RHEUMATOLOGY

Rheumatology 2015;54:1065–1073
doi:10.1093/rheumatology/keu444
Advance Access publication 27 November 2014

Original article

An outsourced health-enhancing physical activity programme for people with rheumatoid arthritis: exploration of adherence and response

Birgitta Nordgren[1], Cecilia Fridén[1], Ingrid Demmelmaier[1], Gunnar Bergström[2], Ingrid E. Lundberg[3], Alyssa B. Dufour[1,4,5], Christina H. Opava[1,6] and the PARA Study Group*

Abstract

Objectives. The aims of this study were to document adherence to and changes in health-enhancing physical activity (HEPA) levels and self-reported and assessed functioning and to explore aspects of adherence and response during the first year of an outsourced 2-year HEPA programme in people with RA.

Methods. Two-hundred and twenty patients participated in this observational cohort study, which included daily physical activity, twice-weekly circuit training and biweekly support group meetings. Self-reported data included current (past week) and maintained (past 6 months) HEPA levels, sociodemographics and disease-related and psychosocial factors. Tests of aerobic capacity and muscle function were performed and anthropometric data were collected.

Results. Eighty-eight per cent of the participants completed 1 year assessments. Self-reported current and maintained HEPA increased. General health perception and a number of other self-reported disease-related and psychosocial factors improved, while exercise self-efficacy declined. Aerobic capacity, timed standing and grip strength improved and waist circumference decreased. The mean number of circuit training sessions performed was 48, the mean number of days with HEPA was 189 and the mean number of support group meetings attended was 9. Better adherence to circuit training improved general health, and better adherence to group meetings improved timed standing. Exercise self-efficacy improved among those adhering more to circuit training or support group meetings.

Conclusion. The outsourced HEPA programme had high retention and reasonable adherence. A number of health outcomes improved. Relationships between adherence to the programme components and response were not clear-cut and need further attention.

Trial registration: ISRCTN register; http://www.controlled-trials.com. Trial registration number ISRCTN25539102.

Key words: clinical trial, health behaviour, exercise, muscular strength, physical fitness, self-efficacy social cognitive theory, trans-theoretical model.

CLINICAL SCIENCE

[1]Division of Physiotherapy, Department of Neurobiology, Care Sciences and Society, Karolinska Institutet, Huddinge, [2]Unit of Intervention and Implementation Research, Institute of Environmental Medicine, [3]Rheumatology Unit, Department of Medicine, Karolinska University Hospital, Karolinska Institutet, Stockholm, Sweden, [4]Harvard Medical School, Institute for Aging Research, Hebrew Senior Life, [5]Beth Israel Deaconess Medical Center, Boston, MA, USA and [6]Department of Rheumatology, Karolinska University Hospital, Stockholm, Sweden

Submitted 24 March 2014; revised version accepted 26 September 2014

Correspondence to: Birgitta Nordgren, Department of Neurobiology, Care Sciences and Society, Division of Physiotherapy, Karolinska Institutet, 23100, SE-141 83 Huddinge, Sweden.
E-mail: birgitta.nordgren@ki.se
*Members of the PARA Study Group are listed in the acknowledgements

Rheumatology key messages

- High retention and reasonable adherence indicated good feasibility of the outsourced HEPA programme in patients with RA.
- Physical activity and several health outcomes improved substantially in patients with RA during the 1 year HEPA programme.
- The relationship between adherence to the HEPA programme components and response in patients with RA was not clear-cut and needs further attention.

Introduction

Physical inactivity is a major threat to public health. The risk of fatal consequences increases with age and the presence of disease and disability represents further obstacles to a physically active life. Thus public health recommendations for health-enhancing physical activity (HEPA), including at least 150 minutes per week of at least moderate-intensity physical activity and twice-weekly strength training, have been released by many agencies and organizations [1–4].

RA confers disability, poor health perception and increased risk of co-morbidity and premature death, mainly due to cardiovascular disease. New drugs and new treatment principles have dramatically improved inflammation control, but do not seem to fully alleviate pain, the development of disability or the risk of cardiovascular disease [5–7]. Thus HEPA might be a valuable complement to drug therapy in rheumatic disease.

The reported prevalence of HEPA in people with arthritis is contradictory due to differing definitions, samples included and assessment methods [8]. Our recent study indicates that while almost 70% of people with RA reported adherence to HEPA, only 22% had maintained it for at least 6 months [9]. Interestingly, factors explaining HEPA variation are not mainly attributed to the severity of disease or disability, but rather to psychosocial factors [9, 10]. Thus the promotion of HEPA is a complex task that needs to include not only instructions on how to perform physical activity, but also motivational and self-regulatory strategies to support behaviour changes [11].

Studies of HEPA programmes in people with RA are scarce and results conflicting. Our previous study of a 1 year HEPA support programme found improved muscle function and health perception without changes in physical activity behaviour and the improvements gained at the end of the programme were lost 1 year later [12, 13]. The only other study performed on HEPA in RA found changes in physical activity behaviour, but no consequent improvement in health outcomes [14].

HEPA is a life-long commitment that should be introduced and encouraged within health care, but it also needs to be performed and supported in other contexts. However, outsourced programmes are poorly studied in populations with RA. Furthermore, adherence and response related to physical activity are seldom explored in depth, identification of the programme components influencing outcomes most efficiently is not done and the characteristics of individuals responding best to a certain programme are poorly described.

The objectives of this cohort study were to document adherence to and changes in HEPA levels and self-reported and assessed functioning and to explore aspects of adherence and response during the first year of an outsourced 2 year HEPA programme in people with RA.

Methods

Design

This article describes the first year of a 2 year prospective observational study of a HEPA programme (trial registration ISRCTN25539102). Recruitment of participants diagnosed with RA [15] started in October 2010 and was performed within the context of the Swedish Rheumatology Quality Registers, comprising approximately 27 000 patients with RA, of whom 9560 are included from the six clinics participating in the present study. A detailed description of the study protocol has previously been published [16]. The study was approved by the Stockholm Regional Ethical Review Board (2010/1232-31/1). All participants were mailed information about the study along with the questionnaires and consented to participate by filling out and returning the questionnaires. Additional information was sent to those targeted for the intervention, who consented by filling out and returning a form with their desired site and time for HEPA programme participation.

Participants

A total of 1932 patients were eligible for the study, as they were 18–75 years of age, independent in daily living [Stanford Health Assessment Questionnaire Disability Index (HAQ-DI) $\leqslant 2$], expressed an interest in participating in organized physical activity, were fluent in Swedish and had not yet participated in a HEPA programme. Two hundred and eighty-six patients consented to participate; 244 were assessed at baseline and 220 started the programme. The selection procedure, describing at each step the differences between those who dropped out and those who made it to the baseline assessments, indicated that sociodemographic and psychosocial factors, rather than disease-related factors, were related to attrition [17]. The 24 patients who were assessed at baseline but did not start the programme did not differ significantly in sociodemographic, disease-related or psychosocial

variables or HEPA compared with the 220 patients who started the programme.

Intervention

Three main components constituted the intervention programme: (i) at least moderate-intensity physical activity for at least 30 min on most days of the week; (ii) at least two weekly 45 min circuit training sessions, including both muscle strength training (50–80% of one repetition maximum, 3×10 repetitions) and aerobic exercises (60–85% of maximal heart rate) and (iii) biweekly support group meetings. The recommended number of circuit training sessions during the year was 104; the possible total HEPA, which included both daily physical activities and circuit training sessions, was 365. A maximum of 20–22 support group meetings were offered by the different participating sites. Participants who signed up and paid for a 1 year membership at a public training centre were initially instructed by the physical therapists (coaches) on how to perform the circuit training. They could then access the training centres whenever they preferred during opening hours and exercise together with regular members. The study coaches were available once a week at fixed times at each centre for optional consultations and advice on circuit training. Pedometers and access to a web page for step registration were provided to each participant in order to encourage daily physical activity. The support group meetings were informed by an active behavioural learning approach in line with social cognitive theory [18] and were guided by coaches who were trained to deliver the programme by facilitating the participants' learning of specific behavioural skills to enable incorporation of HEPA into daily routines [19]. More details of the intervention programme, which also included expert lectures, physical activity in different environments, challenge competitions and self-assessed aerobic capacity tests [20], have been published elsewhere [16].

Measurements

Participants were assessed at baseline and after 1 year using data retrieved from the Swedish Rheumatology Quality Register, patient files, mailed questionnaires, performance tests, anthropometrics and weekly text messages [16, 21].

Self-reports

Data on sociodemographics included age (years), gender, education (university versus below), income (above/below average Swedish income in 2008) and children under the age of 18 years at home (yes/no).

Disease-related variables included disease duration, co-morbidities (including respiratory, cardiovascular, neurological and psychiatric disease, diabetes mellitus or other) and general health perception (primary response variable) [22], pain [23] and fatigue [24, 25] rated on a visual analogue scale. Quality of life was assessed with the EuroQol five-dimensions questionnaire (EQ-5D) [26] and activity limitation with the HAQ-DI [27].

Psychosocial variables were assessed with the Exercise Self-efficacy Scale (secondary response variable) [28, 29], the modified Fear-Avoidance Beliefs Questionnaire (secondary response variable) [30], the scales to measure social support for exercise behaviours [31] and two study-specific items concerning outcome expectations for physical activity on long-term health and present RA symptoms.

Data on self-reported current (in the past week) HEPA were collected with the short form of the International Physical Activity Questionnaire (IPAQ), assessing overall physical activity during the past week without separating aerobic physical activity from muscle strength training [32]. Maintained ($\geqslant$6 months) HEPA was assessed with the Exercise Stage Assessment Instrument (ESAI) [33]. The original one-item ESAI was modified for the present study to include two items: one item on aerobic physical activity, defined as moderate-intensity activity for at least 30 min on at least 5 days/week, and one item on muscle strength training at least twice weekly, both followed by the question 'Are you physically active according to this description?'.

Performance tests and anthropometrics

Performance tests of maximal aerobic capacity estimated from a submaximal bicycle ergometer test [34], lower limb function with the timed-stands test [35] and maximum and average grip strength with the Grippit device [36] were performed (secondary response variables). Anthropometric data on BMI, waist circumference and blood pressure (systolic and diastolic) were collected. Trained physical therapists independent of the intervention supervised tests and collected the data.

Adherence

Two text messages were sent once each week to collect data on the number of days during the past week that participants performed circuit training sessions and on how many additional days of the past week they performed at least moderate-intensity physical activity for at least 30 min [21]. Support group meeting attendance was registered by the coaches.

Statistical analyses

Descriptive statistics were calculated for baseline measurements using mean (S.D.) for continuous variables and proportions for categorical variables. Since the majority of participants reported a 10 for both items concerning outcome expectations, they were dichotomized into 10 *vs* $<$10 for analysis. Differences at baseline between the intervention sample and the 24 dropouts who did not start the programme and for those completing 1 year assessments *vs* those not completing them were examined using Student's *t*-test for continuous variables and χ^2 tests for categorical variables.

Changes from baseline to the end of the intervention year were examined for disease-related and psychosocial variables, HEPA levels, performance tests and anthropometric measures using generalized linear models. Using the two observations, at baseline and at the end of the

intervention year, β-coefficients and standard errors were calculated using a mixed model approach with a subject effect.

Adherence and response were explored in two subsequent analyses incorporating the three programme components—circuit training, total HEPA (including circuit training) and support group meetings—and the primary and secondary response variables.

Adherence

Participants were categorized into adherers and non-adherers based on 50%, 70% and 90% participation in circuit training sessions, total HEPA and support group meetings, respectively. The change in the primary and secondary response variables was calculated between baseline and the end of the intervention year and Student's *t*-test was used to compare the mean changes in the response variables in adherers *vs* non-adherers.

Response

Participants were categorized into responders and non-responders based on 10%, 20% and 30% 1-year improvement in the primary and each of the secondary response variables. Student's *t*-test was used to examine the differences in mean adherence to each of the three programme components in the responders and non-responders.

In addition to the above individual response variables, a total response variable was created based on improvement in general health perception and at least two out of three performance tests. Using the total response variable at the 10% level of improvement at the end of the intervention year, baseline characteristics of participants were compared in responders *vs* non-responders using Student's *t*-test.

SAS/STAT version 9.3 (SAS Institute, Cary, NC, USA) was used for all analyses. Alpha levels were set to 0.05 for presentation of descriptive data for the 1 year change and baseline differences by responder status, while alpha levels were set to 0.01 to account for multiple testing in the exploration of different levels of adherence and response.

Results

Eighty-one per cent of the 220 participants were female, with a mean age of 59 years (S.D. 8.8) and a mean disease duration of 12 years (S.D. 9.6). Fifty-one per cent had a university education, 69% had income above the Swedish national average and 16% had children at home. Seventeen per cent had one and 40% had two or more co-morbidities. The most common co-morbidities were cardiovascular disease ($n = 61$; 51 of which had high blood pressure), lung disease ($n = 21$) and additional musculoskeletal conditions ($n = 22$). Current and maintained HEPA were reported by 60% and 0%, respectively, at baseline. Results of baseline assessments are displayed in Table 1.

Twenty-six participants did not complete the 1 year assessment. They did not differ ($P > 0.05$) from the remaining sample for any of the variables assessed at baseline. Reasons given for dropping out were mainly related to logistics, such as distance to the training centre ($n = 2$), training costs ($n = 2$) and work or family responsibilities ($n = 3$), but also negative feelings about the training concept or the training centre, the group meetings, the coaches and/or peers ($n = 6$). Other reasons were co-morbidities and injuries ($n = 6$). Seven participants gave no reason for dropping out.

One hundred and ninety-four (88%) of the 220 participants who started the programme were assessed after the intervention year with questionnaires ($n = 191$) and/or performance tests ($n = 186$). Their mean number of reported circuit training sessions was 48 (S.D. 36.2), the mean number of days with total HEPA was 189 (S.D. 92.3) and their mean registered support group meeting attendance was 9 (S.D. 6.4).

For those ($n = 186$) who answered the IPAQ at both baseline and the 1 year assessment, the proportion meeting current HEPA (during the previous week) increased from 55% to 82% ($P = 0.0004$). For those ($n = 178$) completing the ESAI at both assessments, the proportion reaching maintained HEPA (during the previous 6 months) increased from none to 37% ($P = 0.0495$). The participants improved their general health perception, quality of life and social support from friends and reduced their pain, activity limitation and fear avoidance beliefs during the 1 year intervention (Table 1). In contrast, exercise self-efficacy declined. The outcome of the performance tests indicated improved aerobic capacity, timed standing and grip strength. Waist circumference decreased (Table 1).

Greater adherence (at 50%, 70% and 90% levels) to group meetings or circuit training was related to greater improvement in exercise self-efficacy, and greater adherence to group meetings was also associated with greater improvements in timed standing compared with those who attended less (Table 2). Adherence to total HEPA was not associated with any of the response variables, nor was circuit training or support group meetings associated with general health perception, fear avoidance beliefs, maximal oxygen uptake (VO_{2max}) or grip strength (complete data not shown).

Responses at the 10% and 20% levels in general health perception were more likely to occur among participants who adhered more to circuit training compared with those adhering less (Table 3). Other response variables were not statistically significantly related to adherence to the three programme components (complete data not shown).

The proportions of responders at the 10% improvement level having a university education, income above average and fewer co-morbidities were statistically significantly higher compared with non-responders, while the proportion of responders meeting current HEPA at baseline was lower than the proportion among non-responders (Table 4). Mean timed standing, mean grip strength and mean systolic blood pressure at baseline were lower among responders than among non-responders.

TABLE 1 Baseline data and 1 year changes for disease-related and psychosocial variables, performance tests and anthropometric measures

	n	Baseline mean (S.D.)	*n*	Year 1 baseline β (S.E.)	*P*-value
Health,[a] VAS (0–100)	214	31 (20.8)	183	−3.56 (1.59)	**0.0255**
Pain, VAS (0–100)	218	29 (22.2)	178	−3.54 (1.71)	**0.0388**
Fatigue, VAS (0–100)	217	37 (25.7)	182	−2.29 (1.57)	0.0987
Quality of life, EQ-5D (0–100)	217	69 (18.4)	188	5.29 (1.29)	<**0.0001**
Activity limitation, HAQ-DI (0–3)	218	0.53 (0.50)	187	−0.20 (0.02)	<**0.0001**
Exercise self-efficacy (6–60)	205	36 (11.8)	183	−3.30 (0.96)	**0.0006**
Fear avoidance beliefs (0–24)	218	6 (4.4)	188	−1.09 (0.33)	**0.0009**
Social support, family (0–65)	198	22 (14.1)	186	1.85 (0.97)	0.0566
Social support, friends (0–65)	189	27 (14.6)	173	2.29 (1.05)	**0.0290**
OE long-term health = 10, *n* (%)	217	172 (79)	186	147 (79)	0.2975
OE RA symptoms = 10, *n* (%)	217	77 (35)	186	79 (42)	0.0997
Estimated VO_{2max}, l/min	173	2.10 (0.55)	137	0.20 (0.13)	0.1189
Estimated VO_{2max}, ml/kg/min	173	28.65 (8.57)	136	1.30 (0.43)	**0.0025**
Timed standing, sec	214	22.6 (8.7)	181	−3.88 (0.41)	<**0.0001**
Grip strength maximum (right), *n*	220	219.35 (113.07)	184	14.23 (3.66)	**0.0001**
Grip strength average (right), *n*	220	186.30 (104.81)	184	13.74 (3.32)	<**0.0001**
BMI, kg/m^2	211	26.7 (4.9)	178	−0.19 (0.13)	0.1563
Waist circumference, cm	218	91.8 (13.5)	182	−1.91 (0.36)	<**0.0001**
Systolic blood pressure, mmHg	219	134.1 (16.4)	182	0.74 (1.08)	0.4956
Diastolic blood pressure, mmHg	219	81.7 (9.7)	182	0.16 (0.59)	0.7911

Alpha level set at 0.05 (shown in bold text). [a]General health perception. EQ-5D: EuroQol five-dimensions questionnaire; HAQ-DI: Stanford Health Assessment Questionnaire Disability Index; OE: outcome expectations; VO_{2max}: maximal oxygen uptake.

Discussion

In this study we evaluated an outsourced comprehensive HEPA programme in people with RA. The results indicate high retention but moderate adherence of about 50% to each of the three programme components. Nevertheless, self-reported HEPA levels, self-reported health outcomes and physical capacity increased significantly during the year. Our explorative analyses, although not clear-cut, revealed a number of interesting relations between adherence and response. A number of characteristics to help target potential responders for outsourced HEPA programmes were also identified.

The study programme was based on public health recommendations on HEPA, evidence-based exercise recommendations for people with RA and theory- and evidence-based behaviour modification techniques. It was delivered by physical therapy coaches specifically trained to deliver the programme in training facilities with convenient access for the participants. Although retention in the study was good, adherence to the three programme components seems modest. It may be that our expectations of reaching the recommended levels of HEPA were set too high in the design of the study; however, the reported mean days of total HEPA during the year still represented a major increase compared with previous levels, which was also indicated by IPAQ and ESAI changes at the 1 year assessments.

The modest, but significant, changes in physical performance are in line with those of our previous 1 year randomized controlled trial of a HEPA programme and better than those of a previous HEPA programme mainly delivered over the Internet [12, 14]. While results from HEPA studies have previously been mixed [12, 14] regarding changes in HEPA behaviour, the results of the present intervention support an improvement. In comparison with clinically supervised long-term exercise studies [37, 38], however, the improvements of physical capacity and activity limitation in HEPA studies seem modest, which indicates that the delivery of outsourced HEPA programmes with limited supervision from health professionals is challenging and may need further improvement.

Greater improvement in timed standing for those attending at least 50% of the support group meetings compared with the rest of the sample may be explained by better quality in total HEPA performance, as they were constantly reminded by group peers and their physical therapist coaches about the necessity of keeping the intensity up. Better adherence to circuit training sessions resulting in improved health perception is in line with recent findings of positive associations between physical activity and perceived health [10, 39] and may be attributed to potentially improved physical capacity following circuit training rather than moderate-intensity physical activity.

The decrease in exercise self-efficacy found at the 1 year assessments of the present study may be an effect of response shift, that is. self-efficacy may decline once a person realizes what it takes to obtain HEPA and feels that

Table 2 Adherence at different levels to the three programme components in relation to 1 year changes in general health perception, self-efficacy and timed standing (0 = non-adherer, 1 = adherer)

Intervention component		Health[a] VAS (0–100)			Exercise self-efficacy (6–60)			Timed standing, s		
		n	Δmean (S.D.)	*P*-value	*n*	Δmean (S.D.)	*P*-value	*n*	Δmean (S.D.)	*P*-value
Circuit training, 50%	0	91	−2 (24.8)	0.4648	85	−7 (13.0)	**<.0001**	89	−3 (6.4)	0.0626
	1	91	−4 (19.1)		88	1 (12.1)		92	−5 (4.4)	
Circuit training, 70%	0	134	−2 (23.7)	0.2131	126	−5 (13.2)	**<.0001**	132	−4 (6.0)	0.3742
	1	48	−6 (16.9)		47	3 (10.5)		49	−4 (3.9)	
Circuit training, 90%	0	160	−2 (23.3)	0.0308	151	−4 (13.0)	**0.0042**	158	−3 (5.7)	0.7080
	1	22	−8 (8.2)		22	4 (11.5)		23	−3 (4.0)	
Total HEPA, 50%	0	76	−4 (24.2)	0.7018	69	−6 (14.1)	0.0168	76	−4 (5.1)	0.6164
	1	106	−2 (20.7)		104	−1 (121)		105	−4 (5.8)	
Total HEPA, 70%	0	128	−2 (23.7)	0.4266	119	−4 (14.2)	0.2019	127	−4 (6.0)	0.8310
	1	54	−5 (18.1)		54	−2 (10.2)		54	−4 (4.1)	
Total HEPA, 90%	0	167	−2 (22.3)	0.0775	159	−3 (13.5)	0.2832	167	−4 (5.6)	0.6334
	1	15	−13 (18.1)		14	−1 (8.1)		14	−4 (4.4)	
Group meetings, 50%	0	83	−5 (20.2)	0.0663	81	−6 (13.5)	**0.0091**	82	−2 (6.6)	**0.0039**
	1	99	−2 (23.6)		92	−1 (12.3)		99	−5 (4.2)	
Group meetings, 70%	0	124	−5 (21.1)	0.3058	118	−5 (13.4)	**0.0025**	122	−3 (6.1)	0.0755
	1	58	1 (23.7)		55	1 (11.5)		59	−5 (3.9)	
Group meetings, 90%	0	170	−3 (22.5)	0.3058	162	−4 (12.9)	0.0125	168	−4 (5.6)	0.4886
	1	12	3 (15.9)		11	6 (13.76)		13	−5 (3.9)	

Alpha level set at 0.01 (shown in bold text). [a]General health perception. HEPA: health-enhancing physical activity; VAS: visual analogue scale.

Table 3 One-year changes in general health perception in relation to each of the three programme components

Response variable		Circuit training[a]			Total HEPA[b]			Support group meetings[c]		
		n	Mean (S.D.)	*P*-value	*n*	Mean (S.D.)	*P*-value	*n*	Mean (S.D.)	*P*-value
ΔHealth[d], 10%	0	83	46 (32.9)	**0.0087**	83	195 (82.5)	0.1198	83	10 (5.6)	0.9770
	1	99	60 (36.5)		99	214 (78.7)		99	10 (6.5)	
ΔHealth[d], 20%	0	91	46 (32.4)	**0.0037**	91	196 (83.0)	0.1216	91	10 (6.0)	0.4201
	1	91	61 (37.0)		91	215 (77.9)		91	10 (6.5)	

0: non-responders; 1: responders. [a]Circuit training sessions recommended: ⩾104. [b]Possible total HEPA sessions, including both circuit training and daily physical activity = 365. [c]Support group meetings = 20–22. [d]Health: general health perception. $P \leqslant 0.05$ in bold. HEPA: health-enhancing physical activity.

it is impossible. Such feelings could possibly have been better addressed in the programme and physical activity better adjusted to each person's preference and level of functioning. Not surprisingly, those with better adherence to circuit training sessions thus improved their self-efficacy for exercise.

Responders to the present HEPA programme had a tendency to have more co-morbidities, less current HEPA and poorer capacity in performance tests at baseline. This might indicate that those with low functioning benefit more from a HEPA programme, a result in agreement with previous studies involving people with arthritis and healthy individuals [40].

As this study is clearly not a randomized controlled trial, the changes described over the intervention year cannot be attributed exclusively to the HEPA programme. An initial intention to use invited patients who abstained from participation to demonstrate the natural course of functioning and health had to be abandoned since the two samples differed at baseline on a number of sociodemographic, disease-related and psychosocial variables [17]. However, the present study was never designed to evaluate effects of the HEPA programme *per se*, but rather to explore adherence and response aspects.

Participant recruitment via a national patient register is indeed a strength of this study, as is the inclusion of a

Table 4 Baseline characteristics of responders (at the 10% level) and non-responders

	Responders ($n = 80$)	Non-responders ($n = 104$)	*P*-value
Age, mean (S.D.), years	58 (9.9)	60 (8.4)	0.2173
Females, *n* (%)	66 (83)	82 (79)	0.5357
University education, *n* (%)	36 (45)	62 (60)	**0.0489**
Income above average, *n* (%)	50 (63)	79 (7)	**0.0485**
Children at home, *n* (%)	16 (20)	15 (14)	0.3164
Disease duration, mean (S.D.), years	12.25 (8.62)	11.68 (9.36)	0.6804
Co-morbidities, *n* (%)			
0	40 (50)	41 (39)	**0.0335**
1	6 (8)	22 (21)	
⩾2	34 (44)	41 (39)	
Health,[a] mean (S.D.), VAS 0–100	31 (21.0)	26 (19.9)	0.1198
Pain, mean (S.D.), VAS 0–100	28 (21.3)	25 (22.0)	0.4611
Fatigue, mean (S.D.), VAS 0–100	38 (25.8)	33 (25.7)	0.2269
Quality of life, mean (S.D.), EQ-5D 0–100	70 (17.3)	72 (16.9)	0.4686
Activity limitation, mean (S.D.), HAQ-DI 0–3	0.56 (0.5)	0.44 (0.5)	0.1023
Fear avoidance beliefs, mean (S.D.), 0–24	6 (3.3)	6 (5.0)	0.5221
Exercise self-efficacy, mean (S.D.), 6–60	35 (12.2)	35 (12.1)	0.9809
Social support, family, mean (S.D.), 0–65	25 (15.0)	28 (14.9)	0.2428
Social support, friends, mean (S.D.), 0–65	20.62 (13.46)	24 (14.4)	0.1813
OE long-term health = 10, *n* (%)	67 (84.8)	80 (78.4)	0.2759
OE RA symptoms = 10, *n* (%)	24 (30.4)	38 (37.4)	0.3337
Current HEPA, *n* (%)	39 (49)	69 (67)	**0.0164**
Estimated $VO2_{max}$, mean (S.D.), l/min	2.05 (0.57)	2.17 (0.54)	0.1751
Estimated VO_{2max}, mean (S.D.), ml/kg/min	27.31 (7.18)	29.91 (9.35)	0.0591
Timed standing, mean (S.D.), s	23.3 (7.5)	20.8 (7.6)	**0.0267**
Grip strength maximum, mean (S.D.)	203.88 (112.24)	234.62 (117.33)	0.0743
Grip strength mean, mean (S.D.)	169.96 (102.51)	202.74 (108.64)	**0.0390**
BMI, mean (S.D.), kg/m^2	27.1 (5.2)	26.6 (4.9)	0.5685
Waist circumference, mean (S.D.), cm	92.5 (14.1)	91.8 (13.8)	0.7046
Systolic blood pressure, mean (S.D.), mmHg	129.3 (15.3)	134.6 (15.9)	**0.0259**
Diastolic blood pressure, mean (S.D.), mmHg	81.0 (9.1)	81.02 (9.9)	0.9611

Alpha levels set at 0.05 (shown in bold text). [a]General health perception. EQ-5D: EuroQol five-dimensions questionnaire; HAQ-DI: Stanford Health Assessment Questionnaire Disability Index; HEPA: health-enhancing physical activity; OE: outcome expectations; VO_{2max}: maximal oxygen uptake.

large, well-defined sample. Despite each participant meeting the inclusion criteria for not obtaining HEPA at baseline, it still seems that they constituted a fairly physically fit and active study sample. This certainly limits the external validity of the study, but also left little room for improvement, resulting in less variation in changes over the year and limited possibilities of identifying relationships between adherence and response. Only 11% of the targeted sample started the programme, clearly showing the difficulties in recruiting participants for long-term interventions [17]. A resulting limitation of our study is that we did not recruit a large enough sample to perform fully powered analyses for women and men separately.

Despite introducing and encouraging the participants to obtain sufficient HEPA, the coaches had limited opportunities to follow-up on individual performance and thus, while HEPA frequency was controlled, its quality was largely unknown. Another coaching challenge was the tailoring of HEPA support to individual needs among groups of participants with substantial variations in both previous HEPA experience and health conditions. On the other hand, peer support was encouraged and many participants met at the training centre or at walking trails to challenge each other to perform at their best.

The influence of social desirability cannot be excluded in a study such as the present one, nor can response shift, as discussed previously for self-efficacy, but it may also be true for HEPA reporting. Physical capacity tests may be biased, although we trained physical therapists at the eight participating sites to perform the tests. Differences in equipment and other local facilities, as well as variations in rigour and accuracy, may have caused bias, but since the same participants were tested at the same units on both occasions, this might be of minor importance.

Outsourcing of HEPA programmes is necessary in order to support people with RA that cannot be constantly supervised in health care environments. The present study used physical therapists trained to coach HEPA

behaviour changes, and although initially uncomfortable with abandoning their role as experts for that of coach, they gradually adjusted and even started to use their new skills in everyday clinical practice [19]. We firmly believe that physical therapists need to be involved in hands-on HEPA instruction, but do not exclude the possibility that trained laypeople could lead the support groups, as has been done successfully in arthritis self-management programmes [41].

The current HEPA programme seemed to suit the needs of certain participants better than others and their experiences indicate a great variation, highlighting the need to individualize HEPA programmes regarding settings, exercise formats and behavioural support [42]. How to target the right people and how to tailor the programmes to their individual needs in order for them to adopt and maintain HEPA is a major challenge for future research.

Acknowledgements

We gratefully acknowledge the participants for their time and effort and the support from professor Staffan Lindblad and the Swedish Rheumatology Quality Register for providing access to data. Members of the PARA Study Group: physical therapists Christina Eriksson, Annelie Nordström, Eva Prinzell and Malin Wisell, Linköping University Hospital, Linköping; Birgitta Folin, Helena Heldt, Carina Sjöman and Maria Wärfman, Norrköping Hospital, Norrköping; Eva Frykstad, Anna Moberg, Hanna Olsson and Johanna Pettersson, Mälarsjukhuset, Eskilstuna; Anna Hallén and Sofia Sandström, Karolinska University Hospital, Solna; Anna Dahlgren and Åsa Lindkvist, Karolinska University Hospital, Huddinge; Erica Christensen, Elin Löfberg and Sara Stråt, Danderyd University Hospital, Stockholm; Katrin Bylander, Ingrid Larsson and Maria Skogemyr, Östersund Hospital, Östersund; Sofia Blomqvist and Susan Sandberg, Sunderby Hospital, Luleå; Anna Nordin, Winternet, Boden; Emma Swärdh, Karolinska Institutet, Stockholm; Anne Marie Norén, Stockholm County Council, Stockholm, Sweden.

Funding: This study was supported by the Swedish Research Council, Combine Sweden, the Swedish Rheumatism Foundation, the Strategic Research Program in Health Care Sciences and the National Postgraduate School of Health Care Sciences.

Disclosure statement: The authors have declared no conflicts of interest.

References

1 World Health Organization. Physical Activity and Adults. http://www.who.int/dietphysicalactivity/factsheet_adults/en/index.html (21 March 2014, date last accessed).

2 National Health Service. Physical activity guidelines for adults. http://www.nhs.uk/Livewell/fitness/Pages/physical-activity-guidelines-for-adults.aspx (21 March 2014, date last accessed).

3 Centers for Disease Control and Prevention. 2008 Physical activity guidelines for Americans. http://www.cdc.gov/physicalactivity/everyone/guidelines/adults.html (21 March 2014, date last accessed).

4 Haskell WL, Lee IM, Pate RR *et al*. Physical activity and public health: updated recommendation for adults from the American College of Sports Medicine and the American Heart Association. Med Sci Sports Exerc 2007; 39:1423–34.

5 Krishnan E, Lingala B, Bruce B, Fries JF. Disability in rheumatoid arthritis in the era of biological treatments. Ann Rheum Dis 2012;71:213–8.

6 Symmons DP, Gabriel SE. Epidemiology of CVD in rheumatic disease, with a focus on RA and SLE. Nat Rev Rheumatol 2011;7:399–408.

7 Taylor P, Manger B, Alvaro-Gracia J *et al*. Patient perceptions concerning pain management in the treatment of rheumatoid arthritis. J Int Med Res 2010;38: 1213–24.

8 Tierney M, Fraser A, Kennedy N. Physical activity in rheumatoid arthritis: a systematic review. J Phys Act Health 2012;9:1036–48.

9 Demmelmaier I, Bergman P, Nordgren B, Jensen I, Opava CH. Current and maintained health-enhancing physical activity in rheumatoid arthritis—the PARA 2010 study. Arthritis Care Res 2013;65:1166–76.

10 Larkin L, Kennedy N. Correlates of physical activity in adults with rheumatoid arthritis: a systematic review. J Phys Act Health 2014;11:1248–61.

11 Demmelmaier I, Åsenlöf P, Opava CH. Supporting stepwise change. Improving health behaviors in rheumatoid arthritis with physical activity as the example. Int J Clin Rheumatol 2013;8:89–94.

12 Brodin N, Eurenius E, Jensen I, Nisell R, Opava CH. Coaching patients with early rheumatoid arthritis to healthy physical activity: a multicenter, randomized, controlled study. Arthritis Rheum 2008;59:325–31.

13 Sjoquist ES, Brodin N, Lampa J, Jensen I, Opava CH. Physical activity coaching of patients with rheumatoid arthritis in everyday practice: a long-term follow-up. Musculoskeletal Care 2011;9:75–85.

14 van den Berg MH, Ronday HK, Peeters AJ *et al*. Using internet technology to deliver a home-based physical activity intervention for patients with rheumatoid arthritis: a randomized controlled trial. Arthritis Rheum 2006;55: 935–45.

15 Arnett FC, Edworthy SM, Bloch DA *et al*. The American Rheumatism Association 1987 revised criteria for the classification of rheumatoid arthritis. Arthritis Rheum 1988; 31:315–24.

16 Nordgren B, Friden C, Demmelmaier I, Bergstrom G, Opava CH. Long-term health-enhancing physical activity in rheumatoid arthritis—the PARA 2010 study. BMC Public Health 2012;12:397.

17 Nordgren B, Friden C, Demmelmaier I, Opava CH. Who makes it to the base? Selection procedure for a physical activity trial targeting people with RA—the PARA 2010 study. Arthritis Care Res 2013;66:662–70.

18 Bandura A. Social cognitive theory: an agentic perspective. Annu Rev Psychol 2001;52:1–26.

19 Nessen T, Opava CH, Martin C, Demmelmaier I. From clinical expert to guide: experiences from coaching people with rheumatoid arthritis to increased physical activity. Phys Ther 2014;94:644–53.

20 Verberkt CA, Friden C, Grooten WJ, Opava CH. Reliability of the Fox-walk test in patients with rheumatoid arthritis. Disabil Rehabil 2012;34:2001–6.

21 Shiffman S, Stone AA, Hufford MR. Ecological momentary assessment. Annu Rev Clin Psychol 2008;4:1–32.

22 Felson DT, Anderson JJ, Boers M *et al*. The American College of Rheumatology preliminary core set of disease activity measures for rheumatoid arthritis clinical trials. The Committee on Outcome Measures in Rheumatoid Arthritis Clinical Trials. Arthritis Rheum 1993;36:729–40.

23 Huskisson EC. Measurement of pain. J Rheumatol 1982;9: 768–9.

24 Tack BB. Self-reported fatigue in rheumatoid arthritis. A pilot study. Arthritis Care Res 1990;3:154–7.

25 Wolfe F. Fatigue assessments in rheumatoid arthritis: comparative performance of visual analog scales and longer fatigue questionnaires in 7760 patients. J Rheumatol 2004;31:1896–902.

26 Hurst NP, Kind P, Ruta D, Hunter M, Stubbings A. Measuring health-related quality of life in rheumatoid arthritis: validity, responsiveness and reliability of EuroQol (EQ-5D). Br J Rheumatol 1997;36:551–9.

27 Fries JF, Spitz P, Kraines RG, Holman HR. Measurement of patient outcome in arthritis. Arthritis Rheum 1980;23: 137–45.

28 Yordy G, Lent R. Predicting aerobic exercise participation: social cognitive, reasoned action and planned behavior models. J Sport Exerc Psychol 1993;15:363–74.

29 Dzewaltowski D. Toward a model of exercise motivation. J Sport Exerc Psychol 1989;11:251–69.

30 Buer N, Linton SJ. Fear-avoidance beliefs and catastrophizing: occurrence and risk factor in back pain and ADL in the general population. Pain 2002;99:485–91.

31 Sallis JF, Grossman RM, Pinski RB, Patterson TL, Nader PR. The development of scales to measure social support for diet and exercise behaviors. Prev Med 1987; 16:825–36.

32 Craig CL, Marshall AL, Sjostrom M *et al*. International physical activity questionnaire: 12-country reliability and validity. Med Sci Sports Exerc 2003;35:1381–95.

33 Burbank PM, Riebe D. Promoting Exercise and Behavior Change in Older Adults: Interventions with the Transtheoretical Model. New York, NY, USA: Springer, 2002.

34 Astrand PO, Ryhming I. A nomogram for calculation of aerobic capacity (physical fitness) from pulse rate during sub-maximal work. J Appl Physiol 1954;7:218–21.

35 Csuka M, McCarty DJ. Simple method for measurement of lower extremity muscle strength. Am J Med 1985;78: 77–81.

36 Nordenskiold UM, Grimby G. Grip force in patients with rheumatoid arthritis and fibromyalgia and in healthy subjects. A study with the Grippit instrument. Scand J Rheumatol 1993;22:14–9.

37 Hakkinen A, Hannonen P, Nyman K, Lyyski T, Hakkinen K. Effects of concurrent strength and endurance training in women with early or longstanding rheumatoid arthritis: comparison with healthy subjects. Arthritis Rheum 2003; 49:789–97.

38 de Jong Z, Munneke M, Zwinderman AH *et al*. Is a long-term high-intensity exercise program effective and safe in patients with rheumatoid arthritis? Results of a randomized controlled trial. Arthritis Rheum 2003;48:2415–24.

39 Wilcox S, der Ananian C, Sharpe PA, Robbind J, Brady T. Correlates of physical activity in persons with arthritis: review and recommendations. J Phys Act Health 2005;2: 230–52.

40 Sjoquist ES, Almqvist L, Asenlof P, Lampa J, Opava CH. Physical-activity coaching and health status in rheumatoid arthritis: a person-oriented approach. Disabil Rehabil 2010;32:816–25.

41 Lorig K, Holman H. Arthritis self-management studies: a twelve-year review. Health Educ Q 1993;20:17–28.

42 Demmelmaier I, Lindkvist Å, Nordgren B, Opava CH. ''A gift from heaven'' or ''This was not for me''. A mixed methods approach to describe experiences of participation in an outsourced physical activity programme for persons with rheumatoid arthritis. Clin Rheumatol 2014 Jun 20 [Epub ahead of print].