

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

3 **KEYWORDS**

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

6

7 **ABSTRACT**

8

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

18 **INTRODUCTION**

19

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

25

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

32

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

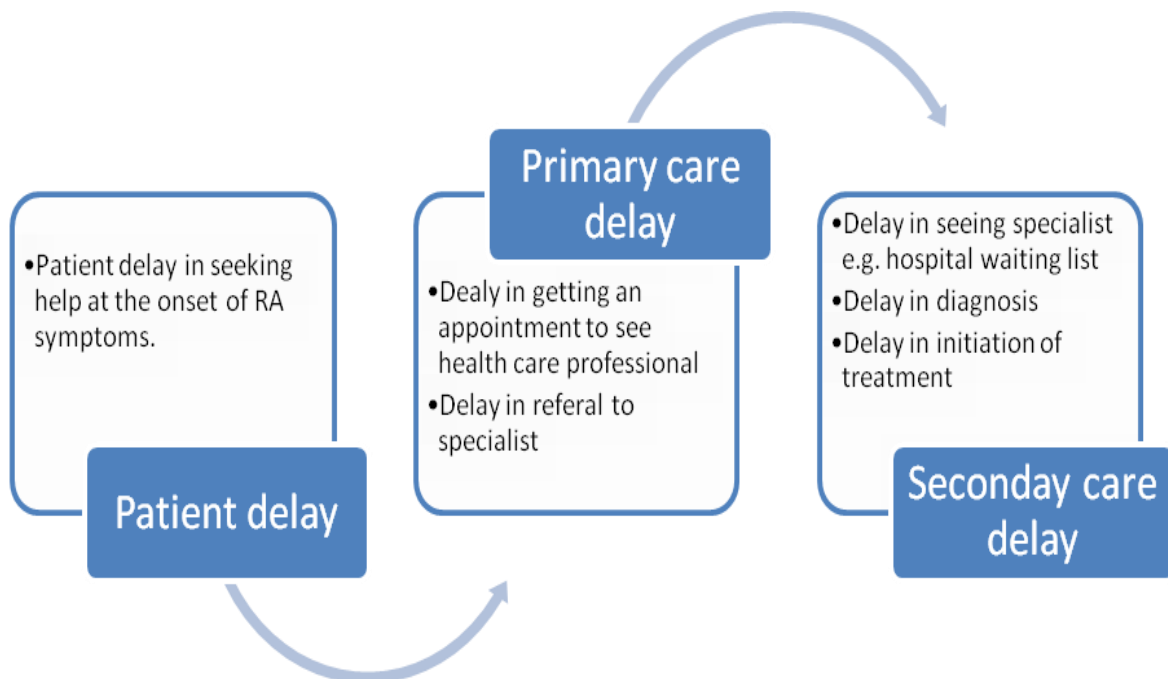
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40 Despite increased recognition of the benefits of early treatment there remains considerable
41 patient delay between symptom onset and the initiation of treatment.[10-16] Delays can

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

47

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



50

51 In the UK, patient delay between the onset of symptoms and seeking help from a healthcare
 52 professional was found to be a median of twelve weeks.[11] Delay attributed to primary
 53 care services were a median of two weeks and delays related to secondary care were a
 54 median of 3 weeks. Therefore, patient delay was the largest contributor to patients not
 55 receiving timely treatment. Long delays in patients seeking help at the onset of symptoms
 56 have also been reported in other UK studies.[16,17] Conversely, in the Netherlands, patient

57 delay is much shorter (median delay is less than 2 months), and it is delay on the part of the
58 initial assessing healthcare professional (GP or family physician) which is the largest
59 contributor to patients not being seen quickly.[6]

60

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

76

77 **PATIENT BARRIERS TO SEEKING HELP AT RHEUMATOID ARTHRITIS ONSET**

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

89

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

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

97

98 The nature of symptom onset and the way that individuals interpreted these symptoms
99 were important factors in decisions to seek help.[23] When the onset of symptoms was

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

117

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

122 Recent research has found that patients often use over-the-counter medicines from

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

127

128 Seeking information about symptoms and about whether to seek medical attention was
129 important to help people to feel reassured that the action they had chosen was correct.

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

140

141 In the UK, primary care services are usually the first point of contact for people experiencing
142 health concerns or illness. To see a rheumatologist, patients are usually referred by a
143 General Practitioner (GP), therefore, at the onset of RA, patients need to be encouraged to
144 consult their GP quickly.[32] Access to primary care services and attitudes towards GPs were
145 identified as drivers of rapid help seeking, but also as barriers to seeking help.[23] Where

146 access was restricted (through limited surgery opening hours) or a patient described a poor
147 relationship with or difficulty communicating with their GP, , delays in seeking help were
148 reported. A large survey of access to primary care service in England found that younger
149 people, people from black and minority ethnic (BME) groups and those in full time
150 employment had lower levels of satisfaction with primary care services and were reported
151 to use services less.[33] Patients registered with small practices had higher levels of
152 satisfaction.

153

154 This summary of the current research exploring the drivers and barriers to help-seeking
155 behaviour at the onset of RA highlights the role of psychology (the broad study of cognition,
156 emotion and behaviour) in understanding how people respond to the early symptoms of RA.
157 Psychologists have also developed models to explain health and illness behaviour, which can
158 help us to understand the relationships between drivers and barrier, and can provide a
159 template for predicting behaviour. These are described in more detail later in this paper.

160

161

162 **THE ROLE OF HEALTH BELIEFS IN EXPLAINING PATIENT DELAY**

163

164 Psychological theories, including the health belief model and theory of planned behaviour,
165 provide a framework for understanding the way that people perceive and react to a health
166 threat.[34-36] These theories examine the cognitions (thoughts, beliefs and perceptions)
167 and decision-making processes which predict future health-related behaviours. Different
168 psychological theories suggest that different sets of cognitions are important in predicting
169 behaviour. For example, the health belief model suggests that perceptions such as
170 perceived susceptibility and severity are helpful in predicting behaviour, while the theory of
171 reasoned action emphasises the role of perceived behavioural control, and intentions to act
172 as being important in predicting behaviour. These models are particularly useful in
173 understanding why people choose to engage in unhealthy behaviours or in health protective
174 behaviours. The self-regulation model (SRM, also referred to as the Common Sense Model)
175 differs from other psychological models because it specifically represents the thoughts and
176 emotional processes a person may face when presented with the threat of new symptoms
177 or an illness.[37,38] When applied to help-seeking behaviour, the SRM suggests that when a
178 person is faced with a new symptom they will attempt to understand and assign meaning to
179 their experiences. The SRM proposes that five key concepts, known as illness
180 representations, are explored when new symptoms are encountered. The five key concepts
181 described by this model are: illness identity, illness cause, illness timeline, illness
182 consequences and illness controllability. Illness representations are important for
183 understanding outcomes and behaviour throughout the course of RA. For example, in
184 people with RA, perceptions about the consequences of disease are associated with clinical

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185 depression,[39] concerns about illness and consequences are associated with lower health
186 related quality of life [40] and disease activity scores are correlated with the perceived
187 consequences of illness and higher illness identity scores[41].

188

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

195

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

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

		Symptoms will be concentrated in the joints of my fingers
Consequences	The consequences of the symptoms	Symptoms will prevent engagement with usual daily activities Symptoms may be life threatening Symptoms will stop me from working

198

199 These representations are cognitively processed alongside emotional reactions such as fear
200 and worry about the illness.

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

215 throughout the illness episode as targets for coping and as points of reference for appraising
216 coping outcomes.”[44]

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

222

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

230

231 **SOCIAL REPRESENTATIONS AND PUBLIC PERCEPTIONS OF RA**

232

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

242

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

254 (similar in structure to illness perceptions).[51] The core difference between illness

255 perceptions and prototypical beliefs are that illness perceptions are derived from personal

256 experience of illness by those who are ill (usually diagnosed with that illness).

257

258 Prototypical models can be unhelpful if they do not concur with actual illness experience or

259 medical models of illness, and may mislead people into believing that the symptoms of

260 conditions such as RA do not require them to seek medical attention.

261

262 Studies investigating prototypical beliefs about RA have examined the knowledge that

263 members of the public have about RA. In Australia, researchers conducted 2038 telephone

264 interviews with members of the public (25% were reported to have RA or another type of

265 arthritis; 81% knew someone with arthritis).[53] When asked what types of arthritis they

266 could name, only 35% of respondents mentioned osteoarthritis and 44% named RA. Overall,

267 a third of respondents could not name any form of arthritis. Male respondents and those in

268 younger age groups (18-29) were more likely just to mention general arthritis or could not

269 name any form of arthritis at all. In contrast, female respondents, those in older age groups

270 and those with a higher level of either education or income, were more likely to name RA.

271 No direct comparisons were made between those with arthritis and the rest of the

272 respondents for knowledge of arthritis types. When asked whom they thought was most at

273 risk of developing arthritis, a third of participants thought it was mainly old people whereas

274 only 20% indicated that people of all ages could develop arthritis. Those with RA or another

275 type of arthritis were slightly more accurate when indicating who was most at risk.

276 In the US, a survey of 300 members of the public found that only 22% of people could name
277 osteoarthritis as a form of arthritis, and that only 13% of people could name RA.[54]
278 Furthermore, 28% of people surveyed thought that arthritis was a natural part of growing
279 older, and almost half of the sample believed that arthritis could be caused by poor diet
280 and/or cold and wet climates. A survey of US college students found that RA was perceived
281 to be less severe and to be more curable than other chronic illness such as AIDS and multiple
282 sclerosis.[55] Similarly, college students in New Zealand perceived RA to be a non-life
283 threatening disease and were unsure of whether RA could be cured.[49] This research
284 highlights that knowledge about arthritic conditions in general is poor and that knowledge
285 about RA in particular is poor in comparison to other conditions.

286

287 In Europe, the public's knowledge of rheumatic disease, including RA, also appears to be
288 poor.[56,57] A survey including 17 true or false statements about rheumatic diseases, was
289 sent to members of the public in the Netherlands,[57] and in Portugal.[56] In the
290 Netherlands, members of the public correctly answered 48% of statements on rheumatic
291 diseases, while in Portugal this figure was 62%. A more detailed comparison between the
292 individual knowledge items showed some interesting differences and similarities between
293 the two countries. Only 17% of the Dutch sample correctly believed that about one in
294 twenty Dutch people is being treated for a rheumatic disease, whereas 84% of Portuguese
295 sample believe the same for the Portuguese people. Thirty-three percent of people in the
296 Netherlands and 47% in Portugal believed that people could die from the consequences of
297 rheumatic diseases. Sixty percent of the Dutch sample and 89% of the Portuguese sample

298 correctly believed that “Rheumatoid arthritis is a rheumatic disease in which the joints are
299 affected with inflammations”.

300 A UK survey of people with RA and those without, found that 30% of participants with
301 arthritis incorrectly believed that arthritis only occurred in cold weather compared to 16%
302 of the subsample of participants who had a friend or relative with arthritis and 23% of
303 participants who did not have arthritis and did not know anyone with arthritis. In addition,
304 36% of arthritis patients incorrectly linked it solely to damp environments compared to 25%
305 of those who knew someone with arthritis and 33% of those who did not have arthritis nor
306 did they know someone with arthritis .[58] Interestingly, 78% of the subsample of
307 participants with arthritis further believed it to be a non-fatal disease, compared to 60% of
308 the participants who had a friend or relative with arthritis and 50% of the participants who
309 did not have arthritis and did not know anyone with arthritis. Seventy-three per cent of the
310 participants aged 65 or older believed that the disease would progressively get worse
311 compared to 50% of the under 35s. The authors of this survey concluded that factors such
312 as age and experience might affect knowledge about arthritis, something which the findings
313 of the Australian study support.[53] Research with older people experiencing joint problems
314 shows that they are able to distinguish between symptoms which are normal for their
315 particular joint problems (what they would call normal aches and pains), and the symptoms
316 of more serious problems such as RA.[59] Interviews with older people revealed that they
317 were able to distinguish between ‘wear and tear-type’ joint pain and other joint pain that
318 they did not consider to be normal for their age (for which they were more likely to seek
319 help). This indicates that older people do use their previous experiences to make decisions,
320 to interpret perceived symptoms, and make decisions to seek help.[47] More recently,

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321 studies of previous experience and knowledge have focused on health literacy, which in the
322 context of help-seeking behaviour represents one's ability to understand and use
323 information, and draw on previously acquired knowledge and skills to make informed
324 decisions on whether to seek medical treatment.[60]

325

326 **THE ROLE OF HEALTH LITERACY IN REDUCING PATIENT DELAY**

327 Health literacy refers to the ability of a person to obtain, interpret and understand health
328 information and use it to their advantage[61] and is defined by the World Health

329 Organisation as: "the cognitive and social skills which determine the motivation and ability
330 of individuals to gain access to, understand and use information in ways which promote and
331 maintain good health".[62]

332

333 Low levels of health literacy are associated with lower levels of health knowledge, poorer
334 self-management skills, less use of preventive services and a great risk of hospitalisation.[63]

335 In a US study of community-dwelling older adults, low health literacy was independently
336 associated with poorer physical and mental health.[63] Research on the impact of health
337 literacy in information seeking found that people with low levels of health literacy were less
338 engaged with health information-seeking behaviour, specifically not going beyond what
339 their GP told them.[64] Participants with intermediate levels of health literacy were more
340 likely to obtain information about arthritis from newspapers and television, and from within
341 their social network. Those with high health literacy levels obtained information about
342 arthritis from the internet and specialist health sources. Furthermore, these participants
343 were often providers of health information within their social network. People with a

344 chronic disease such as RA and low health literacy may have problems communicating with
345 health care professionals and have a lack of knowledge about their disease and
346 medication.[65] These findings suggest that health literacy may have an important impact
347 on health outcomes in established disease.

348

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

354

355 **THE DEVELOPMENT OF INTERVENTIONS TO ADDRESS PATIENT DELAY AT RA ONSET**

356 There is some evidence that careful structured information may change the public's
357 perception of RA. A recent study provided participants with different types of written
358 information prior to being questioned about RA. One third of participants received
359 information about RA which emphasized the consequences of RA and highlighted a number
360 of possible causes, including smoking and drinking coffee, one third of participants received
361 information which emphasized that RA could be treated and discussed infection as a
362 possible cause and the remaining participants received no information other than the name
363 of the disease (RA).[50] Those participants in the latter group were significantly more likely
364 to attribute RA to aging, heredity, injury and overwork, and were significantly more likely to
365 think of it as a disease which could be personally controlled or controlled by treatment.

366 Those participants receiving the other types of information gave answers which indicated

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367 that providing information about RA and its causes had a (short-term) effect on what people
368 believed the causes and impact of RA to be. However, the attribution to aging was made by
369 a high percentage of participants in all three groups, regardless of the information provided.
370 This study found that people without RA draw on the generalized representation of RA,
371 particularly in relation to aging and that they do not fully utilize information about RA when it is
372 provided. Interventions aimed at increasing the awareness of RA in the general population
373 should therefore provide the public with accurate information about RA in a format that is
374 appropriate to their level of health literacy.

375

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

386

387 An additional factor which impacts on the public perception of an illness is the frequency
388 with which it is reported in the media. In a series of experimental studies, Young and
389 colleagues found that participants considered infectious diseases, which received repetitive

390 media attention, to be more severe and more 'disease-like' than comparable diseases which
391 received less media attention.[67] Van der Wardt and colleagues investigated the quantity
392 and the quality of information on health conditions provided by the mass media (specifically
393 nine newspapers and four Dutch TV channels) in the Netherlands over a one year period (in
394 the early 1990s). [68] They concluded that the amount of attention given to a disease by the
395 media was influenced by its fatality rate, not its prevalence. They further concluded that
396 more frequent and more accurate coverage of chronic diseases and in particular rheumatic
397 diseases was needed to do justice to the impact of these diseases on the general public.

398

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

402

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

409

410 **FUTURE PRESPECTIVE**

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

417

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

429

430 The key challenge facing the development of interventions in this area is that appropriate
431 help seeking must be encouraged, in particular rapid help seeking in the context of a new
432 onset of symptoms indicative of RA (e.g. small joint involvement, symmetric joint

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433 involvement, swelling and morning stiffness), without promoting rapid help seeking in the
434 context of other causes of musculoskeletal symptoms where self-management may be more
435 appropriate or urgent assessment is not necessary (e.g. mechanical low back pain,
436 osteoarthritis, fibromyalgia). Strategies to promote help seeking in RA patients should
437 specifically address issues which have been identified to explain patient delay, for example
438 by highlighting that although initial symptoms may be mild, rapid help seeking is still
439 necessary to allow early treatment to limit long term damage. The effectiveness and cost
440 effectiveness of these help-seeking interventions will need to be assessed longitudinally. As
441 awareness of RA is raised, it is possible that there will be an increase in both appropriate
442 and inappropriate help seeking (e.g. seeking help where self-management would have been
443 more appropriate) and data regarding this will need to be captured in any assessment of
444 public health intervention strategies.

445

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

452

Reference List

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