

1           **Improving recognition of anxiety and depression in**  
2           **Rheumatoid Arthritis: a qualitative study.**

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## 28 **Abstract**

29

30 **Background:** Comorbid anxiety and depression are common in patients with  
31 rheumatoid arthritis (RA) but often under-recognised and treated, contributing to  
32 worse outcomes. NICE recommends that RA patients should be offered a holistic  
33 annual review, including an assessment of mood.

34

35 **Aim:** To explore patients' perspectives of anxiety and depression in RA and  
36 preferences for disclosure and management of mood problems.

37

38 **Design and Setting:** Qualitative interview study with patients recruited from a nurse-  
39 led RA annual review clinic.

40

41 **Method:** Patients attending the clinic who scored  $\geq 3$  on the case-finding questions  
42 (PHQ2 and GAD2) were invited for interview. Data were analysed thematically using  
43 principles of constant comparison.

44

45 **Results:** Participants recognised a connection between their RA and mood, though  
46 this was perceived variably. Some lacked candidacy for care, normalising their mood  
47 problems. Fear of stigmatisation, a lack of time and the perception that clinicians  
48 prioritise physical over mental health problems recursively affected help-seeking.  
49 Good communication and continuity of care were perceived to be integral to  
50 disclosure of mood problems. Participants expressed a preference for psychological  
51 therapies, though reported problems accessing care. Some perceived medication to  
52 be offered as a 'quick fix' and feared potential drug interactions.

53

54 **Conclusion:** Prior experiences can lead patients with RA and co-morbid anxiety and  
55 depression to feel they lack candidacy for care. Provision of equal priority to mental  
56 and physical health problems by GPs and improved continuity of care could help  
57 disclosure of mood concerns. Facilitation of access to psychological therapies could  
58 improve outcomes for both mental and physical health problems.

59

## 60 **How this fits in**

61

62 Anxiety and depression are common in RA and negatively impact on  
63 outcomes. Patients reported normalising their mood problems, perceived clinicians  
64 to prioritise physical over mental health concerns and reported GP appointments to  
65 be anxiety provoking, recursively affecting help-seeking. Use of the PHQ-2 and  
66 GAD-2 questions in the context of an annual review for patients with RA may  
67 promote discussion about mood, thus enabling mood problems to be addressed  
68 through signposting to appropriate interventions, improving care and outcomes.

69

## 70 **Introduction**

71 Rheumatoid Arthritis (RA) is a common inflammatory long-term condition  
72 (LTC) leading to joint pain, swelling and deformity (1). In common with other LTCs  
73 (2), RA is associated with an increased prevalence of both depression and anxiety  
74 (estimated to affect 39% and 20% respectively) (3, 4). Co-existent mood disorders in  
75 RA are associated with reduced remission rates (5), increased morbidity and  
76 mortality (6) and raised healthcare costs (2). Despite this studies suggest that  
77 anxiety and depression are under-recognised and under-treated (7). Therefore, the  
78 recognition and treatment of mood disorders in RA should be a health care priority to  
79 improve outcomes.

80 Although the Quality Outcomes Framework (QOF) incentivises an annual  
81 review of RA this doesn't specify mood assessment (8). However, the National  
82 Institute for Health and Care Excellence (NICE) does recommend that clinicians  
83 assess mood within the context of an annual review (QS33). Whether this should  
84 occur in primary or secondary care or how mood should be assessed is not specified  
85 (9).

86 Despite QOF incentives and NICE guidelines promoting a RA annual review,  
87 evidence suggests that the care of patients with RA is fragmented (10). A recent  
88 national GP survey showed that primary care RA annual reviews focus on CVD and

89 osteoporosis screening, leading to duplication of some tests, whilst other key  
90 elements, such as case-finding for anxiety and depression are lacking (11).

91 The NICE guidelines for identification of depression in adults with chronic  
92 physical health problems (12) suggests the most sensitive tools for case-finding are  
93 the GHQ-28 (General Health Questionnaire) and the two-stem questions of the  
94 PHQ-9 (Patient Health Questionnaire), with the two-stem questions being popular  
95 due to their ease of use (13).

96 There is evidence that psychological interventions in RA are effective in the  
97 management of anxiety, depression and pain (14, 15). Self-management  
98 interventions to support patients to manage aspects of their RA independently have  
99 also been found to have positive effects on pain and psychological well-being (16,  
100 17).

101 There is limited literature exploring patient and practitioner perspectives on  
102 the identification and management of mood disorders in RA.

103 Since RA is associated with an increased prevalence of anxiety and  
104 depression and that the case-finding questions are useful screening tools in other  
105 LTCs, further research is required to identify barriers and facilitators to disclosure.

106 A nurse-led RA annual review clinic was established at two community  
107 hospitals in the Midlands, England. This study aimed to recruit patients with RA and  
108 co-morbid mood disorders from the annual review clinic to interview, in order to  
109 explore their perspectives of anxiety and depression in RA and preferences for  
110 disclosure and management of mood problems.

111 This paper reports analysis of interviews with patients who had attended the  
112 review clinic.

113

## 114 **Methods**

### 115 **Recruitment**

116 Patients with established RA normally attending consultant rheumatology  
117 clinics for review, were invited to attend a pilot nurse-led annual review clinic which  
118 aimed to offer a more holistic assessment than than their routine secondary care  
119 review. Patients were asked to complete a short questionnaire, including key  
120 domains highlighted by NICE (18). This had been co-designed with a local patient  
121 group who suggested changes to make it more easily readable. This included work  
122 status, self-reported co-morbidities, disease activity and physical function, together  
123 with the Patient Health Questionnaire (PHQ-2) and Generalised Anxiety Disorder  
124 (GAD-2), to case-find for co-morbid anxiety and depression (19, 20).

125 Between October 2015 to August 2016, patients scoring  $\geq 3$  on the PHQ-2  
126 and/or GAD-2 (table 1) were invited to take part in a single face to face interview.  
127 Ethical approval was obtained.

128

## 129 **Interviews**

130 Interviews were conducted by an academic GP registrar (AM) supervised by  
131 an experienced qualitative researcher (CCG). The interviewer introduced themselves  
132 as a researcher and did not disclose their identity as a GP registrar, to ensure that  
133 participants spoke more freely about their experiences of consulting health care  
134 professionals. Written consent was obtained prior to each interview.

135 Interviews were face-to-face and semi-structured, supported by a topic guide.  
136 The interviewer explored patients' perspectives of anxiety and depression in RA,  
137 views of the nurse-led annual review clinic and experiences of discussing mood  
138 problems with health care professionals and preferences for management. The topic  
139 guide was refined during the course of the study, taking account of emerging  
140 analysis. This included the addition of questions to further explore past experiences  
141 of help-seeking for anxiety and depression.

142 All interviews were audio-recorded and lasted between 12-73 minutes, with an  
143 average length of 34 minutes. 14 interviews were required to reach data saturation.

144

## 145 **Analysis**

146           The first seven interviews were transcribed verbatim by the interviewer to  
147 increase familiarity with the data. An independent transcription company was  
148 subsequently used, but each transcript was checked against the digital recording  
149 and anonymised by the interviewer (AM). Analysis began as soon as the first  
150 transcript was available. Therefore, data collection and analysis were conducted  
151 concurrently, enabling modification of the topic guide to reflect emerging themes.

152           Data were analysed using principles of constant comparison (21). In order to  
153 generate conceptual themes, inductive coding of text segments, followed by re-  
154 coding and memo writing was used. Regular meetings took place between the study  
155 team members to agree analysis and salient themes.

156           Following analysis of the first seven transcripts, 'access to care' was noted to  
157 be a key emerging theme. Therefore, a secondary analysis was performed using a  
158 framework approach (22). This included three important concepts surrounding  
159 Dixon-Woods' model of access to care. (23, 24). Candidacy, referred to the process  
160 by which a person's eligibility to use a service is formulated through their local  
161 interactions with health services. Concordance, indicated the importance of a match  
162 between a users' and practitioners' narrative and successful access to an  
163 intervention. Recursivity referred to the influence of a users' experiences of health  
164 services on their future help-seeking.

165

## 166 **Results**

167           171 patients attending the nurse-led annual review clinic completed the  
168 questionnaire, with 48 (28%) scoring  $\geq 3$  on the case-finding questions, suggesting  
169 that they were anxious and/ or depressed. Of 29 invited to be interviewed, 14 agreed  
170 to participate. From the 15 who did not participate, 5 did not respond to our  
171 telephone calls, 2 declined due to poor physical health, 1 reported they were too  
172 busy and the rest who declined, disclosed no reason. Table 2 summarises the  
173 characteristics of the 14 participants, who were all White British, reflecting the  
174 demographics of the local area. More females participated, reflecting the higher

175 prevalence of RA in women and the proportion of females attending the clinic (68%).  
176 The majority were retired, with an average age of 63.

177 Key themes that will be presented include 'making the link', 'stigma and  
178 shame', 'who to talk to?' and 'what's on offer?' Data are given to support analysis,  
179 with a participant identifier.

180

## 181 **Making the link**

182 Participants perceived their RA to negatively impact on their mood, suggesting  
183 this was due to joint pain or loss of function. Some normalised this as an expected  
184 response to any LTC.

185 *"I think with any illness low mood could be a problem. Especially when you've been  
186 used to being able to do so much, then you come down to doing so little really. It's a  
187 huge change"* P2

188 Some participants perceived their mood to negatively impact on their RA,  
189 precipitating flares.

190 *"She said, 'Do you get depressed?' and I said, 'Not a lot, no, not really,' but it's only  
191 until afterwards when you think about it and you think, 'Yes, you do really,' and it is  
192 connected to the arthritis. It does give me flare-up, no question about it."* P8

193 However, other participants, perceived their mood and RA to be separate.

194 *"I think a lot of my anxiety and depression is to do with my personality, and I'm the  
195 person I am, with or without my arthritis."* P7

196 Some participants described having only recognised the link between their RA  
197 and mood when this was pointed out by a healthcare professional.

198 *"...when she was saying it I was thinking, god, I feel like that, you know, it's so, it's  
199 so, like when somebody else said it, I thought, well I'm not on my own, somebody  
200 else must feel like that."* P14

201            Thus, most participants recognised an interaction between their RA and  
202 mood, though this was perceived variably. Some only recognised a link when this  
203 was suggested by a healthcare professional, facilitating discussion of mood  
204 problems during future RA reviews. Others normalised mental health problems,  
205 potentially resulting in them not seeking help.

206

## 207 **Stigma and shame**

208            Several participants reported having felt too embarrassed to disclose their mental  
209 health concerns to their GP, with some perceiving their low mood as a sign of  
210 weakness.

211            *"It was particularly at first because I had been active and I suppose periodically, you*  
212 *might anyway, feel a bit low you know, when things get on top of you a bit...but*  
213 *certainly I did at first, I felt a bit inadequate and don't like to admit weakness and stuff*  
214 *like that..." P12*

215            Thus, fear of stigmatization was a significant barrier to help-seeking for mood  
216 problems.

217

## 218 **Who to talk to?**

219            Several participants described appointments with their GP as anxiety-  
220 provoking which recursively affected future help-seeking for mental health problems.  
221 Some admitted telling their doctor they were fine in order to finish their consultation  
222 quickly, meaning any underlying problems were not addressed.

223            *"I get ever so anxious. I'm not good with, when I have doctor's appointments or*  
224 *medical appointments. I tend to go in and say yeah I'm fine, just so I can get out*  
225 *again." P7*

226            Some participants suggested that GPs prioritise physical above mental health  
227 problems.



228 *"...doctors are busy enough with physical complaints." P2*

229 Several participants described past negative experiences of help-seeking as  
230 barriers to disclosure of mental health concerns. In addition to a lack of time, some  
231 participants perceived their GP not to listen to their concerns.

232 *"There are a lot of people in that surgery and you go in, you sit down and you've got*  
233 *five or ten minutes and then you're coming back out again and you forget half the*  
234 *stuff you want to really talk about because I've only gone, usually, for my medication.*  
235 *It's just when he does actually say, 'How do you feel?' I just say, 'I feel really down'*  
236 *and he briefly asks me why and I don't feel like I have time to tell him before he's*  
237 *giving me the leaflet." P13*

238 Some participants perceived their GP to be intimidating, which recursively  
239 affected future help-seeking for psychological problems.

240 *"And you go in and he just looks at you, you know, and I think to myself, well I'm not*  
241 *telling you how I feel, you know.....God, well he just sits there and he's very stern*  
242 *looking, and you go in, and he'll say 'what can I do for you?', and you think nothing,*  
243 *I'm out the door!" P14*

244 Several participants also described a lack of continuity of care and difficulty  
245 accessing appointments when required with their GP as barriers to the disclosure of  
246 mood problems.

247 *"I've been there years and years. I just find them a waste of time. You never get to*  
248 *see a doctor. You get palmed off with anybody. You're lucky if you see a doctor*  
249 *there, anybody. I don't feel they are bothered." P9*

250 Other participants described establishing positive relationships with their GP  
251 influenced by body language and rapport which helped to facilitate disclosure of  
252 mental health concerns.

253 *"I just think he'd got a really big heart and I think he was very, very understanding of*  
254 *how you might be feeling and very, very supportive indeed." P11*

255 Participants recognized the pressure of restricted appointment times on GPs,  
256 but felt that provision of time during individual appointments and encouragement to  
257 attend follow-up would be integral to disclosure of psychological concerns.

258 *"I suppose it's because they are so busy and as I've said, I do understand where*  
259 *they're coming from, they have so many people to deal with...and they've only got a*  
260 *certain length of time, you know, they're not, whilst there's some brilliant doctors*  
261 *about and there undoubtedly is, GPs I mean, they do have a really tough job..." P12*

262

263 *"He's just very approachable. You just can talk to him about anything. I did go a few*  
264 *times and he said I must come back." P8*

265 In summary, some participants perceived their GP prioritised physical above  
266 mental health concerns and reported their appointments to be anxiety-provoking,  
267 recursively affecting help-seeking. Lack of time and poor continuity of care were  
268 perceived to be further barriers to disclosure of mood problems. However,  
269 participants suggested that good communication and encouragement to attend  
270 follow-up would facilitate discussion of psychological concerns.

271

## 272 **What's on offer?**

273 Participants had different views on the use of medication for anxiety and  
274 depression. Some cited a preference for non-pharmacological treatments over anti-  
275 depressants.

276 *"I think at the end of the day I think I'd go down the line of, because I take a lot of*  
277 *medication, go down the line of perhaps talking to somebody first, definitely try that*  
278 *before I had any medication." P14*

279 Another participant was prompted by the RA annual review nurse to consider that  
280 a medication change could be helpful.

281 *"...she said to me, have you tried a different anti-depressant, because I've been on*  
282 *the Fluoxetine for several years, and she said there are anti-depressants that are for*  
283 *social anxiety..." P7*

284 Others perceived medication to be offered as a 'quick-fix' option, due to reduced  
285 funding for psychological therapies. As a result, they had considered private therapy.

286 *"I've got a friend who's, well she's retired now but she is a Psychotherapist and I've*  
287 *often thought, perhaps I should talk to X, because she knows my mum as well so*  
288 *well, she worked privately but she did do work for the NHS because she did work*  
289 *across there for the surgery at that time, but of course cutbacks, they cut all that sort*  
290 *of stuff out and they dish out the pills these days, more of them I think sadly." P12*

291 Some participants reported problems accessing talking treatments when  
292 signposted by their GP.

293 *"I think once you start offloading to one person and then you have to come home*  
294 *and make a phone call to go and see other counsellors, it puts people off because*  
295 *there are waiting times. They're ridiculously long." P13*

296 For those who had been able to access psychological support, it was  
297 perceived as beneficial.

298 *"...this cognitive behaviour. And I found it really useful, because it's challenging your*  
299 *own thoughts, and I thought, yes, I am my own worst enemy." P7*

300 Overall, participants expressed a preference for non-pharmacological  
301 treatments, particularly psychological therapies. Some reported problems accessing  
302 treatment, recursively affecting future help-seeking, though those receiving  
303 psychological support perceived it to be helpful.

304

## 305 **Discussion**

306

## 307 **Summary of findings**

308 Most participants recognised the negative impact of RA on their mood, with  
309 some also perceiving low mood or anxiety to precipitate RA flares, though several  
310 only acknowledged a link between RA and their mood when this was highlighted by  
311 a health care professional.

312 Some participants lacked candidacy for care, normalising their mood  
313 problems as an expected response to suffering from RA. Others were prevented  
314 from seeking help due to fear of stigmatisation. Perceived prioritisation of physical  
315 above mental health concerns by GPs recursively affected help-seeking. A lack of  
316 time and poor continuity of care were reported as further barriers to disclosure.

317 However, several participants reported establishing positive relationships with  
318 their GP and felt continuity of care with encouragement to attend follow-up would be  
319 integral to the disclosure of mental health concerns.

320 Participants cited a preference for psychological therapies, though several  
321 reported problems accessing care. Whereas some participants were open to  
322 pharmacological treatments, others perceived medication to be offered as a 'quick  
323 fix' by their GP and feared potential drug interactions.

324

## 325 **Comparison with existing literature**

326 In common with other LTCs (25), this research suggests that patients with RA  
327 may recognise an interaction between their chronic physical illness and anxiety or  
328 depression. However, those who do not perceive a relationship between their mood  
329 problems and LTC may not understand the intention behind asking about mood  
330 during LTC reviews (26).

331 Patients with RA, in addition to other LTCs (27), can lack candidacy for care,  
332 failing to seek help for their anxiety and depression due to perceiving this to be a  
333 normal response to suffering from a chronic physical illness.

334 Patients with LTCs may not seek help for mental health problems due to  
335 associated stigma (28). This finding was echoed in a study of Hispanic patients with  
336 RA (29), who perceived psychological problems as a sign of weakness. Further  
337 barriers to help seeking for anxiety and depression in patients with RA were

338 identified within this study. These included a perception of GPs being dismissive of  
339 mental health concerns and appointments being anxiety-provoking, recursively  
340 affecting help-seeking. Further barriers to help-seeking included a lack of time and  
341 poor continuity of care.

342         However, patients reported being more receptive to the discussion of mood  
343 concerns when they had established rapport with their GP.

344         In common with existing literature (29, 30), patients with RA expressed a  
345 preference for talking treatments, wishing to avoid medication due to potential side-  
346 effects or interactions with existing RA treatments. Patients with RA reported  
347 struggling to access psychological therapies due to long waiting times and perceived  
348 cuts in funding, suggesting a need for improvement in access to psychological  
349 support, as recognised in a survey of rheumatology nurses in 2012 (24).

350

## 351 **Strengths and Limitations**

352         Use of qualitative methods with an exploratory approach ensured new  
353 phenomena were identified. A second stage of more detailed framework analysis  
354 enabled deeper insights into the barriers and facilitators to patients accessing care  
355 for psychological problems.

356         The topic guide was piloted with patients and practitioners to ensure face  
357 validity. This was also refined over the course of the study to ensure exploration of  
358 emerging themes.

359         A potential limitation was that only patients with a high PHQ-2 or GAD-2  
360 score were interviewed. It is likely that different views would have been articulated by  
361 patients who did not have anxiety or depression.

362         Participants were predominantly retired White British females (reflecting the  
363 local demographics), hence a greater range of perspectives may have been obtained  
364 from a more diverse sample. Participants were identified and recruited through a  
365 secondary care clinic, meaning they were all from the same area of England.  
366 However, a range of different socioeconomic statuses were included (table 2).

367

## 368 **Implications for research and practice**

369           Although some patients with RA and co-morbid anxiety and/ or depression  
370 recognise the interaction between their arthritis and mood problems, others only  
371 make this link when it is highlighted by a clinician. Therefore, it is important that  
372 mood is explored as part of an annual review for RA patients, whether this is  
373 conducted in primary or specialist care, as improved recognition and management of  
374 anxiety and depression could lead to reduced overall morbidity and mortality.

375           GPs need to give equal priority to mental and physical health problems to  
376 facilitate disclosure of distress. Provision of time during individual appointments and  
377 encouragement to attend follow-up with the same GP to support continuity of care  
378 could be integral to the disclosure of mood concerns.

379           It is a policy imperative for improving access to psychological therapies (IAPT)  
380 to deliver care for people with depression and LTCs, hence, for patients who are  
381 anxious about self-referral, GPs should make referrals to IAPT. Given the negative  
382 impact of mood on outcomes in RA, such an intervention should be a priority.

383           Given the primary care expertise in managing multimorbidity, developing  
384 practice nurse-led models of care may improve outcomes for patients with RA,  
385 providing patient and cost benefits by preventing duplication of care whilst enabling  
386 earlier intervention and management of multi-morbidities.

387

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392

## 393 **Ethical Approval**

394           Ethical Approval was granted by the West of Scotland Research Ethics Service  
395 Committee (WoSRES/15/WS/0063, Project ID 170210).

396

## 397 **Competing Interests**

398 No competing interests

399

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403 findings.

404

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490 **Table 1. The Case-Finding Questions for Anxiety and Depression**  
491 **(19, 20)**

492

<b>Case-finding questions</b>	<b>PHQ-2</b>	<b>GAD-2</b>
During the past month have you been bothered by...	Feeling down, depressed or hopeless	Feeling nervous, anxious or on edge
	Having little interest or pleasure in doing things	Not being able to stop or control worrying

493

494 **Table 2. Characteristics of participants (n= 14)**

<b>Gender</b>	Male = 2  Female = 12
<b>Ethnicity</b>	White British = 14
<b>Age</b>	40-50 years = 1  50-60 years = 4  60-70 years = 7  >70 years = 2
<b>Employment status</b>	Employed = 3  Retired = 4  Retired through ill health = 6  Unemployed = 1
<b>Index of Multiple Deprivation (IMD)</b> <i>Measure of relative deprivation for neighbourhoods in England, expressed in deciles from 1 (most deprived) to 10 (least deprived)</i>	Mean= 5.4  Standard Deviation= 2.8  Range= 1-9
<b>PHQ-2 Score</b>	Mean= 4.6  Standard Deviation= 1.1
<b>GAD-2 Score</b>	Mean= 4.9  Standard Deviation 1.1