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## Promoting physical activity in patients with rheumatoid arthritis

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# Chapter 8

## Summary and Discussion



## Summary

Over the past decades, the health benefits of a physically active lifestyle such as a reduced risk of cardiovascular disease, diabetes and osteoporosis, have been extensively documented (1–3). These benefits also apply to people with arthritis, with in addition disease specific health gains such as reduced pain, improved mental health and delayed onset of disability (4–6). In general, it is recommended that all adults, including those with disabilities such as arthritis, should accumulate at least 30 minutes of moderate–intensity physical activity on 5 or more days per week (7). Unfortunately, many patients with arthritis do not reach sufficient levels of physical activity to obtain the afore–mentioned health benefits (7–9). Therefore, there is an urgent need to support people with arthritis in developing a sustainable physically active lifestyle.

The aim of the present thesis was to describe the actual engagement of patients with rheumatoid arthritis (RA) in physical activity, and their preferences regarding the delivery of physical activity interventions. Moreover, this thesis includes a synthesis of the evidence regarding the delivery of physical activity interventions by means of the Internet. In addition, an evaluation of the effectiveness as well as barriers and facilitators for future implementation of Internet–based physical activity interventions is presented.

*Chapter 1* provides an introduction to physical activity promotion in general and for patients with RA in particular. It is concluded that, despite the large body of evidence demonstrating that physical activity is beneficial and safe for patients with RA, the majority of patients is not sufficiently physically active. Over the past decades, various physical activity interventions for patients with RA have been developed. The Internet forms a promising mode of delivery for physical activity interventions; however, the evidence regarding the effectiveness of Internet–based physical activity interventions in patients with arthritis is scanty.

After the general introduction in the first chapter, this thesis is divided into two parts:

- Part 1 describes the engagement and preferences of RA patients regarding various types of physical activity.

- Part 2 focuses on a specific, innovative strategy to promote physical activity among patients with RA, i.e. enhancing physical activity levels by means of interventions delivered through the Internet.

### **Part 1: RA patients' engagement in physical activity**

*Chapter 2* describes the results of a study comparing the self-reported physical activity levels of patients with RA with those of the general Dutch population. In this study, a random sample of 400 patients with RA was sent a questionnaire. Proportions of patients meeting the Dutch public health recommendation for physical activity and the total number of minutes of physical activity per week were calculated. These data were compared with similar data from a representative sample of the general Dutch population, derived from a nationwide yearly Dutch survey. The results showed that the proportion of patients with RA meeting the physical activity recommendations was similar to the general Dutch population. However, with respect to the average number of minutes of physical activity per week, the RA patients were less physically active than the general population. Given the fact that people with RA have an increased risk of concomitant diseases such as osteoporosis, hypertension and cardiovascular disease, promoting physical activity for RA patients remains a matter of utmost importance.

In *Chapter 3* the results are reported of a study aimed to measure RA patients' engagement in various types of physical activity, as well as their preferences. Furthermore, in this study perceived barriers for physical activity were evaluated. Almost 80% of the 252 patients who participated in this study were engaged in any type of physical activity in the past 12 months. It appeared that the patients who were not physically active were significantly older, less educated, and more frequently male than the active patients. Almost half of the active patients were engaged in both supervised as well as unsupervised activities. Of the unsupervised activities, cycling and walking were the most frequently mentioned activities. With respect to preferences, supervised group exercise therapy and unsupervised individual physical activity were reported as most favorite activities. Furthermore, supervised physical activity was preferred above non-supervised physical activity and water-based activities above land-based activities. Finally, the most frequently mentioned barriers for physical activity included lack of energy, pain, lack of motivation, lack of information and fear of joint damage. The results of this study emphasize the need for a broad and varied offer of physical activity interventions for patients with RA as well as additional educational efforts.

**Part 2: Physical activity promotion by means of interventions delivered through the Internet**

The aim of the randomised controlled trial described in *Chapter 4* was to compare the effectiveness of two one-year Internet-based physical activity interventions for patients with RA. The first program was an individually supervised program (Individualised Training) in which weekly physical activity schedules with personal feedback, exercise equipment and limited group contacts were provided. The second program consisted of general instructions for home exercises and physical activity only (General Training). The Individualised Training proved to be more effective than the General Training in increasing physical activity. However, there was a declining compliance and a declining amount of moderate physical activity among the patients within the Individualised Training group with time. In general, no differences regarding functional ability, quality of life and disease activity were seen between the two groups.

*Chapter 5* describes the engagement and satisfaction with an Internet-based physical activity intervention in patients with RA. For that purpose, data of the 82 patients participating in the aforementioned Individualised Training group were analyzed. Over the one-year period, the physical activity schedule return rate was rated as being sufficient (median rate 55%) and 70% of the patients logged into the website at least once a week. However, there was a decline in both the physical activity schedule return rate as well as the website login frequency over time. The majority of the patients was satisfied with the amount of e-mail contacts, telephone contacts, usefulness of website information, physical activity schedules, and group meetings. Patients were less satisfied with the online discussion forum and the newsletters. Since the participants of this study were all experienced in using the Internet and e-mail, caution should be taken when extrapolating the results to groups of patients other than experienced Internet and e-mail users, or patients with more severe physical disabilities.

*Chapter 6* describes the results of a systematic literature review concerning the effectiveness of interventions designed to promote physical activity by means of the Internet among healthy persons and patients with various chronic conditions. In this review, only randomised controlled trials were included in which one of the primary goals was to promote physical activity among adults by means of the Internet, and in which at least one of the outcome variables was reported in terms of change in physical activity levels. The results of the 10 trials included in this review suggest that in

comparison with a waiting list group, Internet-based physical activity interventions are more effective with respect to increasing physical activity levels. However, the evidence demonstrating that personalised and supervised Internet-based physical activity interventions are more effective than interventions providing general web-based information is scanty. Most studies are qualitative, observational studies. Moreover, the studies that did systematically evaluate the effectiveness regarding these kinds of Internet-based physical activity interventions, are heterogeneous with respect to the research design and evaluation tools. More uniform research that further explores the potential benefits of this promising mode of delivery for the promotion of physical activity is needed.

Within the field of arthritis research, studies systematically addressing aspects regarding the implementation of evidence-based physical activity interventions are scarce. In *Chapter 7* the results of a case study investigating the potential barriers and facilitators regarding a future implementation of an Internet-based physical activity intervention for patients with RA are described. Identification of these barriers and facilitators took place by using the principles of the RE-AIM model. This model comprises 5 dimensions: Reach, Efficacy, Adoption, Implementation, and Maintenance. However, since in this study actual implementation of the Internet-based intervention did not take place yet, the dimensions 'Efficacy' and 'Maintenance' were left aside. The results of the study showed that on a setting level, a future implementation of the Internet-based physical activity intervention seemed feasible. Rheumatologists and the concerning rheumatologic centres were willing to co-operate. However, on an individual level, the final number of eligible patients to participate in the implementation of the intervention was limited. It appeared that the incorporation of a bicycle ergometer in the Internet-based physical activity intervention limited the implementation on a larger scale considerably, because both the patients' as well as the insurance companies' willingness to pay for the bicycle ergometer was low. Moreover, the prerequisite to give up currently used physical therapy in favour of the Internet-based intervention was found to be an important barrier by patients. Future activities should further explore possible ways to adjust the intervention to make it less costly, for example by transforming it into a more lifestyle-orientated intervention that is closely related to an individual's activities of daily life such as walking, cycling, gardening or climbing stairs (10;11).

## Discussion

Nowadays, the promotion of physical activity is generally accepted as an important part of the non-pharmacological care for patients with RA. In general, the results of the studies presented in this thesis show that indeed in sedentary RA patients physical activity levels can be influenced, but that sustainment is difficult. Attempting to adopt and maintain sufficient levels of physical activity is an example of so-called self-management strategies. Patients with RA employ several self-management strategies which are aimed at controlling or reducing the impact of their arthritis (12). Physical activity is a commonly used self-management strategy among patients with RA (13;14).

Influencing health behaviour such as physical activity is a complex and dynamic process in which multiple factors such as knowledge, attitudes, beliefs, self-efficacy, and individual goals play a role. Understanding how these factors interact and eventually produce changes in behaviour is not easy. Several theories of health behaviour change have been applied to physical activity behaviour, in order to explain when and how people are likely to change this behaviour and maintain the accomplished changes. Two widely used theories in the field of physical activity behaviour change are the transtheoretical Model (15;16) and the social cognitive theory. The transtheoretical model integrates current behavioural status with a person's intention to maintain or change his or her pattern of behaviour. Several narrative reviews (17–19) have examined the suitability of this model for understanding physical activity behaviour and have largely drawn positive conclusions. According to the model, individuals adopting a new behaviour, such as physical activity, move through a series of stages: the precontemplation stage (not physically active and not intending to make changes); the contemplation stage (not currently physically active but thinking about changing in the next 6 months); the preparation stage (engaging in some physical activity, but not participating in regular physical activity); the action stage (being physically active); and the maintenance stage (sustaining the change over time). The social cognitive theory proposes that personal, behavioural, and environmental factors operate as reciprocal interacting determinants of physical activity behaviour (20). This theory considers two key constructs: self-efficacy (i.e. a person's confidence in his or her ability to perform a certain behaviour) and outcome expectations (i.e. the expected results that will occur with performance of the behaviour).

The application of behaviour change theories for understanding physical activity behaviour has been widely discussed. For example, some theories were considered to apply a unidirectional, non-

dynamic view of behavioural change, largely neglecting the fact that individuals may differ with respect to the life goals they pursue (21). Moreover, there is disagreement on which theories lead to more effective physical activity interventions (18;22). In the future, more research should be done in order to establish which (combinations of) theories can serve as helpful blueprints for the development of strategies to increase physical activity levels among sedentary people.

A major challenge for physical activity interventions is the maintenance of health behaviour changes over time. The extended and dynamic course of changes in physical activity behaviour involves a series of episodes of adherence, lapses, relapses, and recovery, as the individual faces new behavioural challenges and contexts (23). Interventions need to take into account these episodes and have to be long enough to support individuals to effectively deal with minor and major setbacks and learn from those experiences. Although it has been demonstrated that regular physical activity, performed over a longer period of time, will lead to positive health effects (11;24), evidence-based information about the minimal duration or length of these interventions to achieve these health benefits is lacking. For that purpose, long-term studies in large groups of patients would be needed. With respect to physical activity promotion among RA patients, discussions can take place during consultations of these patients with several health care professionals such as rheumatologists, physical therapists, clinical nurse specialists, occupational therapists, and social workers. An advantage of this large potential of physical activity related discussions is, that there are appear to be many opportunities for the promotion of physical activity among patients with RA. However, a potential disadvantage is that co-ordination and attunement of advices may be poor. Moreover, health care professionals are usually not explicitly educated with respect to the complex process of changing and maintaining health behaviours including physical activity in patients with chronic diseases. Therefore, in future research the current competencies and educational needs among rheumatologists and allied health professionals regarding this topic need to be investigated.

Furthermore, patients' attitude towards their own physical activity behaviour is an important factor to take into account when trying to promote this behaviour. In the Netherlands, individual or group exercise therapies for people with arthritis are embedded within the Dutch health care system and costs for these therapies are to a large extent reimbursed by health insurance companies. Interventions aimed to guide patients in integrating exercise and physical activity into their individual activities of daily life may appear to be cheaper than more traditional models where exercises are for a large part performed during face-to-face contacts with physical therapists. The



Internet may serve as an attractive mode of delivery for providing support or guidance regarding physical activity in daily life. However, irrespective of the mode of delivery, an active role of the patient is required with patients recognizing and accepting their own responsibility for getting sufficient levels of physical activity. A major challenge for the future is to make a shift from an attitude where exercise and physical activity are seen as therapeutic interventions which patients with arthritis should undergo to a more active attitude where these aspects are integrated in a specific lifestyle required to live with the consequences of arthritis, with the patient himself or herself being primarily responsible.

Over recent years, the interest in using the Internet as an innovative mode of delivery of physical activity promotion is growing. Several factors have facilitated the rapid expansion of Internet-based health interventions: 1. the rapid proliferation of technology and increased availability of the Internet; 2. the relatively low costs of delivering Internet-based interventions; 3. the increase in the public's willingness to more actively manage their own health; and 4. the willingness of the public to use the Internet as a tool for health (25). Internet-based behavioural interventions have proven to be effective with respect to a number of conditions such as interventions aimed at smoking cessation and overcoming depression (26–28). An appealing aspect of Internet-based health interventions is the ability to include various modalities within one intervention such as information transfer, self-assessments, peer support groups, individual online health consultations and computer-generated feedback (29). The systematic review and the comparison of two Internet-based physical activity programs included in this thesis demonstrate that more and more, the effectiveness of Internet-based interventions aimed to modify physical activity behaviour is being evaluated by means of randomised controlled trials.

However, some limitations of delivering behavioural interventions by means of the Internet must be considered. First, maintaining high program adherence over time is difficult, especially because supervision is provided from a distance. This is crucial since it has been demonstrated that a major factor determining the effectiveness of Internet-based behaviour change programs is the extent to which participants actually use the associated tools (30;31). If the Internet is to fulfil its potential as a cost-effective means for delivering physical activity interventions, more research is needed to determine how the actual usage of the website and other elements of the intervention can be enhanced, so that maintenance of the intervention-usage as well as the behavioural changes are obtained. Secondly, when delivering Internet-based interventions, one should take into account

possible unintended harmful consequences of this particular mode of delivery such as loneliness and depression (32;33). In this respect, the Internet may be a poor substitute for face-to-face contacts with real people. Therefore, the balance between use of the Internet and face-to-face contacts should be carefully considered. Moreover, it should be kept in mind that not every patient has access to the Internet, possibly leading to undertreatment of specific groups of patients. Future research should further explore the benefits and potential harms of delivering physical activity interventions by means of the Internet for patients with chronic conditions in general and patients with RA in particular. Thirdly, the issue of reimbursement should be considered. The Dutch health care system is facing various challenges, such as rapidly increasing medical costs, growing life expectancy rates and increasing numbers of people suffering from chronic conditions, including arthritis. Several initiatives have been developed to cope with these trends, for example by trying to reduce the rate of inpatient hospitalizations and the number of physician office visits. The Internet may serve as an important tool to shift the focus of health care from institution-centered to patient-centered and to empower patients to play an active role in the management of their disease.

The provision of Internet-based physical activity interventions for patients with RA is a new development within the health care setting. Despite the potential advantages, in the Netherlands there are as yet no standard policies regarding reimbursement for Internet-based health care services. In order to fully integrate Internet-based health care services into the Dutch health care system, there is a huge need for a broad discussion between legislators, health care providers, and others who influence policies regarding the reimbursement of these services.

The studies included in this thesis as well as the literature have demonstrated that it is not easy to accurately measure physical activity. When using questionnaires, respondents may be influenced by the social desirability of reporting physical activity behaviour (34). In general, people tend to overreport physical activity and underestimate sedentary behaviour such as watching television (35). Indeed, it was found that people who had been encouraged to exercise reported a greater volume of physical activity than could be confirmed by heart rate data (36). Using more objective tools such as activity monitors or pedometers may seem a useful alternative for measuring physical activity, however, these measures appear not measure exact amounts of physical activity either (37;38). Since physical activity is related to other concepts such as quality of life (39;40) and functional ability (41;42), these 'indirect measures' have also been used in physical activity research. However, these

concepts are influenced by a large number of other factors as well, making it hard to establish the net effect of the changes in physical activity levels.

This thesis demonstrates that health behaviour of patients with RA can be influenced, at least when it concerns physical activity behaviour. Future research should further investigate the optimal timing, dosage, frequency, duration and mode of delivery of these interventions. Furthermore, the long-term health benefits should be ascertained more precisely. Increased knowledge about changing physical activity behaviour may help health care professionals to influence other health behaviours, such as smoking cessation and medication compliance. In general, changing health behaviour among patients with RA remains a challenge for both researchers, health care providers, patients, policy makers, as well as insurance companies. With all of these efforts, the growing importance of the Internet within the health care setting should be taken into account.

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