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Physical activity in rheumatoid arthritis

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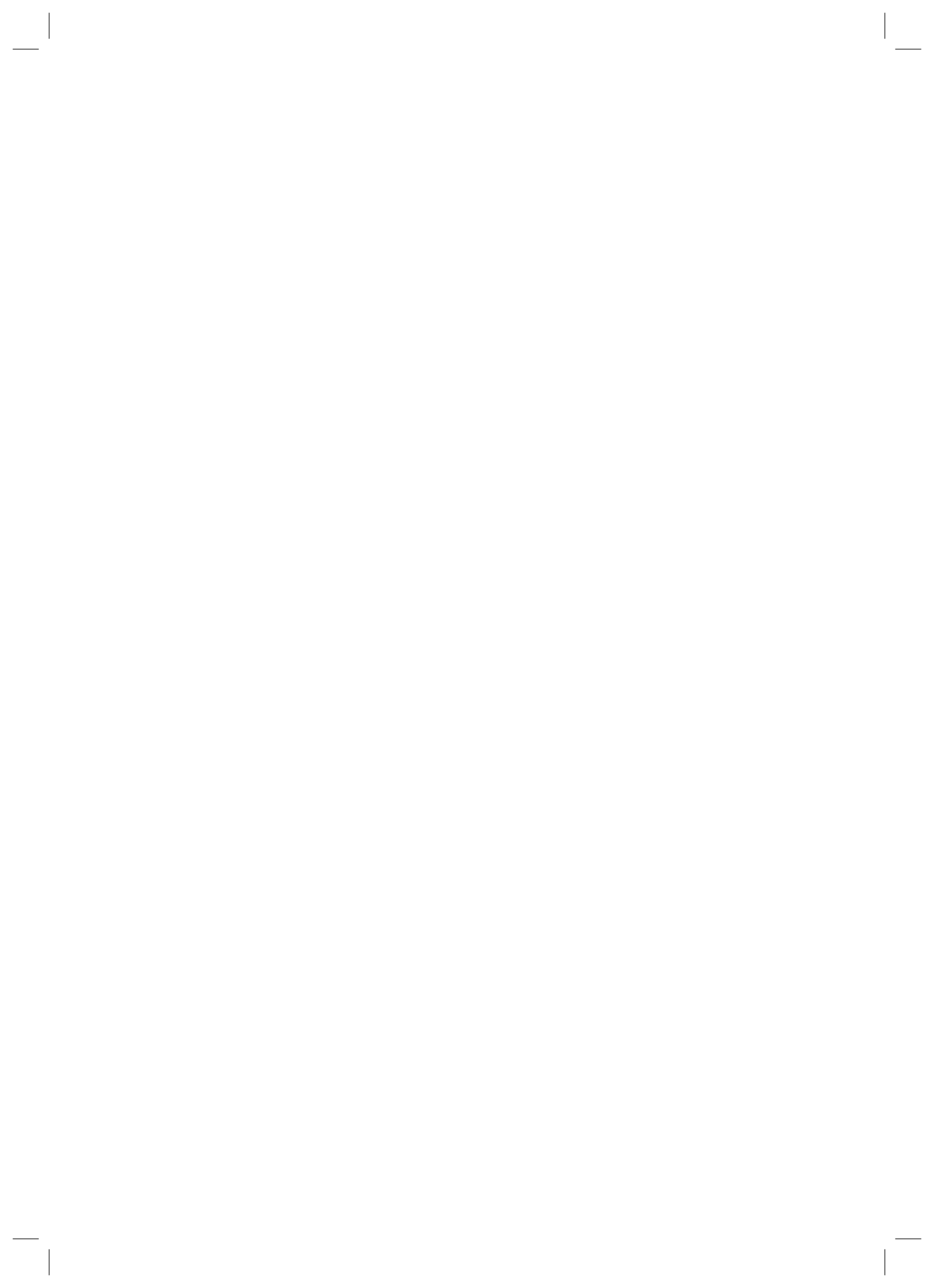
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To the PARA study group



ABSTRACT

Physical activity in rheumatoid arthritis

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Physical activity confers health benefits in the general population and should also be applied to people with rheumatoid arthritis (RA). However, there is a need for more research in this area. The aim of this thesis was thus to explore attitudes to physical activity, to identify correlates and predictors for self-reported physical activity and general health perception, and to investigate the applicability of aerobic fitness testing among patients with RA.

Sixteen patients were recruited for a phenomenographic study (I). A sample of 556 patients (median age 56 years, disease duration ≤ 6.5 years, 75% women) were recruited from 17 rheumatology units for studies on physical activity in RA (PARA studies): 298 for a descriptive cross-sectional study (II), 102 of these for a descriptive prospective study (III), and the 298 together with another 258 patients for a methodological study (IV). Semi-structured, in-depth interviews were carried out for Study I. Self-reported data on physical activity, health locus of control and perceived exertion, tests of body functions (aerobic fitness, lower extremity function, grip force, joint range of motion, balance) and measures of the EULAR minimum core set of disease activity (inflammatory activity, general health perception, pain, disability) were collected for Studies II-IV.

Four different categories of attitudes to physical activity were identified: "motivated and satisfied", "unmotivated and satisfied", "motivated and dissatisfied" and "unmotivated and dissatisfied" (I). A majority of the patients displayed impaired body functions compared to norm data, and about half reported physical activity behaviours that were too low to comply with public health recommendations. Correlations between physical activity and other variables were all low. Variation in general health perception was explained mainly by pain (II). Physical activity, perceived general health and pain were stable over one year, while disease activity (DAS28) decreased and three out of four studied body functions improved. High physical activity at baseline was the only predictor of high physical activity after one year. Low pain, high physical activity and good lower extremity function were identified as predictors of good general health perception (III). Seventy-six percent were able to complete a submaximal test of aerobic fitness. The main reasons for never being tested (16%) or for terminating testing prematurely (8%) were use of beta blockers or impairments. Correlations between work heart rates and perceived exertion were low during aerobic fitness testing.

Despite all efforts to treat patients with RA effectively, impairments remain common. Health perception is still mainly influenced by pain, but also by physical activity and lower extremity function. Fitness testing to design and evaluate physical activity interventions is applicable to most patients. Physical inactivity and unmotivated or dissatisfied attitudes to physical activity highlight the challenge for physiotherapists to promote different kinds of physical activity and contribute to good health among patients with RA.

Keywords: Attitudes, body functions, disability, epidemiology, exercise test, general health perception, physical activity, physical therapy, rheumatoid arthritis

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SAMMANFATTNING

Fysisk aktivitet vid reumatoid artrit

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Nyttan av fysisk aktivitet i befolkningen bör kunna överföras till personer med reumatoid artrit (RA). Dock behövs det mer forskning på området. Syftet med denna avhandling var därför att undersöka attityder till fysisk aktivitet, att identifiera samband med och prediktorer för självrapporterad fysisk aktivitet och självskattad hälsa samt att undersöka tillämpningen av konditionstestning hos patienter med RA.

Sexton patienter rekryterades till en fenomenografisk studie (I). Ett stickprov av 556 patienter (medianålder 56 år, sjukdomsduration ≤ 6.5 år, 75% kvinnor) rekryterades från 17 reumatologenheter för att studera fysisk aktivitet vid RA (PARA-studien): 298 till en deskriptiv tvärsnittsstudie (II), 102 av dem till en deskriptiv prospektiv studie (III) och de 298 samt ytterligare 258 patienter till en metodstudie (IV). Halvstrukturerade djupintervjuer genomfördes i Studie I. Självrapporterad fysisk aktivitet, "health locus of control" och upplevd ansträngning, tester av kroppsfunktioner (kondition/syreupptagningsförmåga, benmuskelfunktion, handstyrka, ledrörlighet, balans) samt mätningar från EULARs "minimum core set of disease activity" (inflammatorisk aktivitet, självskattad hälsa, smärta och aktivitetsbegränsning), samlades in till Studie II-IV.

Fyra olika kategorier av attityder till fysisk aktivitet identifierades: "motiverad och nöjd", "omotiverad och nöjd", "motiverad och missnöjd" och "omotiverad och missnöjd" (I). En majoritet av patienterna hade funktionsnedsättning jämfört med normaldata och ungefär hälften rapporterade fysisk aktivitet som låg under nivån för de allmänna hälsorekommendationerna. Sambanden mellan fysisk aktivitet och andra variabler var alla svaga. Variation i självskattad hälsa förklarades i huvudsak av smärta (II). Fysisk aktivitet, självskattad hälsa och smärta var oförändrade efter ett år medan sjukdomsaktiviteten (DAS28) minskade och tre av fyra studerade kroppsfunktioner förbättrades. Hög fysisk aktivitetsnivå vid första mättillfället var den enda prediktorn för hög fysisk aktivitetsnivå efter ett år. Låg smärta, hög fysisk aktivitetsnivå och god benmuskelfunktion identifierades som prediktorer för god självskattad hälsa (III). Sjuttiosex procent genomförde ett submaximalt konditionstest. Huvudorsakerna till att inte påbörja (16%) eller avbryta (8%) testning var medicinering med betablockerare eller funktionsnedsättning. Sambandet mellan arbetspuls och upplevd ansträngning var lågt under konditionstestning.

Trots alla ansträngningar att effektivt behandla patienter med RA är funktionsnedsättning fortfarande vanligt förekommande. Den upplevda hälsan påverkas ännu i huvudsak av smärta, men också av fysisk aktivitet och benmuskelfunktion. Konditionstestning för att kunna lägga upp och utvärdera interventioner med fysisk aktivitet är tillämplig för de flesta patienter. Fysisk inaktivitet och en omotiverad eller missnöjd attityd till fysisk aktivitet är en utmaning för sjukgymnaster vad gäller att befrämja olika slags fysiska aktiviteter och därmed bidra till en god hälsa bland patienter med RA.

Nyckelord: Attityder, epidemiologi, funktionshinder, fysisk aktivitet, konditionstest, kroppsfunktion, reumatoid artrit, sjukgymnastik, självskattad hälsa

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PUBLICATIONS

This thesis is based on the following papers, which will be referred to by their Roman numerals:

- I. Eurenus E, Biguet G, Stenström CH. **Attitudes toward physical activity among people with rheumatoid arthritis.** *Physiotherapy Theory and Practice* 2003;19:53-62
- II. Eurenus E, Stenström CH, the PARA study group. **Physical activity, physical fitness, and general health perception among individuals with rheumatoid arthritis.** *Arthritis & Rheumatism* 2005;53:48-55
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- IV. Eurenus E, Sturk N, Stenström CH, the PARA study group. **Clinical applicability of two tests of aerobic fitness in patients with rheumatoid arthritis.** Submitted

Permission for reprinting the papers has been received from the publishers.

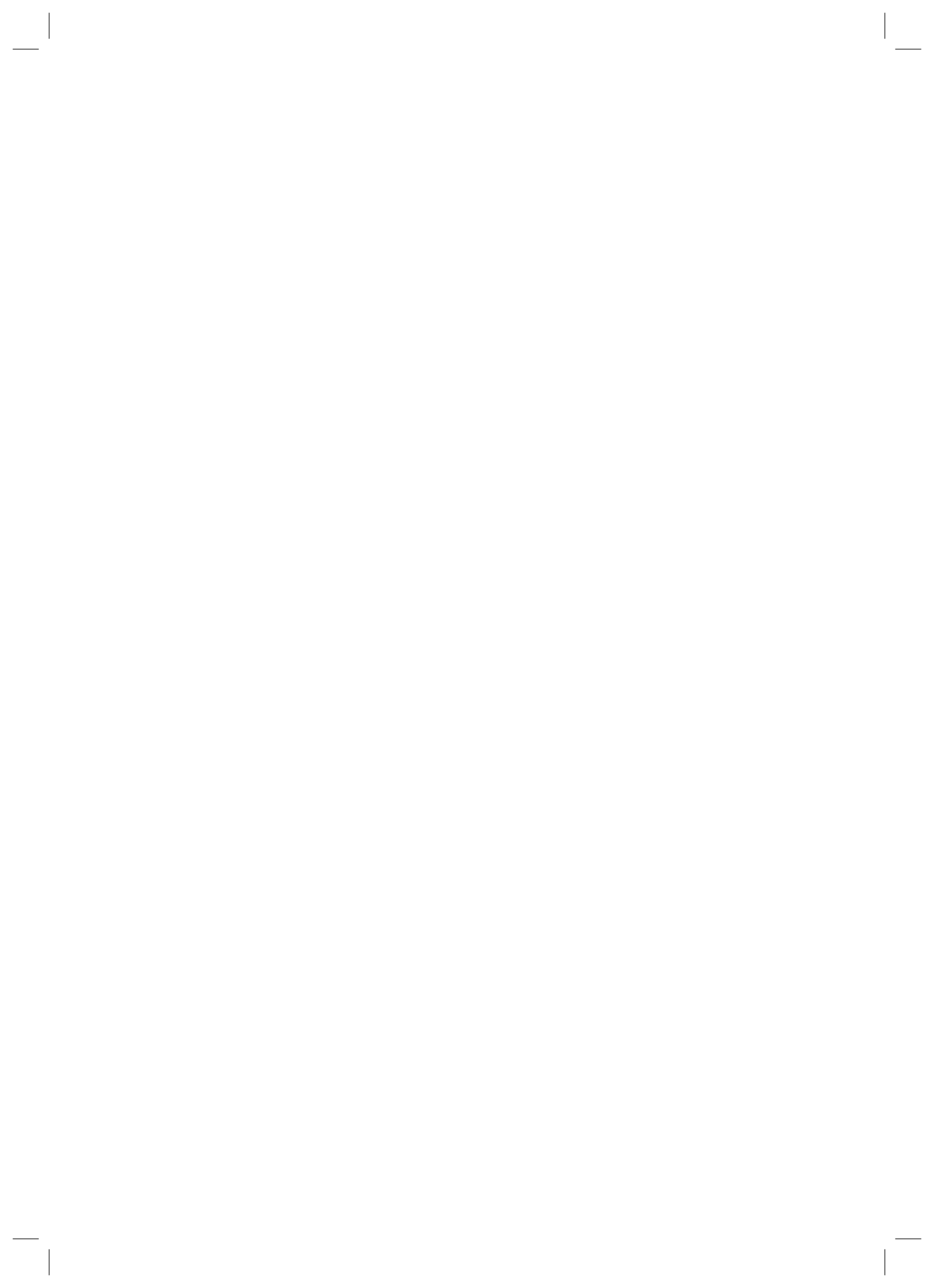
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ABBREVIATIONS

ACR	American College of Rheumatology
ADL	Activities of Daily Living
ANOVA	Analysis of Variance
CI	Confidence Interval
DAS28	Disease Activity Score 28-joint count
DMARD	Disease-Modifying Anti-Rheumatic Drug
EPM-ROM	Escola Paulista de Medicina-Range of Motion
EULAR	European League Against Rheumatism
FIMS	International Federation of Sports Medicine
HAQ	Health Assessment Questionnaire Disability Index
HLoC	Health Locus of Control
ICF	International Classification of Functioning, Disability and Health
md	median
MHLC-C	Multidimensional Health Locus of Control Scales, form C
MET	Metabolic Equivalent Turnover
NIH	National Institute of Health
NSAID	Non-Steroidal Anti-Inflammatory Drug
OR	Odd Ratio
PARA	Physical Activity in Rheumatoid Arthritis
RA	Rheumatoid Arthritis
RPE	Rating of Perceived Exertion
TNF	Tumor Necrosis Factor
AS	Visual Analogue Scale
VO ₂ max	maximum Oxygen uptake
WCPT	World Confederation for Physical Therapy
WHO	World Health Organization
WHR	Work Heart Rate



INTRODUCTION

Rheumatoid arthritis (RA) is a chronic, inflammatory and systemic disease which causes impairments, activity limitations and participation restrictions. The disease is often associated with reduced levels of physical activity and increased risk of co-morbidity and premature death, which lends weight to the importance of implementing a healthy life style. One prerequisite for early optimal care of patients with RA, including physiotherapy, is to survey attitudes, correlates and predictors related to physical activity and perceived health.

PHYSICAL ACTIVITY AND EXERCISE

Physical activity includes everyday physical activity such as household activity indoors- and outdoors, occupational activity and leisure-time physical activity as well as planned exercise. Physical activity has been defined as “any bodily movement produced by skeletal muscles that results in energy expenditure” (17). Physical inactivity denotes a level of activity less than that needed to maintain good health (85).

Exercise is 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” (17). In this thesis “physical fitness” is used when referring to original work using the term and in Studies I-II, while the term body functions, which fits better in the context of ICF (International Classification of Functioning, Disability and Health), is used in Studies III-IV. Aerobic fitness, muscular strength and endurance, joint range of motion and balance are the body functions which are usually targeted for improvement by exercise.

In the literature the concepts aerobic capacity/fitness and cardiorespiratory endurance/fitness are often used interchangeably. In the present thesis the term aerobic fitness is used and reflects the ability of the body’s circulatory and respiratory systems to supply fuel during sustained physical activity (17). It is quantified as estimated maximum oxygen uptake ($VO_2\max$) expressed as litre oxygen uptake per minute or millilitre oxygen uptake per kilogram body weight per minute. Aerobic exercise involves large muscle groups in dynamic activities that result in substantial increases in heart rate and energy expenditure. Regular participation results in improvements in the function of the cardiovascular system and the skeletal muscles, leading to an increase in endurance performance (52).

Muscular endurance relates to the ability of muscle groups to exert external force for many repetitions or successive exertions, while muscular strength relates to the amount of external force that a muscle can exert (17). Resistance exercise aims specifically to increase muscular strength and endurance by varying the resistance, the number of times the resistance is moved in a single group (set) of exercises, the number of sets done and the rest interval provided between sets (52). Flexibility relates to the range of motion available at a joint (17), and flexibility exercise aims to maintain or increase joint range of motion. Balance relates to the maintenance of equilibrium while stationary or moving (17) and balance exercise aims to maintain or improve the ability to balance during postures or activities.

Dose-response refers to the relationship between increasing levels/doses of physical activity or exercise on changes in the levels of a defined health measure (e.g. risk factor, disease, anxiety level and quality of life) (52). The characteristics of frequency, duration and intensity are used to describe the extent of physical activity or exercise. Frequency is easily described as the number of activity sessions per day, week or month, and duration typically refers to the length of time in each session. Intensity describes the effort associated with the physical activity, often divided into low/light, moderate, hard/high, and very vigorous/strenuous. One method of characterising physical activity intensity at different levels of effort referenced to body mass is based on the standard metabolic equivalent turnover, or MET level. This unit is used to estimate the amount of oxygen uptake by the body during physical activity, 1 MET = the energy (oxygen) used by the body at rest (4). Another method of determining physical activity intensity is the Borg's Rating of Perceived Exertion (RPE) used in the present thesis, of how hard someone feels their body is working (11). A physical activity performed at a moderate level of intensity, such as walking briskly, is approximately equivalent to 3-6 METs (range 1-18), 40-60% of max VO_2 or a perceived exertion rating 11-14 on the Borg's RPE Scale (range 6-20).

Physical activity as health promotion

Physical inactivity is a general health problem in the western world (18, 85) and poor aerobic fitness is a significant risk factor for all-cause mortality in both men (10, 69) and women (10, 88). Epidemiological and experimental studies indicate that physical activity reduces the risk of cardiovascular disease (75, 89, 92, 117), type 2 diabetes (64, 92), obesity (133), osteoporosis (92, 139), colorectal cancer (92, 105), depression (25, 92), mental stress and life dissatisfaction (100). It is therefore recommended that each individual accumulates 30 minutes or more of moderate-intensity physical activity on most days of the week (85, 92, 131).

Correlations have been found in cross-sectional studies between physical activity and general health perception (32, 33, 41, 98, 99, 103), between physical fitness and health perception (114) and between physical activity and aerobic fitness (32, 89) in populations with different ages and sex. Physical inactivity (90, 91) as well as lack of exercise (115) are significant predictors of poor health perception.

PHYSIOTHERAPY

Physiotherapy aims to maintain optimal functioning, which could be obtained by physical activity and exercise. Physiotherapy was incorporated into the pedagogical science by Per Henrik Ling in the early 19th Century (3). Ling regarded movements as a medium to gain health with both a preventive and a curative aim. There has long been considerable agreement on one of the main concepts, "human movement", within physiotherapy (49). Carr & Shepherd saw the future development of physiotherapy as applied movement science (15). Bergman later defined the distinctive nature of physiotherapy as based on the knowledge and studies of human movement and the scientific basis as being to a considerable extent made up of movement science (8). The World Confederation for Physical Therapy (WCPT) reflects one central issue of physiotherapy as its focus on the movement needs and potential of the individual (127). WCPT further states that the nature of physiotherapy "is to provide services to people and populations to develop, maintain and restore maximum movement and

functional ability throughout the lifespan". Physiotherapy includes "the provision of services in circumstances where movement and function are threatened by the process of ageing or that of injury or disease" (127).

INTERNATIONAL CLASSIFICATION OF FUNCTIONING, DISABILITY, AND HEALTH

The World Health Organization's International Classification of Functioning, Disability and Health (ICF framework) (130) provides a unified and standardised language and framework for the description of health and health-related status and to permit comparison of data across countries, health care disciplines, services, and time. It is based on the biopsychosocial model, with different biological, individual and social perspectives of health. The structure of the ICF offers the possibility of measuring health status at several levels: impairment, activity limitation and participation restriction and also provides a model for how they interact (Figure 1). This structure enhances the possibility of grasping the total implications of a disease in an individual, also including contextual factors such as environmental and personal factors.

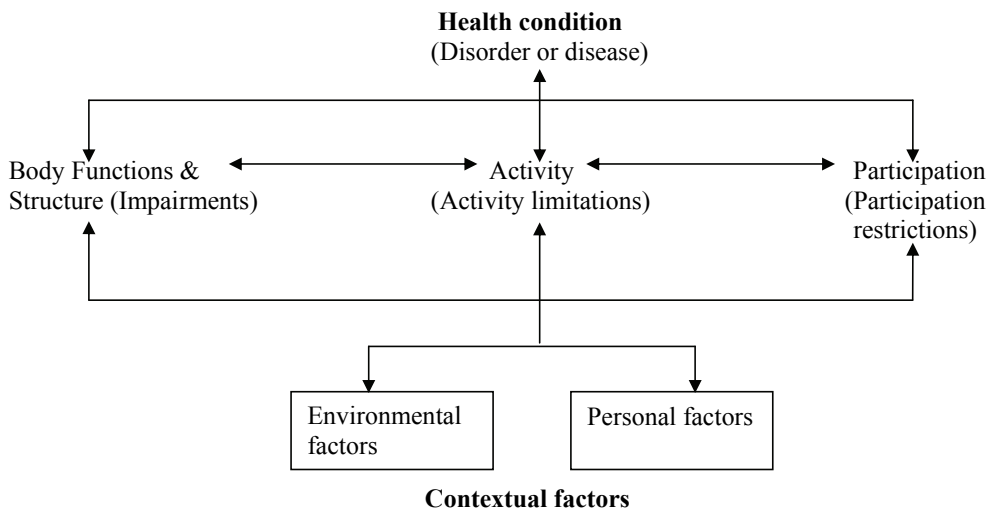


Figure 1. The current framework of disability and functioning.

“Functioning” is the umbrella term encompassing all body functions and structures, the activities we do in daily life (activity), and how we participate in society (participation). “Disability” is the umbrella term for the causality of a health-related condition on different levels as impaired body functions and structures (impairment), limitation of our ability to perform activities of daily life (activity limitation), and restrictions on our ability to participate in society (participation restriction).

HEALTH PERCEPTION

There are many different concepts in the area of general health perception, such as "global health", "well-being", "health-related quality of life" and "health status". Patients' "global assessment of disease activity" is included in the "minimum core set of disease activity" (35) used by rheumatologists. In the present study this measurement is expressed as "general health perception" which attempts to grasp patients' self-rated general health with both physical and mental aspects related to their arthritis, rated on a visual analogue scale (VAS). Subjective health assessments such as self-rated health are often superior to objective assessments frequently used as a predictor of premature mortality but less often as an outcome variable (115). However, there are also difficulties in studying predictors of general health perception, as concluded in a study of patients with juvenile chronic arthritis, probably due to the broad spectrum of factors affecting the outcome (97).

RHEUMATOID ARTHRITIS

Arthritis means inflammation in one or more joints. There are over 100 different kinds of arthritis, and one of the most common is rheumatoid arthritis (RA). RA is an autoimmune disease, which means that the body's natural immune system attacks healthy joint tissue, initiating a process of inflammation and joint damage. The disease is characterised by symmetric arthritis causing pain, swelling, stiffness and often fatigue and its course by periods of disease flare-ups and remissions. The prognosis is difficult to predict in individual cases. Manifestations of inflammation in internal organs may occur in patients with relatively severe RA. The exact cause of RA is not yet known, but genetic and environmental factors contribute to the development of the disease, and long term smoking is found to be one potential trigger (62). There is an increased risk of osteoporosis (67) as well as morbidity (135) and premature deaths related to cardiovascular and cerebrovascular diseases in RA (137). High levels of disease activity (19, 140) are found to be a powerful predictor of premature death in RA.

The prevalence of RA in the population is 0.5-0.7%. The annual incidence of RA is 24/100 000 (116) with an incidence among women twice as high as that among men. The median age for disease onset is 55 years but RA may affect persons of all ages.

The criteria for RA diagnosis are defined by the American College of Rheumatology (ACR) (5) as the presence of four or more of the following: 1) morning stiffness in and around joints lasting at least 1 hour; 2) soft tissue swelling (arthritis) of three or more joint areas observed by a physician; 3) swelling (arthritis) of the proximal interphalangeal, metacarpophalangeal or wrist joints; 4) symmetric swelling (arthritis); 5) rheumatoid nodules; 6) the presence of rheumatoid factor; and 7) radiographic erosions and/or periarticular osteopaenia in hand and/or wrist joints. Criteria 1 to 4 must have been present for at least 6 weeks.

Disability and general health perception

RA is related to body structures, mainly the connective tissues in the musculoskeletal system, and body functions. From the patients' perspective, pain is a dominant concern (14, 48) and many patients with early RA continue to suffer pain despite therapy. Other symptoms such as fatigue (14, 102) and depression also play a major part (102). Reduced aerobic fitness (7, 20, 28, 30, 76), decreased muscular strength (7, 28, 30, 55, 56) and endurance (30), limited flexibility (27, 76), and poor balance (29, 87) have been found in studies involving individuals with RA.

As a result of the clinical progression activity limitations occur within a few years (102), and the increased risk of premature death tends to be associated with activity limitations (136). More activity limitations are found in women with RA than in men and this is explained by lower grip force rather than by gender (118). The use of assistive devices, mostly used while eating and drinking, significantly reduces the difficulties (119). People with arthritis have been found to be as physically active as the general population (138), or less active (18, 30, 51, 109, 121).

RA has many consequences for the individual but also for their significant others and for society in general (102). Many patients are not able to continue to work at the same level as they would if they had not developed RA. It has been estimated that about one-third of people with RA leave employment prematurely, and work disability involves patients with early RA as well as those with long-standing RA (102). Participation restrictions in leisure-time activities have also been reported with a reduction of 2/3 after disease onset and the remaining activities are conducted at a much lower level, e.g. watching TV instead of going to the gym (132).

Not only decreased pain, "mobility" and fatigue, but also a "general feeling of wellness" were identified as important outcomes from treatment in an interview study with patients with RA (14). Moreover, RA is found to have a considerable impact on general health status compared to people with low back pain and the general population (9) and it is therefore important to pay attention to patients' perceived general health within health care. Particularly among elderly women (65–79 years), RA and cancer seem to make the largest contribution to poor self-rated health compared to other chronic diseases (78).

Team care

There is no known cure for RA and treatment will therefore be directed toward relieving symptoms and improving the progression of the disease. The goal of treatment is to decrease disease activity, prevent impairments, activity limitations and participation restrictions, and to achieve and maintain good general health perception. Early treatment of RA results in better outcomes (1). The optimal treatment of RA requires comprehensive coordinated care where different professionals are involved, although more studies on the effectiveness of team care are needed (93). An important part of the treatment is to follow the progression of the disease and evaluate interventions by using outcome measures of effectiveness both of individual treatments and of interventions by the multidisciplinary team. The care and rehabilitation includes a customised combination of medication, surgery, patient education, ADL training, physical activity and exercise, social and psychological counselling and joint protection.

Pharmacological and surgical treatment

When treating patients with RA, the clinicians' focus is on remission (102). The fast-acting first-line drugs, such as aspirin or other Non Steroidal Anti-Inflammatory Drugs (NSAID) and cortisone (corticosteroids), are used to reduce pain and inflammation. The slow-acting second-line drugs, such as gold and methotrexate (also referred to as Disease-Modifying Anti-Rheumatic Drugs or DMARDs) promote disease remission and prevent progressive joint destruction, without having any anti-inflammatory properties. Combinations of NSAIDs, DMARDs and/or cortisone are commonly employed (1). Etanercept (Enbrel), infliximab (Remicade), and adalimumab (Humira) are what are known as biological medications. These new medications intercept a protein (tumor necrosis factor, or TNF) that causes joint inflammation and inhibits it. The biological medications effectively blocks the TNF inflammation messenger from triggering inflammation. Symptoms can be significantly, and often rapidly, improved in patients taking these drugs, resulting in dramatic positive changes for many individuals with rheumatic inflammation. However, restrictions on receiving the drugs and loss of efficacy may pose a problem. The different types of surgical interventions include carpal tunnel release, synovectomy, resection of the metatarsal heads, total joint arthroplasty and joint fusion (1).

Physiotherapy

The main goal of physiotherapy in RA is to reduce pain and restore or maintain optimal functioning (38). The cornerstone of physiotherapy is supervised exercise, which includes various counselling and educational services tailored to the patients' needs, lifestyles and abilities in relation to the consequences of the disease. The aim of physiotherapy is then to raise awareness of exercise and physical activity as ways of managing pain and to improve functioning. However, barriers less explicit than pain need to be explored and overcome to initiate and successfully maintain physical activity in individuals with RA.

The general recommendations on daily physical activity to maintain good health in the general population are also applicable to individuals with arthritis (138). Systematic literature reviews have concluded that moderate or high-intensity dynamic exercise in the short term is effective in increasing aerobic fitness and muscle strength with no negative effects on pain or disease activity (54, 110, 124, 129). However, the effect on activity limitation is still unclear (107, 125, 129). One study indicates that physically active women with both a shorter and a longer duration of RA are able to maintain their aerobic fitness at the same levels as age-matched healthy people (55). The recommended type, frequency, duration, and intensity of exercise for individuals with RA is described in the literature (54, 112). A recent literature review on the outcome of regular moderate or high-intensity exercise effect demonstrates either decreased or stable disease activity in the long term (24). The progression of joint damage is more ambiguous (24). On the one hand, it is indicated that high-intensity weight-bearing exercises are safe for the joints of hands and feet (23), while on the other hand these exercises appear to slightly accelerate joint damage in patients with preexisting extensive damage (81). It should not be forgotten that a basic condition for many physical activities for individuals with RA is feet that function well. A systematic literature review found that orthoses and special shoes are likely to be beneficial in patients with RA (34).

Determinants of physical activity and exercise behaviour

Despite all existing evidence of the benefits of physical activity and exercise, a study has found that opinions and beliefs about the usefulness of exercise for patients with RA still vary among health-care providers at a major university hospital in the U.S. (58). In the Netherlands, patients, rheumatologists and physiotherapists were all found to have more positive expectations of conventional exercise programmes than of high-intensity exercise programmes. The physiotherapists were the least positive about outcomes of high-intensity exercise programmes while the rheumatologists and the patients were more positive (80). However, influencing a physically inactive person's lifestyle is a very complex matter and could vary in different countries. Advice alone is found to be insufficient to promote increased physical activity in adults with arthritis. On the other hand, less than 50% of adults with arthritis reported, in a large population-based survey in the U.S., ever being advised by a health professional to become more physically active (36).

Mixed results are found as to whether personal factors like health locus of control (HLoC) contributes to our understanding of physical activity in the population (99, 113), although high internal HLoC was not proven to do so in a study of individuals with long-term RA (71). Motivation is another factor found in many studies to associate positively with physical activity level (99) and lack of motivation is considered as a potential barrier to exercise that requires the therapist's special attention (59). Studies of self-efficacy as a predictor of exercise behaviour in RA proved to have mixed results, although there are studies supporting personal factors, such as self-efficacy, as strong predictors of exercise behaviour in the population (99, 104). Previous studies have proven that compliance with an exercise regimen is predicted by high self-efficacy for exercise in RA (42, 58, 108) while later findings indicate contradictory results (57). However, in the latter study the exercise behaviour of patients and rheumatologists has been identified as a predictor of patient exercise behaviour six months after a clinic visit. The result is interpreted by the authors (57) in relation to the fact that past exercise behaviour include attitudes and self-efficacy which makes this variable more important and therefore extinguish the influence of personal factors, such as self-efficacy, in the analysis. Past exercise participation (82) and positive attitudes to the usefulness of exercise are well-known predictors of exercise behaviour identified among individuals with RA (42, 50, 58, 82).

Studies of different disease activity variables as predictors of exercise behaviour in RA have also provided mixed results. On the one hand, people with arthritis and less formal education, longer disease duration and higher self-reported disease activity perceived fewer benefits of exercise (22, 82), while on the other measures of disease activity (pain-VAS, DAS, HAQ) did not strongly predict exercise compliance for an intensive exercise programme (79). The most common reason given for lack of success with exercise was that the exercises were too painful (58, 109), and as in the general population (99), lack of time is found to be an important reason for people with RA to remain physically inactive (46, 58, 82). There are also problems of knowing how to exercise correctly and difficulties in establishing habits (46) which is a challenge for physiotherapists to address in their day-to-day work.

Measurement of disease activity and functioning

The value of any research rests in the validity, reliability and applicability of its outcome measures (84). Physician-focused assessments, such as the “Functional classification” (106), were common within rheumatology until self-reported methods were introduced. This change was based on the presumption that patients are more suitable to report their perceptions of health impairment (44). Within rheumatology essential components of the management of RA include systematic and regular evaluation of disease activity (1). The European League Against Rheumatism (EULAR) has suggested the “minimum core set of disease activity” (35) for evaluation of clinical trials in RA and is therefore to a great extent relevant to use this in the present thesis. The core set includes measures of tender and swollen joint count, patient’s assessment of pain, patient’s and physician’s global assessments of disease activity, patient’s assessment of disability and laboratory evaluation of one acute-phase reactant. To provide a global picture, composite measures have been required (102). The most commonly used composite measure is the Disease Activity Score (DAS28) (95) which consists of four of the above mentioned measures; erythrocyte sedimentation rate (ESR), swollen and tender joints (28-joint count) and general health perception.

There are no national or international agreements by other professional groups within rheumatology on a core set of common outcomes compatible with the “core set of disease activity” used by rheumatologists. A core set has been proposed, however (111), and international efforts to reach consensus are ongoing.

Within physiotherapy aerobic fitness tests are certainly valid in determining exercise intensity and in studying the outcome of exercise. A submaximal bicycle ergometer test (141) is frequently used in healthy people and in people with RA and the same applies to a submaximal treadmill test (26, 77). However, their validity and applicability for individuals with RA requires further investigation. Body functions such as muscular strength and endurance, joint range of motion and balance, which are also frequently impaired in RA and usually targeted for improvement by exercise, should also be evaluated by physiotherapists. Regarding measures of physical activity there are various options (101), but in large cross-sectional studies questionnaires are preferable for administration reasons.

While physiotherapists use the ICF terminology, rheumatologists include body structures (tender and swollen joint count), body functions (pain), and activity limitation and participation restriction (HAQ) along with general health perception as “disease activity measures” (35). This, together with a composite measure of disease activity (the DAS28), including general health perception, has caused confusion as to terminology in this thesis. Furthermore, different studies on patients with RA use the HAQ for measuring “functional disability”, (44, 66) or “functional ability” (39, 45, 79), and other terms not compatible with the ICF, although Scott et al have previously classified HAQ as a disability measure according to ICF (102). Terminology related to sports medicine, where “physical fitness components” are compatible with a range of body functions, has also interfered with that of ICF. It has naturally proved difficult to use ICF consistently in the present thesis.

THE SWEDISH RA REGISTER

The register was started in 1997 by the Swedish Society for Rheumatology for epidemiological purposes in the light of the knowledge that efficient treatment at disease onset results in better prognosis. Another aim of the Swedish RA register is to acquire new knowledge through systematic, long-lasting follow-ups of all people affected by RA to measure the disease consequences and effects of interventions. This knowledge is useful in the aim of the very best patient-focused care and treatment and for continuous improvements in the care of patients with RA. All individuals diagnosed with RA are systematically reported to a central database as regards demographics, medications and measures from the "core set of disease activity" (35). However, information about the patients' self-reported physical activity and measured body functions is still lacking in the register. Today almost all rheumatology units are connected to the register with about 15.700 patients included.

THE PARA STUDY

All 42 rheumatology units linked to the RA register through Sweden were invited in 1999 to participate in studies of physical activity of RA (PARA) and seventeen of them agreed. Within the PARA study group one or more physiotherapists took part at each rheumatology unit. The aim of the PARA study was to survey the consequences of physical activity, body functions and disease activity on general health in patients with RA. Physical activity and body functions, as predictors of physical activity and general health perception were also of interest to study, particularly their influence in relation to that of disease activity, pain and different demographic and psychosocial factors in the long term. The established Swedish RA register, together with positive health effects of physical activity in the general population, formed the basis for research in this area.

RATIONALE FOR THESIS

Physical activity confers health benefits in the general population (32, 75, 89, 92, 103), and this also appears to apply to people with RA. However, the need for more research on correlates of physical activity in populations with various health conditions, such as arthritis, has been suggested (33). Our knowledge on predictors of physical activity and general health perception among patients with RA is also limited. Aerobic fitness is an important outcome of physical activity and exercise (60), with low levels of reported physical activity and aerobic fitness as significant risk factors for all-cause mortality in the population (10). Considering the impairments in the form of pain, stiffness and fatigue frequently found among patients with RA, the clinical applicability of commonly used submaximal tests, such as the bicycle ergometer test or the treadmill test, might be questioned. Furthermore, a deeper understanding of different attitudes to physical activity among people with RA could be helpful for developing strategies on how to encourage physical activity in physiotherapy.

AIM

The overall aim of this thesis is to explore attitudes to physical activity, to identify correlates and predictors for self-reported physical activity and general health perception, and to investigate the applicability of one outcome method for physical activity among patients with rheumatoid arthritis (RA).

SPECIFIC AIMS

- I. To describe variations in attitudes to physical activity.
- II. To describe self-reported physical activity and body functions and to identify correlates of physical activity and general health perception.
- III. To describe changes over one year in physical activity, body functions and disease activity, including pain, general health perception, HAQ, and DAS28, and to identify predictors for physical activity and general health perception.
- IV. To describe the clinical applicability of two submaximal methods, the bicycle ergometer test and the treadmill test, to estimate aerobic fitness.

METHODS

DESIGN

The characteristics of Studies I-IV: study design, data sources, analysis and participants are described in Table I.

PARTICIPANTS

All study participants received verbal and written information about the present study. The inclusion criterion was RA diagnosis based on criteria suggested by the American College of Rheumatology in 1987 (5).

Inclusion in Studies II and III required the ability to perform at least three out of five tests of body functions, to complete one of two questionnaires, and the availability of disease activity data from the RA register within one week prior to or after the assessments. For inclusion in Study IV it was only required for each participant that any of the five fitness tests were performed and that disease activity data were available within five weeks prior to or after this assessment. A flow chart for all study participants in Studies I-IV is shown in Figure 2.

Study I. Sixteen outpatients, of whom 14 took part in the day rehabilitation programme at a rheumatology unit of a district hospital, participated. They were chosen strategically to represent different ages, genders, disease duration, level of functioning and health habits.

Study II. Two hundred and ninety-eight patients out of 484 asked to participate in the study fulfilled the inclusion criteria. They were recruited from 17 rheumatology units participating in the national Swedish RA register and involved in the PARA study.

Study III. One hundred and two patients out of 298 patients from Study II recruited from 14 rheumatology units were reassessed one year (9-15 months) after inclusion.

Study IV. Five hundred and fifty-six patients were included. They were recruited either among the originally 484 patients asked to participate in Study II (n=328) or among those (n=228) participating in a randomised controlled intervention study of physical activity performed at nine of the 17 participating units.

Table I. Characteristics of Studies I-IV: study design, data sources, analysis and participants.

Study	I		II		III		IV	
Study design	Explorative cross-sectional		Descriptive cross-sectional		Descriptive prospective		Methodological cross-sectional	
Data sources	Semi-structured in-depth interviews		Self-reported physical activity Tests of body functions The core set of disease activity		Self-reported physical activity Tests of body functions The core set of disease activity		Aerobic fitness tests The core set of disease activity	
Analysis	Qualitative (phenomenography)		Quantitative (multiple regression)		Quantitative (simple & multiple logistic regression)		Quantitative (Kruskall Wallis ANOVA)	
Participants, n	16		298		102		556 (328+228)	
Sex female/male, n (%)	12/4 (75/25)		225/73 (76/24)		76/26 (75/26)		416/140 (75/25)	
Age years, md (range)	61.5 (32-78)		57 (19-90)		57 (19-84)		56 (19-90)	
Disease duration, md (range)	16.5 years (1-45)		14 months (3-78)		15 months (4-78)		19 months (3-78)	
Disability (HAQ), n (%)								
No (HAQ=0)	0 (0) ¹		56 (21)		17 (19)		110 (22)	
Mild (HAQ=>0-1)	12 (75) ¹		155 (59)		58 (64)		290 (59)	
Moderate (HAQ=1.1-2)	3 (19) ¹		50 (19)		14 (16)		88 (18)	
Severe (HAQ=2.1-3)	1 (6) ¹		2 (1)		1 (1)		5 (1)	
Physical activity, n (%)								
At recommended level of physical activity or above	8 (50) ³		147 (53) ⁴		63 (64) ⁴		293 (55) ⁵	
Below recommended level ²	8 (50) ³		132 (47) ⁴		36 (36) ⁴		238 (45) ⁵	

¹The functional classification (classes I-IV) was used instead of HAQ (106) for Study I

²30 minutes or more of moderate-intensity physical activity on most days of the week

³Based on interview data

⁴According to a questionnaire used in Study II & III and for 328 participants from Study IV (32)

⁵According to a questionnaire for 228 participants from Study IV (unpublished data)

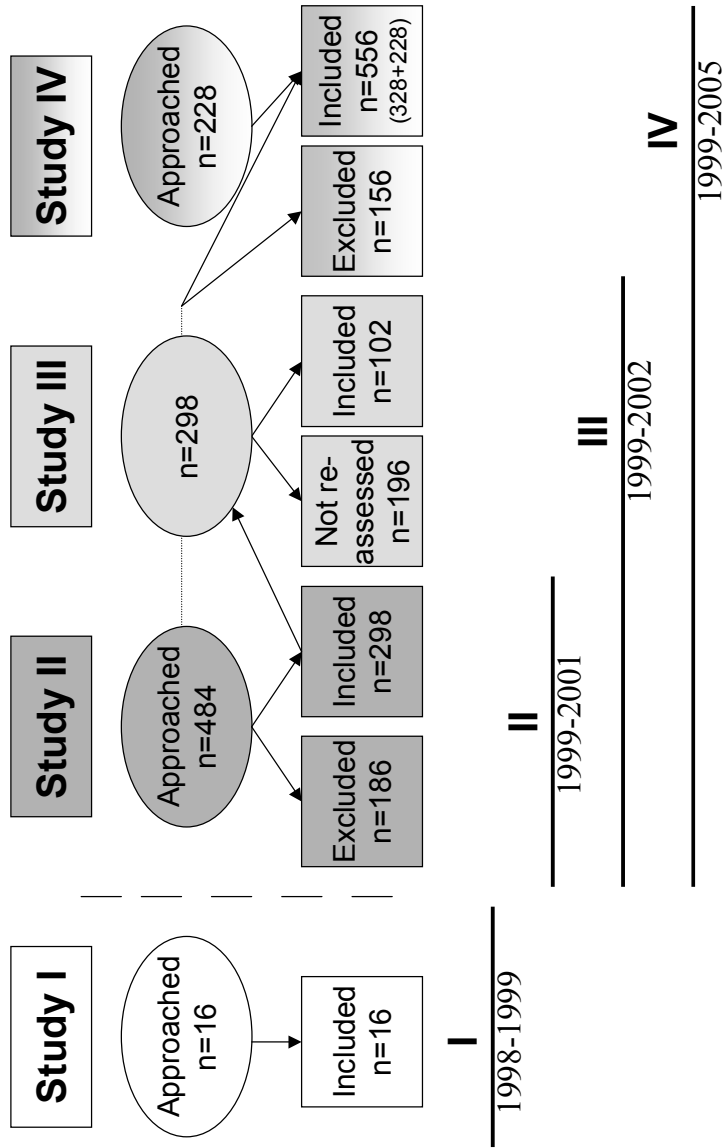


Figure 2. Flow chart for all study participants in the present thesis.

DATA COLLECTION

Phenomenographic interview

For Study I semi-structured, in-depth interviews were performed on the basis of an interview guide. The interviews were guided by an interest in different attitudes to physical activity and the interviews were audio-taped before being transcribed verbatim.

Assessment methods

The assessment methods of disease activity and functioning used in the present thesis are described according to the ICF in Table II.

PROCEDURE

For Studies II-IV the tests of body functions and administration of the questionnaires were mainly performed by one or more physiotherapists at the 17 different rheumatology units within their daily clinical routine. They had been trained to follow specific routines for testing. Demographics and data from the “core set of disease activity” were collected for the Swedish RA register on a physician visit within ten days prior to or after a physiotherapy visit. A minority of the participants (4%) were tested 11 days to five weeks prior to or after their physician visits for Study IV. The patient sample is a sample of convenience as recruitment was influenced by practical circumstances such as the physiotherapists' working hours, the patients' availability, and other logistics at the participating clinics. Similarly, the selection of aerobic fitness test method for each patient in Studies II and IV was not randomised, but rather determined by practical circumstances, mainly related to actual access to equipment at the participating units.

Although not systematically selected, the sample (n=298) of Study II was a representative sample, with regard to age, of those 484 patients asked to take part in studies of physical activity of RA. The 102 patients recruited for Study III also proved to be a representative subgroup of the original sample of Study II (n=298) with regard to age, gender distribution, pain, general health perception, disability (HAQ) and disease activity (DAS28).

Table II. Assessment methods of disease activity and functioning used in Studies I-IV classified according to the ICF.

	Study	Body functions and structure	Activity and participation	Other
Submaximal treadmill test (26, 77)	II, IV	X		
Submaximal bicycle ergometer test (141)	II, IV	X		
Aerobic fitness classification (141)	II, IV	X		
Ratings of perceived central and peripheral exertion (Borg's RPE Scale) (11)	IV	X		
Timed stands test (TST) (21, 83)	II, III	X		
Gripit (86)	II, III	X		
Escola Paulista de Medicina-Range of Motion Scale (EPM-ROM Scale) (134)	II, III	X		
Figure-of-eight (87)	II, III	X		
Self-reported pain rated on a Visual Analogue Scale (VAS) (53)	II-IV	X		
28-joint count (swollen and tender joints) (95)	II	X		
Functional classification (106)	I		X	
Questionnaire on physical activity (derived from LIV90) (32)	II, III		X	
The Health Assessment Questionnaire Disability Index (HAQ) (31, 39)	II-IV		X	
C-Reactive Protein (CRP) (126)	II, IV			X ¹
Erythrocyte Sedimentation Rate (ESR) (126)	II			X ¹
Disease Activity Score (DAS28) (95)	II, III			X ²
The minimum core set of disease activity (35)	II-IV			X ²
Self-reported general health perception rated on a VAS	II, III			X ³
The Multidimensional Health Locus of Control Scales, form C (MHLC-C) (70, 122)	III			X ⁴

¹inflammatory activity, ²not applicable, ³mixed, ⁴personal factors

DATA ANALYSIS

A summary of the statistical methods used is presented in Table III. The transcribed semi-structured, in-depth interviews in Study I were qualitatively analysed in accordance with the phenomenographic method (128). Statements were grouped into meaningful categories according to fundamental similarities and differences related to attitudes toward physical activity. Finally, the internal relationships between the categories were described.

Table III. A summary of statistical methods used in the present thesis.

	Study I	Study II	Study III	Study IV
Descriptive statistics				
Frequency (n), percent (%)	X	X	X	X
Median (md), range	X	X	X	
Median, interquartile range (iq. range)				X
Analytical statistics				
Mann-Whitney's U-test		X		X
Spearman's rank order correlation coefficient (r_s)		X		X
Multiple linear regression		X		
Wilcoxon's matched pairs test			X	
Simple logistic regression			X	
Multiple logistic regression			X	
Kruskal Wallis ANOVA				X
Chi-square test				X

ETHICS

Informed consent was obtained from each study participant. The Research Ethics Committee, Medical Faculty of Umeå University, approved the design of Study I. The Regional Ethics Research Committee at Karolinska Institutet approved the design of Studies II-IV.

RESULTS

STUDY I

During the phenomenographic analysis it became obvious that attitudes toward physical activity could not be understood without the inclusion of attitudes towards the disease and sometimes to life in general. Two dimensions of attitude, named motivation and satisfaction, were identified. Motivation to be physically active was generally described as inner motivational drives related to the person's own needs. Satisfaction with physical activity was generally related to actual level of physical activity. Different combinations of these two dimensions resulted in four qualitatively different attitudes to physical activity: "motivated and satisfied", "unmotivated and satisfied", "motivated and dissatisfied", and "unmotivated and dissatisfied" (Figure 3).

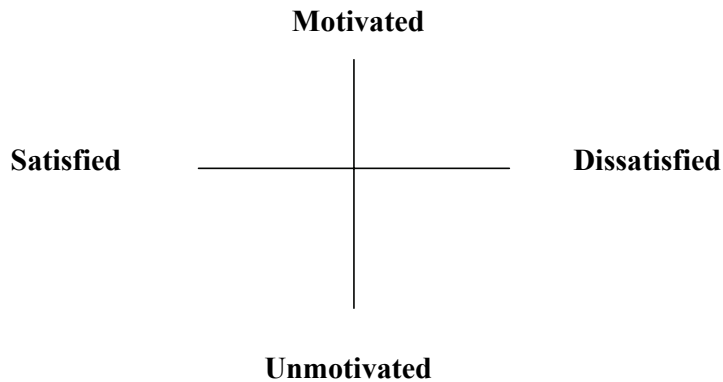


Figure 3. Four qualitatively different attitudes to physical activity in individuals with RA.

STUDY II

About half (53%) of the participants reached the recommended level of physical activity for maintaining good health. The reported physical activity data were fairly normally distributed between five levels of physical activity (very low, low, average, high, very high). The physical activity level did not differ significantly ($p>0.05$) between men and women. Women aged over 65 years seemed to be less physically active than either men of the same age or younger women. Patients with RA (aged 20-65 years) estimated their levels of physical activity at the upper end quite highly compared to the norm data for the same age groups.

Their estimated aerobic fitness was mainly classified as "Low" (36%), "Fair" (37%) or "Average" (20%). Generally, men were found to have average aerobic fitness while women mostly were found to have low or fair aerobic fitness. Very few individuals were found to have good or high aerobic fitness. However, estimated aerobic fitness (VO_{2max}) in patients with RA aged 20-65 years was similar to the norm data for the same age groups. Most patients displayed impaired body functions compared to norm data, as shown in Table IV.

Table IV. Results of body functions testing of 298 people with RA (225 women and 73 men), classified for age and gender as “Normal”, “Decreased” or “Inability to perform the tests”.

	Normal	Decreased	Inability	Missing
	n (%)	n (%)	n (%)	n (%)
Lower extremity function	83 (28)	200 (67)	15 (5)	0 (0)
Female	67 (30)	145 (64)	13 (6)	0 (0)
Male	16 (22)	55 (75)	2 (3)	0 (0)
Grip force peak	13 (4)	274 (92)	5 (2)	6 (2)
Female	8 (4)	207 (92)	5 (2)	5 (2)
Male	5 (7)	67 (92)	0 (0)	1 (1)
Average grip force	17 (6)	270 (91)	5 (2)	6 (2)
Female	12 (5)	203 (90)	5 (2)	5 (2)
Male	5 (7)	67 (92)	0 (0)	1 (1)
General joint range of motion	18 (6)	279 (94)	0 (0)	1 (3)
Female	16 (7)	208 (93)	0 (0)	1 (4)
Male	2 (3)	71 (97)	0 (0)	0 (0)
Balance	97 (33)	193 (65)	8 (3)	0 (0)
Female	82 (36)	137 (61)	6 (3)	0 (0)
Male	15 (21)	56 (77)	2 (3)	0 (0)

Descriptive data on general health perception, pain, disability (HAQ) and disease activity (DAS28) indicated that the patients were moderately affected by the disease, with tendencies towards more pain, disability and disease activity among women. General health perception differed significantly ($p < 0.01$) between men and women, with poorer health reported by women.

Correlations between self-reported physical activity and body functions, demographic factors, general health perception, pain, disability (HAQ) and disease activity (DAS28) were all very low ($r_s < 0.26$). Variation in health was explained (total adjusted $R^2 = 0.65$) by pain and disability.

STUDY III

Physical activity was fairly stable with 64 % of the participants reaching the levels of physical activity recommended for maintaining good health at baseline, and 57 % at re-assessment one year later. While physical activity, balance, general health perception, pain and disability (HAQ) were stable, lower extremity function, grip force and joint range of motion improved and disease activity (DAS28) decreased significantly over one year ($p < 0.05$).

The multiple logistic regression analysis identified a high physical activity level at baseline as the only statistically significant predictor of high physical activity one year later. Low pain, high physical activity and good lower extremity function were identified as significant predictors of good general health perception over a one-year period (Table V).

Table V. Results of multiple logistic regression analysis with high physical activity level and good general health perception after one year as dependent variables. Recalculated odds ratios (OR) and 95% confidence intervals (95% CI) reflect the total effect of the independent variables at baseline.

	OR (95% CI)	Probability
Model for high physical activity level		
Physical activity, high	3.85 (1.67-9.09)	0.001
Model for good general health perception		
Pain, low	8.47 (2.97-24.39)	0.000
Physical activity, high	3.72 (1.39-10.10)	0.009
Lower extremity function, good	2.94 (1.04-8.33)	0.042

STUDY IV

Eighty-eight (16 %) of the 556 participants were not tested at all by either of the aerobic fitness tests, the main reasons for this being that they were taking beta blockers or were restrained by their impairments (Figure 4). Forty-five patients (8%) terminated their tests prematurely, in 32 cases the bicycle test. A too unstable, too high or too low work heart rate (WHR) was the main reason for prematurely terminating either of the tests. The remaining 423 patients (76%), 330 women and 93 men, completed their submaximal tests, either on a bicycle or on a treadmill (Figure 4). Their estimated aerobic fitness was mainly classified as "Low" (30%), "Fair" (40%) or "Average" (23%). The correlations between WHRs and self-rated exertion were very low, if any for each of the tests ($r_s \leq 0.14$).

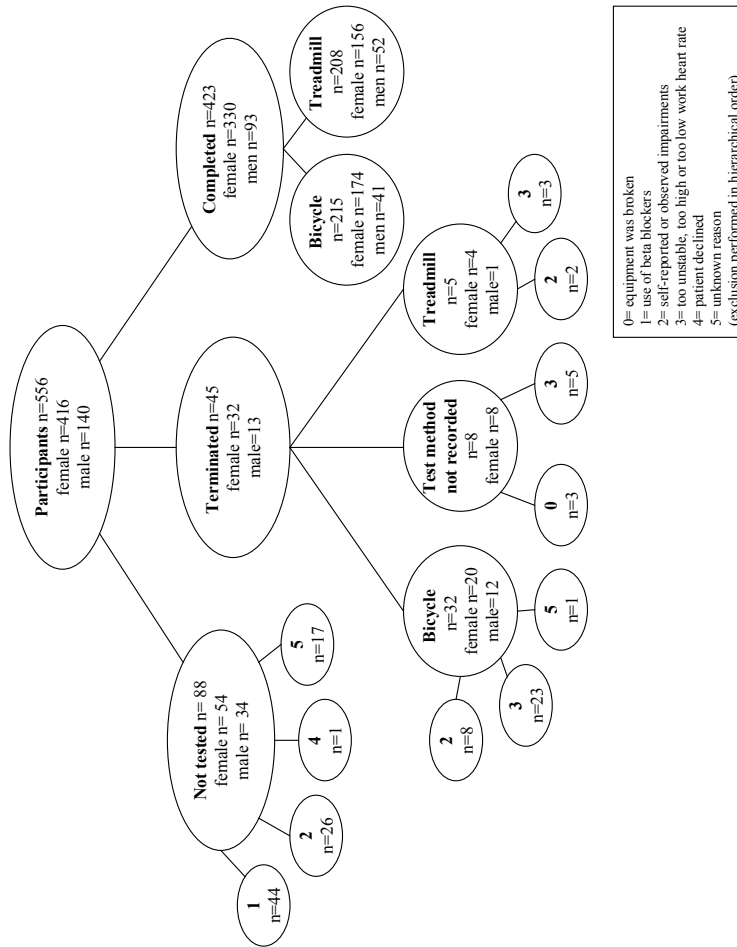


Figure 4. The applicability of two different methods of aerobic fitness testing in 556 patients with RA.

DISCUSSION

MAIN FINDINGS

Attitudes to and self-reports of physical activity

Around half the participants in the present thesis research reached the nationally and internationally recommended level of physical activity for maintaining good health, while the other half did not (Studies II & III). This is in agreement with previous studies of arthritis populations (18, 51) and general populations (18, 32, 51). However, such data have, to our knowledge, never been presented for a large well-defined, clinical sample of patients with RA. The participants who reached the recommended level of physical activity may represent those identified as "motivated and satisfied" in relation to physical activity and already having a physically active life-style before disease onset (Study I).

Those identified as "motivated and dissatisfied", who described physical activity as "hard to get", and those who are "unmotivated and satisfied", who showed an uninterested attitude towards physical activity (Study I), are probably to be found among the participants reporting below recommended physical activity level. Furthermore, women above the age of 65 more frequently reported low physical activity than did older men and younger women (Study II). This validates earlier studies of women with RA (78) and arthritis of various origin (51) and among women in the general population (16, 51, 72).

Attitudes, correlates and predictors of physical activity

The findings of the present thesis research altogether indicate that an active disease, including pain, does not necessarily prevent patients with RA from staying physically active and fit (Studies II & III). There were only weak correlations between self-reported physical activity and measures within the "core set of disease activity" in the present thesis research (Study II) and these disease activity measures did not predict physical activity (Study III). In fact there is no evidence to date to support the supposition that control of inflammation increases physical activity in women with RA (96), and previous findings indicate that exercise compliance is only predicted to a small extent by pain (79). However, it became apparent that attitudes towards physical activity could not be understood without including experiences of and attitudes towards the disease itself (Study I). The disease could, for example, be viewed as a motivator for physical activity among those identified as "motivated and satisfied", but also as a limitation among those who are "unmotivated and satisfied". It is well-known that attitudes towards arthritis are important for compliance with exercise regimes over time (13).

The only predictor for high physical activity was previous physical activity behaviour (Study III). There were only weak correlations between physical activity and body functions (Study II), and none of these measures predicted physical activity (Study III). While physical activity is determined by lifestyle, aerobic fitness, measured as $VO_2\text{max}$, probably has a major genetic component, but can be modified by changed exercise habits (72). It is therefore important to differentiate between those two factors, which although related, are different by definition and in content. For this reason the low correlations found between aerobic fitness and physical activity (Study II), which was also found in a large cross-sectional study of the Irish population (72), was not surprising. However, higher correlations have been found in Swedish and other epidemiological studies (32, 89). Moreover, the fact that fatigue, a common

symptom and identified as an important outcome, was not assessed in the present study of predictors of physical activity either cannot be ignored.

Neither internal nor external health locus of control predicted high physical activity in the present thesis (Study III), which is in accordance with a recent study of patients with long-term RA (71). One explanation for this may be that the patients attributed their HLoC to a great extent to the doctor and that many health professionals do not recommend physical activity to individuals with arthritis (36).

General health perception and its correlates and predictors

General health perception was low-to-moderately influenced and women reported significantly poorer general health compared to men (Study II). Pain is of key significance for people with RA (102). Thus, it is not surprising that general health perception was related to and influenced by pain in the present thesis research (Studies II & III). Despite low levels of self-reported pain, probably because of modern medical treatment and early active rehabilitation, pain still relates to and influences general health perception to a large extent in patients with RA. This was also found in a study reporting decreased pain over seven years, but pain still remained the area of highest priority for improvement (47). Our patients had a fairly short disease duration and the significance of pain might change, as pain in RA seems to change over time and be more significant in early disease, while “mobility/independence” is more important in later disease (14). Neither pain nor general health perception indicated any significant improvements over one year (Study III), which raises questions as to whether present treatment recommendations are effective enough. Thus, it seems that additional efforts are required to influence perceived pain and general health in patients with RA.

Neither internal nor external HLoC predicted good general health perception in the present thesis research (Study III). This might perhaps not have been expected as our patients had a fairly short disease duration. Thus, the confidence in their own ability to influence their health might not indicate a state, but rather vary with the disease fluctuations, as might their estimation of external influence from health professionals.

Pain and general health perception were both rated consecutively on VAS in the present thesis research (Study II & III). It is thus not surprising that they were highly correlated (Study II) and that pain was the most significant predictor of general health perception (Study III). While pain is a well-known predictor of general health perception, to our knowledge this is the first study to identify factors related to physical activity and body functions as important to the perception of health among patients with RA (Study III). Physical activity is a well-known predictor of health perception in the general population (32, 90). However, it might be expected that the significance of pain, in this sample of patients with RA, would override that of physical activity, which was not the case. Thus, our findings indicate that the promotion of physical activity might contribute to improved health perception in patients with RA.

Body functions and “minimum core set of disease activity”, changes over one year

Impairments were very common (Study II) and those related to pain, fatigue and decreased muscle function were also the second largest reason for not performing or prematurely terminating either of two aerobic fitness tests (Study IV). Disease activity (DAS28) decreased

from a moderate to a low level over one year and lower extremity function, grip force and range of motion improved, while all other measures remained unchanged (Study III).

More effort should be put to identify impairments early within care and rehabilitation of patients with RA, which was indicated for example by lower extremity function predicting general health perception over one year (Study III).

Aerobic fitness testing

Our findings indicate that a majority of patients with RA are able to complete aerobic fitness testing in clinical practice with either the ergometer bicycle test or the treadmill test (Study IV). This is encouraging for all physiotherapists who might have hesitated to perform such testing due to expected impairments among their patients.

Low correlations were found between work heart rates and self-rated central and peripheral exertion in patients with RA, irrespective of the test method used (Study IV). This lack of relationship has not, as far as we know, been identified in any previous study of patients with RA. Possible explanations for the low correlations may be the patients' inclusion of disease symptoms, such as pain, stiffness and fatigue, in their exertion ratings, or the comparison of their test efforts to heavier strain during daily activities. Our findings on poor correlations between WHR and RPE indicates that RPE does not provide a good estimate of the actual heart rate during activity, which is suggested for other populations (2).

METHODOLOGICAL CONSIDERATIONS

External validity

The findings of the present thesis can only be generalised to populations similar to the samples included in our studies. Thus, the findings could be considered valid for patients with RA and a relatively short disease duration treated in rheumatological specialist care. Furthermore, our findings cannot automatically be transferred to patients with severe impairment and to those not able to communicate well in Swedish. On the other hand, the main strength of the present thesis research is the large, representative sample, which makes the results highly generalisable to populations similar to the sample under study. Moreover, the data collection was performed by multiple physiotherapists within their daily clinical routine at 17 different rheumatology units, which makes the transferability to clinical settings very high. The results of the qualitative study might also be considered to be transferable as theoretical saturation was reached and the findings constituted a logical unit.

Data collection

Newham stated that perfect measures are very unlikely ever to be developed, and that useful and valid research can, and does, take place with the imperfect tools currently available, so long as the limitations are recognised and understood (84). Not all measurements used in the present thesis research may have been perfect either. However, one important prerequisite for large registers or multicentre studies is the use of simple, comprehensive data collection measures.

Phenomenography fulfilled the purpose of obtaining a description and a deeper understanding of different attitudes toward physical activity in RA well. To ensure the internal validity of the results, two researchers were involved in preparation of the interview guide, the data collection and the qualitative analysis, and both the analysis and the results were discussed with individuals not involved in data collection or analysis.

The poor correlation between self-reported physical activity and body functions found in the present thesis (Study II) may in part be explained by difficulty among patients with RA in estimating their physical activity. Some patients may over-estimate their physical activity level because of pain and fatigue, while others under-estimate their levels because they compare their recent physical activity level with the activity before disease onset. Unfortunately, such possible bias is hard to exclude entirely from any epidemiological research that relies on self-reports. Unpublished data indicate good reliability of the present physical activity questionnaire among patients with RA and its face and content validity should be good, considering the expertise involved in its construction. As far as we know there are no other suitable Swedish questionnaires that are reliable and valid for individuals with RA. A simple assessment of physical activity, graded 1-6, has been developed, but only for an elderly population (40). Activity diaries and interviews, which are other ways of collecting self-reported data on physical activity, are very time-consuming and not feasible in large cohort studies. Objective valid measurements of indirect or direct physical activity, such as heart rate monitoring, the doubly labelled water method and movement counters, are unfeasible because of costs (101).

A global single item is the most common way of asking respondents about their self-rated health and usually the answer is given on a 3-7 unit scale (65, 115). A general assessment of health can also be achieved by questionnaires where several dimensions of health are combined into one scale (9, 115). In the present thesis the VAS was used for the assessment of patients' self-rated general health, which is stated as an important assessment frequently used as a predictor of premature mortality in epidemiological research (115).

The VAS is a very common tool for assessing pain in scientific studies and in clinical practice, but there is criticism of it. It is a unidimensional measure of pain intensity, and the contribution of other dimensions, e.g. emotional and variation over time to rating is unknown. It has, however, been found that patients with cancer tend to indicate emotional aspects in their rating of sensory pain (63). McGill Pain Questionnaire, measuring several dimensions of pain is suggested to be an alternative (68), but was not sufficiently feasible for the present study.

Aerobic fitness is known to predict physical activity in the general population (6, 43). Unfortunately, this was not investigated in the present thesis (Study III). The reason for this was our early presumption that the two fitness tests included would be comparable as to outcome. It has subsequently been found that this is not the case and that the main reason for this is that body weight is not included in the prediction equation for the treadmill test (12). Other reasons may be that the demands as to WHR are greater for the bicycle test and that lower extremity impairments influence the tests differently.

Some factors that might have been related to or have influenced the results, but were not included in the present thesis (Studies II & III), are related to personal or environmental factors. Self-efficacy, intentions to be physically active and motivation are examples of personal factors of possible importance when studying prediction of physical activity in RA. However, the definition of the concept of motivation is not unified. Three broad groups for definition of motivation within rehabilitation have been found in a literature review: motivation as an internal “personality characteristic”, motivation as a quality affected by social factors, and motivation considering social factors in combination with personality or clinic characteristics (73). It may be assumed that cultural differences exist concerning both patients’ and caregivers’ opinions and beliefs about the usefulness of exercise and physical activity (13). Social support and environmental factors, including education, socioeconomic status (99) and accessible facilities for physical activity, are also highly correlated to physical activity in the general population (104). Unfortunately, none of these factors were measured in the present thesis research.

CLINICAL IMPLICATIONS

The results of the present thesis research represent valuable knowledge for physiotherapists in guiding and encouraging their patients to different kinds of physical activity and not necessarily to structured and planned exercise only. It is important to bear in mind that daily physical activity tend to be mixed with planned, structured exercise (120).

There is a case for physical activity intervention strategies especially directed towards older women with RA. To maintain or achieve recommended levels of physical activity, it is important to individualise interventions, including different attitudes to physical activity, in patients with RA. Such interventions are not systematically applied at present, which probably means that those most in need of specific support (unmotivated, elderly women, unfamiliar with physical activities, and with an unhealthy lifestyle), will not have access to it.

High physical activity and good lower extremity function are important predictors of good general health perception and increasing physical activity levels will thus probably contribute to improved health. Pain is probably still under-estimated in the treatment of patients with RA and needs more attention and early intervention.

Simple methods to screen physical activity and body functions are feasible within physiotherapy practice and could be used for regular monitoring and detection of physical inactivity and impairment. Most patients with RA are able to perform aerobic fitness testing and there is thus no general reason for the avoidance of such testing in these patients.

FUTURE RESEARCH

In future studies, it would be interesting to develop and evaluate interventions aiming to support physical activity and good general health perception. An important question is how to identify individuals in need of extra support, for example those described as "unmotivated and satisfied" and "motivated and dissatisfied"? A prerequisite for this is to be aware of all factors influencing motivation (74). Questions are also raised on how to measure motivation in clinical practice. Only five out of 22 studies investigating motivation in relation to health and exercise reported psychometric properties of the measures used (94). Thus, methods to assess

motivation for physical activity should be developed and/or adapted for Swedish patients with RA.

Another interesting area for further research would be to follow the clinical course of early RA over more than one year to study changes in physical activity, body functions, and measures of the "core set of disease activity" in order to investigate whether the predictors of physical activity and general health perception remain the same.

The validity and reliability of the questionnaire for self-reported physical activity used in the present study (32) need to be further studied as to its validity and reliability in patients with RA of all ages, as the highest prevalence of inactivity in adults with arthritis has been found in those aged 65 years or over (37). For use in intervention studies the questionnaire's sensitivity to change needs to be investigated.

Submaximal bicycle ergometer tests have been widely used as outcome measures in exercise studies including patients with arthritis (28, 30, 123), but their validity in patients with RA might be questioned (61). The validity and reliability of the treadmill test used in the present thesis need further investigation. Such a study should include individuals with RA of both sexes, different ages and different body weights to supplement the findings of the original study (77). It would also be of great interest to investigate the correlations between direct measurement of peak VO_2max and estimated VO_2max based on both types of submaximal tests.

GENERAL CONCLUSIONS

In patients with RA similar to those studied in the present thesis:

- attitudes towards physical activity cannot be understood without including attitudes towards the disease itself and sometimes to life in general.
- attitudes can be categorised as “motivated and satisfied”, “motivated and dissatisfied”, “unmotivated and satisfied”, and “unmotivated and dissatisfied”.
- about 50% performed too little physical activity to reach levels recommended to maintain good health.
- a majority display impaired aerobic fitness, lower extremity function, grip force, joint range of motion and balance compared to norm data fairly early in the course of disease.
- physical activity is only weakly correlated to demographic variables, body functions and measures within the EULAR minimum core set of disease activity.
- functioning and health mainly remain stable or improve over one year.
- physical activity is predicted by physical activity one year earlier, while good general health perception is predicted by low pain intensity, high physical activity and good lower extremity function.
- a majority are able to perform aerobic fitness testing in clinical practice despite impaired body functions.
- correlations between perceived central and peripheral exertion and work heart rate are low during aerobic fitness testing.

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Yes, there is goal and meaning in our path -
but it's the way that is the labour's worth.

Excerpt from the poem "On the Move"
from the collection "The Hearths"
Karin Boye

Nog finns det mål och mening i vår färd -
men det är vägen, som är mödan värd.

ur "I rörelse" från "Härdarna"
Karin Boye

