A Necessary Investment in Future Health: Perceptions of Physical Activity Maintenance Among People With Rheumatoid Arthritis

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**Objective.** A few studies with a qualitative design have addressed physical activity (PA) maintenance in people with rheumatoid arthritis (RA), but none of them focused specifically on maintenance of PA according to public health recommendations. The purpose of this study was to describe perceptions of PA maintenance during the second year of an outsourced 2-year support program among people with RA.

**Methods.** For this descriptive design with a qualitative inductive approach, semi-structured interviews were conducted with 18 participants with RA (3 men and 15 women). Variation in age, disease duration, activity limitation, pain, levels of PA, and PA maintenance was targeted through strategic sampling. Qualitative content analysis was used, and a pattern of theme, subthemes, and categories was constructed based on the participants' perceptions of PA maintenance.

**Results.** A main overarching theme, “A necessary investment in future health”—with 3 subthemes of dedication, awareness, and affinity—was identified as participants' perceptions of PA maintenance. Eight categories further described are a changed mindset, habits, commitments, monitoring, insights in PA, health gains, social support, and PA context.

**Conclusions.** PA according to public health recommendations was perceived as a true investment in future health and wellness requiring dedication, awareness, and affinity. To promote PA maintenance, physical therapists working with people with chronic conditions should consider strengthening these prerequisites by targeting patients' negative attitudes to PA, supporting their creation of PA habits to incorporate in daily routines, introducing monitoring of PA intensity, supporting development of PA self-regulation skills, and providing suitable gym facilities with the possibility of peer support.
Recommendations on physical activity (PA) to prevent disability and comorbidity in people with chronic conditions include a minimum of 150 min/wk of moderately intense aerobic exercise, or 75 min/wk of high-intensity aerobic exercise as well as twice-weekly sessions of muscle strength exercises.1 Despite the strong evidence for PA, most people with chronic disability do not reach and/or maintain recommended PA levels.2–6 Supporting not only the adoption of healthy PA behaviors but also their maintenance among patients with chronic disability is an important, yet challenging, task for physical therapists.7,8

A few intervention studies to support PA maintenance in people with rheumatoid arthritis (RA) have been reported. An internet-based intervention found increased PA levels,9 while a coaching program carried out in physical therapist practice reported no change in PA behavior at follow-up.10 A motivational interviewing and self-regulation coaching intervention found greater autonomous motivation and better use of self-regulation skills as a predictor of long-term maintenance of PA.11

Understanding patients’ perceptions of PA and incorporating strategies to address long-term maintenance is crucial. Perceived facilitators, barriers, and benefits to PA and exercise in people with RA have been described in studies with qualitative and quantitative designs.12,15 Findings across studies indicate that pain and fatigue often represent barriers, while reductions in pain and fatigue are perceived benefits of PA and exercise. It is suggested that self-efficacy support and social support from health professionals, family, and friends may encourage people with RA to overcome barriers to PA and exercise and help maintain this important health behavior.12 A synthesis of studies with qualitative designs identified 5 themes—professional knowledge and guidance, part of a community, knowing me, knowing RA, what’s in it for me, and where, when, how much—that are important for PA participation with professional knowledge and guidance as its underpinning factor.13 To our knowledge, only 3 previous studies with a qualitative design have focused specifically on the maintenance of PA behavior in people with RA.14–16 However, none of them focused on PA according to public health recommendations but rather on maintenance of planned and structured exercise15–16 or more general PA, including a variety of aspects from housework and walking to running, cycling, and resistance training.14

The Physical Activity in Rheumatoid Arthritis (PARA) 2010 intervention study17 included 220 participants not reaching PA levels according to public health recommendations.1 A 2-year outsourced PA support program consisted of circuit training at selected public gyms, moderate-intensity aerobic PA in participants’ daily environment, and support group sessions.17 During the first year, support groups were led by physical therapists trained within the study,18 whereas during the second year, participants were expected to take charge of the support groups and were free to choose any gym facility for their exercise. Heart rate monitors, pedometers, and weekly text messages were used to monitor and facilitate PA. The proportion of participants reaching maintained PA according to public health recommendations increased from 0% to 41% during the first year19 and dropped to 27% during the second year of the support program.20 The program was greatly appreciated, and perceptions from first-year participation were related to expectations, facilitators, gains, maintenance, and troubleshooting.21

The present study aimed to explore perceptions of maintaining PA according to public health recommendations during the second year of an outsourced support program among people with RA.

Methods

Design
A descriptive design with a qualitative, inductive approach was applied. Conventional content analysis was used to systematically describe the phenomenon “maintenance of PA.”22 Use of pre-established categories was avoided, but rather the categories were allowed to run from the data to generate new insights.23

Sample and Participants
Eighteen participants were strategically chosen to include both men and women and to represent variation in age, disease duration, perceived pain and health, activity limitation by the Health Assessment Questionnaire Disability Index,24 current PA according to public health recommendations by the International Physical Activity Questionnaire,2,25 and maintained PA by Exercise Stage Assessment Instrument26 (Table). They were recruited from a sample of adults with RA who had completed the outsourced 2-year PA support program, that is, participated in the 2-year assessments, and had previously participated in semi-structured interviews after the first year of the program.21

Ethical approval was obtained from the Regional Ethical Review Board in Stockholm (2011/1241-32), and all participants gave written consent before participating. The participants were guaranteed confidentiality and were informed that they were free to withdraw from the study at any time.

Data Collection
Data on age, gender, and disease duration were retrieved through the Swedish Rheumatology Quality registers and data on disability and physical activity through a postal questionnaire.27

Semi-structured interviews were conducted 1 to 9 months after the end of the second year of the PA support.
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**Table.**
Characteristics of the Participants (n = 18)*

| Characteristic                   | n   |
|---------------------------------|-----|
| Sex, female/male, n             | 15/3|
| Age, y, md (range)              | 66.5 (48–72) |
| Disease duration, y, md (range) | 5 (1–25) |
| Pain, VAS, 0-100, md (range)    | 24 (3–72) |
| Perceived health, EQ-SD VAS, 0-100, md (range) | 75 (30–90) |
| Activity limitation, HAQ-DI, 0-3, md (range) | 0.187 (0–0.625) |
| Current physical activity, IPAQ, n (%) | 14 (68) |
| No                              | 4 (22) |
| Maintained physical activity, ESAI, n (%) | 9 (50) |
| No                              | 9 (50) |

*EQ-SD = EuroQoL 5 dimensions; ESAI = Exercise Stage Assessment Instrument; HAQ DI = Health Assessment Questionnaire Disability Index; IPAQ = International Physical Activity Questionnaire; md = median; VAS = visual analog scale.

In order to minimize bias, the participants chose the setting of the interview: their workplace, their home, by telephone, or in a public place. The interviews were performed by the first author (E.S.). Prior to the data collection, there was no relationship between the interviewer and the participants. An interview guide was developed consisting of main areas of inquiry (Fig. 1). Open-ended questions were used along with follow-up questions to facilitate elaboration and more details from the participants. Follow-up and probing questions were adjusted to individual responses and varied slightly with each participant. Interviews lasted 21 to 59 minutes (mean 32 minutes) and were audio-recorded and transcribed verbatim by the researchers (E.S., I.D.) and undergraduate students under supervision.

**Data Analysis**

A qualitative inductive latent content analysis, influenced by Graneheim and Lundman27 as well as Elo and Kyngäs,28 was conducted (Fig. 2). The principal researcher (E.S.) who conducted the interviews and the primary analysis, and the 3 researchers re-analyzing (I.D.) or peer-reviewing the analysis and results (C.H.O., B.N.) were all female, experienced physical therapists, researchers within rheumatology, behavioral medicine, and PA and with expertise in both qualitative and quantitative research approaches.

**Role of the Funding Source**

The funders played no role in the design, conduct, or reporting of this study.

**Results**

A main overarching theme “A necessary investment in future health” and 3 subthemes—dedication, awareness, and affinity—were identified as participants’ perceptions of maintenance during the second year of an outsourced 2-year PA support program (Fig. 3). The overarching theme can be understood as the participants’ overall effort to accomplish PA maintenance with the subthemes as building blocks. The subthemes are further illuminated through 8 categories and numbers in brackets after each quote refers to the participants’ identity numbers.

**Dedication**

**A changed mindset.** Changed attitudes and ways of thinking were essential for becoming dedicated to PA. Reasons for these changes were related to internal motivation for PA in general and the perceived new life, during and after participation in the support program, in particular. PA was described as pleasurable and a prerequisite for a good life. For some, the support program conferred a new life that included PA; for others, the motivation was there already at the start and they stated that now they would never stop. The implementation phase had taken time for some, but once fully incorporated, their way of thinking was changed to include PA as an ever-present part of life.

It has been rattling around in my head before that, no, if I go out, I get more pain, or if I exercise now, no, I have to rest up until I feel better. It seems to have gone away a bit, that those times when you’re tired and in pain and something, there’s somewhere in the back of my head that, no, I have to do some
exercise in order to stay in the habit. Exercising, because there's some completely different thought in my head. (1785)

What I'm thinking is, that I understand, that it's vital. I need to move. And I, I mean, am I, if I want to have a good life, I need to continue exercising. (2389)

Habits. Creating dedicated habits and implementing PA in everyday life was facilitated by using positive prior experiences, planning of PA, and developing coping strategies for lapses of physical inactivity. Prior experiences of PA enhanced enrolment in the support program for some. For those with prior experience, previous PA behavior made the maintenance of PA natural, and their present PA plan was related to prior experiences. The participants considered planning as essential for PA maintenance. The days were often full of regular activities, and fitting PA into the schedule was described as a challenge. They expressed a need for continuity, a PA program to follow, and clearly set goals. PA should be conveniently organized, such as by predetermined appointments near to home or work. A need for variation or alternative types of PA was highlighted in order to prevent monotony. Outdoor PA in all weather conditions and seasons was challenging, and the participants described difficulties with autumn darkness and a lack of footpaths. Being persistent and strong-willed was important for coping with lapses and...
to familiarize and get an overview of the material, all of the transcribed individual
terviews were first read carefully by the principal author (ES).

- Next, open coding was performed through writing notes and headings describing
physical activity maintenance in the text while reading it. Meaning units connected to
the headings were also identified. The material was read through several times while
headings and meaning units were identified to cover all aspects of the phenomenon.
The headings were then moved/collated from the margins on to a coding sheet. Open
coding was made with all the material by the principal author (ES) and with five of the
interviews by the third author (ID).

- The various codes were compared regarding differences and similarities. Codes with
related meanings were grouped together in categories. To ensure trustworthiness, two
of the authors (ES, ID) repeatedly discussed and compared the emerging categories,
with the content of the original interviews several times, until negotiated consensus
was reached. Discussions with the two authors used as peer experts (CHO, BN) were
held continuously.

- The last step of the analysis, identifying a meaningful underlying essence that run
through the material, resulted in an overarching theme and subthemes.

- Quotes are provided in the result for illustration and trustworthiness.

**Figure 2.**
The steps in the data analysis.

for getting back on track again. Lapses were perceived as
important opportunities for learning how to handle
different setbacks and develop new strategies to prevent
future lapses.

I think I’ll get back on track and of course you’ve got that in
your head all the time. We drew an analogy with if you’re
poorly or something else, then it’s entirely OK to ease up for a
while, as long as you get back on course. And in the worst
case, you stop completely, but then you still have to get back
out again, and that’s in your head in a completely different way
to before. And feeling that it’s doing me some good to get back
out there that alone makes me feel good. Great! And if that
happens a few times, then of course you’re making a habit of
that as well. (1785)

The continuity, the scheduling, that you follow a program.
That’s what it’s about. My whole life, I’ve always been a
planner, at work and all that, and if you don’t have any goals
and no plan, then nothing happen. But here you could see you
could have a plan, and it was easy to follow so there was
nothing to it, reaching your goals worked fine. (1959)

**Commitments.** Commitment in terms of fidelity to the
research program and responsibility for one’s own PA and
health elucidated the participants’ dedication to
maintaining their PA. Participation in the program was
taken very seriously. Completing the program was
prioritized and seen as an obligation. However,
participants also meant that each person should be free to
decide how much effort they could put into the project.
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Figure 3.
Perceptions of physical activity maintenance during the second year of an outsourced 2-year support program.

Feelings of being too busy with program activities were sometimes present, and then the activities were performed more as duties. However, most participants were disciplined and booked appointments with program peers, friends, or with themselves. Economic challenges with a strained personal financial situation could have a negative impact on commitment, particularly if the gym facility was perceived as inflexible regarding the fee. However, some commented that enrollment in the PA support program was optional and viewed this as a non-existent issue.

And prioritizing this: That you’re going in for this. If I’ve got into the project, then you have to take it seriously as it is…. And of course this was, of course for me this was also, it wasn’t that I was supposed to do something for someone else or do work for the company, but rather this was something completely egotistical for me, so I think I sort of consented to this, so I really want to go through with it. (1638)

When it comes to the cost, you could always debate that. Can you afford to invest in that, or do you want to play golf and invest in that, I mean, everything is relative, you know, what you want to invest in. I think that’s up to you. (1638)

Awareness

Monitoring. Registering and reporting PA increased awareness of the PA actually performed that, in turn, influenced maintenance. This was accomplished by positive peer pressure, self-registration, and regular follow-ups by the physical therapist. Reporting own PA during the past weeks to the group was a strong incentive for keeping to the plan, and a guilty conscience was sometimes present when the plan was not adhered to. The peer pressure was expressed as a positive aspect of the group sessions as it toughened people up and allowed them to be pushed in the right direction. Also, reporting PA through automatically generated text messages became a reminder and facilitator for maintenance. Measuring and competing with oneself and no one else was also important. The competitive spirit was facilitated using pedometers, calendars, or heart rate monitors. Thus, self-registration was complementary to peer pressure. Regular follow-ups of physical capacity by physical therapists, as part of the PA support program, were inspiring, encouraging, and highly valued. The participants were concerned about PA maintenance when the monitoring within the program terminated, and they wished that this support had been gradually phased out.

These short text messages you got … they were really great. And when they stopped, then it was sort of, then you lose a little … I’m the kind that needs someone to sort of give me a good hard stare now and again – pull yourself together – and that really feels like a kind of … hi, have you been exercising or not?… Whoa, I was just on my way, oh dear, not at all this week … I need someone to sort of give me a gentle push. … No-one said anything, but there were just these short text messages, … a little reminder … and no, I’ve not done any more, so I have to, I’ve got to pull my socks up a bit next week. (2393)

How it went last week, for example, and that’s good, I think it was good to include that, because otherwise, if you hadn’t had any follow-up from last week, it would have been for nothing and it’s important to see the results. And it says why, too, why didn’t it turn out the way you’d planned, and what can you do to make it better. (1638)

Insights in PA. New knowledge and skills related to PA were clearly articulated. The importance of learning about PA, how it is defined, and its benefits for general health as well as for disease-specific consequences and how it can
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Health gains. Through perceived health gains for both the body and mind, the participants increased their awareness of the importance of maintained PA. Experiencing reduced disease symptoms and improved functioning, also in relation to previous injuries, facilitated the overall motivation for PA participation. Better quality of sleep, higher body energy, and a sense of overall increased vitality were also experienced. Furthermore, being able to move more freely, staying healthy and alert, keeping the body in shape, and being able to participate in both daily chores and leisure time activities were described as being important for PA maintenance as was the ever-present positive feeling of being able to perform more PA at higher intensities than previously. In general, the idea that PA should not be performed while in pain was eliminated and replaced by trust in oneself and one’s body—knowing when to stop and how to adjust PA and keep the intensity at a beneficial level.

You shouldn’t be scared of tiring yourself out . . . in any way. I feel more that I . . . can rely on my body again, if I say so. What I always thought before that sort of, I knew my own limits, and then suddenly it wasn’t my body anymore, that didn’t have any strange, or a whole load of strange new limits that I didn’t recognize. Yeah, I feel that I can dare to get tired more than I did before . . . Sort of more like a different understanding of what the illness is actually like, that it’s not so . . . I can’t ruin, well, anything. (2393)

I’ve discovered that intensity is crucial in raising your fitness level . . . then I discovered that if I don’t strain myself, especially when out walking, and walk really slowly, nothing happens to me, so I need to push myself, I need to feel my pulse rise, I need to feel that I’m sweating so that I, well, that the body has to work a bit, otherwise you don’t see much of a result. (389)

If you want to work more, or psych each other up to going back, it’s a good idea to keep each other updated so you don’t feel left out, or psych each other up to going back . . . Because we benefit from pushing one another a bit . . . I’m thinking it keeps us motivated. (2389)

PA context. Outdoor and indoor exercise facilities influenced feelings of affinity. Some gym facilities provided machines that were easy to use despite reduced grip strength and limited mobility, and there was a great variation in physical fitness among other clients at the centers. This context induced a feeling of “fitting in,” while exercising at other, less adapted gym facilities gave the participants a feeling of being excluded. Gym facilities close to home or workplace contributed to affinity and maintenance of PA.

I do feel that exercising at Itrim, the circuit training; I thought it was right for me. And you did get . . . you could exercise as hard as you wanted; you got to control that yourself. And the circuit training, it’s both strength and condition, I though the set-up itself was good. And the fact that you didn’t need to adjust machines. (2955)

I’d put up these obstacles that you can’t go to gyms or do this type of exercise and you need to wear certain clothes and people have such great bodies and all this that you see on all
Discussion

Several new maintenance aspects are reflected in the main overarching theme identified in our result. They indicate that PA is not only for current enjoyment, symptom reduction, or better performance of daily chores as indicated in previous research on PA adoption and maintenance. PA according to public health recommendations is additionally perceived as a true investment in future health and prevention of disability and comorbidity through fostering dedication to PA, awareness about the prerequisites to sustain it, and the affinity needed for its maintenance.

Previous studies have identified that a positive attitude is instrumental for adherence to exercise in patients with RA,15 that motivation driven by personal needs and satisfaction with PA is related to actual level of activity,16 that maintaining PA is a way of taking responsibility for one's life,14 and highlighted the importance of PA routines.15 They can all be related to dedication, as described in our findings. In addition, we identified perceptions of a changed mindset, with PA as an ever-present part of life that was essential to plan for and commit to as important for maintenance of PA. On the other hand, occasional lack of commitment as described in our study might reflect a previously described desire to “hand oneself over” to health care professionals.16 People with RA might, therefore, need to change their negative thoughts about PA, create habits, and incorporate PA as part of their daily routine to successfully maintain PA.

A need for monitoring new insights into PA and perceived health gains was described in the present results as important to increase awareness. Similar aspects have been described previously, such as better ability to modify exercise,15 to differentiate between reactions of the body through PA,14 and reduction of symptoms, better mental health, and/or increased strength and mobility.12,13,15,30–31 However, perceived benefits of feedback, that is, positive peer pressure, self-registration, text messages, and assessments of physical capacity, for maintenance of PA have not previously been much described in similar populations. Most importantly, perceptions of the importance of PA of high enough intensity as essential for long-term health benefits has not been described previously. It is thus important for people with RA to be introduced to monitoring of PA intensity and coached in how to develop self-regulation skills for PA maintenance.

Our participants described how affinity was fostered through social support and the PA context. It is well known that social aspects positively influence PA behavior in people with RA,12–14,31–35 but although group activities can be enjoyed, social support is not always necessary for maintenance.29 Previous findings suggest that intimidations by others may occur when engaging in public gyms12 and that access to suitable facilities within health care are important for PA adherence,16 but also that a community or public gym setting can be more practical and accessible than a health care facility.15,20 The benefits of public gym settings for long-term PA maintenance, as described by our participants, are probably larger than for occasional PA during a couple of weeks or months. Thus, hearing about other's experiences and feeling connected to others, as well as observing and replicating skills by trusted other people with similar conditions, may encourage affinity and support for PA maintenance, as may a suitable PA facility.

The methodology used in the present study has several strengths. Systematic and independent analyses were made by more than 1 researcher and included peer review. The analytic procedure extended over several months, with periods of intense analysis alternated with periods of less activity, thus creating a distance to data that is likely to enhance the trustworthiness of the results. One limitation of this study was that the time point for the interviews varied between 1 and 9 months after completion of the PA support program. However, memory bias is unlikely since the program was comprehensive, stretched over 2 years, and all participants provided detailed descriptions of their experiences and perceptions on maintenance, resulting in a considerable variation in data. Satisfactory variation seemed to be achieved with the inclusion of 18 participants, since no new aspects of the phenomenon under study emerged during the last interviews. However, in a small sample like ours, all criteria for strategic sampling cannot always be fully satisfied and we acknowledge that; for example, more men and someone with more activity limitation might have added to variation to our results. Transferability was not the main aim of the present study, as it explored perceptions among a limited number of people with RA participating in a PA support program at public gyms. Thus, the results must be interpreted with this in mind and transferred to similar contexts.

PA to promote health and wellness is probably the most important and effective intervention physical therapists can incorporate into their patients’ plans of care.8 The comprehensive, theory-based long-term PA support program of the PARA 2010 study incorporated many elements suggested for health promotion, such as information, skills training, self-monitoring, self-regulation, self-efficacy building, and social support.8 The present results indicate that participants, whether they reached maintained PA according to public health recommendations or not, did indeed understand and embrace the dedication, awareness, and affinity needed to maintain PA as an investment in future health and wellness. We suggest that our example from rheumatology...
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may assist physical therapists working with patients with other chronic disabilities to further understand how to best support them to maintain PA of enough high intensity in outsourced contexts. However, the fact that only one-fourth of the original PARA 2010 study sample and one-half of its present sub-sample reported maintained PA after 2 years illustrate the challenges in forming habits that are truly integrated in daily life. How physical therapists can better address such challenges should be investigated in future studies using both qualitative and quantitative designs.

Conclusion

PA according to public health recommendations was perceived as a true investment in future health and wellness requiring dedication, awareness and affinity. In order to promote PA maintenance, physical therapists working with people with chronic conditions should therefore consider strengthening these prerequisites by targeting their patients’ negative attitudes to PA, supporting their creation of PA habits to incorporate in daily routines, introducing monitoring of PA intensity, supporting development of PA self-regulation skills, and providing suitable gym facilities with the possibility of peer support.

Author Contributions

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Ethics Approval

Ethical approval was obtained from the Regional Ethical Review Board in Stockholm (2011/1241-32). All participants gave their written consent before participating. The participants were guaranteed confidentiality and were informed that they were free to withdraw from the study at any time. All procedures were in accordance with the ethical standards of the Regional Review Board and with the 1964 Helsinki Declaration and its later amendments.

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Disclosure

The authors completed the ICMJE Form for Disclosure of Potential Conflicts of Interest and reported no conflicts of interest.

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