

## Improving recognition of anxiety and depression in rheumatoid arthritis:

a qualitative study in a community clinic

### Abstract

#### Background

Comorbid anxiety and depression are common in patients with rheumatoid arthritis (RA) but are often under-recognised and treated, contributing to worse outcomes. National Institute for Health and Care Excellence (NICE) recommends that patients with RA should be offered a holistic annual review, including an assessment of mood.

#### Aim

To explore patients' perspectives of anxiety and depression in RA and preferences for disclosure and management of mood problems.

#### Design and setting

Qualitative interview study with patients recruited from a nurse-led RA annual review clinic in the Midlands, England.

#### Method

Patients attending the clinic who scored  $\geq 3$  on the case-finding questions (PHQ-2 and GAD-2) were invited for interview. Data were analysed thematically using principles of constant comparison.

#### Results

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

#### Conclusion

Prior experiences can lead patients with RA and comorbid anxiety and depression to feel they lack candidacy for care. Provision of equal priority to mental and physical health problems by GPs and improved continuity of care could help disclosure of mood concerns. Facilitation of access to psychological therapies could improve outcomes for both mental and physical health problems.

#### Keywords

anxiety; arthritis, rheumatoid; case-finding; depression; GAD-2; PHQ-2.

### INTRODUCTION

Rheumatoid arthritis (RA) is a common inflammatory long-term condition (LTC) leading to joint pain, swelling, and deformity.<sup>1</sup> In common with other LTCs,<sup>2</sup> RA is associated with an increased prevalence of both depression and anxiety (estimated to affect 39% and 20% respectively).<sup>3,4</sup> Coexistent mood disorders in RA are associated with reduced remission rates,<sup>5</sup> increased morbidity and mortality,<sup>6</sup> and raised healthcare costs.<sup>2</sup> Despite this, studies suggest that anxiety and depression are under-recognised and under-treated.<sup>7</sup> Therefore, the recognition and treatment of mood disorders in RA should be a healthcare priority to improve outcomes.

Although the Quality and Outcomes Framework (QOF) incentivises an annual review of RA, this does not specify mood assessment.<sup>8</sup> However, the National Institute for Health and Care Excellence (NICE) does recommend that clinicians assess mood within the context of an annual review.<sup>9</sup> Whether this should occur in primary or secondary care or how mood should be assessed is not specified.<sup>9</sup>

Despite QOF incentives and NICE guidelines promoting an RA annual review, evidence suggests that the care of patients with RA is fragmented.<sup>10</sup> A recent national GP survey showed that primary care RA

annual reviews focus on cardiovascular disease (CVD) and osteoporosis screening, leading to duplication of some tests, while other key elements, such as case-finding for anxiety and depression, are lacking.<sup>11</sup>

The NICE guidelines for identification of depression in adults with chronic physical health problems<sup>12</sup> suggests that the most sensitive tools for case-finding are the General Health Questionnaire (GHQ-28) and the two-stem questions of the Patient Health Questionnaire (PHQ-9), with the two-stem questions (Generalised Anxiety Disorder Scale (GAD)-2 and PHQ-2) being popular due to their ease of use.<sup>13</sup>

There is evidence that psychological interventions in RA are effective in the management of anxiety, depression, and pain.<sup>14,15</sup> Self-management interventions to support patients to manage aspects of their RA independently have also been found to have positive effects on pain and psychological wellbeing.<sup>16,17</sup>

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

Because RA is associated with an increased prevalence of anxiety and depression, and because the case-finding questions are useful screening tools in other LTCs, further research is required

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## How this fits in

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

to identify barriers and facilitators to disclosure.

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

This article reports analysis of interviews with patients who had attended the review clinic.

## METHOD

### Recruitment

Patients with established RA normally attending consultant rheumatology clinics for review were invited to attend a pilot nurse-led annual review clinic that aimed to offer a more holistic assessment than their routine secondary care review. Patients were asked to complete a short questionnaire, including key domains highlighted by NICE.<sup>18</sup> This had been jointly designed with a local patient group who suggested changes to make it more easily readable. This included work status, self-reported comorbidities, disease activity, and physical function, together with the PHQ-2 and GAD-2, to case-find for comorbid anxiety and depression.<sup>19,20</sup>

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

### Interviews

Interviews were conducted by an academic GP registrar supervised by an experienced qualitative researcher. The interviewer introduced themselves as a researcher

and did not disclose their identity as a GP registrar, to ensure that participants spoke more freely about their experiences of consulting healthcare professionals. Written consent was obtained prior to each interview.

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

All interviews were audiorecorded and lasted between 12–73 minutes, with an average length of 34 minutes. Fourteen interviews were required to reach data saturation.

### Analysis

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

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

Following analysis of the first seven transcripts, 'access to care' was noted to be a key emerging theme. Therefore, a secondary analysis was performed using a framework approach.<sup>22</sup> This included three important concepts surrounding Dixon-Woods's model of access to care.<sup>23,24</sup>

**Candidacy.** This referred to the process by which a person's eligibility to use a service is formulated through their local interactions with health services.

**Concordance.** This indicated the importance of a match between a user's and practitioner's narrative, and successful access to an intervention.

## Box 1. The case-finding questions for anxiety and depression<sup>19,20</sup>

Case-finding questions	PHQ-2	GAD-2
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

GAD-2 = Generalised Anxiety Disorder Scale-2. PHQ-2 = Patient Health Questionnaire-2.

**Recursivity.** This referred to the influence of a user's experiences of health services on their future help-seeking.

### RESULTS

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

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

Key themes that will be presented include 'making the link', 'stigma and shame', 'who to talk to?', and 'what's on offer?'. Data are given to support analysis, with a participant (P) identifier: sex: male (M), female (F); age, years; and employment status.

### Making the link

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

*'I think with any illness low mood could be a problem. Especially when you've been used to being able to do so much, then you come down to doing so little really. It's a huge change.'* (P10, M, 70, retired)

Some participants perceived their mood to negatively impact on their RA, precipitating flares:

*'She said, "Do you get depressed?" and I said, "Not a lot, no, not really", but it's only until afterwards when you think about it and you think, "Yes, you do really", and it is connected to the arthritis. It does give me flare-up, no question about it.'* (P8, F, 62, retired through ill health)

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

*'I think a lot of my anxiety and depression is to do with my personality, and I'm the person I am, with or without my arthritis.'* (P7, F, 61, retired through ill health)

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

*'... when she was saying it I was thinking, God, I feel like that, you know, it's so, it's so, like when somebody else said it, I thought, well I'm not on my own, somebody else must feel like that.'* (P14, F, 71, retired)

Thus, most participants recognised an interaction between their RA and mood, though this was perceived variably. Some only recognised a link when this was suggested by a healthcare professional, facilitating discussion of mood problems

**Table 1. Characteristics of participants (n = 14)**

<b>Sex</b>	
Male	2
Female	12
<b>Ethnicity</b>	
White British	14
<b>Age, years</b>	
40–49	1
50–59	4
60–69	7
$\geq 70$	2
<b>Employment status</b>	
Employed	3
Retired	4
Retired through ill health	6
Unemployed	1
<b>Index of Multiple Deprivation (IMD)<sup>a</sup></b>	
Mean	5.4
SD	2.8
Range	1–9
<b>PHQ-2 score</b>	
Mean	4.6
SD	1.1
<b>GAD-2 score</b>	
Mean	4.9
SD	1.1

<sup>a</sup>Measure of relative deprivation for neighbourhoods in England, expressed in deciles from 1 (most deprived) to 10 (least deprived). GAD-2 = Generalised Anxiety Disorder Scale-2. PHQ-2 = Patient Health Questionnaire-2. SD = standard deviation.

during future RA reviews. Others normalised mental health problems, potentially resulting in them not seeking help.

### Stigma and shame

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

*'It was particularly at first because I had been active and I suppose periodically, you might anyway, feel a bit low you know, when things get on top of you a bit ... but certainly I did at first, I felt a bit inadequate and don't like to admit weakness and stuff like that ...'* (P12, F, 70, retired)

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

### Who to talk to?

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

*'I get ever so anxious. I'm not good with, when I have doctor's appointments or medical appointments. I tend to go in and say yeah I'm fine, just so I can get out again.'* (P7, F, 61, retired through ill health)

Some participants suggested that GPs prioritise physical above mental health problems:

*'... doctors are busy enough with physical complaints.'* (P10, M, 70, retired)

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

*'There are a lot of people in that surgery and you go in, you sit down, and you've got 5 or 10 minutes and then you're coming back out again and you forget half the stuff you want to really talk about because I've only gone, usually, for my medication. It's just when he does actually say, "How do you feel?" I just say, "I feel really down" and he*

*briefly asks me why and I don't feel like I have time to tell him before he's giving me the leaflet.'* (P13, F, 45, employed)

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

*'And you go in and he just looks at you, you know, and I think to myself, well I'm not telling you how I feel, you know ... God, well he just sits there and he's very stern looking, and you go in, and he'll say "What can I do for you?"; and you think nothing, I'm out the door!'* (P14, F, 71, retired)

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

*'I've been there years and years. I just find them a waste of time. You never get to see a doctor. You get palmed off with anybody. You're lucky if you see a doctor there, anybody. I don't feel they are bothered.'* (P9, F, 68, retired)

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

*'I just think he'd got a really big heart and I think he was very, very understanding of how you might be feeling and very, very supportive indeed.'* (P11, F, 53, employed)

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

*'I suppose it's because they are so busy and as I've said, I do understand where they're coming from, they have so many people to deal with ... and they've only got a certain length of time, you know, they're not, whilst there's some brilliant doctors about and there undoubtedly is, GPs I mean, they do have a really tough job ...'* (P12, F, 70, retired)

*'He's just very approachable. You just can talk to him about anything. I did go a few times and he said I must come back.'* (P8, F, 62, retired through ill health)

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

#### What's on offer?

Participants had different views on the use of medication for anxiety and depression. Some cited a preference for non-pharmacological treatments over antidepressants:

*'I think at the end of the day I think I'd go down the line of, because I take a lot of medication, go down the line of perhaps talking to somebody first, definitely try that before I had any medication.'* (P14, F, 71, retired)

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

*'... she said to me, have you tried a different antidepressant, because I've been on the fluoxetine for several years, and she said there are antidepressants that are for social anxiety ...'* (P7, F, 61, retired through ill health)

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

*'I've got a friend who's, well she's retired now but she is a psychotherapist and I've often thought, perhaps I should talk to X, because she knows my mum as well so well, she worked privately but she did do work for the NHS because she did work across there for the surgery at that time, but of course cutbacks, they cut all that sort of stuff out and they dish out the pills these days, more of them I think sadly.'* (P12, F, 70, retired)

Some participants reported problems accessing talking treatments when signposted by their GP:

*'I think once you start offloading to one person and then you have to come home and make a phone call to go and see other*

*counsellors, it puts people off because there are waiting times. They're ridiculously long.'* (P13, F, 45, employed)

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

*'... this cognitive behaviour. And I found it really useful, because it's challenging your own thoughts, and I thought, yes, I am my own worst enemy.'* (P7, F, 61, retired through ill health)

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

## DISCUSSION

### Summary

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

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

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

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

### Strengths and limitations

Use of qualitative methods with an exploratory approach ensured new phenomena were identified. A second



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### Ethical approval

Ethical approval was granted by the West of Scotland Research Ethics Service Committee [WoSRES/15/WS/0063, Project ID 170210].

### Provenance

Freely submitted; externally peer reviewed.

### Competing interests

The authors have declared no competing interests.

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stage of more detailed framework analysis enabled deeper insights into the barriers and facilitators to patients accessing care for psychological problems.

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

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

Participants were predominantly retired white British females (reflecting the local demographics), hence a greater range of perspectives may have been obtained from a more diverse sample. Participants were identified and recruited through a secondary care clinic, meaning they were all from the same area of England. However, a range of different socioeconomic statuses were included (Table 1).

### Comparison with existing literature

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

Patients with RA, in addition to other LTCs,<sup>27</sup> can lack candidacy for care, failing to seek help for their anxiety and depression due to perceiving this to be a normal response to suffering from a chronic physical illness.

Patients with LTCs may not seek help for mental health problems due to associated stigma.<sup>28</sup> This finding was echoed in a study of Hispanic patients with RA,<sup>29</sup> who perceived psychological problems as a sign of weakness. Further barriers to help-seeking for anxiety and depression in patients with RA were identified within this study. These included a perception of GPs being dismissive of mental health concerns and appointments being anxiety-provoking, recursively affecting help-seeking. Further barriers to help-seeking included a lack of time and poor continuity of care.

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

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

### Implications for research and practice

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

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

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

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

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