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PROMOTING PHYSICAL ACTIVITY IN RHEUMATOID ARTHRITIS

ASPECTS OF COACHING IN PHYSICAL THERAPY

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The important thing is not to stop questioning.

Curiosity has its own reason for existing.

*One cannot help but be in awe when he contemplates the mysteries
of eternity, of life, of the marvellous structure of reality.*

It is enough if one tries merely to comprehend a little of this mystery everyday.

Never lose a holy curiosity.

Albert Einstein

To Viola

ABSTRACT

Background and Aim: Rheumatoid arthritis (RA) is a chronic, autoimmune, inflammatory, systemic disease mainly affecting the joints, often leading to impairments as well as activity limitations and participation restrictions in daily life. Physical activity including exercise is recommended in clinical practice guidelines for patients with RA, and physical therapists (PTs) have an important role in its promotion. However, more knowledge is needed on strategies to promote physical activity. The overall aim of the present work was to explore aspects of coaching in physical therapy that might be of importance for the adoption and maintenance of physical activity behavior.

Patients and Methods: In *Study I*, 18 patients with RA, 14 women and 4 men, aged 34-83 years, median age 60 years, were strategically chosen to participate in semi-structured interviews. In *Studies II and III*, 228 patients with early RA were recruited, 94 (68 women, 26 men, median age 54 years) to an intervention group (IG) and 134 (101 women, 33 men, median age 57 years) to a control group (CG), to a multicentre, randomized controlled intervention. The intervention aimed at promoting the adoption of healthy physical activity and was compared to ordinary treatment. Demographics, assessments of disease activity, body function, activity limitation, personal factors, physical activity and perceived health were collected. In *Study IV*, 25 physical therapists, 24 women and 1 man, aged 28-66 years, median age 44 years, were strategically chosen to participate in semi-structured interviews.

Results: In *Study I*, five qualitatively different ways of understanding exercise maintenance were identified: 'external control', 'sticks and carrots', 'a joint venture', 'the easy way', and 'on one's own terms'. The differences in ways of understanding became clear by distinguishing two aspects related to exercise maintenance, i.e. the type of support needed and personal factors. *Study II* identified and described eight clusters depending on the number of variables affected by the disease. Individuals more affected by their disease improved perceived health following the physical activity intervention compared to those less affected. In *Study III*, the result indicated that the intervention had no significant influence on long-term outcome. However, different patterns in physical activity behavior were observed in the two groups. In *Study IV*, four ways of understanding the promotion of exercise were identified: 'tell and inform', 'to identify and pilot', 'to discuss and enable' and 'to listen and inspire'. The ways of understanding were different regarding four key aspects; knowledge and responsibility in exercise, setting and supervision, tools to support behavior change and the role of the PT.

Conclusions: The coaching intervention in the present work may be most useful for patients more severely affected by their disease. However, no long-term effects of the intervention were found, and this may partly be because the intervention lacked some important behavioral elements for physical activity maintenance, but also due to how the study protocol was implemented. Important aspects of physical activity coaching for patients with RA might be the interaction between the PT and the patient, based on the patients' motivational type in addition to the PT's as well as the patient's regulation of learning. Finding congruence in this interaction could be a way to enhance learning of physical activity behavior by developing patients' self-regulations.

SAMMANFATTNING

Bakgrund och syfte: Reumatoid artrit (RA) är en kronisk, autoimmun, inflammatorisk, systemisk sjukdom som främst drabbar lederna, vilket ofta leder till funktionsnedsättningar, aktivitetsbegränsningar samt delaktighetsinskränkningar i dagliga livet. Fysisk aktivitet inklusive träning rekommenderas i kliniska riktlinjer för patienter med RA, och sjukgymnaster har en viktig roll i dess främjande. Mer kunskap behövs om vilka strategier som fungerar för att främja fysisk aktivitet. Det övergripande syftet med detta avhandlingsarbete var att undersöka aspekter av coaching inom sjukgymnastik som kan ha betydelse för initiering och vidmakthållande av fysiskt aktivitetsbeteende.

Patienter och metoder: I *Studie I* valdes 18 patienter med RA, 14 kvinnor och 4 män i åldrarna 34-83 år, medianålder 60 år, strategiskt till att delta i semi-strukturerade intervjuer. I *Studie II och III*, rekryterades 228 patienter med tidig RA, 94 (68 kvinnor, 26 män, median 54 år) till en interventionsgrupp (IG) och 134 (101 kvinnor, 33 män, median 57 år) till en kontrollgrupp (CG), för en randomiserad, multicenterstudie. Interventionen syftade till att implementera hälsofrämjande fysisk aktivitet och jämfördes med sedvanlig behandling. Demografiska data, mått på sjukdomsaktivitet, funktionsnedsättningar, aktivitetsbegränsningar, personliga faktorer, fysisk aktivitet och upplevd hälsa insamlades. I *Studie IV*, valdes 25 sjukgymnaster, 24 kvinnor och 1 man, i åldern 28-66 år, medianålder 44 år, strategiskt till att delta i semi-strukturerade intervjuer.

Resultat: I *Studie I* identifierades fem kvalitativt olika uppfattningar av vidmakthållandet av träning: "extern kontroll", "piska och morot", "en gemensam satsning", "den enkla vägen" och "på egna villkor". Skillnaderna mellan uppfattningarna framkom genom att urskilja två aspekter i relation till vidmakthållande av träning, d.v.s. den typ av stöd som behövdes samt personliga faktorer. *Studie II* identifierade och beskrev åtta olika kluster beroende på antalet variabler som påverkats av sjukdomen. Individer som var mer påverkade av sin sjukdom upplevde förbättrad hälsa efter interventionen med fysisk aktivitet jämfört med de som var mindre påverkade. I *Studie III* visade resultatet att interventionen inte hade någon betydande långsiktig inverkan. Emellertid observerades olika beteendemönster av fysisk aktivitet i de två grupperna. I *Studie IV* identifierades fyra sätt att uppfatta främjandet av träning: "berätta och informera", "identifiera och leda", "diskutera och möjliggöra" och "lyssna och inspirera". Uppfattningarna skiljde sig åt gällande fyra viktiga aspekter, kunskap och ansvar gällande träning, sammanhang och övervakning, verktyg för att stödja beteendeförändringar samt sjukgymnastens roll.

Slutsatser: Coachinginterventionen i detta arbete skulle kunna vara mest användbar för patienter som är mer påverkade av sin sjukdom än de som är mindre påverkade. Inga långsiktiga effekter av interventionen kunde dock ses, och detta kan delvis bero på att interventionen saknade några viktiga beteendeelement för att främja vidmakthållandet av fysisk aktivitet, men också på grund av hur studieprotokollet implementerades. Viktiga aspekter för coaching av fysisk aktivitet för patienter med RA kan vara samspelet mellan sjukgymnasten och patienten, beroende på patienternas motivation, och även av sjukgymnastens och patientens reglering av lärande. Att finna en gemensam syn i detta samspel kan vara ett sätt att förbättra inlärningen av fysisk aktivitetsbeteende genom att utveckla patientens självreglering.

LIST OF PUBLICATIONS

The thesis is based on the following original papers. Each paper will be referred to by its Roman numeral (Study I-IV)

- I. **Swärdh E**, Biguet G, Opava CH. Views on Exercise Maintenance-Variations among Patients with Rheumatoid arthritis. *Physical Therapy* 2008;88(9):1049-60
- II. **Sjöquist ES**, Almqvist L, Åsenlöf P, Lampa J, Opava CH, and the PARA study group. Physical-activity coaching and health status in rheumatoid arthritis: a person-oriented approach. *Disability & Rehabilitation* 2010;32(10):816-25
- III. **Sjöquist ES**, Brodin N, Lampa J, Jensen I, Opava CH, and the PARA study group. Physical activity coaching of patients with rheumatoid arthritis in everyday practice: a long-term follow-up. *Musculoskeletal Care* 2011;9(2):75-85
- IV. **Swärdh E**, Opava CH, Nygård L, Lindquist I. Promoting exercise in rheumatic diseases: Physical therapists' understanding. Manuscript

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Study IV. This may not be the final version before publication.

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LIST OF ABBREVIATIONS

CG	Control group
CRP	C-reactive protein
DAS 28	Disease Activity Score 28 joint count
DMARD	Disease modifying anti-rheumatic drug
EULAR	European League Against Rheumatism
EQ-5D VAS	The EuroQol visual analog scale
HAQ	The Health Assessment Questionnaire Disability Index
Hc	Homogeneity coefficient
IG	Intervention group
ITT	Intention to treat
Lvcf	Last value carried forward
M	Mean
md	Median
n	Numbers
NSAID	Non steroid anti inflammatory drug
PA	Physical activity
Pm	Pairwise matching
PT	Physical therapist
RA	Rheumatoid arthritis
S	Seconds
Sc	Study complete
SD	Standard deviation
SDT	Self-determination theory
TNF	Tumor necrosis factor
TST	Timed stands test
VAS	Visual analog scale
RA-reg	RA-register

PREFACE

To me, movement through physical activity has always been a source of joy, vitality, self-awareness and an overall healthy lifestyle, whether through dance education since childhood, working as a professional dancer or in physical therapy.

The starting point for writing this thesis was the curiosity about *why* my patients did not always follow my advice on physical activity, even though they were aware of the benefits. I decided, with only 4 years of clinical experience, to follow a more theoretical path to understand *how* to influence physical activity behavior and promote a healthier lifestyle. In my search for answers and a deeper understanding, the path led through the world of both quantitative and qualitative approaches, which has enriched me with many new insights and deepened the knowledge. Also, while working with physical activity within in the Swedish Rheumatism Association, outside the research area, I learned more about health promotion from a community perspective, which gave me inspiration for the last phases of writing my thesis.

This journey has triggered so many new questions, and they are no longer just *why* and *how*, but much more complex. I have learned a lot, developed and grown as a physical therapist but perhaps most importantly, gained a more humble attitude towards all those struggling with behavior change in one way or another. It is my sincere hope that my thesis will be an inspiration to them and to physical therapists working to improve the lives of people with rheumatic diseases through physical activity.

1 INTRODUCTION

1.1 PHILOSOPHY OF SCIENCE

Promoting physical activity is a complex phenomenon that requires a pluralistic worldview. However, different health and science paradigms direct our way of looking upon the world and the nature of knowledge¹. A scientific paradigm was defined by Kuhn as an “accepted example of actual scientific practice that some particular community acknowledges for a time as supplying the foundation for its further practice”².

This thesis embraces different paradigms, both the positivistic and hermeneutic, in order to grasp a wider understanding of physical activity promotion in patients with rheumatoid arthritis (RA). Two general approaches, hypothetico-deductive and inductive reasoning can both result in the acquisition of new knowledge³.

Positivism, as a research paradigm⁴, relies on hypothetico-deductive reasoning where search for generalizations and the discovery of causal relationships is in focus, as well as a priori hypothesis that either will be supported or rejected through inferential statistical analysis. This type of research with quantitative research methods can only partly address all questions about the best decisions in care, but has traditionally been taken precedence over research with a more *hermeneutic* approach⁵ with inductive reasoning. Understanding intentions, values, attitudes and beliefs behind certain behaviours, as well as allowing people to speak with their own voices, are the core elements within the hermeneutic paradigm. Using an inductive reasoning process, where interpretation and structuring meanings that can be derived from data, is more important than predicting the future or controlling the outcomes in research applying qualitative research methods. Qualitative and quantitative research methods differ substantively from one another, but should be seen as complementary rather than conflicting⁶⁻⁸.

1.2 PERSPECTIVE AND FRAMEWORK

Physical activity promotion is based on the *bio-psychosocial approach*⁹, determining the course of health and illness, and involves the complexity of interactions between biological, physiological, behavioural, social and environmental factors. Disease prevention has been in focus for health professionals for several decades, but is often associated with the biomedical model¹⁰, which focuses on top-down strategies provided by experts^{11,12}. However, disease prevention has changed from focusing on reducing elements over which the individual has little control, to emphasizing modifiable behaviors such as avoiding a sedentary lifestyle¹³. When promoting physical activity, the aim is primarily concerned with promoting something positive such as good health¹⁴, thus health professionals need to adopt the bio-psychosocial model as an essential component of care.

In most theories of *physical therapy*, movement is the central concept¹⁵⁻¹⁷, and this was early understood from a biomedical perspective, but is now also underpinned by the bio-psychosocial approach^{18,19}. Movement in physical therapy has been described as a hierarchy of movement including prerequisites, capacity and behavior, involving systems, person and society²⁰. Physical therapists (PT) thus provide services to individuals in order to promote good health by preventing impairment, activity limitations and participation restrictions in daily life²¹. Movement, in this thesis, is primarily understood as a behavior where not only the biological processes are integrated, but also internal and external aspects e.g. feelings, values, expectations, the physical environment and social context²². Even though the professional role has slightly changed over the years, PTs have had a leading role in promoting health through education and therapeutic exercise for over 100 years^{23,24}. From being primarily an occupation of examination and intervention, the role now also includes informing the patients, as well as increasing their knowledge about health issues through more health-focused strategies²⁵. In the 21st century, PTs serve as coaches and need to base patient education on each patient's needs, so that the intervention content is individually tailored^{23,25}. A *behavioral medicine* perspective, defined as “the interdisciplinary field concerned with the development and integration of psychosocial, behavioral and biomedical knowledge relevant to health and illness and the application of this knowledge to prevention, etiology, diagnosis, treatment and rehabilitation”²⁶, thus provides a basis for studying physical activity promotion and its inherent learning processes.

2 BACKGROUND

2.1 RHEUMATOID ARTHRITIS

Rheumatoid arthritis (RA) is a chronic, autoimmune, inflammatory, systemic disease mainly affecting the joints. The exact etiology is unknown, but the processes leading to the disease include autoimmune reactions based on a combination of genetic susceptibility and environmental factors²⁷. The estimated prevalence for RA in Europe and in the US is 0.5-1 % of the general population²⁸ and in Sweden 0.5-0.7 %²⁹. There is predominance for women, the gender ratio is 3:1^{28,30} and the peak age of disease onset is between 55 and 60 years³¹. The classification criteria for RA from 1987³² was used in this thesis and is presented in Table 1. In order to optimize early diagnosis, new classification criteria were established in 2010³³.

Table 1. The 1987 classification criteria for RA
<i>4/7 variables need to be fulfilled for classification as RA</i> <i>Criteria 1 through 4 must have been present for at least 6 weeks</i>
Morning stiffness
Arthritis in at least three joints
Arthritis in hand joints
Symmetric arthritis
Rheumatoid nodules
Serum rheumatic factor
Radiographic changes

2.1.1 Consequences of the disease

RA results in chronic inflammation of peripheral joints, which if untreated often lead to joint destruction and various forms of disability^{34,35}. The disease often exhibits a fluctuating course, with periods of increased disease activity as well as calmer remission periods, but in the long run often with a slow deterioration^{36,37}. Clinical symptoms include swollen and tender joints predominantly in hands and fingers^{38,39}, but almost all other peripheral joints (arms, shoulders, hips, knees, feet and mandibular joints) may be involved causing complex forms of disabling pain. Moreover, a majority of patients with RA have severe fatigue which is thought to relate mainly to pain, but also to cerebral inflammation^{40,41}. Many patients with RA have considerable physical limitations⁴²⁻⁴⁴. Studies have shown that people with RA

have 25-50 % less muscle strength than comparable healthy subjects^{45,46}, and in severe RA it can be reduced with as much as 70 %⁴⁷. Untreated as well as treated RA can cause a lot of these impairments as well as activity limitations and participation restrictions in daily life^{48,49}. An increased mortality of cardiovascular disease in RA has been shown by numerous investigations⁵⁰⁻⁵². Moreover, physically inactive patients with RA have an increased risk of cardiovascular disease compared to more active patients^{53,54}. Consequently, RA places a great disease burden on patients' health-related quality of life, both in the physical and emotional aspects of functioning and well-being⁵⁵⁻⁵⁷

2.1.2 Pharmacological treatment

Disease-modifying anti-rheumatic drugs (DMARDs), TNF- α blockers and other biological agents are often used early on in the treatment, to strive for remission or low disease activity^{58,59}. The drugs relieve pain and stiffness, reduce disease activity and stop or delay the development of structural joint damage⁶⁰⁻⁶². Despite these advanced treatment options, drugs do not have the capacity to induce remissions for all patients with RA, and the mortality associated with the disease remains increased in recent investigations, although new and advanced drugs have been introduced the last decades⁶³. Moreover, it has been reported in population studies that between 40-60 % of the anti-TNF treated patients report persistent pain⁶⁴, indicating that additional treatment strategies may be needed for pain reduction in RA. In addition, long term medication with pain-relieving agents, such as non-steroidal anti-inflammatory drugs (NSAIDs), which is very common in RA, is associated with increased risks for side effects like gastrointestinal ulcer and hypertension⁶⁵. Although treatments have improved, aggressive inflammation in RA may lead to significant impairments and disability in some patients already a few years after disease onset⁶⁶. Thus, as a consequence, there is a continuous need for non-pharmacological treatment that may be life-long.

2.1.3 Non-pharmacological treatment

In order to optimize RA treatment, besides pharmacological interventions, there is a need for guidance of physical activity, support and patient education to cope with the disease⁶⁷. These non-pharmacological treatment strategies for e.g. pain control, fatigue reduction and improvement of body functions, activities and participation in daily life, are often provided by multidisciplinary rheumatology teams consisting of

different health care professionals including nurses, PTs, occupational therapists, orthopedic surgeons, dieticians, social workers and psychologists⁶⁸. One important goal of non-pharmacological treatment is to encourage patients to take the leading role in managing their disease through different self-management strategies, such as physical activity⁶⁹.

2.1.4 Physical therapy within rheumatology

PTs have a significant role in the care of patients with rheumatic diseases^{55,70} even though the nature of their function and practice might differ with the health care systems in different countries. Bed rest, assisted range of motion and hands-on treatment were advocated for patients with rheumatoid arthritis until the mid-1970s, making the role of the PT quite different from the present⁷¹. Today, there are few indications for rest therapy, and prolonged complete bed rest is generally avoided in favor of activity^{67,72-74}.

Current practice

Physical therapy treatment often includes interventions aiming at increasing physical activity⁷⁴. Manual therapy, different physical modalities, assistive devices and orthoses can be used as a complement in order to make physical activity possible⁷⁵. Joint protection and self-management interventions can also be part of the treatment⁷⁶. The strongest evidence lies in physical activity and self-management interventions^{71,72,77}, and these are now important parts of physical therapy within rheumatology. Physical activity is recommended in both non-pharmacological clinical practice guidelines⁷⁸, British Health Professionals in Rheumatology guidelines⁷⁹ as well as in the EULAR recommendations for the management of early arthritis⁷⁷. The costs of treatment of rheumatic diseases, such as RA, are increasing, and by developing successful health promotion interventions including physical activity and creating new roles for PTs, the limited resources could be used more effectively in the future.

2.2 PHYSICAL ACTIVITY

2.2.1 Definitions

The promotion of physical activity is the key construct in this thesis. In general, *physical activity* is defined as “any bodily movement produced by skeletal muscles that result in energy expenditure”⁸⁰. This term means that almost everything a person does is included in the concept physical activity. *Exercise*, includes a subset of physical activity defined as “planned, structured and repetitive bodily movement done to improve or maintain one or more components of physical fitness” and can be performed at a variety of intensities⁸⁰. Exercise can be divided into aerobic exercise (cardio respiratory endurance), resistant exercise (muscular strength and endurance), flexibility or neuromotor exercise (balance, agility, coordination). *Physical fitness* comprises “sets of attributes that people have or achieve that relate to the ability to perform physical activity”⁸⁰.

2.2.2 Recommendations

Recommendations most frequently referred to in both research and clinical practice have previously been either the guidelines for maintaining or improving *fitness* or the guidelines for maintaining or improving *general health*. The one for *fitness* advise adults to do aerobic exercise 3-5 times per week along with strength and flexibility exercise, whereas the one for *general health* advise adults to do 30 minutes of at least moderate-intensity physical activity on most, preferably all, days of the week. The 30 minutes can be accumulated in several bouts of at least 10 minutes duration⁸¹. The guidelines for *general health* were used in this thesis, however the recommendation was updated in 2007 by the American College of Sports Medicine and the American Heart Association⁸², to include both *general health and fitness*. It still emphasizes 30 minutes of moderate intensity physical activity on at least five days per week (compared to most days of the week), but also comprise an alternative of three occasions of 20 minutes of vigorous intensity per week. On top of this, strength-training exercises should be performed twice a week. Further, the new recommendation separates healthy adults versus older adults and adults with chronic conditions. Even though recommendations change and are updated with regular intervals, the promotion of physical activity probably faces the same challenge in relation to psychological factors, socio-demographics, as well as behavioral attributes and skills.

2.2.3 Physical activity in RA

Physical inactivity remains common among individuals with arthritis, despite the broad spectrum of health benefits from such activity. Studies describing physical activity levels among people with RA are not always comparable due to different classifications of physically active and inactive participants, which exclude a definitive conclusion on the physical activity levels in RA ⁸³. Almost 50 % of individuals with newly diagnosed RA in Sweden do not meet the recommended levels of 30 minutes of physical activity on moderate-intensity most days of the week, and women over 65 years of age are particularly inactive ⁴². A recent Swedish study reported that 69 % reached this recommendation ⁸⁴, however, only 11 % reported maintenance (>6 months) of 30 minutes of physical activity on moderate-intensity at least five times per week in combination with resistance training at least twice per week ⁸⁴. In the US, more than 60 % of adults with self-reported arthritis do not meet the physical activity recommendation of 30 minutes of moderate-intensity physical activity on five or more days of the week or at least 20 minutes of vigorous-intensity physical activity on three or more days per week ⁸⁵, and they are also less likely to engage in these recommended levels of moderate-, or vigorous-intensity physical activity than adults without arthritis ⁸⁶. However, in the Netherlands, the proportion of patients with RA (58 %) meeting the physical activity recommendations of 30 minutes of moderate-intensity on five or more days of the week, was similar to that of the general population. Noticeably, with respect to the average number of minutes of physical activity per week, the patients with RA (45-64 years) were less physically active on light, and moderate intensity than the general population ⁸⁷. Also, in the Netherlands, 80 % of patients with RA participate in some type of leisure-time physical activity or exercise and favour physical activity under supervision ⁸⁸. In a study including 21 countries in Europe, as well as US, Canada and Argentina, a low proportion of patients with RA perform exercise. Only 13.8 % report physical exercise ≥ 3 times weekly and the majority of patients in these countries were physically inactive, performing no regular exercise ⁸⁹.

2.2.4 Correlates of physical activity in adults and adults with arthritis

Several reviews of correlates of physical activity in the adult population exist, but less fewer in the arthritis population. Some of the correlates of physical activity in arthritis⁹⁰⁻⁹⁶ are similar to those in the adult population⁹⁷⁻¹⁰⁰, although some are unique (Table 2). The summary of correlates in Table 2, is based on results from research with both quantitative and qualitative approaches, and may not all be considered as causal factors. The modifiable correlates are those that might be able to influence and change through health care interventions.

Table 2. Overview of previously studied modifiable and non-modifiable correlates of physical activity in adults and adults with arthritis				
Correlate	Modifiable		Non-modifiable	
	Adults	Adults with arthritis	Adults	Adults with arthritis
Demographic and biological		-BMI	-Education -Gender -Genetic -Ethnic origin	-Education
Psychological	-Self-efficacy -Perceived health -Enjoyment -Expected benefits -Intentions -Self-motivation -Stages of change	-Self-efficacy -Mental well-being -Outcome expectations -Perceived benefits -Perceived barriers		
Behavioral attributes and skills	-Processes of change		-Past exercise history	-Prior physical activity
Social	-Social support -Physicians influence	-Social support -Advice from a health care professional		
Environmental			-Availability of physical activity equipment -Transportation -Neighborhood design -Recreation facilities	-Community barriers -Availability of community resources
Other		-Arthritis symptoms -Co-morbidity -Disability -Arthritis education course		

2.2.5 Outcome of physical activity in RA

Numerous beneficial effects from physical activity including exercise have been reported in individuals with RA ¹⁰¹⁻¹⁰⁴. Most studies that have investigated the short-term effects of aerobic and strengthening exercise have been performed in clinical environments with support from PTs. Those participating in appropriate land-based or aquatic exercise programs can experience improvements in their physical and psychosocial status without exacerbating their disease ^{105,106}. Women who have been exercising since disease onset can maintain the same strength and aerobic capacity as matched healthy controls ⁴⁶. Only a few randomized controlled trials of exercise interventions have included follow-ups of at least one year ¹⁰⁷⁻¹⁰⁹. Thus, patients with early RA, performing a home-based exercise program with minimal supervision from a PT during two years can not only increase physical fitness, joint flexibility and muscle strength, and decrease pain in short-term, they also sustain the improvements in muscle strength three years after ending the program if they continue to exercise ^{108,110,111}. Also, high-intensity exercise during two years can increase aerobic fitness, functional ability and lower disease activity, and further sustain muscle strength gains without increasing disease activity or progression of radiological damage, for those continuing with exercise in the following 18 months ^{109,112}. A relatively new approach to promote physical activity including exercise is to use the internet. Both an internet-based individualized exercise intervention and an internet-based general exercise intervention during one year, can reduce activity limitations and improve quality of life ¹¹³, but these improvements are not sustained at a two-year follow-up ¹⁰⁷. While the effects of exercise in a clinical setting are rather well documented, studies regarding the effects of physical activity in daily life are still scarce, but advocated ¹¹⁴. A one-year coaching intervention aimed at implementing healthy levels of physical activity, with face-to face meetings and telephone contacts, can improve general health perception, lower extremity function and grip force ¹¹⁵.

With all the positive short-term effects of different physical activity interventions including exercise, the challenge of maintaining these effects still needs further research due to the inconclusive results. Diminishing resources within health care, including those for physical therapy, require innovative solutions to satisfy the need for physical activity among patients. Performing randomized controlled trials with good external validity, e.g. interventions in daily clinical practice could be a step in the right direction. Most studies reporting results from physical activity interventions are based

only on the results on group levels, and these trials do not allow conclusions about which participants that actually benefit the most from the intervention. Insight into the specific characteristics of those succeeding and to whom the intervention should be provided is consequently needed.

2.2.6 Change of physical activity

Regardless of delivery mode, physical activity interventions in individuals with arthritis seem to result in only moderately positive effects on the actual amount of physical activity according to a meta analysis ¹¹⁶. In one of the above interventions, the proportions of patients accumulating the recommended amount of physical activity did not differ between the coached intervention group and the control group receiving regular treatment ¹¹⁵. In the above mentioned internet-based study, a larger proportion of the patients receiving the individualized exercise intervention reached the recommended amount than those receiving the general exercise intervention. However, this difference between the groups was not sustained at follow up ¹⁰⁷.

2.2.7 Patient perspectives on physical activity in arthritis

Very few studies with a qualitative approach have focused on physical activity in rheumatic diseases from the patients' perspectives. Those performed have focused on attitudes to physical activity in RA ¹¹⁷, factors perceived to influence exercise ⁹³ and exercise participation ⁹¹ in arthritis, and perceptions related to physical activity in everyday life in RA ¹¹⁸, to the effects of exercise on joint health ¹¹⁹, to exercise as treatment in osteoarthritis ¹²⁰, and to the intensity of physical activity in RA ¹²¹.

These are all important issues, but since physical activity often is cyclical, research in specific phases is needed. The long term goal of physical activity interventions should be maintenance, in order to increase and sustain health and physical fitness in rheumatic disease. None of the studies above have focused on perception on physical activity maintenance per se, and highlighting this topic from a patient perspective could further guide the promotion of physical activity in physical therapy.

2.3 PROMOTING PHYSICAL ACTIVITY

2.3.1 Health promotion

Health promotion, a concept identified already in the 1970s, became highlighted in the latter part of the 20th century¹³ and is associated with a holistic view on the individual, where participatory and bottom-up strategies are used¹¹. Health promotion is defined as “the process of enabling people to increase control over, and improve their health”¹²². The core values in health promotion are: equity, participation and empowerment¹⁴, which fit well into the concept of self-management in RA care¹²³. A patient with a chronic disease such as RA has to make daily choices on whether to achieve health goals, such as increasing physical activity. In this way, the patient becomes responsible for managing the disease^{124,125}. One important part of health promotion is to explicitly provide information, health education, and enhancing life skills such as physical activity behavior¹²².

2.3.2 Physical activity as a behavior

Adoption and maintenance of physical activity include behavioral learning. Two essential and empirically supported theories are often used to describe and explain this process; respondent and operant learning²². Respondent learning¹²⁶ can be described as learning by association. This means that behavioral learning occurs as a result of conditioning, i.e a *neutral stimulus* (high intensity exercises in a gym) is conditioned to an *unconditioned stimulus* (pain due to overload) and an *unconditioned biological response* (fear and discomfort) via its simultaneous occurrence with the unconditioned stimulus. This mechanism can explain why an individual avoids physical activity. The next time the person enters the gym, he or she is struck by fear and discomfort and may attribute this to the gym and the exercise equipment, and not to the unfortunate mistake of overload leading to pain. Operant learning¹²⁷ refers to learning by consequences. A positive consequence of a behavior increases the likelihood that the behavior will be repeated, and vice versa; a negative consequence decreases the likelihood of re-occurrence. For example, an individual who participates in water exercise and experiences a good night's sleep as an immediate consequence will probably attend the next class due to a positive reinforcement of behavior.

2.3.3 Adoption and maintenance of physical activity behavior

In chronic diseases such as RA, the individuals often have to make permanent changes in lifestyles and create new patterns of behavior, and the goal in physical therapy is often to make the individuals as independent as possible regarding physical activity. In the literature about physical activity interventions different concepts and terms, such as adoption and maintenance, are often used when describing the results and for understanding the behavior^{128,129}. The *adoption period* is the initiation of physical activity that often accompanies an intervention or that can occur naturally in an individual. Sustained participation in physical activity that occurs over extended periods of time is referred to as *maintenance*, often defined as regular performance for more than six months. It has been suggested that maintenance should be treated as a fixed or static state where change in physical activity behavior is considered as a process with maintenance as the last step. However, since factors that enable people to adopt physical activity behavior are not necessarily those that make them to sustain that behavior over time, it might be vital to describe maintenance as a journey itself, with separate core processes¹²⁸⁻¹³⁰.

2.3.4 Health behaviour theories

A health behavior, such as physical activity has been defines as “those personal attributes such as beliefs, expectations, motives, values, perceptions, and other cognitive elements; personality characteristics, including affective and emotional states and traits; and overt behavior patterns, actions and habits that relate to health maintenance, to health restoration, and to health improvement”¹³¹. Health behavior is complex, and theories have been developed to understand it, to explain its determinants and further to guide health promotion such as increasing physical activity^{132,133}. Most health behavior theories focus on multiple determinants of behavior on the individual, interpersonal, group, organizational, and/or community levels¹³⁴, and during the past 20 years there have been massive gains in the science and practice of health behavior change^{135,136}. However, no single theory dominates the research or practice related to behavioral change and health promotion, nor does the literature provide a single answer to which theories that most precisely predict behavior¹³⁷⁻¹⁴⁰.

2.3.5 Effective physical activity interventions

Health behavior theories are important to incorporate in both physical activity promotion research and rehabilitation ¹⁴¹. Theoretically informed programs are more effective in changing health behavior than those not theoretically informed ^{138,140,142,143}. In a review of behavior change theories to promote physical activity in healthy adults, Keller et al ¹⁴⁴ found that despite differing theoretical perspectives, the studies reviewed incorporated similar intervention approaches. The most useful approach might therefore be to combine concepts from more than one theory. There is also strong evidence that individually adapted health behavior change interventions are effective in increasing levels of physical activity. These interventions support participants behavioral skills, i.e. setting goals for physical activity, self-monitoring, building social support, behavioral reinforcement, structured problem-solving and relapse prevention ¹⁴⁵. Further, a review of maintenance of physical activity and dietary behaviors in people with and without disease concluded that interventions lasting more than 24 weeks, using more than six behavioral technique including follow-up prompts and face-to face contacts, are more likely to be successful ¹⁴⁶. A meta-regression identified self-monitoring as the most important behavioral technique to include in interventions designed to promote physical activity ¹⁴⁷. However, identifying *how* concepts may effectively work in an intervention is important. A descriptive taxonomy of behavior change techniques for physical activity and healthy eating behavior have therefore been developed by Abraham and Michie ¹⁴⁸. This 40-item taxonomy helps specifying active ingredients in an intervention for reporting, evaluating and implementing evidence.

2.3.6 Coaching physical activity

The term coach originated in the sixteenth century and described something that “carried people from where they were to where they wanted to go” ¹⁴⁹. At present, health care includes strategies to guide the patients to make the right decisions and support them to start new behaviors through “coaching”. The term “health coaching” is widely used by health professionals, but it does not guarantee the quality of health advice given, and it may contain totally different interventions ¹⁵⁰⁻¹⁵². Health coaching is yet about “giving people the information they need to make informed decisions about how to lead healthy lives” ¹⁵¹. In the present thesis, the concept of coaching is used when explaining the physical therapist’s role in promoting physical activity.

Coaching physical activity requires good counselling skills from the health professional and an understanding that it is a complex behaviour¹⁵³. There is, however, inconclusive evidence to support short-term improvement in physical activity from counselling by clinicians. This may relate to the methodological limitations in identifying the specific features of the intervention¹⁵⁴. Behavior change and physical activity promotion should also be seen as processes, where behaviors are gradually moved in steps towards becoming healthier¹⁵⁵. The process can take months to years and works differently from individual to individual. In the light of the increasing use of physical activity coaching in everyday practice among physical therapists, and the insufficient research, both randomized controlled trials and studies exploring coaching in depth are needed. Gaining a deeper insight might help to further develop evidence based clinical practice in physical therapy.

2.4 RATIONALE FOR THIS THESIS

The evidence thus clearly indicates that physical activity including exercise can improve physical and psychological status as well as reduce pain in patients with RA, but despite this the overall physical activity levels in people with RA remain low worldwide. In guidelines and recommendations for the physical therapy management of patients with RA, physical activity and self-management programs are the most frequently recommended. Nevertheless, pragmatic studies of physical activity coaching in daily clinical practice are sparse. Further, no interventions to promote physical activity can be beneficial for all participants, and therefore person-based studies might be useful supplements to traditional randomized controlled studies. Also, previous studies on physical activity in RA mainly focused on adoption and short-term results. Only a few exploring maintenance exist, both with respect to long-term follow ups and as a concept. Therefore, the knowledge on exercise maintenance has to be expanded, especially with regard to the patients' perspectives. PTs often act as coaches and different promotion strategies are probably used in their daily practice. Most PTs agree that physical activity is an important health behavior to promote in RA, but complex notions of what works in the coaching as well as how it works, may exist. Thus, PTs' understanding of clinical practice needs further exploration.

3 AIM

This thesis concerns the promotion of physical activity in patients with RA. The general aim, extending beyond that of the four included studies was to explore aspects of coaching in physical therapy that might be of importance for the adoption and maintenance of physical activity behavior.

Specific aims of the studies included in this thesis were:

Study I

To explore and describe ways of understanding exercise maintenance among individuals with RA who have already started to exercise.

Study II

To investigate whether a selection of correlates of health perception can create cluster typologies in individuals with RA and to evaluate whether the magnitude of change in health status differs between clusters after a one-year coaching intervention targeting adoption of health-enhancing physical activity.

Study III

To investigate the long-term effects of a one-year coaching intervention carried out in everyday practice to promote the adoption of health-enhancing physical activity in patients with early RA.

Study IV

To explore and describe ways of understanding promotion of exercise among physical therapists working with patients having rheumatic diseases.

4 METHODS

4.1 STUDY DESIGNS

Four studies are included in this thesis. Two of them (Study I and IV) have a qualitative approach and the other two (Studies II and III) a quantitative approach. An overview of the studies is presented in Figure 1.

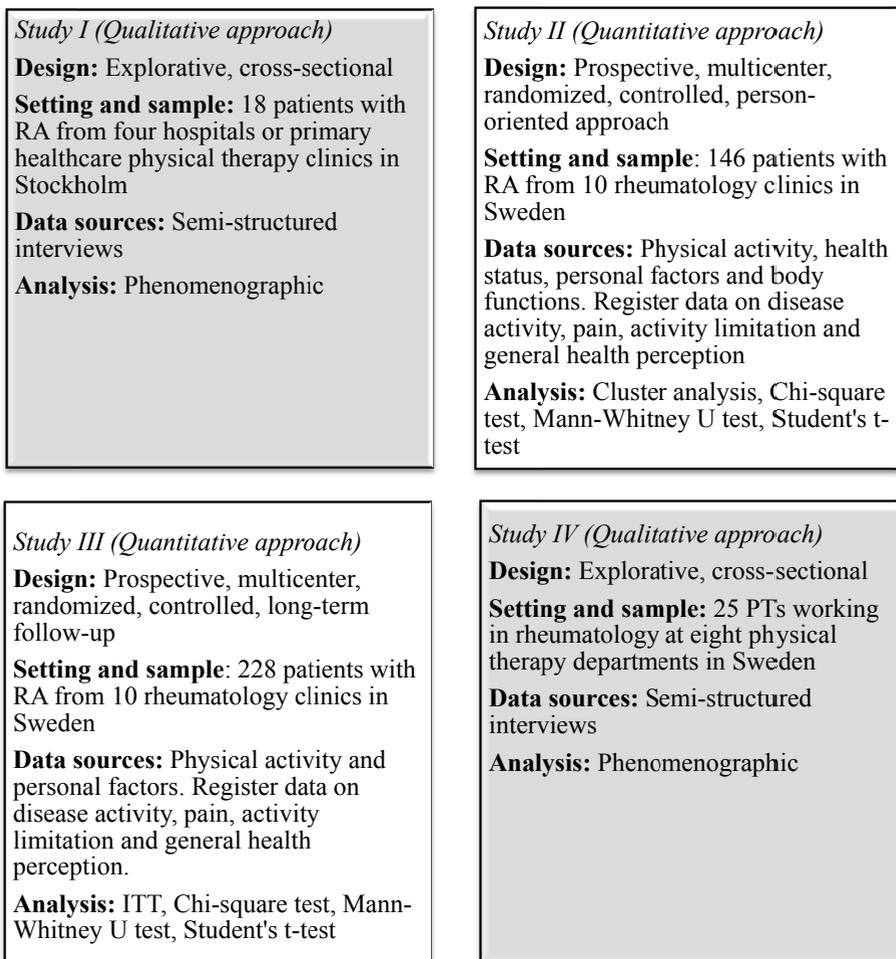


Figure 1. Overview of the studies

4.2 PARTICIPANTS

Three out of four studies (I-III) include patient samples (I-III), and one study (IV) includes a PT sample. Neither the patients in Study I nor the PTs in Study IV participated in Studies II and III.

4.2.1 Study I

A total of 18 participants with RA were interviewed during 2005. They were purposefully chosen to represent variation in socio-demographic, disease-related and exercise-related characteristics (Table 3). The sample was thus chosen for heterogeneity rather than for representativity in terms of distribution along demographic lines. Criteria for inclusion in the study were: confirmed diagnosis of RA since at least two years, performance of planned regular exercise for two months in the past year with support from a PT, and attempts to perform exercise without support from a PT and outside the healthcare system. Further, they should have no obvious difficulties with the Swedish language.

Gender, female/male, n	14/4
Age, years, md (range)	60 (34-83)
Disease duration, years, md (range)	15 (3-53)
Married/partner, n	11
Children, n	16
Occupational status, n	
Full-time work	5
Old age pension or disability pension	5
Full-time sick listed	2
Part-time sick listed	2
Part-time disability pension	4
HAQ, 0-3, md (range)	0.82 (0-1.63)
Exercise before disease onset *, n per week	
0 times	4
1-2 times	5
3-4 times	6
5 or more	3
Exercise past month *, n per week	
0 times	0
1-2 times	5
3-4 times	8
5 or more	5

* At least 30 min at the time

4.2.2 Study IV

A total of 25 PTs were interviewed during 2009 and 2010. In the search for variation in ways of understanding the phenomenon, the participants were strategically chosen for maximum variation in socio-demographic, work-related and exercise-related characteristics (Table 4). The participants had gone through their physical therapy education at different universities in Sweden, Hungary or Finland, with examination between the years 1965 to 2008. Criteria for inclusion in the study were: PT working primarily within the field of rheumatology with no obvious difficulties with the Swedish language.

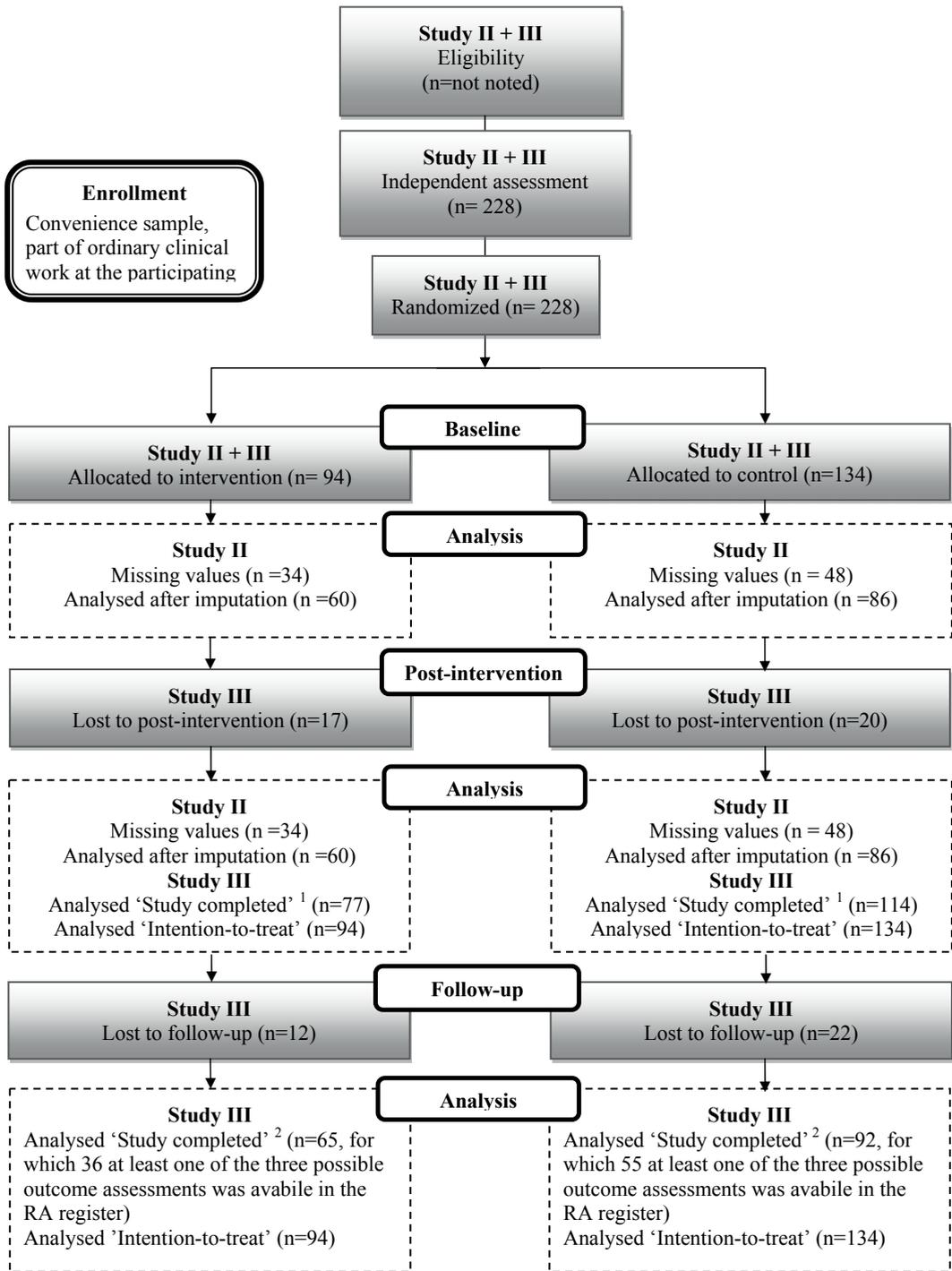
Gender , female/male, n	24/1
Age , years, md (range)	44 (28-66)
Working as PT , years, md (range)	15 (1-45)
Working within rheumatology , years, md (range)	9 (1.5-30)
Previous or present work as an exercise coach (e.g. sport associations), yes/no, n	13/12
PT's own exercise behavior past month , (≥30 minutes on moderate intensity), n per week	
0	1
1-2	12
3-4	11
5-7	1
Additional profession , yes/no, n (nurse, behavioral scientist, assistant nurse, dance teacher, computer programmer, health educator, and teacher)	11/14

4.2.3 Studies II and III

A total of 228 patients (Table 5) with recently diagnosed RA were recruited at ten rheumatology clinics in Sweden 2000-2004. The patients were asked to participate one year after inclusion in the Swedish RA register, a national quality register. They were informed and asked to participate either by mail prior to their physician visits or when seeing their physician at the clinic. Our sample compared well to other patients with newly diagnosed RA included in the RA register at the 10 participating clinics during the same period¹⁵⁶. All participants were randomly allocated, individually without stratification by the throw of a dice, at each participating clinic, to the IG or the CG.

Criteria for inclusion in the study were: age 18 or above with ability to speak Swedish. Also, they should have a RA diagnosis confirmed by a rheumatologist according to the classification criteria for RA from 1987³², be enrolled in the Swedish RA register, be able to perform body function testing and complete questionnaires. A flow-chart of the participants and drop-outs is described in Figure 2.

Table 5. Characteristics of the participants in Study III (n=228)		
	IG	CG
Participants, n	94	134
Gender, female/male, n	68/26	101/33
Age, years, md (range)	54 (22-90)	56 (21-83)
Disease duration, md (range)	23 (9-25)	24 (6-35)
Disease activity, M (SD)	3.16 (1.46)	3.29 (1.54)
ESR, mm/h, M (SD)	13.5 (12.9)	17.5 (15.9)
CRP, mg/l, M (SD)	12.9 (19.9)	12.9 (17.7)
Activity limitation, md (range)	0.5 (0-2.25)	0.5 (0-2.50)
Pain, md (range)	23 (0-93)	22 (0-90)
General health perception, md (range)	30 (0-87)	33 (0-87)
Health status, md (range)	70 (5-98)	70 (4-100)
Self-efficacy, md (range)	9 (0-10)	8 (0-10)
Outcome expectations, md (range)	8 (0-10)	8 (0-10)
Muscle function LE, md (range)	21 (8-43)	20 (10-46)
Healthy physical activity, %	47	51
Medication		
No, n	0	0
Cortisone, n	21	40
NSAID's, n	27	32
DMARD's, n	88	123
Anti TNF- α , n	7	7



¹ Study completed at post-intervention= independently assessed by a physical therapist

² Study completed follow-up= filled in and posted a questionnaire on physical activity

Figure 2. Flow chart of the participants at each stage of Study II & III

4.3 STUDIES II AND III - INTERVENTION

The rationale of the intervention, provided to patients allocated to the intervention group in both Studies II and III, was to implement healthy physical activity (30 minutes/day, moderately intensive, > 4 times/week) through a one-year coaching intervention between baseline and post-intervention. The intervention was not based on one single existing behavior theory or model, even though behavioral medicine elements were part of the intervention.

The coaching intervention was led by PTs, specifically trained within the study, at each participating clinic with initial face-to face meetings once or twice (Table 6). Regular telephone support was then given a total of 8-10 times. Tests of body functions were performed 3 times, with oral or written feedback of the results. Participants in both the IG and the CG were allowed to seek ‘ordinary’ physical therapy treatment during the entire study period. This could include patient education, treatment with physical modalities and organized exercise at a maximum of twice per week, a concept normally applied to patients with RA. Information regarding the actual amount of physical therapy treatment was however not documented in either group.

Table 6. Overview of components in the coaching intervention

Information about the benefits of physical activity
Discussions on the patient’s thoughts about their physical capacity
Discussions on possibilities for physical activity
Concrete goals for physical activity according to structured manual
Action planning
Discussions on perceived obstacles and problem-solving strategies
Problem-solving strategies for present and future barriers
Tests of body functions
Activity logs two weeks prior to test occasion

Training of physical therapists

At least one PT coach from each clinic participated in a one-day session with an experienced psychologist before the intervention period. The psychologist provided lectures in behavioral medicine elements. The coaches were trained in the different components of the intervention, such as identifying present and future obstacles to maintain physical activity and how to overcome these with different strategies, and goal-setting following graded activity. Role-plays between the coaches were also performed, and time was given for reflections. Training in the performance of assessments as well as an overview of the definitions, requirements and benefits of physical activity were also part of the education for the coaches. A recall session was held after six months, and regular recall sessions on the study protocol were held once or twice every year during the intervention period.

4.4 DATA COLLECTION

The most frequently used method of collecting data in a phenomenographical study is semi-structured individual interviews. An interview guide includes themes and questions that focus on the research aim, and often contain an entry question, but the dialog and follow up questions vary from participant to participant. Written and oral information about the study as well as about confidentiality was given to the participants prior to the interviews, both in Study I and IV.

4.4.1 Study I

The interviews were mainly held at the physical therapy clinics. The interviewer (ES) was a PT experienced in rheumatology, but with no relation to the participants. Demographic and background data were collected with questionnaires. The interview guide covered different themes focusing on exercise maintenance (Table 7). The interviews lasted 25-75 minutes, were tape recorded and subsequently transcribed verbatim by the interviewer.

Table 7. Interview guide in Study I.
1. Describe the importance exercise has for you
2. Are you satisfied with the amount of exercise you're doing just now?
3. Describe for me a really good exercise session you've had.
4. Can you describe a less good exercise session you've had?
5. Tell me about your experience of exercise maintenance led by a physical therapist.
6. Tell me about your experience of exercise maintenance on your own without direct support from a physical therapist and outside the health care.
7. What's it like to end an exercise period with a physical therapist, and the actual decision to maintain exercise on your own?
7. Describe what makes it easier, and what makes it more difficult, to exercise on your own compared to with support from a physical therapist and you're your experience is here.
9. Can you say anything about what you consider is useful and good exercise for a person with rheumatoid arthritis and in what form it should be done
10. What do you think your continued regular exercise behavior is going to look like in the future?

4.4.2 Study IV

An initial focus group interview with nine experienced PTs within rheumatology was carried out in order to develop appropriate domains of content for the individual interview guide. The focus group was moderated by an experienced PT and teacher with knowledge in qualitative research approaches. An experienced PT (ES) within rheumatology with knowledge in behavioral medicine and exercise as well as within qualitative research method took notes during the interview. The focus group interview was tape-recorded, but not transcribed. The interview guide covered different themes focusing on exercise promotion (Table 8). The individual interviews took place at the PTs' workplaces. The individual interviews lasted 39-87 minutes, were tape recorded and subsequently transcribed verbatim by the interviewer (ES).

Table 8. Focus group interview guide themes and their development into the individual interview guide themes in Study IV.

Focus group interview	Individual interview
<i>Opening question:</i> ‘Please describe a situation or a case you have experienced that you think has taught you something important about promoting exercise’.	
Patient cases that had been a success versus a failure to the PT	Patient cases that had been a success versus a failure to the PT
PTs promotion of exercise adoption	Adoption versus maintenance of exercise
PTs support for exercise maintenance	Social support
The focus in exercise promotion	Goal-setting The patient’s previous exercise experiences The environment and context The team Follow-ups The planning The conversation
PTs reason for and satisfaction with exercise promotion	The role of the PT The most important focus in PT work

4.4.3 Procedure Studies II and III

The local PTs collected self-reported data and performed clinical tests at outpatient visits at both baseline and post-intervention. Socio-demographic and disease-related data were retrieved at baseline and post-intervention from the Swedish RA register. No PT assessment was carried out at follow-up, where only a questionnaire on physical activity and personal factors related to exercise was mailed out, and disease-related data were retrieved from the Swedish RA register.

4.4.4 Assessments in Studies II and III

The measurements chosen for the studies are valid and/or reliable for the RA population, and some are also part of internationally recommended core sets for outcome measures in clinical trials in RA ¹⁵⁷. An overview of the assessments is displayed in Table 9.

ICF	Variable	Instrument	RA-reg.	PT
	Disease activity	DAS 28	X	
Body function	CRP	Blood sample	X	
Body function	Pain	VAS	X	
Body function	Muscle function	TST		X
Activities and participation	Activity limitation	HAQ	X	
Activities and participation	Physical activity	Questionnaire		X
Activities and participation	General health perception	Global VAS	X	
Activities and participation	Health status	EQ-5D VAS		X
Personal factors	Self-efficacy	Questionnaire		X
Personal factors	Outcome expectations	Questionnaire		X

- *Disease activity* was assessed with the Disease Activity Score (DAS28) ¹⁵⁸, 0-10 (0=no activity, 10=very high activity), based on erythrocyte sedimentation rate (ESR, mm/h), number of swollen (n=28) and tender (n=28) joints and the patient's perceived general health (VAS, 0-100).

- *C-reactive protein* was measured in mg/l.

- *Pain*, measured as self-reported pain the previous week, was rated on a Visual Analogue Scale ¹⁵⁹ (VAS 0-100, 0=no pain).

- *Muscle function of the lower extremities* was measured with the Timed Stands Test (TST) ^{160,161}, i.e. the time needed to rise ten times from a standard chair is recorded (s).

- *Activity limitation* during the previous week was assessed with the Health Assessment Questionnaire Disability Index (HAQ) ¹⁶². The HAQ is a 20-question survey addressing eight areas of activities of daily living rated from 0 (no limitation) to 3 (severe limitation).

- *Physical activity behavior* was assessed with a self-report questionnaire designed for the present study. The questionnaire included three questions on the frequency of low-, moderate-, and high-intensity physical activity accumulated to 30 minutes totally per day of a typical week. All three questions were assessed on a four-point response scale: never/irregularly, 1-3 days/week, 4-5 days/week, 6-7 days/week
- *Self-reported general health perception* was rated on a visual analogue scale (global VAS, 0-100, 0= totally fine) ¹⁵⁷.
- *Health status* was assessed with the EuroQol-VAS (EQ-5D VAS) ^{163,164}. This 20 cm vertical 0-100 thermometer scale assesses current self-perceived health status with the question ‘your own health state today?’, 0 signifies worst imaginable health status and 100 the best imaginable health status.
- *Self-efficacy* for performing regular physical activity was measured with a self-reported question designed for the present study, using a 10-point response scale, 0 representing ‘not at all sure’ and 10 representing ‘totally sure’:
How sure are you that you can perform regular physical activity at low-to-moderate intensity to a total of 30 minutes, four times a week?
- *Outcome expectations* for symptom decrease following physical activity was measured with a self-reported question designed for the present study, using a 10-point response scale, 0 representing ‘not at all sure’ and 10 representing ‘totally sure’:
How sure are you that physical activity can decrease your symptoms?

4.5 PHENOMENOGRAPHY

Phenomenography was the research approach used in Studies I and IV. This research orientation was developed in the 1970s in Sweden in an attempt to formulate research questions about learning and understanding in an educational environment ¹⁶⁵. More recently, the approach has been used in health care research ¹⁶⁶⁻¹⁶⁸, and in that context it is important to recognize how different phenomena, such as physical activity promotion, can be understood in different ways, by both the patients and the health professionals. This approach might thus be a valuable tool for identifying elements related to PTs teaching role as well as the patients learning experience. The approach is used to describe the variation in people’s way of thinking, experiencing, understanding and interpreting different phenomena in the world ¹⁶⁹, and is based on the assumption that every phenomenon can be experienced in a number of qualitatively different ways ¹⁶⁵. Phenomenography is less concerned with individual experience than it is with emphasizing collective meaning, and researchers describe people’s experiences and

understanding through the eyes of another person, by stepping back from their own experience and observing from the outside to get a second-order perspective. Understandings are “the by-products of our thoughts, education, experience, culture, history, and the ideals and values that society insists on”¹⁶⁹, and are considered fundamental to the way in which people act, form beliefs, and experience phenomena as well as the way in which people explain to themselves and others what goes on around them.

4.6 DATA MANAGEMENT AND ANALYSIS

An overview of the analysis for the studies is presented in Table 10.

Table 10. Data analysis methods in Studies I-IV				
Methods	Study I	Study II	Study III	Study IV
Descriptive analyses				
- Median and range	X	X	X	X
- Interquartile range		X		
- Number and frequencies	X	X	X	X
- Mean and SD			X	
- Quartiles		X		
- Cluster analysis		X		
Qualitative analysis				
- Phenomenography	X			X
Inferential analyses				
- Chi-square test		X	X	
- Mann-Whitney U-test		X	X	
- Student's t-test		X	X	
- Spearman's rank correlation		X		

4.6.1 Studies I and IV

Transcripts from the interviews were analyzed using the phenomenographic approach¹⁶⁶, where the transcribed interviews were read carefully with the aim of becoming familiar with the material and get a sense of the whole. Each interview was then analyzed separately to distinguish different kinds of aspects related to the phenomenon, which were compared in order to find sources of variation or agreement between the interviews. The characteristics in the data represented a basis for the descriptions of each participant's predominant way of understanding the phenomenon. A preliminary pattern of qualitatively distinct and different categories was constructed, crosschecked with the original interviews and revised before the final categorization was established. The essence of the similarities within each category was described and then labeled. The analysis was continued by noting differences and similarities in the experiences, which was done by contrasting the excerpts in all the interviews with one another. These procedures were performed through continuous discussions with another author as well as with peer-experts.

4.6.2 Studies II and III

Correlations

Relationship between the cluster variables as well as between cluster variables and a predefined criterion-related variable in Study II was tested with Spearman's correlation coefficient. The correlation was interpreted according to Altman¹⁷⁰: $r < 0.25$ as little; $r = 0.26-0.49$ as low; $r = 0.50-0.69$ as moderate; $r = 0.70-0.89$ as high; and $r = 0.90-1.00$ as very high.

Cluster analysis

Ward's hierarchical clustering method and K-means cluster analysis was applied to determine the number of clusters and to optimize the homogeneity, as well as to explain variance in Study II^{171,172}. Average linkage and beta-flexible cluster analysis were used to establish reliability of the cluster solution. For missing data, the standard procedure for imputation was used¹⁷³. The explanatory power and generalizability of the patterns were evaluated with ; (a) a homogeneity coefficient (HC) less than 1.00 (preferably 0.5), (b) a percentage of the total error sums of square (EESS) of desirably at least 67 %, and (c) an averaged squared euclidean distance (ASED) preferably less than 0.3 in a split-sample replicability¹⁷⁴.

Differences between groups and clusters

Analyses between clusters in Study II and between the IG and the CG in Study III were performed with the Chi-square test (nominal data), the Mann-Whitney *U* test (ordinal data) or with Student's *t*-test (interval data). The threshold for statistical significance was set to 0.05.

Intention-to-treat

Data were analyzed in Study III on the basis of 'intention to treat'¹⁷⁵ with last-value-carried-forward, the last observed value is used to fill in missing values at the later time points in the study (lvcf) as well as for those completing (sc) the two-year study.

Power analysis

It was estimated in a power analysis for Study III that 40 % of the IG participants and 20 % of the CG participants would report their general health perception as improved (>15 of 100 mm). With 80 % power and a significance level of 0.05, 91 participants would be required in each group.

The cluster analysis in Study II was performed using the statistical package for pattern-oriented analysis, *SLEIPNER 2.0*. Other statistical analysis in Study II and all statistical analyses in Study III were performed using STATISTICA, version 7.1, STATSOFT Inc, Tulsa, US.

4.7 ETHICS APPROVAL

All participants in Studies I-IV received oral and written information about the aim, method and the procedure of the specific study. They were informed that their participation was voluntary and could be terminated at any time without stating reason, and without it affecting their care. They were also informed that all information would be treated confidentially. Written consent was also obtained from each study participant in Study I and IV. The Medical Ethics Research Committee of Stockholm approved the design of Study I (D-nr 2005/371-31) and the Research Ethics committee at Karolinska Institutet approved the design of Studies II and III (D nr 00-010). The Regional Research Ethics committee at Karolinska Institutet approved the design of Study VI (2009/1570-31/5).

5 RESULTS

5.1 STUDY I

Ways of understanding exercise maintenance among individuals with rheumatoid arthritis

Five qualitatively different ways of understanding exercise maintenance were identified: *external control*, *sticks and carrots*, *a joint venture*, *the easy way*, and *on one's own terms*. The differences in ways of understanding between the categories became clear by distinguishing two aspects related to exercise maintenance, i.e. the *type of support* needed and *personal factors*. The outcome space was interpreted as a continuum of resources: the setting, the time and the support needed from a physical therapist (Figure 3).

“External control” involves monitoring and support from a PT as well as organized exercise. In order to feel safe, the PT's role is to note improvements or deteriorations as well as to instruct and adjust the exercise. The patient relies on the PT and no effort is made to continue regular exercise independently.

“you'll be...informed and guided so you perform the things right. Well, it's the competence; you have to trust them, so to speak”.

“Sticks and carrots” is about support and guidance from a PT, but at the same time making agreements in order to create positive pressure and demands on the patient. The physical therapist's role is to encourage and motivate as well as to instruct and observe, and to adjust the exercise content. Because of lack of confidence and insecurity in personal ability to find appropriate exercise, giving up exercise with support from the PT is not an option for the patient.

“it's better that there are demands, you're forced, like ... that's how it is for me, it's ... you've fixed a time, – that's when it works”.

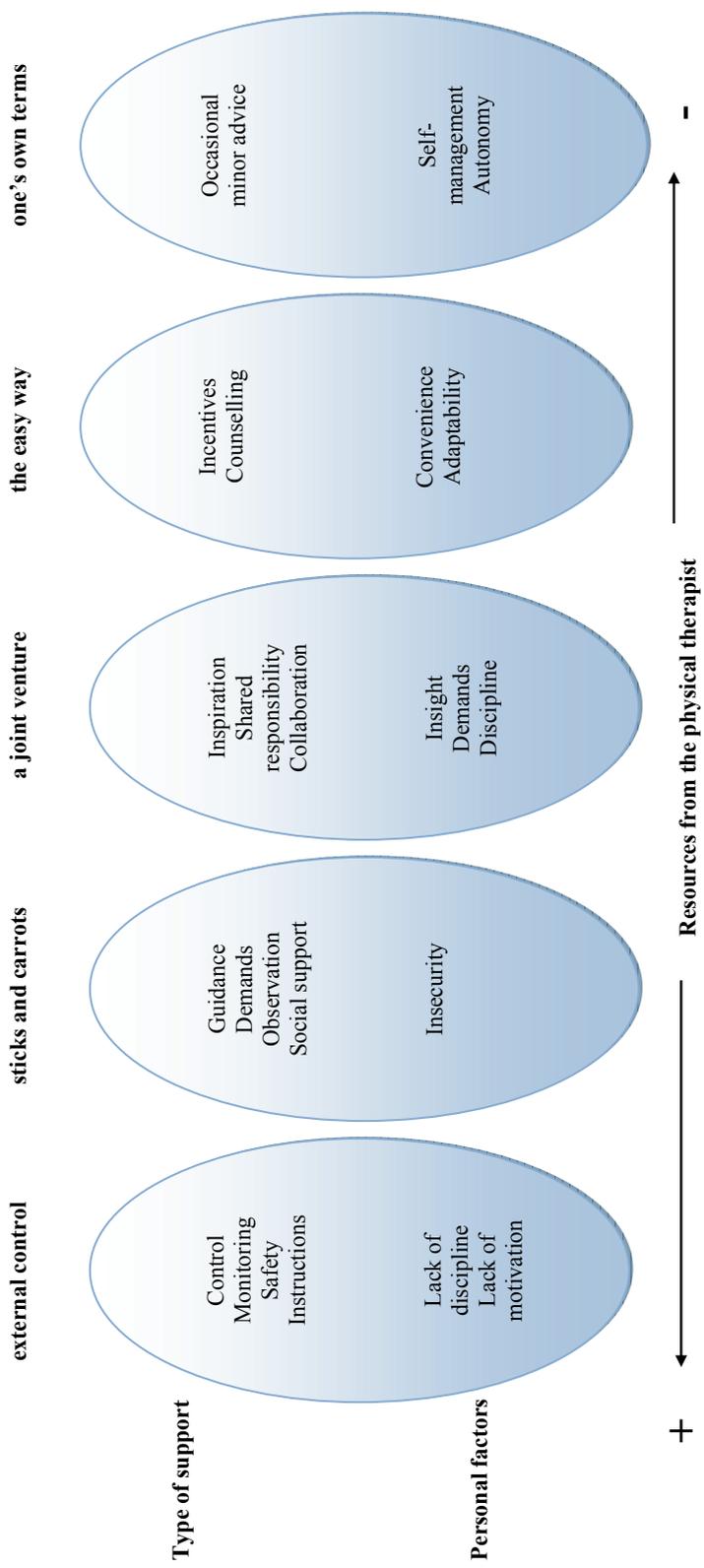


Figure 3. Outcome space; ways of understanding exercise maintenance

"A joint venture" calls for inspiration and collaboration between the patient and the PT. Beliefs in the ability to perform different types of exercise, knowledge, skills and responsibility is present, but support from a PT is a self-evident part. The PT provides guidance and exercise options as a motivator and encouraging coach. The patient experiences an urge to push harder when exercise is led by a PT.

"training on your own or with a physical therapist are not alternatives – I usually do both, anyway".

"The easy way" means that exercise can be handled without support from a PT, but if it would be offered, it is perceived as convenient, pleasant and positive. The PT, who provides incentives, can help establish exercise habits. It is natural to keep on exercising, even though the support is withdrawn, since the patient possesses confidence and beliefs in the ability to carry out regular exercise in most contexts.

" it's kind of nice to have someone who tells you...I think it's nice at the start, but then I think, you can manage it, once you have found out the way you should do it. Then you have to keep going and really, no one but you yourself can do that".

"On one's own terms" focuses on a feeling of being independent and not being a burden on health care. The patient has strong autonomy and do not want external demands or pressure on exercise behaviors. The patient gets satisfaction from matching exercise to the course of the disease, which enhances beliefs in one's ability to perform exercise. However, a PT can sometimes be helpful in creating and updating exercise programs.

"freedom, I can feel myself how my strength is giving out or my body's saying 'no': the physical therapist can't know this spot on".

5.2 STUDY IV

Ways of understanding exercise promotion among PTs working with patients having rheumatic diseases

Four qualitatively different ways of understanding the promotion of exercise were identified: *to tell and inform*, *to identify and pilot*, *to discuss and enable* and *to listen and inspire*. The ways of understanding were found to be different regarding four key aspects; *knowledge and responsibility in exercise*, *setting and supervision*, *tools to support behavior change* and *the role of the PT* (Table 11). The categories were interpreted in the outcome space as hierarchically organized and interrelated regarding aspects of teaching and learning (Figure 4).

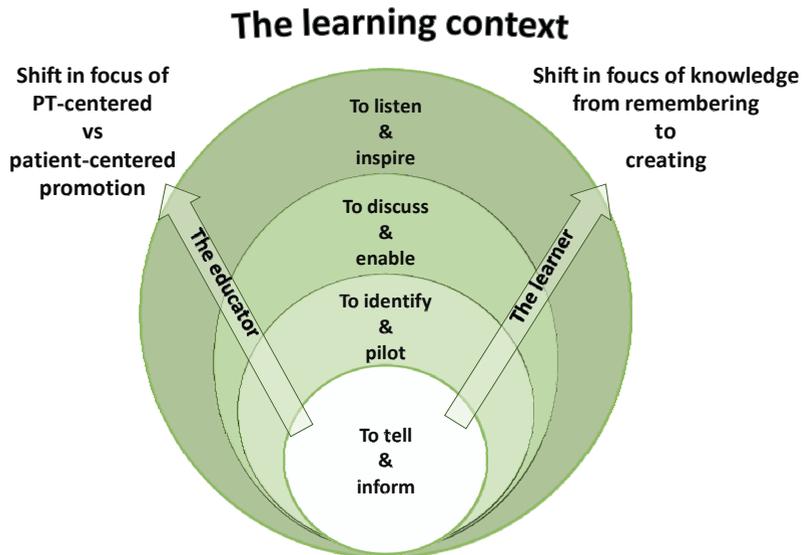


Figure 4. Outcome space; ways of understanding exercise promotion

"To tell and inform" focuses on the PT as an expert who gives the patient information regarding exercise and in that way hopes to get the patient to start exercising. The patient performs a specific exercise program under supervision and uses a diary to keep track of what he/she has committed to do. The PT also argues the effects on the disease and the body if exercise is not performed, almost as intimidation.

"Well, it's informing and hoping that in the long run they will understand and feel for themselves that doing nothing is not so great, or... but like we said before, we can't reach everybody."

"To identify and pilot" means providing the patient with insight on exercise and create personal responsibility. Focus lies in designing a high-quality exercise program in the clinic and implementing the program as a routine. The PT takes on the role of an expert and discusses why exercising has failed in the past, recognizes different barriers as well as pros and cons of positive exercise behavior. The PT can also act as a sounding board in discussions.

"If we talk about the first meeting I have with the patient, the conversation then goes towards why they should exercise, and connecting a lot of that to the disease. And with pain and fatigue and so on, and trying to put together, starting to draw a little and things like that, to try and get them on board. Also talking about what they have done before, and what they are up for, and well, inquiring a little. Then when I have gotten a little further, when they perhaps have started exercising, I probably talk more specifically about exercise, I start with more motivational things, then I talk more about exercise specifics, about what happens where, when you do something. I really want them to know what they do and why"

"To discuss and enable" calls for a patient understanding of the relationship between the importance of exercise and the effects on the disease through different bodily experiences. The exercise goals should be feasible in the long run, and must focus on parts that the patient can handle and agree to continue with, outside the clinic. The PT takes on a teaching role and jointly creates a plan for maintenance with the patient; modifying thoughts about the goals hopefully makes exercising realistic and lasting.

"Then I would sit down and discuss that somehow the patient has to, I mean bring up these, what it is that isn't working, what obstacles you see, advantages and things like that. It may be a small thing for me that's like big deal to the patient, and that you sort of... well, walking with poles for example, and it's raining, then they don't go out. But is there something else you can do instead like, finding different ways."

"To listen and inspire" involves making the patient recognize why and when there is a need for exercise, thus giving him/her the ability to control some parts of the disease. The exercise is based on behaviors that already work well for the patient, and by transferring the exercise responsibility to the patient he/she can grow as an individual without being dependent on a PT. By creating reflective thinking instead of providing fixed solutions, inspiring patients to find new pathways and affecting the patient's self-image, the PT eventually kicks the patient out of the nest.

"She felt that, no, her whole life situation, she wanted to change it. But she was scared. She wanted me to do it. Well, we set that as a goal, and set up milestones that we checked off, just like that. And then when she saw that it actually worked, she got motivated, this really works... She is here to support me, but I'm the one who has to actually do the work. I think I learned that... I can be there to support, but I can't carry the patient, the patient has to do the work. But as an expert, I can help and support, but I guess that as physical therapists, I think we want independent patients. We don't want them attached to us, that they are dependent on us, that they, with our knowledge we can make them grow, to become independent individuals."

Table 11. Key aspects within and between the categories of descriptions.

	To tell & inform	To identify & pilot	To discuss & enable	To listen & inspire
<i>Knowledge and responsibility in exercise</i>	To provide facts on exercise	To provide insight on exercise and create personal responsibility	To create understanding on relation between exercise and the effects on the disease	To create trust in the body and reflections on self-reliance
<i>Setting and supervision</i>	To design exercise programs and provide support	To provide different exercises and find opportunities for exercise	To create realistic exercise goals and adjust them to patients' needs	To plan for exercise sustainability and to fit it into life puzzle
<i>Tools to support behavior change</i>	To put pressure on patients and inform the PT	To identify patterns and enhance motivation	To provide awareness of exercise effects	To acknowledge the capacity and create reflective thinking
<i>The role of the PT</i>	To be an expert who persuades	To be an expert and a sounding board	To modify ideas and arouse enthusiasm	To inspire and affect self-image

5.3 STUDY II

A person-oriented approach to a coaching intervention

Of 228 participants included in the randomized controlled trial at baseline, 64 % (146 patients) with complete data both at baseline and post-intervention were included in the present analysis. There were no statistically significant baseline differences between the final cluster sample and the excluded participants regarding cluster variables or descriptive variables. Both the cluster sample and the excluded participants consisted of 41 % IG participants.

Clustering participants on the basis of variables associated with general health perception

An acceptable classification of eight clusters, i.e. participants with different patterns in disease activity, pain, lower extremity function, activity limitations and physical activity behavior, were revealed both at baseline and post-intervention (Figure 5). The clusters were labeled less affected (0-2 variables) or more affected (3-5 variables) according to the number of included variables with median/mean values higher than the total sample median/mean value. Supporting cluster validity, participants in less affected clusters reported significantly better general health perception at baseline than those in more affected clusters.

Stability of cluster solution over time

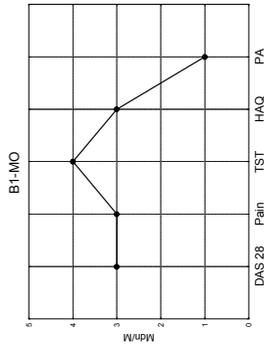
Partial structural stability was achieved, where seven of the clusters remained stable over time from baseline to post-intervention; one more affected cluster dissolved and one new less affected cluster was formed (Figure 5).

The effect of a one-year coaching intervention on self-reported health status

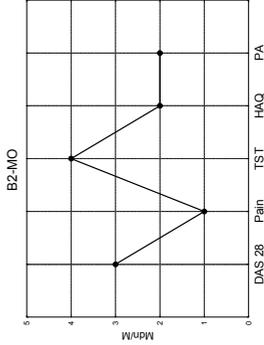
At baseline, the participants in less affected clusters reported better health status (less=80, more=60) than those in more affected clusters, in both IG and CG. Based on the cluster solution at baseline, the IG participants in more affected clusters improved significantly over the IG participants in less affected clusters regarding health status (more=16, less=-0.5). Further, the IG participants in the four more affected clusters significantly improved their health status compared to the CG participants in the same more affected clusters (more=16, less=0).

Figure 5. Graphic view of the eight-cluster solution at baseline and post-intervention, showing median values of the ordinal scales used in the cluster analysis; disease activity (DAS 28), pain, lower-extremity muscle function (TST), activity limitation (HAQ) and physical activity behaviour (PA). Hc = Homogeneity coefficient in the cluster. Pm = Pairwise matching between the clusters at baseline and post intervention.

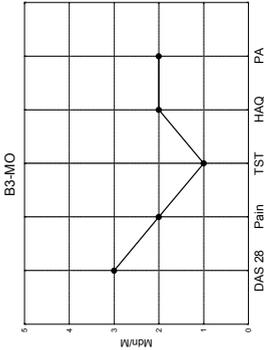
Baseline



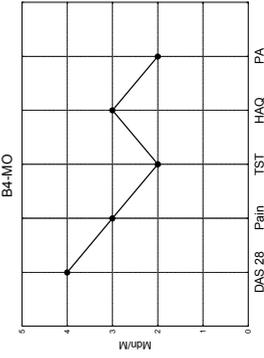
Hc = 0.673
Pm = 0.043



Hc = 0.740
Pm = 0.088



Hc = 0.943
Pm = 0.214



Hc = 1.210
Pm = 2.201

Post intervention

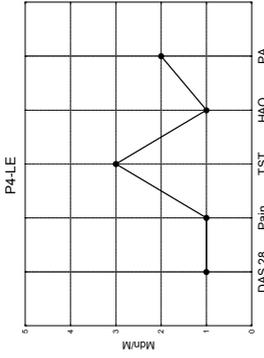
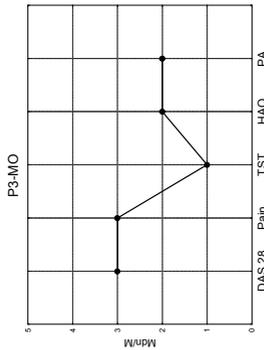
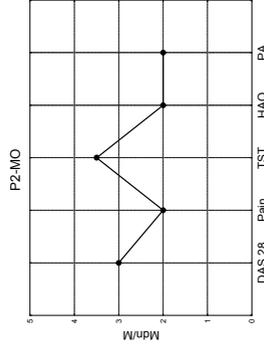
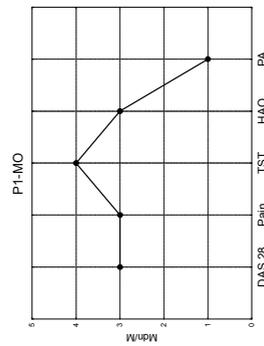
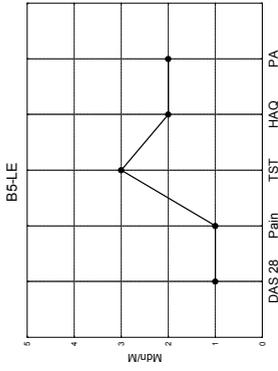
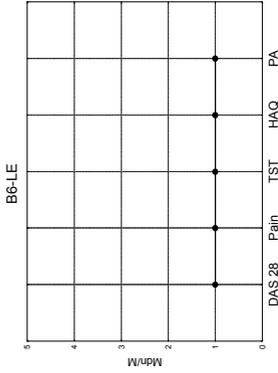


Fig. 5 continued

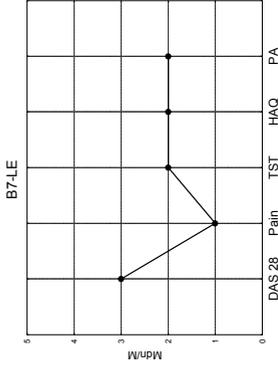
Baseline



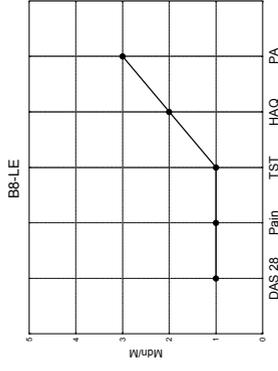
Hc = 0.465
Pm = 0.100



Hc = 0.510
Pm = 0.053

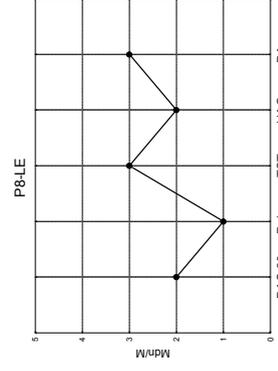
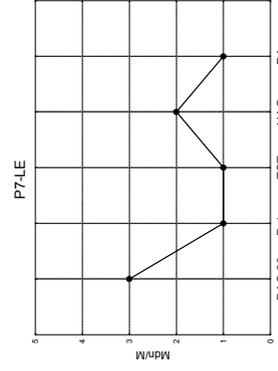
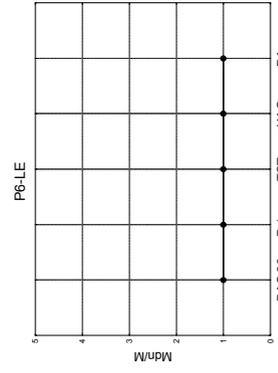
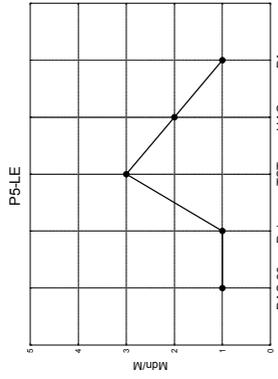


Hc = 0.746
Pm = 0.252



Hc = 0.757
Pm = 0.313

Post int



5.4 STUDY III

The long-term effects of a one-year coaching intervention

The retention rates for the whole study period of two years, i.e. those who filled out and mailed the follow-up questionnaire on physical activity behavior, were 69 % (65 patients) and 69 % (92 patients), in the IG and the CG respectively. The drop-outs were comparable with their respective group peers in all outcome variables and demographic variables at baseline.

The long-term effect on general health perception

Participants in the CG reported significantly better general health perception than the IG (lvcf) at follow-up (19 vs. 32), but not when analyzing only those who completed the study (sc) (17 vs. 24.5). No significant differences were found between the IG and the CG in proportions of individuals with improved general health perception more than 15 from baseline to follow-up (lvcf or sc).

The long-term effects on disease activity, pain, activity limitation, self-efficacy and outcome expectations

Participants in the CG reported significantly lower pain than the IG (lvcf) at follow-up (18 vs. 32), but not when analyzing only those who completed the study (sc) (17 vs. 23.5). No differences were found between the IG and the CG in proportions of individuals with decreased pain more than 15 from baseline to follow-up (lvcf or sc). No significant differences between IG and CG in any of the other outcomes were found at follow-up (lvcf or sc).

The adoption and maintenance of health-enhancing physical activity

There were no significant differences in physical activity behavior, reported as unchanged, improved or deteriorated between the IG and the CG from baseline to follow up. However, different patterns of change in physical activity behavior were observed in the IG and the CG throughout the whole two-year study period. At post-intervention, a trend could be seen towards a higher proportion of participants in the IG (54 %) achieving health enhancing physical activity than in the CG (44 %), but this changed after the follow-up year, when the proportions were almost identical again.

6 DISCUSSION

The findings in this thesis illuminate physical activity promotion in patients with RA, both from a patient and a PT perspective, as well as through the result of a coaching intervention.

6.1 PATIENTS' AND PHYSICAL THERAPISTS' UNDERSTANDINGS

In Study I, different aspects of support from a PT, e.g. control, guidance, collaboration, counseling and brief advice were important. This is consistent with other studies where support constitutes a powerful factor for^{97,176}, and a predictor of exercise behavior^{177,178}. Advice from health professionals is suggested as important¹²⁵, and in patients with osteoarthritis, PTs' professional care influence exercise behavior, and encouragement and understanding from a PT are described as external facilitators¹⁷⁹. Further, communication and a sense of positive connection with the PT are considered equally important to the actual results of the physical therapy session¹⁷⁹. However, more active involvement by participants is also related to better adherence in patients with osteoarthritis¹⁸⁰. The type of support needed from a PT in Study I was closely related to the appraisal of different personal factors, e.g. motivation, insight and discipline. Motivation by enjoyment or by result has also been found as an internal facilitator for exercise in patients with osteoarthritis, with motivation by enjoyment as a predominant factor¹⁷⁹. Without motivation and discipline, exercise maintenance might be facilitated only by a controlled context and in a clinical setting. Thus, a relevant question is whether patients would continue to exercise if the shared responsibility disappeared or if the need for support restrained their own resources.

The ways of understanding exercise promotion described in Study IV is in accordance with PTs' experience of client participation, either as a paternalistic partnership with the PT as an expert and a compliant patient, an unequal partnership where the patient is persuaded to follow the PT's decision or as a collaboration of equal partnership¹⁸¹. Similarly, the ways health care professionals understand diabetes care include a focus on the professionals, described as a way to treat patients by giving information and advice, or as a way to share information with emphasis on creating awareness and understanding. A focus on the patient was described in the same study by highlighting the collaboration between the health care professional and the patient, in addition to the importance of patients assuming responsibility for their own health¹⁸². This resembles

the PTs' different way of understanding exercise promotion in the present work. Different types of communication were also present among the PTs, which is important to acknowledge, since the basis for patients' appreciation of a PT is mainly defined in terms of their communication skills, including teaching¹⁸³. One-way communication contains pitfalls with respect to the patients' learning experience, since the PTs might not be aware whether or not their message is understood. A much more patient-centered¹⁸⁴ communication is where the patients identify and outline various problems and discuss them with their PT using open-ended questions, and with feedback from their PT can recognize and summarize exercise-related thoughts and ideas.

6.2 THE COACHING INTERVENTION

6.2.1 The effects

The main finding in Study II indicates that the changes of perceived health were not only affected by cluster belonging and time, but also by the intervention, and thus a possible adoption of health-enhancing physical activity. Additionally, participants benefiting the most from the coaching intervention were more affected by the disease at baseline. The medication with DMARD or anti TNF- α drug did not differ between the more or less affected clusters, but individuals in the less affected clusters might have valued the benefits of adopting health-enhancing physical activity less, since their perceived health was fairly good already at baseline. Another explanation for the present result might be that participants more affected by their disease were in need of general support during the early phase of the disease, in an attempt to reduce stress, fear, anxiety and insecurity not necessarily related to physical activity^{185,186}. This raises questions as to whether the reason for the increase in perceived health could be the emotional, informational and instrumental support provided as part of the intervention^{187,188}. Behavioral interventions can be evaluated on different levels, e.g. by determinants of behavior, the behavior itself, physiological-biochemical variables or health outcomes¹⁸⁹. It has been suggested that behavior should be the key outcome even though the immediate goal is to achieve health¹⁹⁰. Since, physical activity behavior was used as a cluster variable and not assessed as an outcome at the end of the present coaching intervention, this could have created diffuse causal pathways.

In Study III, no long-term effect on perceived health was found at follow-up of the coaching intervention. Further, even though not a primary outcome, physical activity behavior was assessed at the two year follow-up. Different patterns of change in

physical activity behavior were observed in the two groups directly after the one-year coaching ¹¹⁵. One explanation could be that the PTs were a valuable support to the IG participants during the first year of the study ¹⁹¹, and that their withdrawal after one year created a void during the follow-up year. Further, increased health perceptions might take time to achieve and the participants might have followed a stepwise change of physical activity behavior ¹⁹², where they could easily drop from a stage of action to one of preparation, thus decreasing perceived health again at the time of follow-up.

6.2.2 The content and delivery

The coaching intervention had many advantages as it lasted one year, used more than six behavioral techniques and included face-to face contacts, all previously found to be beneficial for maintenance of physical activity, but it lacked follow-up prompts ¹⁴⁶. Another weakness is that self-efficacy ¹⁹³ that is well-known for its positive association with physical activity behavior ^{194,195} although assessed, was not explicitly addressed in the intervention. The participants were encouraged to adopt health-enhancing physical activity in daily life, therefore most participants could have performed the physical activity on their own. Still, changing self-efficacy for physical activity in interventions is most effective when applying vicarious experience, i.e. seeing a ‘similar other’ successfully perform physical activity and appraising one’s own performance against that of that ‘similar other’ ¹⁹⁶. Furthermore, self-monitoring, the most important behavioral technique to include in physical activity promotion ¹⁴⁷, was not used in a satisfactory way in the coaching intervention. The activity logs were only used for three to four two-week periods, which was probably too short for the participants to fully learn how to use them for self-monitoring in an effective way.

Thus, the content of the intervention was basically good, but since no fidelity checks were made, the PTs could possibly have failed to deliver the coaching as intended, and thus the integrity of the treatment might have been threatened ^{197,198}. The PTs’ skills in following the study protocol might be dependent on their theoretical understanding of the different parts of the intervention ¹⁹⁹. Although a one-day session, and one recall session was provided to the coaches, where some behavioral medicine components were described, this might have been insufficient. A biomedical approach to physical activity has traditionally influenced PTs’ practice in rheumatology, and thus the new behavioral medicine elements in this intervention might have been hard for the PTs to fully embrace and apply. Also, communicating and promoting physical activity over

6.3.1 Coaching from a motivational perspective

Coaching physical activity can be viewed from different perspectives, and the combined results of Studies I-IV can be interpreted through the affective component, of learning a new behavior, e.g. motivation. Hypothetically, from being purely qualitatively different understandings, the patients' ways of understanding exercise maintenance (Study I) could be regarded as motivational types for engaging in physical activity. In the same way, the PTs' ways of understanding exercise promotion (Study IV) could be viewed as ways to develop controlled or autonomous self-regulations in their patients. In the motivation continuum (Figure 6), amotivation indicates a lack of intention to act with intent. Five motivational types are classified as motivated. Four of these are labeled extrinsic motivation, i.e. to which extent self-regulations are controlled or autonomous, and one is labeled intrinsic motivation. Furthermore, according to SDT, the process in which behaviors become more valued and autonomously self-regulated requires developing a sense of autonomy (to feel volitional), competence (to feel confidence and competent to change) and relatedness (to feel close to and understood by important others)²⁰⁰. This process, to move from external regulation to intrinsic regulation, could be facilitated by health care professionals. Many behaviors related to health promotion, such as physical activity, are not intrinsically motivated but probably extrinsic in nature²⁰². Thus, patients might engage in physical activity for reasons other than those assumed by their PTs and, in order to adopt and successfully maintain a behavior outside the controlled setting of physical therapy, the patients have to personally value the importance of physical activity. This has been investigated in a previous study indicating that adults engaging in health-enhancing levels of physical activity are more satisfied regarding needs of autonomy, competence and relatedness, and possess higher levels of autonomous self-regulations compared to those not engaging in such activity²⁰³. Furthermore, support for positive relations between identified regulation and short-term exercise and between intrinsic regulation and long-term exercise, were found in a review of SDT and physical activity²⁰⁴.

6.3.2 Coaching as learning and teaching

A health care professional-patient relationship may resemble that of an educational context. The coaching of health behaviors might thus also be improved by incorporating learning and teaching interactions. In an attempt to describe this interaction, it has been suggested that a teacher can regulate the students' learning by

strong control, lose control or shared control, while the students' regulation of learning can be low, intermediate or high²⁰⁵. More or less congruence or friction might occur in the interaction between the PTs' regulation of learning and the patients' regulation of learning. Congruence is accomplished when the learning strategies of both PTs and patients are compatible, and friction occurs in the opposite situation. Further, constructive friction relates to a patient facing a challenge in increasing skills in learning physical activity behavior, hence needing stimulation by the PT. Destructive friction occurs when the patient possesses skills not recognized or valued by the PT, or when the PT's demands on the patient are too high, both decreasing skills in the patient's learning of a new behavior.

6.3.3 A suggested synthesis

Figure 7 suggest a synthesis of the promotion of physical activity behavior from a motivational and a learning/teaching perspective. Although not explicitly represented in the synthesis, the coaching in Studies II and III might have been influenced by one or more of its elements.

As to SDT motivational types for engaging in physical activity, patients with ways of understanding exercise maintenance (Study I) as in *external control* might be those motivated by external regulation, i.e. participating in exercise only due to rewards or external demands by their the physician or PT. Patients with ways of understanding as in *sticks and carrots* and *a joint venture* might be motivated to some extent by introjected regulation to avoid guilt in relation to exercise expectations from their PTs, or to seek external approval. The latter way of understanding may also be connected to identified regulation, similar to those with a way of understanding as in *the easy way*. This type of motivation is more internally focused and occurs when a patient understands the reason for engaging in exercise. The way of understanding, *on one's own terms*, may relate to patients with integrated regulation. These patients value the importance of the behavior and have integrated it to the self. None of the ways of understandings described in Study I seem to relate to intrinsic regulation. Since exercise is often associated with possible benefits related to the disease rather than to pure enjoyment and satisfaction, it might be more difficult for patients with arthritis to reach intrinsic motivation. Similarly, PTs with ways of understanding exercise promotion (Study IV) as in *to tell and inform* might enhance external regulation by applying pressure and providing facts by using their expertise.

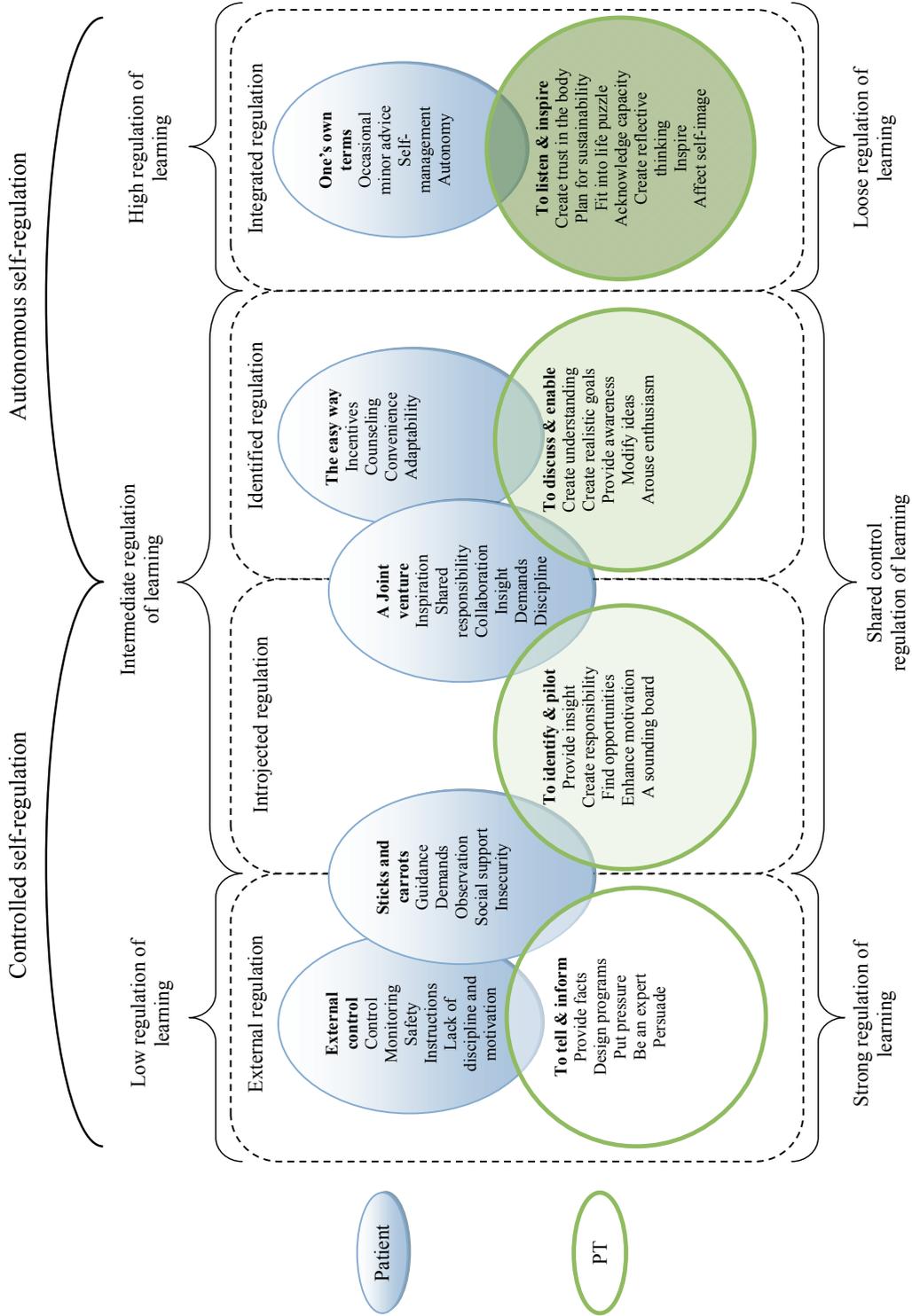


Figure 7. A synthesis of the promotion of physical activity behavior from a motivational and learning perspective.

Introjected regulation can be enhanced by the PTs' appreciation as a sounding board and an expert, as in the ways of understanding *to identify and pilot*. PTs with a way of understanding as in *to discuss and enable* try to create a connection between the exercise and its effects as well as to create realistic goals without external pressure, thus enhancing identified regulation. Facilitating integrated regulation through encouragement to explore the value of exercise with respect to the patients' life situation and by affecting self-image may apply to PTs with a way of understanding as in *to listen and inspire*.

From a learning and teaching perspective, a patient's way of understanding exercise maintenance as in *a joint venture* or *the easy way* (Study I) might be congruent with a PT's way of understanding exercise promotion as in *to identify and pilot* or *to discuss and enable* (Study IV), since intermediate and shared control regulation of learning is compatible. The patient has some skills, thoughts and internal reasons for exercising, but still needs development of self-regulation to become more autonomous. However, if the same PT coaches a patient with a way of understanding as in *external control* or *sticks and carrots*, constructive friction may be the result since the patients' low regulation of learning could be challenged to create new ways of learning the behavior. On the other hand, if patients with a way of understanding as in *one one's own terms* are coached by PTs with a way of understanding as in *to tell and inform*, they would be hampered in their learning through destructive friction since they already possess autonomous regulation, and would likely not benefit from detailed instructions from a PT or by a controlling behavior. Furthermore, when a PT with a way of understanding as in *to listen and inspire*, although probably possessing a wider range of regulation of learning strategies, is coaching a patient with a way of understanding as in *external control*, destructive friction may occur due to the patient's low regulation of learning and the PT's loose regulation of learning. Thus, it is important to bear in mind that the patient is a learning and reflecting individual and not merely one that is compliant and to recognize the importance of creating a space where both the patient and the PT can feel free to enter their understandings, like a play "to follow and let oneself be followed"²⁰⁶.

6.4 METHODOLOGICAL CONSIDERATIONS

In medical research, experimental designs (RCTs) as in Study III are traditionally considered as the gold standard and superior to any other designs. RCTs have strengths and limitations²⁰⁷. It is an excellent method to screen for natural variations caused by disease and environmental circumstances, thus deciding whether an intervention is useful or not. However, using a group-based design implies that the population group is a sufficient characterization on which to make treatment decisions. The person-oriented approach that was used in Study II is on the other hand a holistic and interactionistic approach that examines individual patterns of behavior¹⁷⁴. A person does not exist in isolation, nor does a variable. Thus individuals in cluster analyses are represented by a constellation of variables. The results are informative regarding what applies to homogenous subgroups of individuals, and enable conclusions to be made about subgroups within a sample. Both RCTs and person-oriented methods are designed to generate answers about frequencies and strengths of association, but they do not provide an understanding of patients' experiences. The qualitative research method used in Studies I and IV is concerned with describing complex phenomena that occur in a natural setting. It does not seek quantified answers, only to understand the phenomena, and could therefore be more suited to detect subtleties in and surrounding an intervention process²⁰⁸.

6.4.1 Studies I and IV

Trustworthiness

The interviewer's (ES) familiarity with the population groups through prolonged engagement and persistent observation as a physical therapist within rheumatology was judged both as a strength and a limitation. There is a risk of losing relevant follow-up questions due to the researcher only noticing aspects related to his/her own experience. However, knowing the population will also lead to careful questioning about the meaning of what is really said, as well as continuous checking for clarification of the information, which is useful for interpretation of the findings^{209,210}. In Study I, the participants had no relation to the interviewer and were not in a position of dependence. They described the role of the PT as both important and less important, which indicates that there was little interviewer bias. Finding depth in the interviews is important, and our analysis and understanding indicated that even the shortest interview yielded sufficient depth in the data by providing rich quotes. One important question is whether the full variation of understanding of the phenomena was captured in the categories

described. The number of participants to be approached was not predefined and there might have been more categories, but no new information was revealed during the last interviews, therefore recruitment of participants was stopped. Feedback from the participants was not used as triangulation, as it is not regarded as an appropriate phenomenographic validity check. The aim is not to capture a particular individual's understanding, but to capture the range of understanding within a particular group²¹¹.

Since it is important that the data is dependable and that the results are stable, the data were approached from more than one perspective, and in both studies several researchers were involved in the analysis or as peer-reviewers²¹². The researchers' combined expertise covered, in Study I: physical therapy, rheumatic diseases, psychosomatic diseases, teaching, and qualitative research, and in Study IV: physical therapy, occupational therapy, rheumatic diseases, teaching and qualitative research. Grouping interviews into categories of description was agreed upon by the researchers involved. A qualitative approach does not attempt to generalize the results to the whole population group, but the findings must be recognizable in a clinical setting and understandable to others²¹³. Thus, the majority of participants in the studies were women and relevant background data was collected for descriptive purposes.

6.4.2 Studies II and III

External validity

A coaching intervention including the challenge to adopt health-enhancing physical activity might attract patients that already have an interest in physical activity. The result should therefore be interpreted with caution and presumed to be valid mainly for patients holding such an interest in physical activity. However, one could assume that those are the individuals PTs are most likely to reach in clinical practice, and thus the results are probably valid for those at target. When interpreting the present results, it is also important to consider that only 64 % of the eligible participants were included in the cluster analysis in Study II. Furthermore, only 69 % of the Study III participants in the IG and 69 % in the CG completed the follow-up period by filling out and mailing the questionnaire on physical activity two years after study start. However, there were no significant baseline differences in Study II between the final cluster sample and the excluded participants regarding cluster variables or descriptive variables. In Study III, no statistically significant differences were found in any outcome variables or demographic variables at baseline between those that were drop-outs at follow-up and

their respective group peers. Further, cluster solutions are sample-dependent, so replication in other samples is needed despite the fact that the eight-cluster solution was largely reproduced in the random two-thirds of the sample. The labels for the clusters in Study II have not been validated by other qualitative or quantitative means. However, to give the clusters clinical relevance, they were labeled according to the number of included variables with median/mean values higher than the total sample median/mean value.

Internal validity

Outcomes in RCTs can be biased by expectations, but prevented by blinding. The present RCT was only assessor-blinded since blinding the PTs who delivered the intervention or the patients receiving the intervention was not possible. Further, to prevent selection bias, allocation to IG or CG was generated by the throw of a dice. Also, an intention to treat analysis was performed with last-value-carried-forward. Another design weakness is the lack of information regarding the actual amount of extra physical therapy received outside the study intervention, which could have influenced the differences between the IG and the CG. Furthermore, several PTs collected data and delivered the intervention, which might also have affected the outcome. To reduce this risk, the PTs underwent a training program and the assessments chosen were well known within clinical care in rheumatology.

The assessments used in this thesis have both strengths and limitations. Most of the assessments used were valid and/or reliable for the RA population. The level and frequency of physical activity was self-reported by a questionnaire. Thus, the questions on physical activity, self-efficacy and outcome expectations were tested for test-reliability in the present work with satisfactory results. The limitation of self-reported assessment for physical activity is the complex nature of physical activity itself. Recall bias may exist and differ between individuals, as may over-reporting due to social desirability²¹⁴. Another possible bias is the individual understanding and interpretation of what different intensities actually mean¹²¹. On the other hand, the self-reported questionnaire only included three questions and was filled out at baseline at the physical therapy clinics, thus the PT could answer any questions or resolve ambiguities. Using a questionnaire designed for this specific study also make comparison to other populations difficult, due to different methodological aspects. The change of main outcome measure for perceived health from EQ VAS at post

intervention to the Global VAS in Study III might be questioned, but this was done for practical reasons due to the attrition rate for EQ VAS. This was not expected to be a problem because the two measures correlated well at baseline. Still, these data were collected in different contexts by either physical therapists or at medical check-ups, which might have influenced the results.

Statistical considerations

Some of the ten rheumatology clinics participating did not report to the RA register at the time of two-year follow-up, which resulted in loss of data on general health perception, pain, disease activity and activity limitation. Study III was thus underpowered to detect important differences such as the 20 % difference in proportions of patients improving by 15 mm or more on the perceived general health scale. Therefore, although little difference was observed between groups, the statistical tests were unlikely to provide evidence against the null hypothesis. This weakness could only partly be considered as compensated for by our use of intention-to-treat analysis. Last-value-carried-forward is a simple method of imputation that might be exposed to bias, which was still used it as it is the most frequently used method in the actual field. The determination of the size of clinically relevant change on the ordinal scales VAS pain and EQ-5D VAS might also be questioned. However, the estimated measurement error and clinical importance in the present work were based on previous studies^{215,216}. In Study II, not all cluster variables produced the same data level, and the variables not already producing ordinal categorical data were transformed to make them contribute approximately equally to the definition of clusters and to the elimination of potential effects of scale differences. The variables were thus either categorized according to previous suggestions or on data (lower quartile, median and highest quartile) from the present sample. This reflects a pragmatic approach to make the categorization clinically relevant.

6.5 FUTURE RESEARCH

In future research, exploring different ways of understanding the adoption of physical activity including exercise among patients with RA would be of interest, in order to subsequently relate them to the ways of understanding exercise maintenance that were identified in this thesis. Furthermore, the exploration and evaluation of PTs' professional support regarding adoption and maintenance of physical activity promotion would be a valuable complement to the ways of understanding exercise maintenance described in the present work. Studying different motivational styles defined in terms of the SDT motivation continuum among patients with RA, would form a valuable basis for PTs' work with physical activity promotion. Fidelity issues are another important area for future study, i.e. to what extent PTs deliver coaching as intended, and in what way they influence the outcome of physical activity interventions.

6.6 CONCLUSIONS

The following conclusions are based on the present work investigating aspects of coaching in physical therapy that might be of importance for physical activity behavior by exploring patients' ways of understanding exercise maintenance, PTs' ways of understanding exercise promotion and the effects of a one-year coaching intervention delivered in everyday practice by PTs.

- Exercise maintenance in patients with RA can be described by the categories 'external control', 'sticks and carrots', 'a joint venture', 'the easy way', and 'on one's own terms', based on the type of support needed along with personal factors, and can be interpreted as a continuum with respect to the resources required from a PT.
- Partially time-stable patterns of general health can be identified in patients with early RA, and a one-year coaching intervention targeting the adoption of health-enhancing physical activity confer the largest self-reported health status improvement in patients more severely affected by their disease at baseline, although the underlying mechanisms remain unclear.
- A one-year coaching intervention targeting adoption of health-enhancing physical activity in patients with early RA does not confer a long-term increase in perceived health, and the coaching intervention does not result in maintenance of health-enhancing physical activity behavior.

- The understanding of exercise promotion among PTs can be described in four categories, hierarchically organized and interrelated regarding aspects of teaching and learning: 'to tell and inform', 'to identify and pilot', 'to discuss and enable' and 'to listen and inspire'. These categories differ regarding the key aspects knowledge and responsibility in exercise, setting and supervision, tools to support behavior change and the role of the PT.
- Important aspects of physical activity coaching for patients with RA might be the interaction between the PT and the patient, based on the patients' motivational type in addition to the PT's as well as the patient's regulation of learning. Finding congruence in this interaction could be a way to enhance learning of physical activity behavior by developing patients' self-regulations.

7 ACKNOWLEDGEMENT

It's the Journey that's Important...

*Life, sometimes so wearying
Is worth its weight in gold
The experience of traveling
Lends a wisdom that is old
Beyond our 'living memory'
A softly spoken prayer:
"It's the journey that's important,
Not the getting there!"*

*Ins and outs and ups and downs
Life's road meanders aimlessly?
Or so it seems, but somehow
Leads us where we need to be,
And being simply human
We oft question and compare....
"Is the journey so important
Or the getting there?"*

*And thus it's always been
That question pondered down the ages
By simple men with simple ways
To wise and ancient sages....
How sweet then, quietly knowing
Reaching destination fair:
"It's the journey that's important,
Not the getting there!"*

(John McLeod)

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