

# An Outsourced Health-enhancing Physical Activity Program for People with Rheumatoid Arthritis: Study of the Maintenance Phase

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**ABSTRACT. Objective.** To describe changes of health-enhancing physical activity (HEPA), health perception, and functioning during the second year of a 2-year support program, determine aspects of adherence and response, and describe perceptions of the program.

**Methods.** Out of 220 individuals with rheumatoid arthritis (RA), 177 participated in the followup. Group support, strength training, and moderate-intensity aerobic activity were encouraged. Data collection included HEPA, perceived health, functioning, and perceptions of the program. Participants with unchanged/improved general health perception and at least 2 of aerobic capacity, grip strength, or timed standing were considered responders.

**Results.** Current and maintained HEPA decreased from 82% to 75% ( $p = 0.0141$ ) and from 41% to 27% ( $p < 0.0001$ ) during the second year. Minor declines in quality of life and activity limitation occurred ( $p = 0.0395$  and  $0.0038$ , respectively), while outcome expectations for benefits of physical activity increased ( $p = 0.0010$  and  $0.0186$ ) and waist circumference tapered off ( $p = 0.0070$ ). Strength training was performed on average 41 and 35 times among responders ( $n = 54$ ) and nonresponders ( $n = 105$ ), respectively ( $p = 0.2708$ ); HEPA 194 and 171 days, respectively ( $p = 0.0828$ ); and support group meetings 12 and 10 times, respectively ( $p = 0.0943$ ). Strength training, aerobic activity, and short text message reminders were perceived as most valuable; step registration and the self-monitoring walk tests were less appreciated.

**Conclusion.** About one-fourth of the originally sedentary individuals with RA sustained their new HEPA behaviors after 2 years and most improvements of health and functioning were sustained. Structured use of behavior change techniques and a second year to support maintenance with a reduced program might help patients with RA to sustain HEPA behavior. (First Release May 1 2018; *J Rheumatol* 2018;45:1093–1100; doi:10.3899/jrheum.171002)

## Key Indexing Terms:

CLINICAL TRIAL      EXERCISE      HEALTH BEHAVIOR      FOLLOWUP STUDY

Health-enhancing physical activity (HEPA) is recommended to every adult as part of a healthy lifestyle, to reduce the risk of major diseases and premature death<sup>1,2</sup>. Older individuals and those with chronic conditions such as arthritis represent

no exceptions, but they are advised to perform moderate-intensity aerobic activity for a minimum of 30 min for 5 days each week or vigorous-intensity aerobic activity for a minimum of 20 min for 3 days each week; in addition,

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*This study was funded by the Swedish Research Council, Forte Foundation, Combine Sweden, the Swedish Rheumatism Foundation, the Norrbacka-Eugenia foundation, the Strategic Research Program in Health Care Science, and the National Postgraduate School of Health Care Sciences.*

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*Accepted for publication February 6, 2018.*

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muscle-strengthening activities are recommended for a minimum of 2 days each week<sup>3</sup>. HEPA might be particularly important to reduce the increased risk of cardiovascular disease and early mortality seen in rheumatoid arthritis (RA)<sup>4</sup>. Nevertheless, a majority of people with RA do not maintain regular physical activity<sup>5,6</sup>.

The value of therapeutic exercise, a subset of physical activity, in preventing disability in RA is widely recognized<sup>7</sup>. While therapeutic exercise is often performed in hospitals and other healthcare facilities under supervision of physiotherapists, HEPA is mainly performed in an everyday context. HEPA support programs tailored to the needs of people with RA might help overcome disease-specific barriers related to impairment and activity limitations. A number of randomized controlled trials investigating the outcome of interventions to promote physical activity in RA have been performed<sup>8,9,10,11,12</sup>, but only 2<sup>9,11</sup> used HEPA programs for a minimum of 12 months and investigated HEPA maintenance over another 12 months<sup>13,14</sup>. Neither study reported levels of maintained HEPA at 2-year followup. Further, new HEPA studies should look at barriers to participation, use behavior change theory and behavior change techniques as well as multiple measures of exercise adherence, and determine which intervention components truly had a positive effect<sup>15,16</sup>.

In the PARA 2010 study, we included a well-defined sample of persons with RA<sup>17</sup> and developed a 2-year outsourced HEPA support program aiming at adoption and longterm maintenance of HEPA<sup>18</sup>. Evaluation after 1 year indicated high retention and reasonable adherence. The program was perceived as feasible, and self-reported HEPA levels, health perception, and physical capacity increased<sup>19,20</sup>. To our knowledge, no previous study has reported on outcomes of a 2-year HEPA intervention in persons with RA.

The aims of our present study were to describe changes of HEPA levels, general health perception, and functioning during the second year of a 2-year HEPA support program, investigate aspects of adherence and response, and describe the perceived value of the program.

## MATERIALS AND METHODS

*Design.* Our report describes the second year of a 2-year intervention in a prospective cohort study ([www.isrctn.com/ISRCTN25539102](http://www.isrctn.com/ISRCTN25539102))<sup>18</sup>.

*Participants.* Patients diagnosed with RA<sup>21</sup> were recruited from the Swedish Rheumatology Quality Registers (SRQ) from October to December 2010. There were 1932 persons aged 18–75 years, independent in daily living [Health Assessment Questionnaire Disability Index (HAQ-DI)  $\leq 2$ ]<sup>22</sup>, interested in participating in organized physical activity, fluent in Swedish, and not already maintaining (> 6 mos) recommended levels of HEPA at start of the 2-year intervention. Of these, 220 entered the program and 194 completed the first intervention year. The selection procedure<sup>17</sup> and dropout analysis for the first intervention year<sup>19</sup> have been reported previously. Our present study reports on the 177 participants who provided self-reported data and/or were assessed for physical performance at both 1- and 2-year assessments.

*Intervention.* The intervention program included 3 main components<sup>18</sup> to promote HEPA according to recommendations<sup>3</sup>: (1) at least 2 weekly strength training sessions; (2) physical activity of at least moderate intensity for  $\geq 30$  min for the 5 remaining days of the week; and to support HEPA, (3) support group sessions using weekly goal-setting, planning, and followup according to social cognitive theory<sup>23</sup>.

Strength training was provided as circuit training at 9 assigned training centers in 6 Swedish cities. Study participants committed to pay a fee for a 1-year membership, allowing them to drop in whenever they preferred during opening hours. A circuit consisted of 5 devices for strength training of major muscle groups. Study participants, like any other member, joined the circle by selecting a free station and then moved around the circle to complete 3 laps, resulting in  $3 \times 10$  repetitions for each muscle group. At the start of the 2-year intervention, a physiotherapist instructed each participant on how to perform efficient exercise and was then available for consultations once a week, at fixed times, during the first year. Trained fitness instructors were always available at the centers. For the second year, membership could be continued at the assigned centers or at any other training facility. Pedometers and access to a Web page for step registration were provided to each participant and use of a self-administered walk-test to monitor aerobic capacity was taught and recommended<sup>24</sup>.

The maximum number of biweekly support group meetings offered during the first year varied from 20 to 22, depending on different logistics at the participating sites. They were guided by physiotherapists from 6 rheumatology clinics (8 sites) trained within the study to encourage the adoption and maintenance of HEPA<sup>25</sup>. No such support was provided during the second intervention year, but a handbook outlining 10 optional sessions was provided and participants were encouraged to take charge of the group sessions.

*Assessments.* Participants were assessed at baseline and after 1 and 2 years, with data retrieved from the SRQ, patient files, weekly short text messages, a postal questionnaire, physical performance tests, and anthropometrics<sup>18</sup>. Physical therapists, independent from the intervention, were trained to administer the questionnaire and conduct all performance tests.

*Background information.* Sociodemographic data included age, sex, education (university vs below), income (above/below average Swedish income in 2008), and children < 18 years at home (yes/no). Disease-related data included disease duration and comorbidities (respiratory, cardiovascular, neurological and psychiatric disease, diabetes mellitus, or other).

*Physical activity.* Two weekly text messages were sent to monitor each participant's adherence. One concerned the number of circuit training sessions performed in the past week and the other the number of additional days with physical activity performed on at least a moderate intensity level for  $\geq 30$  minutes<sup>26</sup>. The physiotherapists reported participants' attendance at support group meetings during the first year, but no reports on the number of group sessions attended were collected during the second year.

Self-reported current (past week) HEPA was assessed with the short form of the International Physical Activity Questionnaire, assessing overall physical activity during the past week without separating aerobic physical activity from muscle strength training<sup>27</sup>. Maintained (> 6 mos) HEPA was assessed with the Exercise Stage Assessment Instrument (ESAI)<sup>28</sup>. The original ESAI was modified from 1 to 2 items to suit the aims of our present study: 1 item defining aerobic physical activity as that of moderate intensity for  $\geq 30$  min for at least 5 days/week, and 1 item on muscle strength training at least twice weekly. Both items were followed by the question, "Are you physically active according to this description?"

*General health perception.* General health perception (primary response variable) was rated on a visual analog scale (VAS)<sup>29</sup>.

*Functioning.* Pain<sup>30</sup> and fatigue<sup>31</sup> were rated on VAS. Quality of life was assessed with the EuroQol (EQ-5D) thermometer<sup>32</sup> and activity limitation with the HAQ-DI<sup>22</sup>. Psychosocial variables were assessed with the Exercise Self-Efficacy Scale (secondary response variable)<sup>33</sup>, modified Fear-Avoidance Beliefs Questionnaire (secondary response variable)<sup>34</sup>, Social Support for Exercise Behaviors Scales<sup>35</sup>, and 2 study-specific items

concerning outcome expectations for physical activity on longterm health and current RA symptoms, respectively. Maximal oxygen uptake ( $VO_{2max}$ ) was estimated from a submaximal bicycle ergometer test<sup>36</sup>, lower limb function was assessed with the Timed-Stands Test<sup>37</sup>, and maximum grip strength with the Grippit device<sup>38</sup> (secondary response variables). Anthropometric data on body mass index, waist circumference, and blood pressure (systolic and diastolic) were collected.

*Perceived value of HEPA program.* Perceptions related to HEPA maintenance during the second intervention year were assessed with a 10-item questionnaire developed specifically for our present study. Response options were categorical or rated on ordinal scales (1–5).

*Data management and analyses.* Differences between those who completed both the 1- and 2-year assessments and the 17 dropouts were examined using Student t test for continuous variables and chi-squared tests for categorical variables. Descriptive statistics were calculated for 1-year measurements using means (SD) for continuous variables and proportions for categorical variables. Because the majority of participants reported a “10” for both items concerning outcome expectations, they were dichotomized into 10 versus < 10 for analysis.

Changes from end of the first intervention year to end of the second year were examined using generalized linear models. Using the 2 observations, at 1 year and at the end of the second year,  $\beta$  coefficients and standard errors were calculated using a mixed model approach with a subject effect.

For analysis of adherence, participants were categorized into adherers or non-adherers during the second year based on their 50%, 70%, and 90% participation in circuit training sessions and total days of HEPA (circuit training and aerobic activity), respectively. Adherence categorization for group meetings was based on 50%, 70%, and 90% attendance. Changes in the 6 response variables were calculated between the end of the first intervention year and the end of the second. Student t test was used to compare the mean changes in the response variables in adherers versus non-adherers.

For analysis of response, participants were categorized into responders and nonresponders based on 10%, 20%, and 30% second-year improvements in each of the 6 response variables. Student t test was used to examine the differences in mean adherence to each of the 3 program components in the responders versus nonresponders.

A total response variable was based on unchanged or improved values during the second year in perceived health and at least 2 of the 3 secondary response variables presumed to reflect HEPA performance. Using this response variable, participant characteristics at the end of the first year were compared in responders versus nonresponders using Student t test or the chi-squared test. This test was also used to compare responders to non-responders regarding their participation in circuit training, and total days with HEPA and in support group meetings.

SAS/STAT version 9.3 (SAS Institute) was used for all analyses. Alpha levels were set to 0.05 for presentation of descriptive data for the 2-year change and 1-year differences by responder status, while  $\alpha$  levels were set at 0.01 to account for multiple testing in the study of different levels of adherence and response.

*Ethical approval.* The Stockholm Regional Ethical Review Board approved the study (2010/1232-31/1). Information about the study along with the questionnaires was mailed to all participants. They consented to participate by filling out and returning the questionnaires. Those consenting received additional practical information and consented by filling out and returning a form with the desired site and time for their HEPA program participation.

## RESULTS

The mean age of the 177 participants was 60 years (SD 8.9), mean disease duration was 12 years (SD 9.2), and 144 (81%) were female. The 177 participants did not differ from the 17 two-year dropouts regarding age, disease duration, or proportion of women ( $p > 0.05$ ). Neither did they differ in health perception, timed standing, or grip

strength ( $p > 0.05$ ), but they had significantly better estimated mean maximal oxygen uptake (30 vs 22 ml/kg/min,  $p = 0.0207$ ).

*Physical activity.* The mean number of reported circuit training sessions was 37 (SD 33.9), and the mean number of total days with HEPA was 179 (79.2). The mean number of support group attendance was 10 (6.2). The proportions of participants meeting current HEPA had decreased from 82% during the first year to 75% ( $p = 0.0141$ ). The proportions reaching maintained HEPA decreased from 41% to 27% ( $p < 0.0001$ ).

*Functioning.* Deteriorations in quality of life and activity limitation were observed at the end of the second year compared to the first-year outcome. The proportions of participants with high expectations for longterm and short-term outcomes of physical activity increased. Deterioration of grip strength and reduction of systolic blood pressure and waist circumference occurred during the second year, while all other variables remained unchanged (Table 1).

*Adherence and response.* Different levels of adherence to any of the 3 HEPA program components during the second year were not statistically significantly related ( $p > 0.05$ ) to change in any of the 6 response variables (data not shown). Different levels of response, neither total nor single-variable, were statistically significantly related to adherence to any of the HEPA program components except for timed standing, which improved among those having participated less in support group meetings (Table 2).

The mean number of reported circuit training sessions was 41 (35.3) among second-year total responders ( $n = 54$ ) and 35 (33.4) among nonresponders ( $n = 105$ ,  $p = 0.2708$ ). Their mean number of total days with HEPA was 194 (80.8) and 171 (76.9), respectively ( $p = 0.0828$ ), and the mean number of registered support group meetings 12 (6.1) and 10 (6.1), respectively ( $p = 0.0943$ ). Total second-year responders more frequently reached HEPA levels, perceived better health, and performed better in timed standing at the end of Year 1 compared to nonresponders. No other differences were observed between second-year responders and nonresponders (Table 3).

*Perceived value of program.* Of the participants, 29% reported regular participation in support group meetings during the second year, and another 17% reported occasional attendance. The reported content of the group meetings ranged from physical activity performance (17%), having meals together (33%), and miscellaneous (49%) including pep talks, walk tests to monitor aerobic capacity, and circuit training; group meetings also included social activities. Of those participating in group meetings, 75% had invited their physiotherapist on some occasion. The structured handbook had been used regularly by 19% and occasionally by 36%. Strategies for maintenance and relapse prevention that they

Table 1. Changes from the end of the first intervention year to the end of the second for perceived health and functioning.

Variables	Year 1, n	Year 1, Mean (SD)	Year 2, n	Year 2–Year 1, $\beta$ (SE)	p
Health, VAS, 0–100	171	26 (21.8)	169	2.94 (1.55)	0.0574
Pain, VAS, 0–100	174	24 (21.3)	173	2.13 (1.53)	0.1628
Fatigue, VAS, 0–100	174	32 (24.5)	173	0.79 (1.6)	0.6223
Quality of life, EQ-5D, 0–100	170	76 (18.1)	170	–2.87 (1.39)	<b>0.0395</b>
Activity limitation, HAQ-DI, 0–3	174	0.30 (0.42)	174	0.04 (0.01)	<b>0.0038</b>
Exercise self-efficacy, 6–60	167	33 (12.0)	164	0.01 (0.96)	0.9947
Fear avoidance beliefs, 0–24	172	5 (4.2)	172	–0.44 (0.27)	0.0989
Social support, 0–65					
Family	152	24 (12.6)	142	0.62 (1.02)	0.5454
Friends	159	29 (13.1)	162	–0.91 (1.09)	0.4043
OE longterm health = 10, n (%) <sup>*</sup>	174	141 (81)	174	153 (88)	<b>0.0186</b>
OE RA symptoms = 10, n (%) <sup>*</sup>	174	76 (44)	174	97 (56)	<b>0.0010</b>
VO <sub>2max</sub> , ml/kg/min	135	30.0 (7.95)	133	–0.73 (0.45)	0.1001
Time standing, s	169	18 (6.6)	166	0.28 (0.36)	0.4474
Grip strength max, right, n	172	235 (112.0)	172	–7.12 (3.3)	<b>0.0309</b>
BMI, kg/m <sup>2</sup>	172	26 (4.9)	168	0.01 (0.11)	0.9457
Waist circumference, cm	172	90 (13.8)	170	–0.85 (0.32)	<b>0.0070</b>
Systolic blood pressure, mmHg	171	134 (18.0)	168	–2.33 (1.11)	<b>0.0351</b>
Diastolic blood pressure, mmHg	171	82 (9.1)	168	–1.16 (0.6)	0.0530

<sup>\*</sup> Does not indicate change Year 2–Year 1, but proportions with OE = 10 and p values indicating changes in proportions. Alpha level set at 0.05 (shown in bold face). Health: general health perception; VAS: visual analog scale; HAQ-DI: Health Assessment Questionnaire–Disability Index; OE: outcome expectations; VO<sub>2max</sub>: maximal oxygen uptake; RA: rheumatoid arthritis; BMI: body mass index.

Table 2. Response (1) versus no response (0) based on 3 improvement levels (10%, 20%, and 30%) of health perception and timed standing in relation to adherence to circuit training sessions and total days of HEPA during Year 2, and to group meeting adherence during Year 1.

Variables	Response	Circuit Training <sup>a</sup>			HEPA <sup>b</sup>			Support Group Meetings <sup>c</sup>			
		n	Mean (SD)	p	n	Mean (SD)	p	n	Mean (SD)	p	
$\Delta$ Health	10%	0	104	36 (33.8)	0.6542	104	183 (82.9)	0.3700	107	11 (6.4)	0.8394
		1	51	38 (34.4)		50	170 (69.3)		58	10 (5.8)	
	20%	0	112	34 (33.1)	0.2991	111	181 (81.0)	0.5009	117	10 (6.3)	0.8708
		1	43	41 (36.0)		43	172 (73.2)		48	11 (5.9)	
	30%	0	120	36 (33.6)	0.7279	119	182 (80.0)	0.3511	127	10 (6.3)	0.5612
		1	35	38 (35.4)		35	168 (74.4)		38	11 (5.9)	
$\Delta$ Timed standing	10%	0	124	38 (33.7)	0.8775	123	183 (76.7)	0.3991	131	11 (6.0)	0.1851
		1	29	37 (37.1)		29	169 (88.6)		32	9 (6.6)	
	20%	0	144	38 (34.0)	0.5339	143	181 (79.2)	0.6013	152	11 (6.1)	<b>0.0008</b>
		1	9	31 (39.2)		9	167 (78.0)		11	5 (3.8)	
	30%	0	150	38 (34.3)	0.3271	149	180 (79.5)	0.6867	158	11 (6.1)	<b>&lt; 0.0001</b>
		1	3	19 (30.6)		3	162 (52.8)		5	3 (1.9)	

<sup>a</sup> Circuit training recommended for Year 2  $\geq$  104. <sup>b</sup> Possible total HEPA days including both circuit training and moderate-intensity aerobic physical activity = 365. <sup>c</sup> Support group meetings during Year 1 = 20–22. Alpha level set at 0.01 (shown in bold face). HEPA: health-enhancing physical activity; Health: general health perception.

had learned during the first intervention year were reportedly used by 35% of the participants. The perceived value of different HEPA program components was highest for circuit training, daily physical activity, and short text message reminders, while step registration and walk tests to self-monitor aerobic capacity were perceived as of the least value (Table 4).

## DISCUSSION

To our knowledge, our study is the first to evaluate a 2-year HEPA program in people with RA, which was outsourced to public gyms. Our results indicate what outcomes to expect and clearly illustrate the challenges of evaluating complex, nonpharmacological interventions in contexts other than healthcare facilities.

**Table 3.** End of Year 1 characteristics of participants with improved/unchanged outcomes (total responders) and deteriorated outcomes (total nonresponders) at the end of Year 2 as compared to the end of Year 1. Values are mean (SD) unless otherwise specified.

Characteristics	Responders, n = 54	Nonresponders, n = 105	p
Age, yrs	59 (9.6)	61 (8.4)	0.1784
Females, n (%)	46 (85)	81 (77)	0.2310
University education, n (%)	34 (63)	50 (48)	0.0664
Income above average, n (%)	42 (78)	70 (67)	0.1694
Children at home, n (%)	12 (22)	12 (11)	0.0718
Disease duration, yrs	11 (8.3)	13 (9.5)	0.3003
Comorbidities, n (%)			
0	23 (43)	46 (44)	0.3686
1	8 (15)	24 (23)	0.3686
2 +	23 (43)	35 (33)	0.3686
Current HEPA, n (%)	49 (91)	80 (76)	<b>0.0421</b>
Maintained HEPA, n (%)	27 (50)	62 (59)	0.2610
Health, VAS, 0–100	19 (17.4)	28 (23)	<b>0.0060</b>
Pain, VAS, 0–100	21 (17.4)	25 (23)	0.2235
Fatigue, VAS, 0–100	29 (22.4)	34 (25.7)	0.2535
Quality of life, EQ-5D, 0–100	78 (15.0)	76 (18.9)	0.3735
Activity limitation, HAQ-DI, 0–3	0.29 (0.39)	0.30 (0.45)	0.8572
Exercise self-efficacy, 6–60	35 (11.2)	33 (12.5)	0.2571
Fear avoidance beliefs, 0–24	5 (4.2)	5 (4.2)	0.8521
Social support, 0–65			
Family	30 (13.4)	27 (13.3)	0.2823
Friends	27 (12.7)	22 (12.7)	0.0707
OE longterm health = 10	48 (89)	80 (76)	0.0556
OE RA symptoms = 10	23 (43)	46 (44)	0.8834
VO <sub>2max</sub> , ml/kg/min	31 (9.1)	29 (7.5)	0.2613
Timed standing, s	16 (5.6)	19 (7.1)	<b>0.0119</b>
Grip strength max right, n	240 (104.0)	235 (118.3)	0.7527
BMI, kg/m <sup>2</sup>	26 (5.0)	27 (4.9)	0.2293
Waist circumference, cm	87 (14.2)	91 (13.4)	0.1328
Systolic blood pressure, mmHg	132 (18.8)	134 (17.0)	0.5639
Diastolic blood pressure, mmHg	81 (9.9)	82 (8.6)	0.4143

Alpha level set at 0.05 (shown in bold face). Health: general health perception; HEPA: health-enhancing physical activity; VAS: visual analog scale; HAQ-DI: Health Assessment Questionnaire–Disability Index; OE: outcome expectations; RA: rheumatoid arthritis; VO<sub>2max</sub>: maximal oxygen uptake; BMI: body mass index.

**Table 4.** Perceived value (1–5) of HEPA program elements for maintenance of physical activity among 172 of 177 participants answering the study-specific questionnaire.

HEPA Program Component	Median	Range
Group support	3	1–4
Handbook	2	1–3
Planning	3	2–4
Maintenance and relapse prevention strategies	3	1–3
Circuit training	4	3–5
Daily physical activity	4	4–5
Pedometer	3	1–4
Step registration	1	1–1
Short text messages	4	3–5
Walk test to self-monitor aerobic capacity	1	1–3

HEPA: health-enhancing physical activity.

The 220 participants included at baseline constituted 11% of the potentially eligible participants and differed from those declining<sup>17</sup> mainly regarding psychosocial matters.

Eighty-eight percent of the included sample completed 1-year assessments<sup>19</sup> and 81% completed the 2-year assessments reported in this paper. The retention rate was thus reasonably good, but differences between those entering and completing the study compared to those who declined or dropped out raise questions about external validity. This has not been described in detail in previous HEPA studies but indicates that patients with RA consenting to and completing participation are not those that would likely benefit the most.

Huge variation in adherence to the program was indicated in the text messages, but most study participants established and maintained circuit training habits and HEPA levels corresponding to at least 150 min a week. This must be considered a good outcome and thus the HEPA goals of our study might have been set too high. The proportion of participants reporting current HEPA dropped slightly during the second year but was still 20% higher compared to baseline. This compares very well with a previous 1-year randomized controlled trial (RCT) of Internet-based HEPA support, in

which about 20% of initially sedentary participants with RA still performed HEPA on most days of the week at 2-year followup<sup>13</sup>. Further, our results indicated that maintained HEPA had reportedly been performed by 27% of our participants during the second year, which represented a reduction from Year 1, but the results were still a substantial increase from baseline, when none of our participants maintained HEPA<sup>20</sup>. Considering the huge challenges of health behavior change, a 27% increase of maintained HEPA is a most satisfactory outcome of our program and is also considerably higher than the 7% still performing HEPA at 2-year followup of the previous 1-year RCT of Internet-based HEPA support<sup>13</sup>. Structured use of behavior change techniques and a second year to support maintenance with a reduced program, as in our study, might thus help people with RA to maintain HEPA behavior.

Increased outcome expectations of HEPA on longterm health and RA symptoms during the second year might indicate changed cognitions related to HEPA among the participants during the maintenance phase and, in turn, positive influence on future HEPA participation<sup>19</sup>. The most likely explanations for lack of improvements, or even decline, during the second year of aerobic capacity, muscle function, activity performance, and quality of life were our participants' relatively high performance at the end of the first year<sup>20</sup>, consequently leaving little room for improvement<sup>39</sup>. Another could be that withdrawal of scheduled support from physiotherapists and peers during the second year resulted in suboptimal progression of HEPA intensity<sup>40,41</sup>. However, it is worth noting that our participants still had a high aerobic capacity compared to the general population and other studies of persons with RA of similar age<sup>39,42,43,44</sup>, probably indicating a better cardiovascular disease (CVD) risk profile and a lower 10-year CVD risk<sup>44</sup>.

No significant relationships were observed in response and adherence. This might be partially attributed to limited statistical power, because participants were unevenly distributed over groups of adherence and response, or lack of improvements in outcome variables. Another reason might be that our expectations for 50%, 70%, and 90% adherence and 10%, 20%, and 30% outcome improvements were too optimistic for nonpharmacological interventions.

Our inclusion of behavior change techniques recommended for interventions aiming at adoption and maintenance of HEPA behavior<sup>45,46</sup> was not highly valued by the majority of our participants. It may be that the physical therapists, although trained to encourage participants to practice self-regulation, failed to target autonomous motivation that is important for the maintenance phase<sup>12,46</sup>. Further, guidance of support group meetings and tailoring the content and support to individual needs and preferences represented challenges to physiotherapists<sup>25</sup>, which most likely influenced the HEPA maintenance in our study. Interestingly, a previous study of views on delivery of HEPA programs

among patients with RA indicated that group-based programs, peer support, expert physiotherapist input, self-set goals, and coping strategies would support adherence<sup>47</sup>. Because those things are very much in line with what we did in our study, it seems easier said than done.

The strengths of our study are a well-defined sample, a longterm perspective, and a combination of data collection methods, including validated questionnaires, short text messages, and performance tests. In particular, the use of continuous short text messages might reduce recall bias, whereas the social desirability related to self-reporting is still a problem<sup>48</sup>. The major limitation of our study is its cohort design and the subsequent uncertainty in attributing the observed changes in behavior, health, and functioning entirely to the HEPA program. However, while randomized controlled designs reduce threats to internal validity, cohort studies may, particularly in those with longterm perspective, reduce threats to external validity, with less inclusion bias and better attrition and adherence. Objective measures of HEPA behavior would be desirable<sup>49</sup> but are not feasible for monitoring hundreds of participants over 2 years, and using them for shorter periods during longterm interventions might cause social desirability bias because participants cannot be blinded to whether they carry them during a particular period of time. Our results from the recruitment process for this HEPA program<sup>17</sup> and the present 2-year evaluation indicate that more effort should be put into recruiting and retaining individuals with low aerobic capacity, fatigue, and negative attitudes toward physical activity, because they are likely to benefit most from HEPA programs. Further, it is important that HEPA goals are tailored to each individual and are not too ambitious. Gradual withdrawal of support seems to increase HEPA maintenance and should be incorporated in clinical programs. Short text messages are feasible to supervise, but also to prompt, HEPA adherence<sup>20</sup>.

Future studies should further investigate appropriate education and training of physiotherapists to provide behavior change support. Also, the perceptions of people with RA and negative attitudes toward physical activity need further study. Our study provides a novel model for data analysis of adherence and response, to provide a more individualized picture in studies on complex nonpharmacological interventions with a pragmatic design. It could be further developed and tested as a potential parallel to calculation of dose-response models in drug studies<sup>50</sup>. Although maintained HEPA decreased during the second intervention year, about one-fourth of our study participants not obtaining adequate HEPA at baseline sustained HEPA behaviors in line with international guidelines after 2 years. It remains unclear whether improvement in health and functioning relates to the HEPA program and its different components.

#### ACKNOWLEDGMENT

We acknowledge the kind contribution of the study participants, the Swedish Rheumatology Quality Registers, and the PARA Study Group.

## REFERENCES

1. World Health Organization. Physical activity and adults. [Internet. Accessed March 28, 2018.] Available from: [www.who.int/dietphysicalactivity/factsheet\\_adults/en/index.html](http://www.who.int/dietphysicalactivity/factsheet_adults/en/index.html)
2. Haskell WL, Lee IM, Pate RR, Powell KE, Blair SN, Franklin BA, 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.
3. Nelson ME, Rejeski WJ, Blair SN, Duncan PW, Judge JO, King AC, et al. Physical activity and public health in older adults: recommendation from the American College of Sports Medicine and the American Heart Association. *Med Sci Sports Exerc* 2007;39:1435–45.
4. Zegkos T, Kitas G, Dimitroulas T. Cardiovascular risk in rheumatoid arthritis: assessment, management and next steps. *Ther Adv Musculoskelet Dis* 2016;8:86–101.
5. Demmelmaier I, Bergman P, Nordgren B, Jensen I, Opava CH. Current and maintained health-enhancing physical activity in rheumatoid arthritis: a cross-sectional study. *Arthritis Care Res* 2013;65:1166–76.
6. Tierney M, Fraser A, Kennedy N. Physical activity in rheumatoid arthritis: a systematic review. *J Phys Act Health* 2012;9:1036–48.
7. Swärdh E, Brodin N. Effects of aerobic and muscle strengthening exercise in adults with rheumatoid arthritis: a narrative review summarising a chapter in physical activity in the prevention and treatment of disease (FYSS 2016). *Br J Sports Med* 2016;50:362–7.
8. Brus HL, van de Laar MA, Taal E, Rasker JJ, Wiegman O. Effects of patient education on compliance with basic treatment regimens and health in recent onset active rheumatoid arthritis. *Ann Rheum Dis* 1998;57:146–51.
9. van den Berg MH, Runday HK, Peeters AJ, le Cessie S, van der Giesen FJ, Breedveld FC, 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.
10. Mayoux-Benhamou A, Giraudet-Le Quintrec JS, Ravaud P, Champion K, Dernis E, Zerkak D, et al. Influence of patient education on exercise compliance in rheumatoid arthritis: a prospective 12-month randomized controlled trial. *J Rheumatol* 2008;35:216–23.
11. Brodin N, Eurenus E, Jensen I, Nisell R, Opava CH; PARA study group. Coaching patients with early rheumatoid arthritis to healthy physical activity: A multicenter, randomized, controlled study. *Arthritis Rheum* 2008;59:325–31.
12. Knittle K, De Gucht V, Hurkmans E, Peeters A, Runday K, Maes S, et al. Targeting motivation and self-regulation to increase physical activity among patients with rheumatoid arthritis: a randomised controlled trial. *Clin Rheumatol* 2015;34:231–8.
13. Hurkmans EJ, van den Berg MH, Runday KH, Peeters AJ, le Cessie S, Vlieland TP. Maintenance of physical activity after Internet-based physical activity interventions in patients with rheumatoid arthritis. *Rheumatology* 2010;49:167–72.
14. Sjöquist ES, Brodin N, Lampa J, Jensen I, Opava CH; PARA Study Group. Physical-activity coaching in everyday practice of patients with rheumatoid arthritis. A long-term follow-up. *Musculoskel Care* 2011;9:75–85.
15. Ezzat AM, MacPherson K, Leese J, Li LC. The effects of interventions to increase exercise adherence in people with arthritis: a systematic review. *Musculoskeletal Care* 2015;13:1–18.
16. Larkin L, Gallagher S, Cramp F, Brand C, Fraser A, Kennedy N. Behaviour change interventions to promote physical activity in rheumatoid arthritis: a systematic review. *Rheumatol Int* 2015;35:1631–40.
17. Nordgren B, Fridén C, Demmelmaier I, Opava CH. Who makes it to the base? Selection procedure for a physical activity trial targeting people with RA. *Arthritis Care Res* 2014;66:662–70.
18. Nordgren B, Fridén C, Demmelmaier I, Bergström G, Opava CH. Long-term health-enhancing physical activity in rheumatoid arthritis — the PARA 2010 study. *BMC Public Health* 2012;12:397.
19. Nordgren B, Fridén C, Demmelmaier I, Bergström G, Lundberg IE, Dufour AB, et al; PARA Study Group. An outsourced health-enhancing physical activity programme for people with rheumatoid arthritis: exploration of adherence and response. *Rheumatology* 2015;54:1065–73.
20. 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 program for persons with rheumatoid arthritis. *Clin Rheumatol* 2015;34:429–39.
21. Arnett FC, Edworthy SM, Bloch DA, McShane DJ, Fries JF, Cooper NS, et al. The American Rheumatism Association 1987 revised criteria for the classification of rheumatoid arthritis. *Arthritis Rheum* 1988;31:315–24.
22. Fries JF, Spitz P, Kraines RG, Holman HR. Measurement of patient outcome in arthritis. *Arthritis Rheum* 1980;23:137–45.
23. Bandura A. Social cognitive theory: an agentic perspective. *Annu Rev Psychol* 2001;52:1–26.
24. Nordgren B, Fridén C, Jansson E, Österlund T, Grooten W, Opava CH, et al. Criterion validation of two submaximal aerobic fitness tests, the self-monitoring Fox-walk test and the Åstrand cycle test in people with rheumatoid arthritis. *BMC Musculoskelet Disord* 2014;15:305.
25. 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.
26. Shiffman S, Stone AA, Hufford MR. Ecological momentary assessment. *Annu Rev Clin Psychol* 2008;4:1–32.
27. Craig CL, Marshall AL, Sjöström M, Bauman AE, Booth ML, Ainsworth BE, et al. International physical activity questionnaire: 12-country reliability and validity. *Med Sci Sports Exerc* 2003;35:1381–95.
28. Burbank PM, Riebe D. Promoting exercise and behavior change in older adults: interventions with the transtheoretical model. New York: Springer; 2002.
29. Felson DT, Anderson JJ, Boers M, Bombardier C, Chernoff M, Fried B, 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.
30. Huskisson EC. Measurement of pain. *J Rheumatol* 1982;9:768–9.
31. 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.
32. 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.
33. Nessen T, Demmelmaier I, Nordgren B, Opava CH. The Swedish Exercise Self-Efficacy Scale (ESES-S): reliability and validity in a rheumatoid arthritis population. *Disabil Rehabil* 2015;37:2130–4.
34. 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.
35. 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.
36. Åstrand P, Rodhal K, Dahl H, Stromme S. Textbook of work physiology: physiological bases of exercise, 4th rev. Champaign: Human Kinetics; 2003.

37. Newcomer KL, Krug HE, Mahowald ML. Validity and reliability of the timed-stands test for patients with rheumatoid arthritis and other chronic diseases. *J Rheumatol* 1993;20:21–7.
38. Nordenskiöld 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.
39. McArdle WD, Katch FI, Katch VL. Exercise physiology: Nutrition, energy, and human performance. Philadelphia: Lippincott Williams & Wilkins; 2010.
40. Oja P. Dose response between total volume of physical activity and health and fitness. *Med Sci Sports Exerc* 2001;6 Suppl:S428-37; S452-3.
41. American College of Sports Medicine Position Stand. The recommended quantity and quality of exercise for developing and maintaining cardiorespiratory and muscular fitness, and flexibility in healthy adults. *Med Sci Sports Exerc* 1998;30:975-91.
42. Munsterman T, Takken T, Wittink H. Are persons with rheumatoid arthritis deconditioned? A review of physical activity and aerobic capacity. *BMC Musculoskelet Disord* 2012;13:202.
43. Yu CA, Rouse PC, Veldhuijzen Van Zanten JJ, Ntoumanis N, Kitas GD, Duda JL, et al. Subjective and objective levels of physical activity and their association with cardiorespiratory fitness in rheumatoid arthritis patients. *Arthritis Res Ther* 2015;17:59.
44. Metsios GS, Koutedakis Y, Veldhuijzen van Zanten JJ, Stavropoulos-Kalinoglou A, Vitalis P, Duda JL, et al. Cardiorespiratory fitness levels and their association with cardiovascular profile in patients with rheumatoid arthritis: a cross-sectional study. *Rheumatology* 2015;54:2215-20.
45. Michie S, Abraham C, Whittington C, McAteer J, Gupta S. Effective techniques in healthy eating and physical activity interventions: a meta-regression. *Health Psychol* 2009;28:690-701.
46. Fjeldsoe B, Neuhaus M, Winkler E, Eakin E. Systematic review of maintenance of behavior change following physical activity and dietary interventions. *Health Psychol* 2011;30:99–109.
47. Withall J, Haase AM, Walsh NE, Young A, Cramp F. Physical activity engagement in early rheumatoid arthritis: a qualitative study to inform intervention development. *Physiotherapy* 2016; 102:264-71.
48. Sallis JF, Saelens BE. Assessment of physical activity by self-report: Status, limitations, and future directions. *Res Q Exerc Sport* 2000;2 Suppl:S1-14.
49. Ferguson T, Rowlands AV, Olds T, Maher C. The validity of consumer-level, activity monitors in healthy adults worn in free-living conditions: a cross-sectional study. *Int J Behav Nutr Phys Act* 2015;12:42.
50. Felson DT, Anderson JJ, Boers M, Bombardier C, Furst D, Goldsmith C, et al. American College of Rheumatology. Preliminary definition of improvement in rheumatoid arthritis. *Arthritis Rheum* 1995;16:727–35.

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#### APPENDIX 1.

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