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# Physical activity engagement in early rheumatoid arthritis: a qualitative study to inform intervention development



Janet Withall<sup>a,\*</sup>, Anne M. Haase<sup>b,1</sup>, Nicola E. Walsh<sup>a,2</sup>, Anita Young<sup>c</sup>, Fiona Cramp<sup>a,3</sup>

<sup>a</sup> Faculty of Health & Applied Sciences, University of the West of England, Bristol BS16 1DD, United Kingdom

<sup>b</sup> Centre for Exercise, Nutrition and Health Sciences, School for Policy Studies, University of Bristol, Bristol BS8 1TZ,

United Kingdom

<sup>c</sup> Patient Research Partner, United Kingdom

## Abstract

**Background** Physical activity (PA) in patients with rheumatoid arthritis (RA) is lower than in the general population. PA can improve physical function in RA, decrease chronic inflammation and reduce pain, without adversely affecting disease activity.

**Objectives** To explore patient's views on approaches to delivering PA programmes and inform a programme to maximise functional ability through long-term engagement with PA.

**Methods** Qualitative data were collected *via* three focus groups which explored the views of people with RA of their PA support needs following diagnosis; experiences relating to PA; motivators and facilitators to support PA engagement and the suitability for people with RA of evidence based PA programmes designed for other long-term conditions.

**Results** Study participants (15 female, 4 male; 59.9 (standard deviation (SD) 10.3) years) had a mean time (SD) since diagnosis of 44 (34) months. Data analysis yielded 4 key themes relating to PA programmes: (1) why people join and why they drop out; (2) venue and timing; (3) what people want to do and hear; and (4) who should deliver programmes and how.

**Conclusion** Patients with RA are interested in PA programmes 6 to 12 months after diagnosis, which support safe exercise and provide expert physiotherapist input. Recommendation by trusted health professionals and promotion of the benefits for 'people like me' would positively impact recruitment and retention. Key elements of the programme include proficient, safety-oriented exercise guidance, RA education, peer support, relaxation, coping strategies and self-set goals. Findings indicate that a group-based programme with a social aspect would support adherence.

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### Introduction

Rheumatoid arthritis (RA) is a chronic inflammatory auto-immune disease that primarily affects synovial joints

\* Correspondence. Tel.: +44 0117 3421763.

*E-mail addresses:* janet.withall@uwe.ac.uk (J. Withall), anne.haase@bristol.ac.uk (A.M. Haase), Nicola.walsh@uwe.ac.uk (N.E. Walsh), anita.young@blueyonder.co.uk (A. Young), and can lead to loss of function and decreased mobility. Physical activity (PA) in RA is lower than in the general population [1] and has been shown unequivocally to be associated with work disability and reduced physical function [2]. Research has shown that high intensity training programmes [3] and class based exercise [4] can improve physical function in RA, while PA decreases chronic inflammation and reduces pain [5], all without adversely affecting disease activity.

PA is defined as "any bodily movement produced by skeletal muscles that results in energy expenditure [above resting levels]" [6]. In addition to the benefits associated

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fiona.cramp@uwe.ac.uk (F. Cramp).

<sup>&</sup>lt;sup>1</sup> Tel.: +44 0117 3311082.

<sup>&</sup>lt;sup>2</sup> Tel.: +44 0117 3288801.

<sup>&</sup>lt;sup>3</sup> Tel.: +44 0117 3288501.

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with RA, regular PA can reduce the incidence of a wide range of chronic conditions, promote physical and mental health and improve perceptions of fatigue and quality of life [7]. Despite all these potential benefits only 14% of people with RA exercise more than 3 times per week [8], illustrating the impact of chronic conditions where pain and other physical and psychosocial limitations are factors [9,10].

Fatigue, pain, decreased mobility, lack of professional input, inaccessible facilities, surgery, medications, potential embarrassment, fear of falling and the psychological effects of the disease have been identified as barriers to PA in RA [11]. Even when pain free, people with RA often fear that PA will exacerbate their symptoms [12]. Overall, these findings suggest a need to identify programmes that support long term engagement with PA for recently diagnosed people with RA to minimise inappropriate health beliefs and prevent unnecessary reductions in function. This assertion is supported by National Institute for Health and Care Excellence (NICE) guidelines which indicate that people with RA should have access to specialist physiotherapy to encourage regular physical exercise [13].

Basing PA interventions on appropriate health behaviour change models has been shown to increase the likelihood of success and is recommended by NICE [14,15]. There is a dearth of evidence regarding health behaviour change models to promote long term engagement with PA interventions in inflammatory arthritis, with the quality of the research poor and the findings somewhat inconsistent [16,17]. However there have been successful theory-based interventions to increase PA in other long term conditions; elements of which may be transferable to people with RA [18,19].

The UK's Medical Research Council recommends a development-evaluation-implementation model for the development and testing of complex interventions [15]. The engagement of the intended patient group is central to ensuring that interventions are as appealing and acceptable as possible. The ultimate aim of this study is to develop and test an intervention (Promoting Engagement with Physical Activity-Rheumatoid Arthritis (PEPA-RA)) based on Self Determination Theory (SDT) [20], to promote long term engagement with PA by people with RA. The intervention would target patients up to two years from diagnosis in an attempt to prevent unnecessary physical de-conditioning due to inactivity and promote good PA habits [21]. This paper reports the results of the formative research conducted to inform the development and design of PEPA-RA. Specifically, in this study, we sought to: (1) understand motivators and facilitators of engagement in PA post diagnosis of RA; (2) identify factors that might affect programme recruitment and retention; and (3) explore people with RA's perceptions of a variety of PA programmes based upon existing evidence in other long-term conditions to identify key PA programme elements.

#### Methods

### Design

Data were collected *via* three focus groups conducted during July and August 2014. Group participants were recruited by researchers from rheumatology clinics at University Hospitals Bristol NHS Foundation Trust (UHBristol) and the Royal National Hospital for Rheumatic Diseases, Bath (RNHRD) rheumatology clinics. In addition a research nurse reviewed patient notes at the RNHRD and contacted those who met the inclusion criteria by telephone.

Focus groups were used as the data collection device as they allow participants to refine and test their thoughts and responses against those of others, and to explore and challenge their peers' opinions, so generating data of additional depth [22]. Qualitative approaches are highly appropriate for understanding complex personal and social issues such as engagement in physical activity and the influence of chronic disease on PA and are useful when, as in this case, there is limited existing knowledge.

#### Participants

Study inclusion criteria were 18 years plus and with a diagnosis of RA from a rheumatologist, according to ACR criteria (see Appendix A, see supplementary data) [23] within the last 5 years. This was considered to enable good recall of the early stages after diagnosis. Age and diagnosis were procured from patient notes. Date of diagnosis was self-reported at recruitment.

Supplementary Appendix A related to this article can be found, in the online version, at http://dx.doi.org/10.1016/j.physio.2015.07.002.

#### Procedure

Patients who met the inclusion criteria were provided with participant information sheets and a reply slip. On receipt of a completed reply slip the patient was allocated to a focus group. Participants' travel expenses were reimbursed.

Participants were purposefully sampled to reflect a range of age and gender. Due to the relative heterogeneity of the research population in relation to the subject of enquiry, a sample size of approximately 20 was proposed to be sufficient to collect data of an appropriate breadth and depth [22].

The focus group interview guide was semi-structured and designed to explore patients' views of their PA support needs following a diagnosis of RA; their experiences relating to PA and motivators and facilitators of engagement in PA. Following a discussion of these issues three different PA programmes were presented to the focus groups (see Appendix B, see supplementary data). Two of these were based upon successful interventions that the authors had experience of delivering, namely ESCAPE (Enabling Self-Management and Coping with Arthritic Knee Pain Through Exercise) [19], Download English Version:

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