Perceptions of the effects of exercise on joint health in rheumatoid arthritis patients

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Abstract

Objectives. Exercise is important in RA management. However, RA patients are less active than the general population. This qualitative study explores the perceptions of patients regarding the effects of exercise on joint health.

Methods. A purposive sample of 12 female and 6 male RA outpatients [age: 23–76 years; disease duration: 2.5 months to 33 years; HAQ score: 0–2.13] participated in four moderated focus groups. The main questions addressed were: (i) How do you feel exercise affects your joints?; and (ii) What affects your exercise behaviour? Transcriptions were independently analysed with 455 meaning units identified. An inductive, thematic analysis was conducted using established techniques. Discussion with a third analyst contributed to consensus validation.

Results. Sixteen constructs emerged, clustering into five themes, reflecting the issues relating to exercise and joint health in RA patients. Emergent themes were: ‘health professionals showing a lack of exercise knowledge’, ‘not knowing what exercise should be done’, ‘worry about causing harm to joints’, ‘not wanting to exercise as joints hurt’ and ‘having to exercise because it is helpful’.

Conclusions. RA patients demonstrated awareness of the advantages of exercise for their joints, both experientially and through education. However, they perceived that health professionals lacked certainty and clarity regarding specific exercise recommendations and the occurrence of joint damage. Thus, to enhance patient-centred exercise prescription in the RA population, uncertainties surrounding joint health, pain symptoms and exercise specificity need to be addressed, alongside continual emphasis of exercise benefits.

Key words: Rheumatoid arthritis, Exercise, Patient perceptions, Joint health, Joint damage, Focus groups, Qualitative, Health professionals, Health behaviours, Health beliefs.

Introduction

Exercise is now considered an important component in the management of RA, with known physiological and psychosocial advantages for the patient [1–8]. Furthermore, advances in exercise prescription for RA patients have occurred, including the recommendation to perform high-intensity exercise in order to maximize benefit [9]. However, RA patients are less active than the general population [10] and greater medical costs are associated with this inactivity [11]. Therefore, one of the key roles of rheumatology health-care professionals is to promote exercise and the maintenance of an active lifestyle, thus maximizing quality of life and functional ability.

Understanding the perceptions of RA patients regarding exercise is salient to the role of the health professional and has thus received previous research attention. For example, it has been suggested that a positive mindset regarding exercise may be necessary to challenge the long-standing opinion that exercise exacerbates disease [12]. Research has also revealed that while patients with arthritis believed exercise to be an important factor in treatment, uncertainty about which exercises to do, and
how to do them without causing harm, prevented many patients from exercising at all [13]. Furthermore, the outcomes expectations of patients, rheumatologists and physiotherapists for high-intensity exercise have been found to be significantly less positive than those for a conventional exercise programme [14]. Limitations within the existing literature may partially explain these perceptions as while high-intensity weight-bearing exercise has been shown to be safe and effective for the small joints in the hands and feet [2, 5, 15–17], unanswered questions remain as to whether high-intensity weight-bearing exercise could result in further damage in those patients with significant radiologic damage of the large joints [5].

A qualitative study of OA patients’ beliefs about exercise following the onset of disease revealed a subgroup of patients who had previously exercised but had stopped because of their symptoms and because they believed exercise was damaging their joints [18]. However, the perceptions of RA patients regarding exercise and joint health are yet to be explored. A better understanding of these perceptions could help to identify the underlying concerns that may be limiting the potential for the positive effects of exercise to become apparent in RA patients. Therefore, the aim of the current study was to generate qualitative data using a focus group methodology to describe the perceptions of the effects of exercise on joint health among RA patients. A qualitative research approach provides an unconstrained and flexible means of exploring issues from the participant perspective, facilitating emergence of aspects of their experience that may not have been considered previously. Furthermore, the interactive aspect presents an environment within which participants are influencing and being influenced by others, often challenging these perspectives and thus fostering rich, plentiful data [19, 20]. The overall objective was to enhance the information available to health professionals, allowing for a targeted, patient-centred approach to exercise prescription.

Methods

Participant sampling

Following ethical approval from North Wales Research Ethics Committee (West), potential participants were identified from the Department of Rheumatology, Betsi Cadwaladr University Health Board. They were initially informed about the study by a nurse specialist or approached by a researcher during an exercise class [Rheumatology Exercise Programme (REPS)] held at the hospital. REPS consisted of an 8-week circuit-based exercise programme of 8–12 stations incorporating high repetition, low-resistance exercises, physiological range of motion stretches and cardiovascular exercises, each of 2–2.5 min duration.

A participant information sheet provided further details and a formal invitation was sent to the patients by post. Drawing upon the broad expertise of the research team, a purposive sampling framework was created, whereby participants were selected to reflect a range of the disease population [20, 21]. Thus, focus groups of RA patients were created including both genders and varying disease duration, thus incorporating a broad range of experiences. Due to an under-representation of younger (<40 years) females with shorter disease duration (<2 years) and younger males with longer disease duration (>2 years), the fourth and final focus group consisted of patients recruited to address this disparity. Figure 1 shows the recruitment of participants; 34 patients were given the information sheet and a total of 18 patients attended a focus group discussion. All participants gave written, informed consent.

Focus group methods

Moderated focus group interviews of four to six RA patients were conducted at Bangor University, lasting ~2 h each. The moderator and assistant moderator were both researchers, specializing in the areas of joint health in RA and motivational qualitative research, respectively.

Patient feedback was incorporated during the development of the interview guide (available as supplementary data at Rheumatology online), which was designed primarily to ascertain the perceived effects of exercise on joint health. In addition, factors affecting exercise behaviour were explored. Thus, following a section of introductory questions, participants were guided and encouraged by the moderator to discuss their experiences, opinions and concerns relating to two main questions:

(i) How do you feel exercise affects your joints?
(ii) What affects your exercise behaviour?

The interview guide included prompts to further explore patient perceptions in relation to exercise type and the opportunity to discuss the effects of diagnosis on exercise behaviour. Finally, patients’ thoughts regarding the statement: ‘Many people are afraid to exercise because they believe that it will cause further damage to their joints’ [22] were also invited. The assistant moderator’s role included...
providing a closing summary, inviting additional points and clarifying any misinterpretations with the participants. The sessions were digitally audio-recorded and discussions relating to exercise and joint health were transcribed verbatim.

Data analysis

An inductive approach to the qualitative analysis was employed, applying methods described by Krueger and Casey [23]. Following each focus group, and before transcription, a written summary was made independently by the assistant moderator. As advocated by Pope et al. [24], systematic content analysis of the data from the focus group transcripts occurred concurrently with data collection in order to improve moderation techniques and maximize the information gained. Principles from Heidegger’s hermeneutic circle were adopted for data analysis, whereby the moderator read and re-read the discussion transcript in detail, identifying and coding key concepts and ideas by highlighting discrete words, sentences and series of sentences relevant to the issue of exercise and joint health [25, 26]. These quotes formed the basic meaning units for analysis, which were categorized through a process of comparing and contrasting. Preliminary themes were then identified to organize and understand the data [27].

To enhance scientific rigour, an additional researcher independently analysed the transcripts from each focus group, using a method of reading and re-reading the transcripts to confirm the emerging concepts, ideas and themes [28]. Finally, a further discussion, involving the two initial analysts and an additional researcher took place during which data from the three focus groups were integrated, discussed and clarified. Factors including frequency, specificity, emotional expression and extensive-ness of the comments were also considered during the process [21, 23]. Through ongoing interrogation of data, maps and diagrams were developed in order to accurately depict the perspectives of people with RA in relation to exercise and their joint health. Divergences in opinion were considered with further discussion until consensus was formed on the constructs and themes to be included in the analytical model.

Results

Eighteen patients participated in four focus groups. The characteristics of these patients are detailed in Table 1. All patients fulfilled the ARA (1987) revised criteria for the classification of RA [29] and had access to multidisciplinary rheumatology team care. Six patients had been regular attendees of the specialised exercise class (REPS).

The meaning units consisted of a total of 455 quotes that were relevant to the issue of exercise and joint health. These varied in length from one word, to a sentence, to a paragraph. Identified concepts and ideas were represented in both of the main questions, thus the findings were integrated for analysis. Sixteen constructs were established, clustering into five themes, reflecting participants’ perceptions regarding exercise and joint health (Fig. 2). Analysis of the fourth focus group’s data did not reveal any concepts or ideas additional to the original analysis, suggesting theoretical saturation had been reached. However, these data allowed further development of the model through clarification of the existing constructs.

The following themes emerged from the analysis: ‘Health professionals showing a lack of exercise knowledge’, ‘Not knowing what exercise should be done’, ‘Not wanting to exercise as joints hurt’, ‘Worry about causing harm to joints’ and ‘Having to exercise because it is helpful’. Quotes illustrating these themes and the relevant constructs are described in the following section, with additional extracts available as supplementary data at Rheumatology online.

Health professionals showing a lack of exercise knowledge

This theme reflects patient perceptions that, while health professionals advocated exercise, they appeared to be uncertain regarding the specifics of exercise prescription and concerns about exercise and joint health. This is illustrated by the following extract:

FG3,P12: …If I do that sort of thing and I get pain, I can go on doing it, now my next question (to a health professional) is am I doing myself harm if I get pain?
P11: mmmmm
P13: Yeah
P12: [The health professional] can’t tell me, right
P14: No, that’s what worries me
P12: Nobody knows

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M: male; F: female; Y: yes; N: no; REPS: Rheumatology Exercise Program.

TABLE 1 Characteristics of the RA participants (n = 18) in the four focus groups
When introduced to the quote ‘Many people are afraid to exercise because they believe that it will cause further damage to their joints’;

FG2,P8: ‘… I think it’s a symptom of misinformation and no information. That’s why people believe that. They are not educated on Day 1 to believe that things are possible with the right help. . . .’

Not knowing what exercise should be done
This theme reflects patients’ concerns about not knowing enough about exercise with respect to their disease, including doubts about the best forms of exercise to undertake, knowing when it is best to exercise, how much they should do and when they should stop.

FG3,P12: ‘I would really like to know what they call exercise and whether or not it conforms to what I think is exercise.’

FG4,P16: ‘Yeah, it’s, what is the exercise about. How do I do it, will it affect my worse little bits. You’ve got to go through the bit about it, you’ve got to read what the exercise is, you’ve got to look at what the exercise is, will I be alright with it . . .’
Patients were unsure if their current disease activity affected whether or not exercise would be beneficial:

FG1,P3: ‘The only thing I can say is that there is no absolute this or that for me, sometimes it helps sometimes it doesn’t. If I have a week when I don’t do any exercise I can feel great, I can have a week when I do exercise and I feel great. There’s not rhyme or reason to it for me.’

Furthermore, patients were unclear how much exercise they should do:

FG2,P9: ‘It’s difficult to know where to draw the line between ‘oh for goodness sake, give it a bit of effort’…or ‘you know this is harmful, it’s time to stop.’

Not wanting to exercise as joints hurt

This theme reflects the negative influence of pain on patients’ exercise behaviour. This was discussed in terms of disease-related pain before exercise:

FG2,P10: ‘There’s only one word that affects my exercise behaviour and that’s pain.’
FG2,P8: ‘I mean you can’t exercise if you are in pain can you. You can’t really do anything.’
FG4,P18: ‘…if it hurts you don’t want to move.’

Exercise-related pain experienced during and following an exercise bout was also discussed:

FG2,P7: ‘Immediately it would ache for a bit, then ease off and then the day after, it would still be, I know that was what aggravated it.’

Worry about causing harm to joints

As illustrated in the discussion excerpt below, this theme reflects the apprehension expressed by patients regarding joint damage as a potential consequence of exercise:

FG3, P12: ‘The worry is whether you are damaging yourself really.’
P13: ‘Yeah.’
P11: ‘Am I going to be worse as a result of it?’
P12: ‘That’s a significant anxiety for me.’

Previous damage, repetitive or impact-based exercise and pain additionally reinforced this concern:

FG4,P16: ‘You can do all the exercises out, it won’t affect what’s at the back of your head saying, if I do that, will I do any damage to what’s already been damaged?’
FG2,P10: ‘…if you do something and it’s that painful, it must be doing your joints some damage.’
FG1,P6: ‘I’ve had two painful knees and I do think that after exercise its worse and I wonder if there’s any damage caused.’
FG2,P8: ‘….got to be careful of a repetitive move.’
FG2,P10: ‘I think impact is really disastrous…’

FG4,P15: ‘…I don’t think weight impact, I don’t think that would be very helpful.’

I have to exercise because it is helpful

This theme reflects the notion that patients felt they needed to exercise in order for strength, mobility and pain relief benefits to occur:

FG1,P1: ‘I feel exercise is necessary, essential and helpful for joint health.’
FG1,P3: ‘I only do it because I know it benefits me. I don’t do it because I enjoy it.’
FG3,P14: ‘Just that it helps to keep them lubricated doesn’t it. It helps keep you moving, exercise. If you don’t they seize up completely.’
FG4,P18: ‘…you are not so creaky for the rest of the day.’
FG1,P5: ‘If you’re strong where the muscles are, it helps to take the weight off the joint.’
FG4,P15: ‘….best way to relieve pain is to do something and it seems to soothe it and it goes away.’

Participants also highlighted the importance of functional advantages, often through a fear of becoming less able:

FG3,P14: ‘It might have done me good in strengthening me, it must have done because I got from my wheelchair onto sticks.’
FG2, P10: ‘I’m frightened that if I don’t get up every morning, if I stay in bed it will become progressive.’
FG4,P18: ‘We’ve all seen the arthritis people sat in the corner in a wheelchair, nobody wants that.’

Disconfirming elements

While the model aims to encapsulate overall patient perceptions and represents the majority of views, disconfirming elements became evident during model development. For example, in relation to the theme ‘having to exercise because it is helpful’, some patients felt that exercise was not ‘helpful’ because it caused pain. For example, ‘I actually find if you push yourself it makes it worse (P4,FG1)’.

Secondly, in relation to the theme ‘not wanting to exercise as joints hurt’, patients (especially those REPS class attendees), suggested that they would continue exercising even if it was painful as they felt it was ‘worth the risk’. As mentioned previously, in relation to the themes ‘not knowing what exercise should be done’, and ‘health professionals showing a lack of exercise knowledge’, REPS class attendees demonstrated more knowledge of the types of suitable exercise they could do. An example is provided in a quote from P3,FG1: ‘There are lots of exercises that you can do at home…I’ll go to the stairs and spend 10 minutes as fast as I can up one step down, up down. Just that little exercise that we did.’

Additional concepts and ideas

Although not specific to joint health and thus beyond the scope of this research paper, additional concepts and ideas were revealed as barriers to exercise. These
included fatigue, muscle pain and a lack of enjoyment, motivation and confidence. Concepts and ideas also emerged as factors which encouraged patients to exercise: social interaction, low cost, easy access, weight reduction and assistance from instructors. Lifestyle time constraints, medications and physical capabilities were also highlighted as factors affecting patients’ exercise behaviour.

Discussion

Using focus groups as an exploratory method, the current study adopts an inductive approach to describe the perceptions of RA patients regarding exercise and joint health. The analytical model summarizes the qualitative content of the focus groups, using words derived from the patient discussions and thus particularly pertinent to the RA population.

Consistent with the findings of previous research, it was evident that RA patients in the present study were aware of the benefits of exercise for their joints, but were unsure of the specific exercise recommendations [30]. The additional concepts and ideas (e.g. barriers, benefits and encouraging factors) emerging from the qualitative data of the present study are also similar to findings from previous studies of patients with arthritis [30–32].

The current analysis highlights the challenges faced by patients when attempting to exercise appropriately, with difficulties arising as a result of incomplete information provided by health professionals (i.e. advising exercise but lacking a definitive explanation of how to do so). Further to this, the model presents the questions as indicated by patients regarding the recommended approach to exercise. These correspond with suggestions by the American College of Sports Medicine, who express exercise prescription using the FITT principle [33]. This incorporates the following: how often per week the patient should exercise (frequency), how energetically or vigorously the patient should exercise (intensity), how long the patient should exercise to obtain benefits (time) and what type of exercises should be prescribed to the patient (type) [34]. In addition, whilst it was clear that current disease state (i.e. pain and fatigue levels) often determined participation, patients were also unsure whether or not this determined the overall benefit of exercise. These queries suggest that patients require knowledge of the specifics of exercise prescription in order to include exercise as part of their RA treatment.

Joint pain was a definitive barrier in all groups and was perceived as a prominent factor in determining the patients’ exercise behaviour, a finding similar to that of previous research [30, 35]. However, novel findings were also revealed, including the notion that patients perceived uncertainties within the health profession regarding pain, joint health and exercise. In particular, this was in relation to whether the sensation of pain equated to the occurrence of damage and the effects of different types of exercise on the health of their joints. As previously identified in OA patients [18], worry that exercise may have detrimental effects on joint health was also exemplified in the present study. Additionally however, it emerged that patients were apprehensive when considering the effects of impact and repetitive exercises. Although the area requires further investigation, this corresponds with the current empirical evidence recommending that those patients with extensive damage to the large joints should avoid high-intensity, weight-bearing exercise [36]. These concerns, coupled with a perception that health professionals are irresolute regarding the effects of different types of exercise on joint health, pose a further challenge to RA patients.

As evident from past research, including findings from randomized controlled trials [1–9], exercise is considered to be fundamentally beneficial for RA patients. The strength of tendons and connective tissue are enhanced by exercise, thus increasing joint stability. Joint lubrication, range of movement and flexibility is also increased [37]. Furthermore, there is also an essential role for high-intensity, weight- and impact-bearing exercises in improving BMD [38]. Despite the aforementioned reservations, patients demonstrated an awareness of these advantages in terms of improving strength, mobility and function and reducing pain. Subsequently, if the perception of exercise as a positive feature of RA treatment is to supersede the apparent negative connotations, continual emphasis of these benefits is of great importance [12, 32, 39].

As may be expected of attendees of a specialized exercise class, the first focus group demonstrated more experiential and education-derived knowledge as to the beneficial effects of exercise. In contrast, the knowledge of non-attendees appeared to be mainly speculative. While exercise class attendees did not highlight disadvantages to the same extent, queries relating to pain and its link with harm were expressed nonetheless, especially regarding exercises of a higher intensity. Upon analysis of the focus groups involving the non-exercise class attendees, a lack of clarity regarding exercise prescription became markedly evident. Although these patients were aware that it would be advantageous for them to partake in exercise, they appeared to have numerous unanswered questions.

While offering a comprehensive account of the current perceptions of RA patients regarding exercise and joint health, and also drawing upon the valuable, interactive elements of focus group methodology (see pp. 3 and 5 of this article for examples), the present study has a number of limitations. First, self-selected participants may be different in terms of disease severity, attitudes about health and exercise and socio-demographics, when compared with the disease population as a whole. Similarly, local communities vary widely in the availability of resources and programmes for individuals with arthritis [30]. Therefore, the findings may not be as applicable in geographical areas with a different level of emphasis on exercise prescription for RA patients. A second limitation is that we used a relatively small sample of patients. However, our purpose to achieve sample saturation (i.e. recruiting patients with a range of characteristics and
Implications

In addition to the pivotal role of the rheumatologist in influencing exercise prescription [40, 41], the following implications of the present study are also relevant to other health professionals involved in the treatment of RA patients (i.e. nurse specialists, physiotherapists, occupational therapists). Primarily, in order to enhance exercise prescription for RA patients, it is evident that the benefits of exercise need continual emphasis. In addition, concerns regarding joint health and pain symptoms need to be addressed, alongside the specificity of exercise recommendations. This means that further research is necessary to attend to the fact that RA patients are currently faced with ambiguous and incomplete information regarding exercise and the health of their joints. Further investigations to include larger populations of RA patients and additionally the perceptions and knowledge requirements of health professionals regarding exercise and joint health would be a valuable addition to this field of research.

Rheumatology key messages

- Patients are aware of the likely benefits of exercise, but require clarification of specific exercise recommendations.
- Health professionals need to impart more knowledge regarding exercise prescription and joint health.

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Supplementary data

Supplementary data are available at Rheumatology online.

References