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]

39

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.**
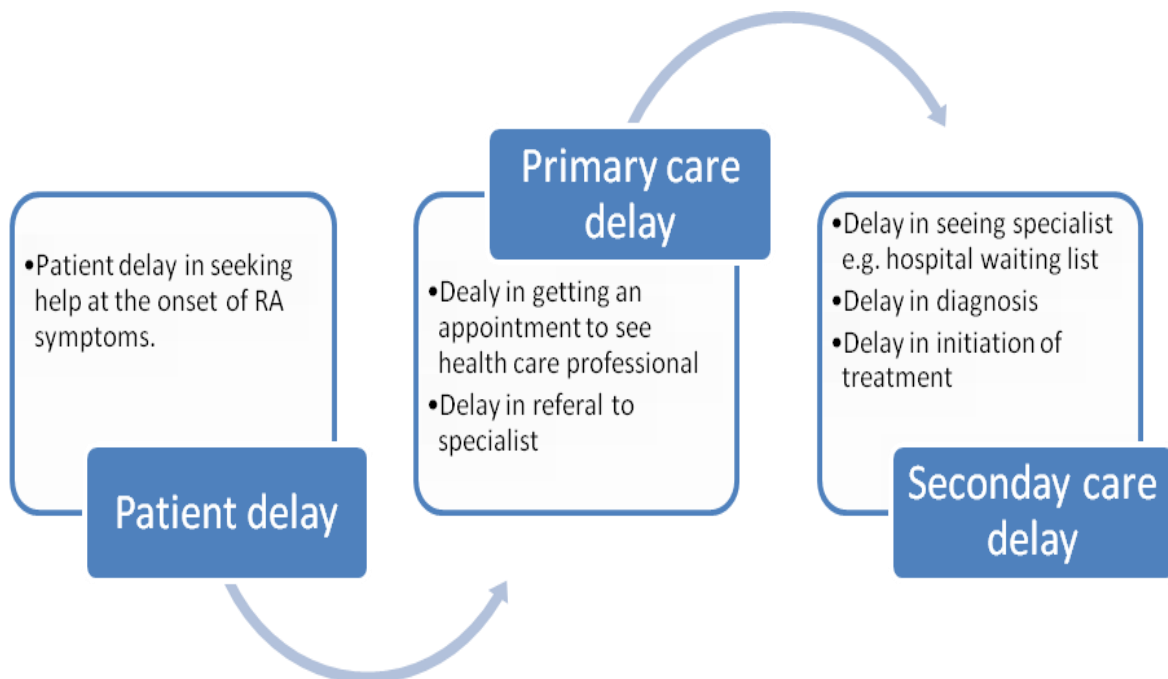
50

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

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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 counties 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

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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

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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

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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

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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

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		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

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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

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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

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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.

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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 that 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

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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,

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

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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 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

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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**

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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

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