RA. Participants
10 recognized that RA itself could not be cured and although many participants were uncertain of
11 RA specific medications used to manage the illness, some suggested steroids, "autoimmune
12 drugs" and "(joint) injections" for RA management. Participants further believed that certain
13 symptoms of RA, in particular the pain, could be controlled to some extent.

14
15 *"You have to put yourself in your doctor's hands. You know, you assume, be it right or*
16 *wrong, that they know what they're talking about and that they steer you in the right*
17 *direction.... I should imagine there are treatments, but just to ...what percentage they*
18 *would help or whatever, I don't know. I hope there are some that can sort of alleviate*
19 *some of the pain."* (p03)

20
21 *"If you've got rheumatoid arthritis you would be on steroids ... but that's about all (I*
22 *know)."* (p08)

23
24 Several participants mentioned the roles of physiotherapy and hydrotherapy in
25 managing arthritis and indicated that these might be an option for RA. Participants also
26 mentioned a number of lifestyle changes, including changes in diet, which might help control the
27 symptoms, although some were uncertain whether diet changes would indeed help with
28 controlling RA symptoms, especially without medical guidance. The potential benefit of taking
29 "supplements", such as cod liver oil and glucosamine, was commonly highlighted. Another

1 lifestyle adaptation which was mentioned was weight loss. Lastly, several participants indicated
2 that they would use appliances at home or at work (e.g. special cutlery, chairs or grab rails) to
3 help with day-to-day tasks if they were to suffer with RA. These were usually mentioned by
4 those with experience of these appliances either for themselves or a family member with
5 arthritis

6

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

11

12 Many felt that it was not a condition which could be entirely self-managed and that
13 some form of medical advice was needed. However, although the need for medical input was
14 recognized, many participants stated that they would put up with the symptoms for some time,
15 for example until they started to have an impact on daily life. In addition, several participants
16 indicated that would initially try and control the symptoms themselves before consulting the GP,
17 for example using over-the-counter analgesics, such as paracetamol or ibuprofen, to help
18 relieve pain. Some participants would discuss potential causes and management strategies with
19 family or friends. Others would use the internet or reference books to find out information about
20 symptoms.

21

22 *“I suspect a lot of people don’t go to the GP about arthritis much, they’ll just go and get*
23 *themselves some painkillers or you know some painkiller ointment or rub it on, that what*
24 *I seem to recall the old ladies... and gentlemen used to do.” (p01)*

25

26

Discussion

27

28 This study shows that members of the public often had a limited understanding of the
29 nature of RA, which in turn may impact the way that they react to initial symptoms and seek
help, may influence the way they would cope with having RA if they were to develop the disease

1 and may influence their attitude towards people with RA. We found that the SRM was a useful
2 framework for understanding prototypical illness models, and identifying commonly held
3 perceptions amongst members of the public.

4 Overall, knowledge about the **identity** of RA was of variable accuracy. Although
5 symptoms such as joint pain, stiffness and restricted movement were recognized as features of
6 arthritis, the symptoms of RA were often confused with those of the more common condition
7 OA. Few participants correctly recognized the auto-immune or systemic nature of RA. Perceived
8 **causes** of RA included over-exercising, physical occupations, diet and the 'normal ageing
9 process'; the role of genetic factors was mentioned by only a few participants. RA was correctly
10 perceived by many participants to have potentially serious **consequences** for day-to-day
11 activities and quality of life. Participants had a fair idea of the **timeline** of the disease and
12 perceived RA to be a lifelong condition which could be symptomatically managed, but not cured.
13 However, the perceptions regarding the **controllability** of RA varied and, although the need for
14 medical input was acknowledged, there was a general lack of knowledge regarding specific
15 medical treatments that could modulate the disease's natural course, as opposed to simply
16 controlling its associated symptoms. Many participants expressed an intention to self-manage
17 with over-the-counter analgesics for some time prior to consulting a GP.

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

25 Many of the comments made by the interviewees indicate that they were thinking of
26 other types of arthritis and other causes of musculoskeletal symptoms when answering
27 questions about RA. In fact, although none of the participants had RA themselves or knew
28 someone with the disease, many spoke about their experiences with joint problems in general
29 and with OA in particular in response to many of the interview questions. It is clear that the

1 prototypical beliefs about RA in our sample were often colored by these experiences. This also
2 reflects the general confusion at the level of the general public between RA and other forms of
3 arthritis, including OA. For certain prototypical beliefs, such as the identity and controllability
4 beliefs, this confusion between RA and OA may lead to illness misperceptions (e.g. regarding
5 the appropriateness of self-management).

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

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

23

24 **Conclusion**

25 This qualitative study has provided an indication of the current perceptions and
26 understanding of RA symptoms by members of the public without a diagnosis of RA.
27 Furthermore, the focus on RA and its symptoms, unlike existing studies which have examined
28 arthritis in general has proven to be beneficial, as the current research has highlighted that
29 people often confuse RA, OA and other joint-related conditions. The current research also

1 demonstrates the suitability of the SRM as a framework for understanding people's knowledge
2 and perceptions of RA. Future studies should quantify these perceptions of the identity, causes,
3 consequences, timeline and controllability of RA in a larger, more representative sample. This
4 will ultimately help inform effective and appropriate public health interventions to improve public
5 understanding of RA and to reduce delays in help-seeking with the early symptoms of RA.
6

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19

1 Table 1. *Interview guidelines*

<p>Introductory questions</p> <ul style="list-style-type: none"> • Have you ever experienced problems with your joints? <ul style="list-style-type: none"> ○ 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?
<p>Specific symptoms</p> <p>Swollen joints</p> <ul style="list-style-type: none"> • 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? <ul style="list-style-type: none"> ○ If different: Why do you think that is? ○ Would it worry you? <p>Joint stiffness in the morning</p> <ul style="list-style-type: none"> • 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? <p>Painful joints</p> <ul style="list-style-type: none"> • What would you do if you experienced pain in one of your joints (e.g. of 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. 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 RA

- What do you understand about what may cause joint pain?
- Tell me what you know about arthritis in general?
- Tell me what 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 RA

- 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?
- 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 kind of treatments do you know?

1 *Answers to this question used to identify whether participants fulfilled the inclusion criteria
2 current analysis

1 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 due 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 work
11	60	Female	Retired
12	49	Male	Manual work
13	44	Female	Office worker
14	70	Female	Retired
15	31	Female	Office worker

2

3

1 Table 3. *Themes and subthemes*

Theme title	Subthemes
1.Identity beliefs	Reported lack of knowledge Perceived symptoms of RA Underlying processes (wear and tear; inflammation) RA as a systemic disease or auto-immune 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 hydro therapy 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)

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