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Barriers and facilitators for physical activity in rheumatic and musculoskeletal disease: a European-based survey

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Abstract

Physical activity (PA) is a key strategy for improving symptoms in people with rheumatic and musculoskeletal diseases (RMDs). The aim of this study was to investigate and rank the importance of known barriers and facilitators for engaging in PA, from the perspective of people living with RMD. Five hundred thirty-three people with RMD responded to a survey (nine questions) disseminated by the People with Arthritis and Rheumatism (PARE) network of the European Alliance of Associations for Rheumatology (EULAR). The survey required participants to rank — based on their perceived importance — known PA barriers and facilitators from the literature, and specifically RMD symptoms as well as healthcare and community factors that may affect PA participation. Of the participants, 58% reported rheumatoid arthritis as their primary diagnosis, 89% were female, and 59% were between 51 and 70 years of age. Overall, participants reported fatigue (61.4%), pain (53.6%) and painful/swollen joints (50.6%) as the highest ranked barriers for engaging in PA. Conversely, less fatigue (66.8%) and pain (63.6%), and being able to do daily activities more easy (56.3%) were identified as the most important facilitators to PA. Three literature identified PA barriers, i.e., general health (78.8%), fitness (75.3%) and mental health (68.1%), were also ranked as being the most important for PA engagement. Symptoms of RMDs, such as pain and fatigue, seem to be considered the predominant barriers to PA by people with RMD; the same barriers are also the ones that they want to improve through increasing PA, suggesting a bi-directional relationship between these factors.

Key Points

- Symptoms of rheumatic and musculoskeletal disease (RMD) are the predominant barriers for lack of physical activity engagement.
- RMD symptoms are the factors that people with RMDs want to improve when engaging in PA.
- The barriers that stop people living with RMDs to do more PA are the ones that can be significantly improved through PA engagement.

Keywords Exercise · Fatigue · Pain · Physical activity · Rheumatic and musculoskeletal disease · Rheumatoid arthritis

Introduction

There is ample evidence demonstrating that increasing physical activity (PA) can significantly improve disease-related outcomes in rheumatic and musculoskeletal diseases (RMDs). Specifically, higher levels of PA have been related to lower fatigue, pain and inflammation as well as reduced risk of systemic manifestations, such as

cardiovascular disease, muscle wasting and mental health in people with RMD [1, 2]. As a result, the European Alliance of Associations for Rheumatology (EULAR) now acknowledges the importance of PA in the multidisciplinary RMD management and thus, has published relevant recommendations [3, 4]. However, the implementation of PA in both healthcare and community settings is failing predominantly due to significant barriers to PA experienced by people with an RMD, which can be categorized into three different disciplines: (a) barriers related to RMD symptoms, such as fatigue and pain, (b) healthcare-related barriers, such as lack of PA knowledge by healthcare

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professionals and doctors, and (c) community-related barriers, such as lack of knowledgeable exercise professionals and RMD-specific PA programs [5]. While some research studies have explored PA barriers and facilitators in RMD [5–7], little has been done to identify how barriers and facilitators are ranked and, specifically, which are the most important ones for engaging in PA, from the RMD patients' perspective. This knowledge is vital for the successful development and implementation of PA programs which currently lacks such insight. Indeed, knowledge on the most important barriers can potentially help strategize what capacity building and/or patient empowerment initiatives should be prioritized. The lack of a coherent approach about these matters contributes to low PA and cardiorespiratory fitness levels seen in RMDs [8, 9]. Therefore, the aim of the present study was to investigate and rank, from the perspective of RMDs patients, the importance of known barriers and facilitators for engaging in PA.

Methods

Participants

A total of 533 people with RMD volunteered to take part in the present survey, which was part of the EULAR funded project entitled “Implementation of Physical Activity into routine Clinical practice in Rheumatic Musculoskeletal Disease (IMPACT-RMD),” and focused on capacity building of healthcare professionals and doctors across the EU through e-Learning [10]. The survey was administered through the EULAR People with Arthritis and Rheumatism (EULAR-PARE) network while ethical approval was obtained by the University of Wolverhampton Ethics Committee, UK, and the study complied with the Declaration of Helsinki. PARE is a EULAR-only network of representatives of RMD user groups around Europe that work together towards improving the quality of care of people living with RMDs. All participants were informed about the purpose and methodology of the study, in the first page of the survey, and those who provided consent were then able to fill in the survey questions.

Design

The survey contained nine questions which were developed by researchers and clinicians and discussed and determined through input from people living with RMDs. Specifically, PA barriers and facilitators from the literature were identified by the IMPACT-RMD members, which were then included into the close-ended survey questions after consultations with representatives from seven different RMD patient organizations. Questions 1 and 2 asked participants if they currently do PA and

how RMD symptoms affected their everyday life, respectively. The next three questions required participants to rank literature-identified PA facilitators (questions 3 and 5) and barriers (question 4), depending on their perceived importance. In specific, people living with RMDs were asked to provide responses for multiple answers per survey question, and specifically “*how important is it for the following symptoms to improve, through physical activity*” (question 3), “*what stops you from becoming more physically active*” (question 4) and “*what would help you do more physical activity*” (question 5). The participants were asked to rank barriers and facilitators using a visual analogue scale ranging from 0 to 100%, where zero (0) was “not at all” and 100 was “very much.” The survey also asked about their primary diagnosis (question 6), as well as information about their age (question 7), gender (question 8) and their country (question 9, to ensure participants represented countries across Europe). All questions of the survey and responses appear in Tables 1 and 2 (Table 1 contains survey questions 6–8 while Table 2 provides information for survey questions 2–5).

Table 1 Participants' general characteristics ($n=533$)

	Survey item	Percent % (n)
Primary diagnosis	Rheumatoid arthritis	58.2% ($n=310$)
	Sjogren's syndrome	9.2% ($n=49$)
	Lupus	5.8% ($n=31$)
	Ankylosing spondylitis	4.9% ($n=26$)
	Osteoarthritis	3.9% ($n=21$)
	Fibromyalgia	4.5% ($n=24$)
	Spondylarthritis	2.6% ($n=14$)
	Psoriatic arthritis	2.4% ($n=13$)
	Systemic sclerosis	1.7% ($n=9$)
	Osteoporosis	0.6% ($n=3$)
	Vasculitis	0.4% ($n=2$)
	Auto-immune related lung disease	0.2% ($n=1$)
	Myositis	0.2% ($n=1$)
	Inflammatory myositis	0.2% ($n=1$)
Age (years)	Other	4.1% ($n=22$)
	31–40	8.3% ($n=44$)
	41–50	16.3% ($n=87$)
	51–60	30.2% ($n=161$)
	61–70	28.5% ($n=152$)
	71–80	2.4% ($n=12$)
Gender	> 80	0.4% ($n=2$)
	Female	9.6% ($n=51$)
	Male	89.3% ($n=476$)

Table 2 Ranking of RMD barriers and facilitators

Survey question	Barrier and/or facilitator	Score (% out of 100)
Survey question 2 (barrier):	Fatigue	60.5
How much do the following symptoms affect your everyday life (0 is “not at all” and 100 is “very much”)	Pain	54.5
	Poor sleep	49.4
	Joint/muscle stiffness	52.4
	Activity limitation	47.7
	Painful/swollen joints	47.5
	Low mood/anxious feeling	43.0
	Loss of appetite	15.8
	Fever	14.5
Survey question 3 (facilitator):	Improve general health	78.8
How important is it for the following symptoms to improve, through physical activity? (0 is “not at all” and 100 is “very much”)	Improve fitness	75.3
	Improve mood/reduce anxious feelings	68.1
	Reduce fatigue	65.3
	Reduce joint muscle stiffness	65.2
	Improve sleep	64.8
	Reduce activity limitation	62.9
	Reduce pain	61.8
	Reduce number of painful/swollen joints	57.4
Survey question 4 (barrier):	Fatigue	61.4
What stops you from becoming more physically active? (0 is “not at all” and 100 is “very much”)	Pain	53.6
	Painful/swollen joints	50.6
	Activity limitation	46.4
	Poor sleep	43.8
	Low motivation for physical activity	42.0
	Fear of exacerbating symptoms	41.8
	Low mood/anxious feelings	35.3
	Lack of time	31.8
	Lack of expertise in local gym	28.8
	Lack of doctor’s/healthcare practitioner’s advice	27.0
Survey question 5 (facilitator):	Having less fatigue	66.8
From the factors below, what would help you do more physical activity? (0 is “not at all” and 100 is “very much”)	Having less pain	63.6
	Being able to do easier my daily activities	56.3
	Being able to sleep better	55.5
	More knowledgeable exercise professionals	55.4
	Improved access to physical activity facilities/classes	54.3
	Having more time during the day	48.2
	Better doctor’s/healthcare practitioner’s advice	43.7
	More support from family/friends	42.9
	Better community support	36.3
	Being in closer proximity to gym	26.6

In the right “Score” column, the three highest scores appear in bold for every question

Results

General characteristics as well as the primary self-reported diagnosis of the participants are presented in Table 1. Of the 533 participants, 85% ($n = 450$) reported that they

currently do some PA, with the remaining 15% ($n = 77$) reported no engagement in PA.

Results from the remaining questions of the survey appear in Table 2, and these appear in the order that they have been ranked and prioritized by people living with RMD.

Discussion

To the authors' knowledge, this is the first study that has investigated the prioritization and ranking of well-established (based on the available literature) PA barriers and facilitators in people living with RMDs. Our results revealed that fatigue seems to be one of the predominant barriers to engagement in PA, together with pain and painful/swollen joints. When asking about factors that affect the everyday life of people with RMD, fatigue was again reported as the most important symptom, followed by pain. Surprisingly, poor sleep was ranked by participants as more important than other detrimental RMD symptoms. Our findings support the notion that RMD symptoms are the most important to address, in order to support PA engagement, and that these factors appear to be more vital than doctors' or healthcare professionals' knowledge and advice, or community support.

Interestingly, three barriers to PA that have been established in the literature — i.e., general health, fitness and mental health — were also perceived as being the most important parameters that people with RMDs wanted to improve via PA engagement. In addition, fatigue and pain were ranked highly as symptoms that they would like to improve through undertaking more PA. Taken together, the current data suggest the existence of a paradox: the barriers that stop people living with RMDs to do more PA, are the ones that can be significantly improved through PA engagement. This is in line with recent, systematic reviews and meta-analyses, which suggest that activity limitation and pain [11], as well as fatigue [12], can be significantly improved via PA. The same has been observed in a recent prospective observational study, which demonstrated a bi-directional relationship between PA behaviour and pain and fatigue in people living with rheumatoid arthritis [13]. Perhaps this paradox should be one of the main messages that RMD healthcare professionals and doctors should offer to people with RMD to facilitate more engagement in PA. These findings may also be important for the development of targeted capacity building and patient empowerment initiatives for helping people with RMD to do more PA, focusing predominantly on better control of the disease (pain and swollen/tender joints) prior to supporting them to engage in PA. However, the use of pain relief medication to reduce pain and help engage in PA may not be a viable solution [14], while everyday ergogenic aids, such as caffeine, to help reduce fatigue prior to an exercise bout require further investigation through appropriately designed trials.

It is noteworthy that the implementation of PA in healthcare and community settings does require tailoring the PA intervention according to the needs and preferences of the target population, and thus, all the barriers and facilitators reported herein may be important. However, the present

data provide important insights about the prioritization of the existing PA barriers and facilitators, which predominantly seem to be disease-related symptoms. It may be important that these have to be systematically assessed in routine clinical practice [15] so that PA targets are co-produced and re-established at regular intervals, given that the physiological and psychological adaptations, that can be achieved through PA engagement, can be met and new ones to emerge (either from the patient or the healthcare professional's perspective).

The present study is limited by certain factors, such as the inclusion of a relatively higher number of rheumatoid arthritis patients compared to other RMDs. The low number of other RMDs did not allow for meaningful comparisons between the different RMDs. The present sample also consisted of more females, and separate analyses of male and female samples were again not possible due to inadequate numbers. Furthermore, it is worth mentioning that the survey questions did not enquire about the participants' medication or disease activity at the time of the survey, factors that may have had an impact on the patients' self-reporting PA levels and relevant barriers, albeit this was done to minimize the biases of self-reporting. Therefore, future work is needed to unravel how patient-related and contextual factors relate to barriers and facilitators of PA in the RMD population. Finally, the study lacks an a priori power calculation, and thus, these results should be confirmed in future relevant studies. Within these limitations, it is concluded that patient-important RMD outcomes, such as pain and fatigue, seem to be the predominant barriers to PA in RMDs, than those related to healthcare, community and social support. At the same time, people with RMDs report that barriers to PA are also outcomes they want to improve through increasing PA engagement, suggesting a bi-directional relationship between these factors. The present results should be confirmed by future studies.

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Declarations

Conflict of interest EN has received speaker honoraria/participated in advisory boards for Celltrion, Pfizer, Sanofi, Gilead, Galapagos, AbbVie, Lilly, Fresenius and holds research grants from Pfizer and Lilly. GEF has received honoraria/speaker fees from Abbvie, Novartis, Pfizer, UCB, AEnorasis, Genesis.

All other authors have nothing to declare.

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