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Hagel, Sofia

2012

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*Citation for published version (APA):*

Hagel, S. (2012). *Team rehabilitation and health care utilization in chronic inflammatory arthritis patients*. [Doctoral Thesis (compilation), Rheumatology]. Section for Rheumatology, Department of Clinical Sciences, Lund.

*Total number of authors:*

1

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# **Team rehabilitation and health care utilization in chronic inflammatory arthritis patients**

Av

**Sofia Hagel**

**Legitimerad sjukgymnast**



**LUND**  
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## **Akademisk avhandling**

Som med vederbörligt tillstånd av Medicinska fakulteten vid Lunds Universitet för avläggande av  
doktorsexamen i medicinsk vetenskap kommer att offentligen försvaras i  
Belfragesalen, BMC, Hus D, 15e våningen, Klinikgatan 32, Lund,  
fredagen den 14 september 2012, kl 09.00

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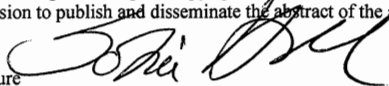
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Organization LUND UNIVERSITY  Department of Clinical Sciences, Lund, Section for Rheumatology, Lund University, Lund, Sweden  Author(s) Sofia Hagel	Document name DOCTORAL DISSERTATION  Date of issue 2012-06-25  Sponsoring organization	
Title and subtitle Team rehabilitation and health care utilization in chronic inflammatory arthritis patients		
Abstract <p>The aim of this thesis was to study outcome and evaluation of rheumatological multidisciplinary team rehabilitation programmes in patients with chronic inflammatory arthritis (CIA); rheumatoid arthritis (RA), ankylosing spondylitis, psoriatic arthritis and other spondyloarthritides, and to analyse health care utilization over the last decade in patients with RA. In Study I the outcome of an 18 days outpatient multidisciplinary team rehabilitation programme in 174 patients with CIA was analysed. The patients were evaluated pre- and post the rehabilitation programme and 4 and 12 months thereafter. Health related quality of life (HRQoL), general health and aerobic capacity was significantly improved at the end of the rehabilitation programme and after 12 months.</p> <p>In Study II 731 patients with CIA participated in different team rehabilitation programmes in four European countries and were evaluated pre- and post rehabilitation. Through analysis of covariance we studied which patients improved the most by team rehabilitation. Females experiencing more pain, fatigue and lower psychosocial wellbeing improved most in HRQoL. HRQoL for half of the patients improved according to analysis of Minimal Important Difference.</p> <p>In Study III we analysed the validity and responsiveness of 15 standardized outcome measures used to evaluate outcomes from multidisciplinary team rehabilitation in 216 patients with CIA. According to our linking of the outcome measures to the International Classification of Functioning, Disability and Health (ICF) most ICF components were reasonably well covered except environmental aspects. Further, out of three outcome measures used to evaluate HRQoL, the Euroqol-5Dimensions (EQ-5D) performed as well as the more extensive short form 36 health survey (SF-36) and Nottingham health profile (NHP). Aerobic capacity did not correlate to other measures of observed physical functioning. It was highly responsive to change.</p> <p>In Study IV we wanted to study health care utilization in patients with RA over time. By using the Skåne Health Care Register we identified 3977 persons who had been diagnosed with RA when consulting health care during 1998-2001. Two referents from the general population per RA patient were matched for age, sex, and area of residence. The annual mean number of hospitalizations and outpatient clinic visits 2001-2010 and the annual ratio (RA cohort/referents) were analysed.</p> <p>The overall inpatient and outpatient health care utilization was found to decrease in RA patients as compared to the general population.</p> <p>To conclude, multidisciplinary team rehabilitation is beneficial for patients with CIA with regards to HRQoL, general health and aerobic capacity both short and long term. Further, patients with more severe disease consequences benefit most from rheumatological team rehabilitation.</p> <p>When evaluating HRQoL in rheumatological team rehabilitation the commonly used questionnaires EQ-5D, NHP and SF-36, showed important differences in construct validity and responsiveness and are thus not interchangeable.</p> <p>Improving aerobic capacity is an important aspect of team rehabilitation not covered by other outcome measures on physical function and thus important to evaluate.</p> <p>Patients with RA have utilized less health care during the last decade which might be an effect of changing treatment strategies.</p>		
Key words Rehabilitation, rheumatoid arthritis, psoriatic arthritis, spondylarthritis, ankylosing spondylitis, multidisciplinary team, rheumatological team care, health care utilization, outcome measures, aerobic capacity, ICF, physical functioning,		
Classification system and/or index terms (if any)		
Supplementary bibliographical information	Language	
ISSN and key title 1652-8220	ISBN 978-91-87189-22-7	
Recipient's notes	Number of pages 116	Price
	Security classification	

Distribution by (name and address)

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# **Team rehabilitation and health care utilization in chronic inflammatory arthritis patients**

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2012



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Cover page illustration painted by one group of patients when leaving the Rheuma Rehab.

ISSN 1652-8220

ISBN 978-91-87189-22-7

Lund University, Faculty of Medicine Doctoral Dissertation Series 2012:59

Printed by Media-Tryck, Lund University, 2012

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## Abstract

The aim of this thesis was to study outcome and evaluation of rheumatological multidisciplinary team rehabilitation programmes in patients with chronic inflammatory arthritis (CIA); rheumatoid arthritis (RA), ankylosing spondylitis, psoriatic arthritis and other spondyloarthritides, and to analyse health care utilization over the last decade in patients with RA.

In Study I the outcome of an 18 days outpatient multidisciplinary team rehabilitation programme in 174 patients with CIA was analysed. The patients were evaluated pre- and post the rehabilitation programme and 4 and 12 months thereafter. Health related quality of life (HRQoL), general health and aerobic capacity was significantly improved at the end of the rehabilitation programme and after 12 months.

In Study II 731 patients with CIA participated in different team rehabilitation programmes in four European countries and were evaluated pre- and post rehabilitation. Through analysis of covariance we studied which patients improved the most by team rehabilitation. Females experiencing more pain, fatigue and lower psychosocial wellbeing improved most in HRQoL. HRQoL for half of the patients improved according to analysis of Minimal Important Difference.

In Study III we analysed the validity and responsiveness of 15 standardized outcome measures used to evaluate outcomes from multidisciplinary team rehabilitation in 216 patients with CIA. According to our linking of the outcome measures to the International Classification of Functioning, Disability and Health (ICF) most ICF components were reasonably well covered except environmental aspects. Further, out of three outcome measures used to evaluate HRQoL, the Euroqol-5Dimensions (EQ-5D) performed as

well as the more extensive short form 36 health survey (SF-36) and Nottingham health profile (NHP). Aerobic capacity did not correlate to other measures of observed physical functioning. It was highly responsive to change.

In Study IV we wanted to study health care utilization in patients with RA over time. By using the Skåne Health Care Register we identified 3977 persons who had been diagnosed with RA when consulting health care during 1998-2001. Two referents from the general population per RA patient were matched for age, sex, and area of residence. The annual mean number of hospitalizations and outpatient clinic visits 2001-2010 and the annual ratio (RA cohort/referents) were analysed.

The overall inpatient and outpatient health care utilization was found to decrease in RA patients as compared to the general population.

To conclude, multidisciplinary team rehabilitation is beneficial for patients with CIA with regards to HRQoL, general health and aerobic capacity both short and long term. Further, patients with more severe disease consequences benefit most from rheumatological team rehabilitation.

When evaluating HRQoL in rheumatological team rehabilitation the commonly used questionnaires EQ-5D, NHP and SF-36, showed important differences in construct validity and responsiveness and are thus not interchangeable.

Improving aerobic capacity is an important aspect of team rehabilitation not covered by other outcome measures on physical function and thus important to evaluate.

Patients with RA have utilized less health care during the last decade which might be an effect of changing treatment strategies.

## List of papers

This thesis is based on the following papers, which will be referred to in the text by their Roman numerals (I - IV)

**I** Team-based rehabilitation improves long-term aerobic capacity and health-related quality of life in patients with chronic inflammatory arthritis.

Hagel S, Lindqvist E, Bremander A, Petersson IF  
*Disability and Rehabilitation* 2010; 32(20):1686-1696.

**II** Which patients improve the most from arthritis rehabilitation? Results from patients with inflammatory arthritis in northern Europe, the STAR-ETIC collaboration.

Hagel S, Lindqvist E, Petersson IF, Meesters JJJ, Klokke M, Aanerud GJ, Stovgaard IH, Hørslev-Petersen K, Strömbeck B, Vliet Vlieland TPM, Bremander A, and the STAR-ETIC group  
Submitted

**III** Validation of outcome measurement instruments used in a multidisciplinary rehabilitation intervention for patients with chronic inflammatory arthritis: Linking to the International Classification of Functioning, Disability and Health, construct validity and responsiveness to change.

Hagel S, Lindqvist E, Petersson IF, Nilsson JÅ, Bremander A  
*J Rehabil Med* 2011;43:411-419

**IV** Trends in 21st century health care utilization in a rheumatoid arthritis cohort compared to the general population.

Hagel S, Petersson IF, Bremander A, Lindqvist E, Bergknut C, Englund M  
Submitted

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The studies presented were supported by the Region Skåne and the Faculty of Medicine, Lund University, Lund University Hospital Funds, the Osterlund Foundation, the Swedish Rheumatism Foundation, the Swedish Research Council, , the Norrbacka-Eugenia Foundation, the Maggie Stephens Foundation and Capio's Research Foundation, Sweden.

The European League Against Rheumatism (EULAR) has financially supported the STAR-ETIC by EULAR grant CLI022.



## Aims of this thesis

The overall aim of the studies presented in this thesis was to determine whether patients with CIA benefit from team rehabilitation. A further aim was to develop and use appropriate methods of evaluating team rehabilitation, and to establish whether health care utilization had changed among patients with RA over the past decade.

This thesis is based on four studies on:

- the long-term clinical outcome of a comprehensive 18-day multidisciplinary rehabilitation programme in patients with rheumatoid arthritis, ankylosing spondylitis, psoriatic arthritis and other spondyloarthritis,
- the outcome of arthritis rehabilitation programmes for patients with CIA from selected centres in four European countries focusing on factors predicting change in HRQoL, and the estimation of the proportion of patients achieving clinically relevant improvement,
- how well established outcome measures used for the evaluation of team rehabilitation cover the ICF domains, and to evaluate the construct validity and responsiveness of the instruments to change,
- health care utilization over time (2001-2010) in a population-based RA cohort and a reference cohort.

## Thesis at a glance

### Study I

This was an observational, prospective study on the outcome of an 18-day team rehabilitation programme (day care) in patients with chronic inflammatory arthritis (CIA). The 174 patients were evaluated at the beginning, at the end, and at 4 and 12 months after the rehabilitation programme. Health-related quality of life (HRQoL), general health and aerobic capacity improved significantly as a result of rehabilitation, and remained significantly improved at follow-up after 12 months.

### Study II

The second study was an international, observational, prospective multi-centre study (STAR-ETIC) on team rehabilitation outcome. Data were obtained from 731 patients with CIA at the beginning and end of rehabilitation programmes in four European countries. In an analysis of covariance we identified potential baseline predictors of rehabilitation induced improvement in HRQoL. Female patients struggling with more pain, fatigue and lower psychosocial wellbeing were found to benefit most from the rehabilitation programmes. The HRQoL of half of the patients improved using the concept of Minimal Important Difference (MID).

### Study III

The third study was a methodological analysis of the validity and responsiveness of 15

standardized outcome measures used to evaluate rehabilitation outcome in 216 patients with CIA. The outcome measures were found to cover the components body function, activity and participation of the International Classification of Functioning, Disability and Health (ICF) well, but not the environmental aspects. Further analysis of validity and responsiveness showed that outcome measures evaluating HRQoL did not evaluate similar aspect of disease. The EQ-5D, a brief HRQoL outcome measure, performed as well as other more extensive HRQoL outcome measures (SF-36 and NHP). Aerobic capacity did not correlate to other measures of observed physical functioning. Further, aerobic capacity was highly responsive to change.

### Study IV

The final study was based on data from the Skåne Health Care Register regarding the utilization of health care in the period 2001-2010. Closed cohorts of rheumatoid arthritis (RA) cases (n=3977) and reference subjects (n=7954) were identified. Annual mean hospitalizations per patient and annual mean outpatient health care visits per patient tended to decrease in the RA cohort over the study period, while it was fairly stable in the reference cohort. A decrease in the health care utilization for physicians and physiotherapist was seen, but the utilization of other health care professionals did not significantly change over time.

## Description of Contributions

### Paper I

Study design:	Sofia Hagel Ann Bremander Elisabet Lindqvist Ingemar Petersson	Ann Bremander Kim Hørslev-Petersen Mari Klokkeud Elisabet Lindqvist Jorit Meesters
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Data analysis:	Sofia Hagel Ann Bremander Elisabet Lindqvist Ingemar Petersson	Stovgaard Britta Strömbeck Thea Vliet Vlieland
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### Paper II

Study design:	Sofia Hagel Ann Bremander Kim Hørslev-Petersen Mari Klokkeud Elisabet Lindqvist Jorit Meesters Ingemar Petersson Inger Henriette Stovgaard Britta Strömbeck Thea Vliet Vlieland	
Data collection:	Sofia Hagel Ann Bremander Kim Hørslev-Petersen Mari Klokkeud Elisabet Lindqvist Jorit Meesters Ingemar Petersson Inger Henriette Stovgaard Britta Strömbeck Thea Vliet Vlieland	
Data analysis:	Sofia Hagel Ann Bremander Elisabet Lindqvist Ingemar Petersson	
Manuscript writing:	Sofia Hagel	
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### Paper III

Study design:	Sofia Hagel Ann Bremander Elisabet Lindqvist Jan-Åke Nilsson Ingemar Petersson
Data collection:	Sofia Hagel Elisabet Lindqvist
Data analysis:	Sofia Hagel Ann Bremander
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### Paper IV

Study design:	Sofia Hagel Ann Bremander Martin Englund Elisabet Lindqvist Ingemar Petersson
Data collection:	Charlotte Bergknut Martin Englund Ingemar Petersson
Data analysis:	Sofia Hagel Martin Englund Ingemar Petersson
Manuscript writing:	Sofia Hagel
Manuscript revision:	Ann Bremander Charlotte Bergknut Martin Englund Elisabet Lindqvist Ingemar Petersson

## Abbreviations and definitions

AS	ankylosing spondylitis	HAQ	health assessment questionnaire
ASAS	Assessment of Ankylosing Spondylitis International Society	HLA-B27	human leucocyte antigen, allele type B27
ASES	arthritis self-efficacy scale	HRQoL	health-related quality of life
BASDAI	Bath ankylosing spondylitis disease activity index	HSCL-25	Hopkins symptom checklist 25 questions
BASFI	Bath ankylosing spondylitis functional index	IQR	interquartile range
BAS-G1/G2	Bath ankylosing spondylitis general health over the last week (G1), over the last six months (G2)	MCID	minimally clinically important difference
BASMI	Bath ankylosing spondylitis metrology index	MID	minimal important difference
CI	confidence interval	NHP	Nottingham health profile
CIA	chronic inflammatory arthritis	NRS	numeric rating scale
CRP	C-reactive protein	OMERACT	Outcome Measures in Rheumatology
CVD	cardiovascular disease	OT	occupational therapist
DAS28	disease activity score based on 28-joint count	PA	peripheral arthritis
DMARD	disease-modifying anti-rheumatic drug	PRO	patient-reported outcome
ESR	erythrocyte sedimentation rate	PsA	psoriatic arthritis
EQ-5D	euroqol-5dimensions	PT	physiotherapist
EULAR	European League Against Rheumatism	RA	rheumatoid arthritis
GRAPPA	Group for Research and Assessment of Psoriasis and Psoriatic Arthritis	RCT	randomized controlled study
ICD	International Classification of Diseases	ROM	range of motion
ICF	International Classification of Functioning, Disability and Health	SD	standard deviation
		SF-36	the short form 36 health survey
		SHCR	Skåne health care register
		SOFI	signals of functional impairment
		SpA	spondyloarthritis
		SW	social worker
		TNF- $\alpha$	tumour necrosis factor-alpha
		VAS	visual analogue scale
		WHO	World Health Organization

## Introduction

The rapid development and change of treatment and care for patients with inflammatory arthritis over the past two decades is striking. Certain treatment modalities such as pharmacological and surgical treatment have been well evaluated in both prospective and retrospective settings. Evidence of the benefit of some non-pharmacological interventions such as cardiovascular and muscular strength exercises has also been found. However, there is less scientific evidence of the benefits of complex non-pharmacological interventions

such as team-based rehabilitation, thus making proper studies in this area needed. This thesis describes studies on, and the evaluation of, team-based rehabilitation in different settings, in different countries, using different methods. The patterns of health care utilization in defined population-based cohorts of rheumatoid arthritis patients and reference subjects have also been studied.

The historical perspective is included in the background as well as the prospects for the future in the general discussion.

## Background

### Health

'Health is a state of complete physical, mental, and social wellbeing and not merely the absence of disease or infirmity' (World Health Organisation 1946). Today we would probably exclude 'complete' from the definition to provide better agreement with the more modern understanding of the complex concept of health. To study different aspects of health different models have been used.

#### *Health status and health-related quality of life*

Health status is defined as a measure of the feelings and functions of a person, including the severity and the impact of symptoms, activity limitations (on functioning) and participation in life (Ware 1995). Health related quality of life (HRQoL) is a concept integrating health status with subjective wellbeing (Smith et al. 1999), since quality of life denotes people's emotional, social and physical wellbeing, and their ability to function in their daily living. For rehabilitation and treatment the aspect of HRQoL is of outmost importance. HRQoL can be described as 'the extent to which needs are fulfilled', and when evaluated it intends to provide a summary of the impact of a disease from the patient's perspective (McKenna et al. 2004). HRQoL can be evaluated with generic or disease-specific outcome measures. Instruments for measuring HRQoL are based on one of two approaches: health status or health care use (i.e. the direct and indirect approaches) (Khanna et al. 2007). In the present work, the generic outcome measures SF-36 and NHP were used together with the indirect utility measure EQ-5D.

### **The international classification of functioning, disability and health (ICF)**

In 2001, the World Health Organization (WHO 2012a) approved the International Classification of Functioning, Disability and

Health (ICF). The ICF was developed to help overcome the difficulties encountered when describing disease, its treatment and the evaluation of outcome, and the complex relations between them. The ICF was developed to integrate the domains of functioning, disability and health, where functioning is not regarded as a direct consequence of disease, rather as 'the interaction between personal attributes and environmental influence' (Rauch et al. 2008). Disability can be interpreted as the result of a complex interaction between an individual and his or her environment (Kostanjsek 2011a; Kostanjsek et al. 2011b; Kostanjsek et al. 2011c). Health according to ICF (i.e. the degree of functioning and disability) is dependent on: a) body function (physiological and psychological functions), b) body structure (anatomical locations/parts/structures), c) activities (tasks) and d) participation (involvement in life situations, daily living and work). Functioning and disability are also regarded as being modified by contextual factors: e) environmental factors (surroundings and societal factors) and f) personal factors (individual circumstances, background and life, not related to health), together representing circumstances in the individual's life (Cieza et al. 2005a; Stucki et al. 2005; World Health Organization 2012a). The structure and concepts of the ICF are illustrated in Figure 1.

In the context of the ICF, rehabilitation has been defined as a health strategy aimed at enabling people with impaired health to achieve and maintain optimal functioning in interaction with the environment (Stucki et al. 2007a). Rehabilitation should thus be considered one of four health strategies together with prevention, cure and support (Stucki et al. 2007b).

The ICF framework has been applied and endorsed by the network Outcome Measures in Rheumatology (OMERACT) (Stucki et al.

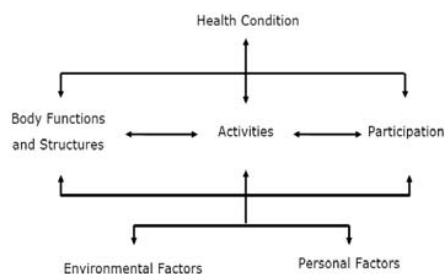


Figure 1. Illustration of the ICF structure and concepts.

2007c; Boonen et al. 2009a) and by the Assessment of Spondyloarthritis International Society (ASAS) (Boonen et al. 2009b; Boonen et al. 2010).

## Rehabilitation

‘Rehabilitation of people with disabilities is a process aimed at enabling them to reach and maintain their optimal physical, sensory, intellectual, psychological and social functional levels. Rehabilitation provides disabled people with the tools they need to attain independence and self-determination’ (World Health Organisation 2012b). The term rehabilitation also denotes the medical specialty of ‘physical medicine and rehabilitation’, ‘physical therapy and/or rehabilitation medicine’ (Encyclopaedia Britannica 2012). The organisation of this specialty differs between countries, and will not be further elaborated on in this thesis. The work described in this thesis concerns the rehabilitation of patients with inflammatory joint diseases, where patients most often seek health care at departments of rheumatology, orthopaedic surgery or primary health care.

## Chronic inflammatory arthritis

The concept of chronic inflammatory arthritis

(CIA) in this work covers RA and spondyloarthritis (SpA) with the subgroups of ankylosing spondylitis (AS) and psoriatic arthritis (PsA) (van Eijk-Hustings et al. 2012). CIA is diagnosed according to established criteria including clinical findings, laboratory analyses and sometimes imaging. The diagnostic and therapeutic strategies for CIA are based on national (Socialstyrelsen 2012; Svensk Reumatologisk Förening 2012) and international guidelines (Smolen et al. 2010; Braun et al. 2011). The importance of early diagnosis, early, effective treatment and regular follow-up and evaluation of RA and SpA has been emphasized (van Vollenhoven et al. 2009; Rostom et al. 2010; van Vollenhoven et al. 2012).

### *Rheumatoid arthritis*

Rheumatoid arthritis is a chronic systemic inflammatory disease in which genetic, as well as environmental factors, such as tobacco smoking, influence both the onset and the course of the disease. A prevalence of 0.5-0.7% has been reported in Swedish adults (Simonsson et al. 1999; Englund et al. 2010), with a higher prevalence among women (0.94%) than in men (0.37%) (Englund et al. 2010). Women have also been found to suffer worse consequences of the disease than men (Hallert et al. 2003; Tengstrand et al. 2004; Sokka et al. 2009; Ahlmen et al. 2010; Camacho et al. 2011; Hallert et al. 2012). The symptoms of RA include joint swelling, pain, morning stiffness and impaired physical functioning (Heiberg et al. 2002; Scott et al. 2005; Hallert et al. 2012). Fatigue defined as an ‘overwhelming feeling of tiredness’ is another problem frequently reported by patients (Wolfe et al. 1996; Carr et al. 2003). The disease course is usually relapsing-remitting, with flares alternating with periods of lower disease activity (Lindqvist et al. 2002; Bingham et al. 2011). The consequences of the disease for patients cover a broad spectrum including destruction of the joints leading to impaired joint function (Lindqvist et al. 2003; Nyhäll-Wählin et al. 2011), psychological distress (Smedstad et al. 1996; Smedstad et al. 1997)

osteoporosis and extra-articular manifestations involving other organs such as the lungs, heart, nerves and skin. RA patients also have an increased risk of cardiovascular disease (Nyhäll-Wåhlin et al. 2011; Turesson et al. 1999; Turesson et al. 2004; Kozera et al. 2011) and increased mortality (Gabriel 2008a; Gabriel 2008b; Myasoedova et al. 2011).

### *Spondyloarthritis*

Spondyloarthritis is a term encompassing AS, PsA, unspecified SpA, arthritis associated with irritated bowel disease and reactive arthritis. A prevalence of SpA of 0.45%-1% has been reported (Haglund et al. 2011; Reveille et al. 2012).

### *Ankylosing spondylitis*

Ankylosing spondylitis is a chronic inflammatory disease affecting the spine and often also peripheral joints, with a prevalence of 0.12% in the Swedish population aged 15 years and older (Haglund et al. 2011). AS is strongly associated with positive HLA-B27, although the pathogenesis is not completely known (McHugh et al. 2012). AS causes pain and stiffness and also impairs functional abilities as well as the ability to work and the social life of the patient (Dagfinrud et al. 2004a; Dagfinrud et al. 2005a; Strömbeck et al. 2009; Strömbeck et al. 2010; Bakland et al. 2011). Extra-articular manifestations occur in some patients in the eye (uveitis/iritis), the gastrointestinal system, in the cardiovascular system, the skin or the skeleton (Carter et al. 2011; Bremander et al. 2011; El Maghraoui 2011).

### *Psoriatic arthritis*

The exact prevalence of PsA is uncertain, but in a Swedish register study a prevalence of 0.25% was found in those aged 15 years and older seeking health care (Haglund et al. 2011). Joint pain and swelling, joint stiffness, enthesitis, fatigue and malaise are common manifestations of PsA. Some studies have reported co-morbidities and extra-articular manifestations such as cardiovascular events and hypertension, obesity, hyperlipidaemia

and diabetes mellitus (type 2) (Gladman et al. 2009; Husted et al. 2011; Khraishi et al. 2011).

### *Pharmacological interventions*

The understanding of the pathogenesis of RA, SpA and other forms of CIA has improved over recent decades. New drugs have been developed and the ability to suppress inflammation has increased. Useful pharmaceuticals include disease-modifying anti-rheumatic drugs (DMARDs), methotrexate being the most commonly used drug (Neovius et al. 2011). In 1999 TNF- $\alpha$  blockers were introduced. TNF- $\alpha$  blockers have good short- and long-term effects on pain, stiffness, physical function (Geborek et al. 2002; van Vollenhoven et al. 2009) and HRQoL (Gulfe et al. 2010). A lower incidence of severe extra-articular manifestations has been reported in RA patients treated with TNF blockers (van der Horst-Bruinsma et al. 2009; Nyhäll-Wåhlin et al. 2012). Also other biological agents have successively been developed and the modern treatment aim is to start pharmacological treatment early and to strive for remission or at least low disease activity (Smolen et al. 2010).

### *Surgical interventions*

Surgical treatment of CIA has been practiced over the years to reduce the inflammatory process in the joints and/or tendon sheaths, to correct malalignment and immobilize painful joints (arthrodesis) and to replace joints severely affected by the disease (arthroplasty). Tendon surgery has also been practiced, especially in the hands. During the past decade, changes in surgical interventions have been reported. The numbers of synovectomies, arthroplasties and arthrodeses performed in hands and upper and lower limbs have been reported to decrease from mid 1990ies and forward (Weiss et al. 2006; Weiss et al. 2008; Dafydd et al. 2012; Hekmat et al. 2011; Shourt et al. 2012). The decreasing number of surgical interventions in RA patients can probably be the result of the improved pharmacological treatment (Pincus et al. 2005; Tanaka et al. 2008; Hekmat et al. 2011).



### *Nonpharmacological interventions - single and complex interventions*

Evidence concerning the benefits of exercise and an active lifestyle was first presented in the late 1980s (Minor et al. 1988; Galloway et al. 1993; Neuberger et al. 1993; Stenstrom 1994a; Ekdahl et al 1989; Ekdahl et al 1992), since then evidence has continued to grow. Dynamic exercise to gain muscular strength, muscular endurance and function is together with aerobic exercise to improve aerobic capacity examples of single interventions previously studied (Stenstrom 1994b; Dagfinrud et al. 2004b; Cairns et al. 2009; Hurkmans et al. 2009; Dagfinrud et al. 2011; Hurkmans et al. 2011a).

### *Complex interventions*

Complex intervention denotes nonpharmacological treatment targeting more than one aspect of health. Complex interventions are preferably delivered by teams (Iversen et al. 2006). Thus team treatment is an example of complex intervention, beneficial for patients with complex consequences of the disease (Guillemin et al. 2011). Multidisciplinary teams were introduced in health care in the early 20th century, and are now active in both primary and secondary care for both in- and outpatients (Vliet Vlieland 2003; Prvu Bettger et al. 2007; Kilpatrick et al. 2011; Jesmin et al. 2012).

## **History of rheumatological care**

Findings from excavations have shown that AS affected the ancient Egyptians (Ruffer 2011), as well as people living in the 900th century and mediaeval times (Leden et al. 2009; Leden et al. 2010). Different medical and non-medical methods of treatment have been described throughout history. However, patients with CIA had to struggle for centuries with ineffective treatment. Physical disability affected the individual's ability to earn a living, and to live independently.

To improve life for patients with CIA the Svenska Vanförestaltnernas Centralkommitté, now the Swedish Institute of Assistive Technology, was established in 1911. Through

this organisation people suffering from inflammatory and tubercular arthritis and post-polio syndrome were offered medical treatment (including splints and assistive devices) and vocational training at a number of institutions in different parts of Sweden (Leden et al. 1996). Three specialized hospitals run by the association Riksförbundet mot Reumatism (RMR), at Spenshult, Strängnäs and Östersund were opened between 1953 and 1969. Regional health care authorities successively took over responsibility for, and the organization of, rheumatic care from 1969 (Leden 1995; Leden et al. 1996; Klareskog 2005).

Rheumatological orthopaedic surgery was first practised on patients with inflammatory arthritis in Heinola, Finland in the late 1950s and early 1960s (Vainio et al. 1961; Lindstroem et al. 1963; Mitchell 1964). New pharmaceuticals such as corticosteroids (1948), gold (1929), sulfasalazine (1940-70) and penicillamine (1960) were also developed, providing sufferers of RA some relief in their daily life (Leden 1995; Klareskog 2005). Although relieving some symptoms, these drugs were accompanied by significant risks of severe adverse events. It was not until the late 1980s, when methotrexate and combination therapy, and later also biological treatment (TNF- $\alpha$  blockers and others), enabled more successful suppression of disease activity, that people with inflammatory arthritis could live a more normal life (Kavanaugh et al. 2012).

### *Development of rheumatological team rehabilitation*

The idea of rehabilitating patients with RA was first practiced in the 1950s, in the USA. In an article from 1949, Rusk suggested that team rehabilitation should be introduced as the third phase of medicine, following diagnosis and treatment (Rusk 1949). His idea has persisted, although rehabilitation is nowadays considered to be complementary to pharmacological and surgical treatment.

In 1966, Håkan Brattström, an orthopaedic surgeon, and Merete Brattström, a physician in rehabilitation medicine with rheumatological

training, at the Lund University Hospital visited hospitals treating and rehabilitating patients with CIA in the USA and Canada. Their ideas on surgery and rehabilitation in inflammatory arthritis were strengthened, and they returned to Lund with improved knowledge and new ideas. In 1968 the Reumatikerdispensären, a multiprofessional outpatient clinic, was started in Lund (Brattstrom et al. 1970; Brattstrom et al. 1977; Brattstrom et al. 1980). Their rehabilitation model spread throughout Scandinavia.

Rheumatological team rehabilitation has been described, used and evaluated in Northern Europe over the past 20-30 years. A randomized controlled study in the Netherlands showed that patients participating in an 11-day inpatient rehabilitation programme improved significantly compared to controls receiving ordinary out-patient care. The improvement persisted after 2 years (Vliet Vlieland et al. 1997a; Riemsma et al. 1998). In a systematic review, the benefits of in- versus outpatient rehabilitation were inconclusive (Vliet Vlieland et al. 1997b). In a later study, where inpatient and day patient multidisciplinary team care and clinical nurse specialist care were compared the latter was found to provide comparable quality of life and utility, but at a lower cost than the multidisciplinary interventions (van den Hout et al. 2003).

Patients receiving care from the clinical nurse specialist expressed less satisfaction than the patients' counselled by inpatient or outpatient teams (Tijhuis et al. 2002). In the long term, the different kinds of rehabilitation were found to be comparable (Tijhuis et al. 2003). In an observational study conducted in southern Sweden it was found that a 3-week outpatient intervention was suitable and beneficial for patients with both long and short durations of disease (Jacobsson et al. 1998). In Table 1 the evidence on rheumatological rehabilitation has been summarized. Both short-term and long-term effects on several aspects of health have been described (Vliet Vlieland et al. 1997a; Jacobsson et al. 1998). However, evidence is scarce since limited numbers of participants

and outcome measures evaluated in each study together with limited description of the performed interventions hamper replication and comparison (Vliet Vlieland 2003; Hammond 2004a).

An area with special needs for complex interventions including also non-medical activities is vocational rehabilitation. Improved ability to work has been found in RA patients as a result of team rehabilitation adopting a vocational approach (Nordmark et al. 2006). A Dutch study on vocational team rehabilitation of patients with arthritis at risk of losing their job reported that the same percentage (23-24%) had lost their jobs within 24 months, but that the patients who had been counselled had less fatigue and better mental health (de Buck et al. 2005). The findings of another Dutch study as to whether a vocational rehabilitation programme increased or decreased the total cost to society were unclear/inconclusive, however, rehabilitation varied widely in content from only two counselling sessions to (a) more extensive programme(s) (van den Hout et al. 2007).

## Rheumatological rehabilitation teams

A team is defined as two or more professionals working together with the patient (Petersson 2006). Within rheumatology, the team often comprises a rheumatologist, a nurse, a physiotherapist (PT), an occupational therapist (OT), a social worker (SW) and/or a psychologist, and sometimes a podiatrist, dietician, assistant nurse or orthopaedic surgeon (Vliet Vlieland 2003).

The work of a multidisciplinary team is coordinated by one of the team members and is usually carried out in parallel with little overlap. In the interdisciplinary team the members have a higher degree of communication and regular meetings when treatment goals and plans are discussed (Korner 2010). In a transdisciplinary team the team members are responsible for problem solving and goal setting across the disciplines, instead of between the disciplines, as in an

Table 1. Description of studies on rheumatological team rehabilitation in RA patients from 1996 until today.

STUDY Author Year Study design	Patients n age % females	Controls n age % females	Team members	Intervention/Team rehabilitation programme	Length of intervention	Follow up Length of study	Follow up Points of evaluation	Evaluation methods	Outcome
Vliet Vlieland 1996 RCT	39 56 years 64	41 UC 55 years 76 + non allocated group	Rheumatologist, nurse, PT, OT, SW	Inpatient. Nursing, bed rest, 11 days ROM, Muscle strength. Info on: joint protection, self-care, daily living. (Joint splints, adaptive equip). Coping/finance.	11 days	1 year	Pre, 2, 4, 12 weeks 1 year	VAS dis act VAS pain VAS fatigue VAS morning stiff HAQ AIMS Grip strength SW joints RAI ESR VAS physician disease activity	Sign* Sign* Sign* Sign* NS Sign* Sign* Sign* NS NS
Vliet Vlieland 1997 RCT	-	-	-	-	-	2 years	-	-	NS
Jacobsson 1998 Observational	87 55 years 74	-	Rheumatologist, nurse, PT, OT, SW	Outpatient. Nursing. ROM, 3 weeks, foot situation, physiotherapy(?), social situation. Education according to a structured programme {Lindroth, 1997 #1000}	3 weeks, working days	3 months	Pre, post and 3 months	VAS pain VAS global dis act HAQ SOFI RAI ESR Swollen joint DAS, Likert	Sign Sign Sign Sign Sign Sign Sign No sustained differences in clinical effectiveness between clinical nurse specialist and multidisciplinary in-/out patient setting.
Tijhuis 2002 RCT Clinical Specialised nurse/inpatient- /outpatient multidisciplinary programme	71/71/68 54/60/60 years 72/75/79	-	Clinical nurse specialist vs in- and outpatient team Rheumatologist, nurse, PT, OT, SW	Clinical nurse specialist provided information about RA, prescribed joint splints and, adaptive equipment. Nurse also referred to PT, OT and SW if needed. Inpatient and day patient multidisciplinary followed a programme of equal intensity, tailored to individual needs.			Pre, 6, 12, 24 weeks and 1 year	HAQ MACTAR RAND-36 RAQOL DAS	

STUDY Author Year Study design	Patients n age % females	Controls n age % females	Team members	Intervention/Team rehabilitation programme	Length of intervention	Follow up Length of study	Follow up Points of evaluation	Evaluation methods	Outcome
Tijhuis 2003 RCT	-"-	-"-	-"-	-"-	-"-	-"-	-"-	-"-	No differences between the groups
van den Hout 2003 RCT	-"-	-"-	-"-	-"-	-"-	-"-	-"-	-"-	Clinical nurse specialist provided equivalent quality of life and utility, at lower costs
Breedland 2011 RCT	19 45 years 63	15 WLC 52 years 80	PT, OT, SW, psychologist, dietician	Outpatient group programme, exercise of partly individualized exertion and multidisciplinary education on disease consequences and activity management. WLC remained on waitinglist.	8 weeks Exercise 2 days/week, 3 hours /week Education 1 day/week, 1 hour.	22 weeks	Pre, post and 22 weeks	Vo2max Muscle strength AIMS2 ASES	Sign* NS NS NS

\*=At end of rehabilitation

RCT= randomized controlled trial, UC=usual Care, PT=physiotherapist, OT=occupational therapist, SW=social worker, ROM=range of motion , VAS=visual analogue scale, HAQ=health assessment questionnaire, RAI=Richie articular index, DFI=Dougados functional index , HAD=hospital anxiety and depression scale, WLC=waiting list control

interdisciplinary team (Cartmill et al. 2011). Different health professionals have distinct roles (van Eijk-Hustings et al. 2012), as has the patient (de Wit et al. 2011a).

Teams in rheumatological rehabilitation have been responsible for the transfer of knowledge on pain management, joint protection, activities in daily life and other aspects of health improvement (Lindroth et al. 1997). The growing evidence of the benefits of a more physically active lifestyle in patients with CIA has been incorporated into team rehabilitation. Team rehabilitation can take place in an inpatient or outpatient setting (day care) (Vliet Vlieland 2003).

### Evaluation of modern rheumatological team rehabilitation

Team rehabilitation is multimodal and complex, and one reason for the limited evidence of its benefits could stem from difficulties in describing and evaluating the complex models

(Wade et al. 2000; Dieppe 2004; Prvu Bettger et al. 2007; Guillemin et al. 2011; Tugwell et al. 2011). The formerly used biomedical model has also contributed to the lack of relevant and reliable descriptions of health status and the effects of pharmacological and nonpharmacological/complex interventions in patients with chronic diseases (Guillemin et al. 2011).

Different conceptual models of description and evaluation have been suggested. Structure, process and outcome are regarded as essential parts of the Integrated (Health Care) Team Effectiveness Model (Lemieux-Charles et al. 2006), and Wade suggested that they should be included in the description and analysis of team rehabilitation (Wade et al. 2000; Wade 2005). A framework for the description of rheumatological team rehabilitation was developed by a literature review and a Delphi process in which health professionals and patients from four European countries participated. Following that framework it is essential to also describe the

### STAR-ETIC framework

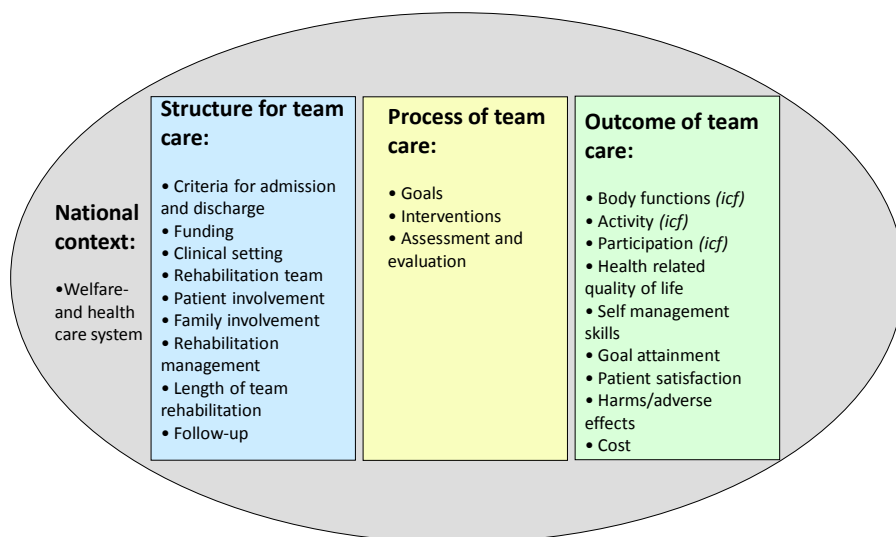


Figure 2. Description of the STAR-ETIC framework (Klokkeerud et al. 2012)

national context in which the rehabilitation is being undertaken, in addition to the structure and process for team care, Figure 2 (Klokkerud et al. 2012).

Randomized controlled trials (RCTs) have been a golden standard in evaluation of health care interventions but observational studies contribute with other aspects (van Vollenhoven et al. 2011) especially in complex interventions (Prvu Bettger et al. 2007). Well-designed clinical trials evaluated with patient-centred outcomes are needed, especially on patients with early disease (Hammond 2004a). Specific information on different areas of rehabilitation is insufficient, contrary to increasing evidence in guidelines and systematic reviews (Guillemin et al. 2011).

In order to describe the outcome of team rehabilitation, measures describing HRQoL, pain, fatigue, physical function have been suggested by OMERACT, GRAPPA and ASAS in their recommendations on monitoring and evaluation of patients and health care interventions (Tugwell et al. 1993; Gladman et al. 2005; Gladman et al. 2007a). There is a well documented interaction between general health and most of the above described aspects of health in interventions and evaluations. Each item is therefore presented separately below.

#### *Health related quality of life*

All forms of CIA have negative effects on HRQoL (Dagfinrud et al. 2004a; Kiltz et al. 2009; Salaffi et al. 2009; West et al. 2009; Lee et al. 2010; Ovayolu et al. 2011; Strand et al. 2012a). Conflicting findings on the interaction between HRQoL and measures of disease activity have been presented, but in a large Danish study on RA patients, HRQoL and measures of disease activity were found to be strongly related. When disease activity was well controlled, HRQoL among the patients was found to be comparable to that of the general population (Linde et al. 2010). Socio-demographic characteristics have also been found to affect HRQoL (Kiltz et al. 2009). Other important consequences of CIA such as fatigue (Rat et al. 2012), not being able to cope,

helplessness and poor self-reported functioning (Nicassio et al. 2011) are closely related to HRQoL. Improved HRQoL has been found in patients with CIA treated with DMARDs and TNF-blockers (Emery et al. 2006; van der Heijde et al. 2009; Gulfe et al. 2010; Kavanaugh et al. 2010; Saad et al. 2010; Staples et al. 2011; Strand et al. 2012a; Strand et al. 2012b).

HRQoL can be evaluated with generic or disease-specific outcome measures. Instruments for measuring HRQoL are based on one of two approaches: health status or health care use (i.e. the direct and indirect approaches) (Khanna et al. 2007). In the present work, the generic outcome measures SF-36 and NHP were used together with the indirect utility measure EQ-5D.

Different aspects affecting health are presented separately below.

#### *Pain*

Pain is one of the key symptoms of CIA, often presenting at the onset of the disease. Pain caused by structural damage can be persistent also when disease activity is well controlled using DMARDs (Radner et al. 2012). Pain has a significant impact on HRQoL if not managed (Ahlstrand et al. 2011; Smolen et al. 2012). The relief of pain is an important target in rheumatological rehabilitation using different interventions ranging from pharmacotherapy to surgery, and including physical treatment (cold or heat), TENS, physical exercise, balneotherapy, and ergonomic devices (Hurkmans et al. 2009; Baillet et al. 2010; van den Berg et al. 2012). Pain measures are included in most patient reported outcome measures for disease activity and disease severity within rheumatology. Pain is also included in measures of HRQoL such as EQ-5D, the SF-36 and the NHP.

#### *Fatigue*

Fatigue is a clinical feature in all forms of CIA and has been found to be associated with pain, disease activity, physical functioning and HRQoL (Dagfinrud et al. 2005b; Aissaoui et al. 2011; Garip et al. 2011; Rat et al. 2012). Hewlett et al. recently reported that patients with RA

highlight fatigue as a major concern, as important as pain, overwhelming, unmanageable and ignored by clinicians (Hewlett et al. 2011). Up to 70% of RA patients suffer from fatigue, while the prevalence of fatigue in other forms of CIA is unknown. In recent years it has been recommended that fatigue should be included as an RA outcome measure in clinical practice and clinical trials. This has led to international consensus in the (OMERACT) network that fatigue should be measured in all RA trials (Hewlett et al. 2005a; Hewlett et al. 2005b; Kirwan et al. 2007; Repping-Wuts et al. 2008).

#### *Mental wellbeing*

Psychological distress, anxiety and depression are well documented comorbid features of both recent onset and longstanding CIA. Depression has been reported in 13-42% of patients with RA. Mental wellbeing has also been proved to be affected by sociodemographic status (Margaretten et al. 2011a; Margaretten et al. 2011b; Gafvels et al. 2012). Depression is also a comorbid feature in AS and PsA (Carneiro et al. 2011). An inverse relation has been reported between coping and pain and disease activity in all forms of CIA (Martindale et al. 2006; Brionez et al. 2009; Carneiro et al. 2011; Gafvels et al. 2012). Physical and mental aspects are often parallel aspects of the disease consequences for patients with CIA. Mental aspects are a natural part of the care in team rehabilitation, but psychologists and/or psychiatric specialists must be consulted for more severe problems.

#### *Self-efficacy*

Perceived self-efficacy refers to 'the belief in one's own capability to organize and perform the activities needed to reach a desired outcome or result' (Bandura 1986; Bandura 2004; Primdahl et al. 2012). Self-efficacy has been proved to benefit from education programmes, or rather self-management programmes, where the patients are trained in self-care skills (O'Leary et al. 1988; Lorig et al. 1998a). Self-management has been defined as 'an individual's ability to manage the

symptoms, treatment, physical and psychosocial consequences and lifestyle changes inherent in living with a chronic condition' (Barlow et al. 2002). Nonpharmacological care and complex interventions comprise patient education which include information and advice about the disease, medication, exercise, finding an appropriate activity level, joint protection and non-pharmacological pain relief methods (Vliet Vlieland et al. 2011) these kinds of interventions are targeting both self-management and self-efficacy. Self-efficacy in RA patients has been found to be related to, among other things, physical activity levels and also to predict improved health status (Osborne et al. 2007; Knittle et al. 2011).

Patient education has been proven beneficial to improve pain, HRQoL and self-efficacy. Patient education and self-management programmes were developed and introduced in the USA and the UK during the 1970s. The aim of self-management was to improve patients' knowledge of the implications of the disease; originally to inform the patient about joint protection and also to empower the patient according to the recently developed theories on self-efficacy (Lindroth et al. 1989; Hammond et al. 1999; Helliwell et al. 1999; Hammond et al. 2004b). Unfortunately, this led to only short-term benefits (Schrieber et al. 2004).

#### *Physical functioning*

Strength, mobility, freedom of movement, balance and coordination are essential for physical functioning. One major feature of CIA is impaired physical function resulting from pain, stiffness, fatigue, swelling and inflammatory activity (Eberhardt et al. 1990; Lee et al. 2010). Reduced range of motion (ROM), muscle strength and aerobic capacity are other consequences of the disease affecting functioning, which appear later (Ekdahl et al. 1989; Ekdahl et al. 1992). In a Swedish survey on RA patients with a disease duration of less than 6.5 years, decreased lower-limb muscle function was found in 72%, reduced grip strength in 94%, reduced ROM in 94% and reduced functional balance in 68% of



the patients (Eurenius et al. 2005). Similar findings in patients with more longstanding disease support these findings (Ekdahl et al. 1989; Ekdahl et al. 1992; Van den Ende et al. 1998).

Since Steinbrocker's evaluation of functioning in the 1940s different aspects have been recommended for the evaluation of physical function. These can be observed by a rheumatologist, nurse, PT or an OT or the perceived function can be reported by the patient using PROs. Evaluation of function is important and is included in the OMERACT core sets for evaluation and monitoring of all types of CIA (Buchbinder et al. 1995; van der Heijde et al. 1999; Gladman et al. 2007a; Gladman et al. 2007b). The patient perspective is advocated by the OMERACT and the EULAR networks (Kirwan et al. 2005b; de Wit et al. 2011b; Kirwan et al. 2011).

### *Physical activity*

Patients with inflammatory arthritis are at risk of developing cardiovascular comorbidities (Turesson et al. 2004; Gladman et al. 2009; Bremander et al. 2011; Peters et al. 2010; Atzeni et al. 2011; Boehncke et al. 2011; Husted et al. 2011; Papadakis J.A., 2012). Traditional risk factors and inflammatory burden have been recognized as causative factors (Peters et al. 2010). The contribution of low physical activity to lower daily energy expenditure has been reported among patients with RA and SpA (Eurenius et al. 2005; van den Berg 2007a; Sokka et al. 2008; Metsios et al. 2009; Henchoz et al. 2012; Lee et al. 2012). The recommended physical activity for the general population is exercise at a moderate intensity for at least 30 minutes, at least 5 days a week or physical activity at a vigorous level for at least 20 minutes, at least 3 days a week (Work Group Recommendations 2002; Garber et al. 2011). Physical activity has been found to improve disease-specific consequences such as impaired health status and muscle strength in patients with RA (Brodin et al. 2008).

In Swedish patients with RA, 47% were physically active at levels insufficient to promote general health (Eurenius et al. 2005).

One year later, the physical activity of the same patients was similar. The only predictor of high physical activity found was high self-reported physical activity one year earlier (Eurenius et al. 2007). Patients with RA who exercise or who are physically active seem to overestimate their level of physical exertion (Cuperus et al. 2012; Eurenius et al. 2005). Lack of knowledge and motivation, together with the belief that exercise will have harmful effects and cause fatigue and pain have been reported as preventing physical activity (Kamwendo et al. 1999; van den Berg et al. 2007b; Swardh et al. 2008). Recent research has also shown that health professionals were uncertain about adequate levels of physical activity for RA patients (Hurkmans et al. 2011b). Furthermore, exercise programmes for patients with AS did not achieve sufficient levels of exertion to affect the participants' health (Dagfinrud et al. 2011). The significantly lower daily energy expenditure of RA patients has mainly been explained by less physical exertion than in healthy controls (Henchoz et al. 2012).

### *Aerobic capacity*

Regular physical activity at a sufficient level is needed to maintain a certain aerobic capacity. Aerobic exercise has been found to be safe and beneficial, promoting HRQoL. Long-term aerobic exercise also seems to have a beneficial effect on cardiovascular health in patients with CIA (Turesson et al. 2007; Metsios et al. 2008; Metsios et al. 2009; Halvorsen et al. 2012; Janse van Rensburg et al. 2012).

## **The patient's perspective**

Throughout history, the patient has been regarded as a passive care taker and the physician's view of the patient's situation and physician-defined outcomes have dominated. However, today patients are considered as active health care consumers and in rehabilitation they are obvious members of the team (Petersson 2006). During the past decade, the patient's perspective has become the subject of growing interest since it is now



considered to be as informative as, or more informative than, the physician-assessed outcome (Pincus et al. 2009; Guillemin et al. 2011). Moreover, patients and physicians have been found to assess disease activity differently in RA (Barton et al. 2010), AS (Spoorenberg et al. 2005) and PsA (Dandorfer et al. 2012). Patient perspective sessions were introduced by OMERACT in 2002 (Kirwan et al. 2003). The importance of including and raising awareness of the patient perspective has also been underlined in other contexts, for example, the CARE conferences (Iversen 2009; Petersson et al. 2005; Kjekken et al. 2010). The incorporation of patients' perspectives has helped health care professionals to understand the importance of targeting fatigue in treatment and evaluation, and the importance of studying and evaluating flares and other aspects of daily life that are affected by CIA (Kirwan et al. 2005a,b; Kirwan et al. 2007a,b; Alten et al. 2011; Bingham et al. 2011; Hewlett et al. 2012). The patients are now also often active participants in both the planning and the performance of research projects (Kjekken et al. 2010).

### *Health care utilization*

Increased utilization of health care is an inevitable consequence of CIA. The intermittent course of the disease with flares and relapses, impaired physical function, and comorbidities all contribute to an increased need of health care. However, new effective pharmacological strategies seem to be reducing the need for hospital resources and improving productivity in patients with established disease (Bansback et al. 2005; Olofsson et al. 2010). Patients with early RA treated according to new regimens could be expected to suffer from less comorbidity, less impaired work ability and shorter periods of hospitalization in the future (Bansback et al. 2009). However, although RA-related orthopaedic surgery and length of hospitalization have been found to decrease (Sandhu et al. 2006; Weiss et al. 2008; Hekmat et al. 2011; Shourt et al. 2012) it is difficult to predict what the future will bring in the long term in RA-related health care. Information on actual health care utilization is scarce and, to some extent, conflicting (Fautrel et al. 2011). Improved pharmacological treatment modalities place high demands on monitoring, and thus contribute to some treatment-driven health care utilization.

# Methods - Data sources

## 1. The STAR-ETIC project

The Scandinavian Team Arthritis Register (STAR) was initiated in 2005 by members of Swedish and Norwegian rheumatological teams and researchers. It was soon extended to include Danish and Dutch arthritis rehabilitation teams within the European Team Initiative for Care (ETIC), and became the STAR-ETIC project, [www.star-etic.se](http://www.star-etic.se) (Study II). Eighteen sites (7 specialist centres and 11 rehabilitation institutions) practicing team rehabilitation for arthritis patients were involved in this project.

The main objective of the STAR-ETIC project was to describe and explore the structure, the process, and the outcome of rehabilitative team interventions in patients

with inflammatory arthritis in Northern Europe. Inclusion criteria were patients aged 18 or more scheduled for a rehabilitation period of at least one week duration and with an inflammatory joint disease, CIA. Exclusion criteria were severe psychiatric comorbidity or inability to communicate in written Swedish/Dutch/Danish/Norwegian. Evaluations were performed at the beginning and end of rehabilitation and at two points of follow-up, 6 and 12 months after rehabilitation. Patients' diagnosis was confirmed by a rheumatologist at each site. Brief information on each participating country is given below, further information on structure and process at the participating countries is presented in Table 2.

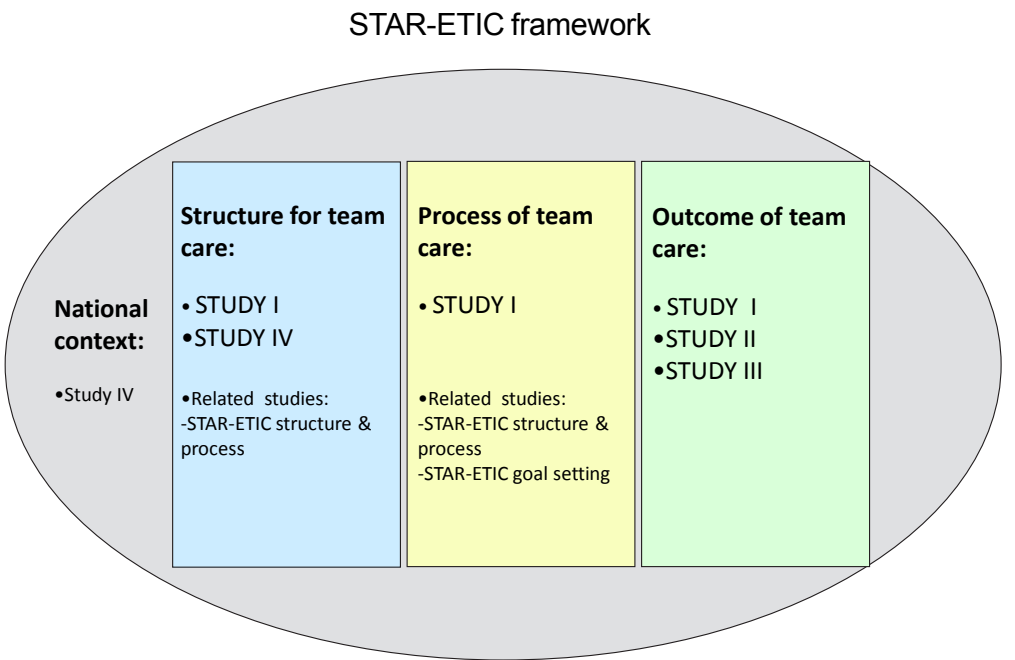


Figure 3. Description of aspects of the STAR-ETIC framework covered by studies I-IV and related studies.

**Table 2. Short description of the structure and process components of arthritis rehabilitation as performed within the STAR-ETIC project. The details are presented as present (x=yes, provided) or not (- =no, not provided) or not applicable (na) according to study sites in the four STAR-ETIC countries.**

Country	Denmark (n=91)	the Netherlands (n=85)	Norway (n=157)	Sweden (n=410)
Study Site	Site D1	Site NL1	Site N1 Site N2 Site N3 Site N4 Site N5	Site S1 Site S2 Site S3
Criteria for admission and discharge				
Referred from medical doctors within or outside hospital	x	x	x	x
Discharge set at admission	x	-	x	x
Discharge predetermined (fixed programme)	-	-	-	-
Discharge dependent on goal achievement	-	x	-	-
Clinical setting (type of setting)				
Hospital inpatient	x	-	x	-
Hospital outpatient	-	x	-	-
Rehabilitation centre	-	-	-	-
Rehabilitation team (type of professions on department level)				
Medical doctor (rheumatologist)	x	x	x	x
Physiotherapist	x	x	x	x
Occupational therapist	x	x	x	x
Nurse	x	x	x	x
Social worker	x	x	x	x
Psychologist	-	-	-	-
Nutritionist	x	-	-	-
Other	x	-	x	x
Rehabilitation team (communication form)				
Weekly team meetings	x	x	x	x
Other meetings when needed	x	x	x	x

Rehabilitation management										
Individual rehabilitation plan	X	X	X	X	X	X	X	X	X	X
Standardised tool	-	X	-	-	-	-	-	-	-	-
Electronic based tool	-	X	-	-	-	-	-	-	-	-
Goals										
Individual goals defined	X	X	X	X	X	X	X	X	X	X
Developed together with team member(s)	X	X	X	X	X	X	X	X	X	X
Goals classified according to the ICF	-	X	-	-	-	-	-	-	-	-
Group sessions										
Group education	X	-	X	X	X	X	X	X	-	X
Group exercise	X	X	X	X	X	X	X	X	X	X
Type of individual treatment modalities										
Information/ counselling1	X	-	X	X	X	na	X	X	X	na
Individual exercises2	X	X	X	X	X	na	X	X	X	na
Individual physical treatment, or hands on	-	-	X	X	X	na	X	X	X	na
Self training	X	-	X	X	X	X	X	X	X	na

### *Rehabilitation settings*

#### Sweden

In Sweden three different rehabilitation settings participated.

- The Rheuma Rehab, the department for rheumatological rehabilitation, at the Clinic of Rheumatology Lund, Skåne University Hospital (Studies I, II and III). One version of the rehabilitation programme was developed for patients with peripheral arthritis (PA), another version of the programme was developed for patients with SpA, with mainly axial problems. Criteria for referral: 1) a diagnosis of CIA, 2) stable and effective pharmacological treatment, 3) a specified need for team-based rehabilitation, not met at a routine outpatient clinic, and 4) ability to dress and groom. Patients were enrolled in groups of 6-7, for the 18-working-day programme of rehabilitation. Follow-up after 4 and 12 months was mandatory, and was regarded as part of the programme (Study I and III). A follow-up after 6 months was added during participation in the STAR-ETIC project (Study II).

- The Department of Rheumatology in Malmö, Skåne University Hospital (Study II). Patients were enrolled in groups of approximately 4-6 patients. This five days outpatient rehabilitation programme was mainly educational focusing primarily on patients with early disease. The programme included some introduction in physical activity/exercise.

- The Spenshult Hospital for Rheumatic Diseases (Study II). Patients with a diagnosis of CIA with a specified need for team-based rehabilitation not met at a routine outpatient clinic were referred to this inpatient rehabilitation. Rehabilitation length and content was tailored to the patients' individual needs and progress.

#### Denmark

- The Kong Christian X Hospital, University of Southern Denmark (Study II). Patients with a diagnosis of CIA with a specified need for team-based rehabilitation were referred to this inpatient rehabilitation. Length and content of rehabilitation was

tailored to the patients' needs and progress.

#### Norway

- In Norway five different rehabilitation settings participated, representing 13 specific rehabilitation units (Study II). Four hospitals participated, whereof three provided inpatient rehabilitation (NRRE Diakonhjemmet Hospital, Martina Hansen Hospital, and Lillehammer Rheumatological Hospital) and one provided outpatient rehabilitation (Ostfold Hospital).

Nine inpatient rehabilitation centres participated in the STAR-ETIC project. Six of the rehabilitation centres provided data for patients with inflammatory arthritis, Valnesfjord, Borger Bad, Skogli, Jeløya and Tonsåsen rehabilitation centers and Vikersund Kurbad. In Norway patients older than 75 years were excluded from the project.

#### The Netherlands

- In the Netherlands the day patient multidisciplinary team care ward of the Rheumatology Rehabilitation Clinic, the Department of Rheumatology, Leiden University Medical Center participated (Study II). Patients with a diagnosis of CIA with a specified need for team-based rehabilitation were referred to this outpatient rehabilitation. Length and content of rehabilitation was tailored to the patients' needs and progress.

## **2. The Skåne health care register**

In Sweden, all health care providers, public and private, are required to regularly provide information to the authorities for reimbursement purposes, which ensure high-quality reporting. In Skåne, the southernmost county of Sweden, all health care visits, inpatient and outpatient, are registered in the Skåne Health Care Register (SHCR). The unique personal identification number facilitates registration and analysis (Strömbeck et al. 2009). For all health care providers, date of visit and information on health care provider is recorded. For public care diagnostic codes are registered according to the International

Classification of Diseases (ICD) 10 system (Study IV).

Vital events (date of birth and death, marriage and change of residential address) of all inhabitants of Sweden are registered in the national population register by the personal identification number. Information from the population register is used for various reasons including voting records and tax purposes.

## Methods - Patients

The patients studied were 18 years or older with a diagnosis of inflammatory arthritis. Studies I, II and III were based on the outcomes of a group of patients included in a rehabilitation programme at Rheuma Rehab, at the Rheumatological Department in Lund, Skåne University Hospital. In Study II, patients from the STAR-ETIC project in Sweden, Denmark, Norway and the Netherlands were also included in the analysis. In Study IV the health care used by all patients diagnosed as having RA in Skåne during the years 1998-2001 was analysed over the period 2001-2010. Some of these patients (n=17) were also included in the cohorts in Studies I, II and III (Figure 4, Table 3).

In studies I, II and III patients were consecutively enrolled in the Rheuma Rehab programme in Lund between January 2002 and June 2008, Figure 4. In Study II patients with CIA who completed a rehabilitation programme at one of the sites for rehabilitation within the

STAR-ETIC project, and for whom PROs had been filled out at admission and discharge were included. For patients who had undergone two rehabilitation periods only data from the first period were included. In Table 4 characteristics of participants in the different Studies are presented.

The health care utilization cohort in study IV was based on data from the SHCR. Residents of Skåne County, 18 years or older were defined as 'cases' if diagnosed with RA (ICD-10 codes M05, M06) on at least two separate visits to a physician during the period 1998 to 2001, whereof at least once to a specialist in rheumatology or internal medicine (n=3977) (Table 4, Figure 4). Reference subjects (n=7954) were randomly matched by age, sex and area of residence.

In Figure 3 a description on how the Studies I, II, III and IV cover context, structure, process and outcome according to the STAR-ETIC framework is presented.

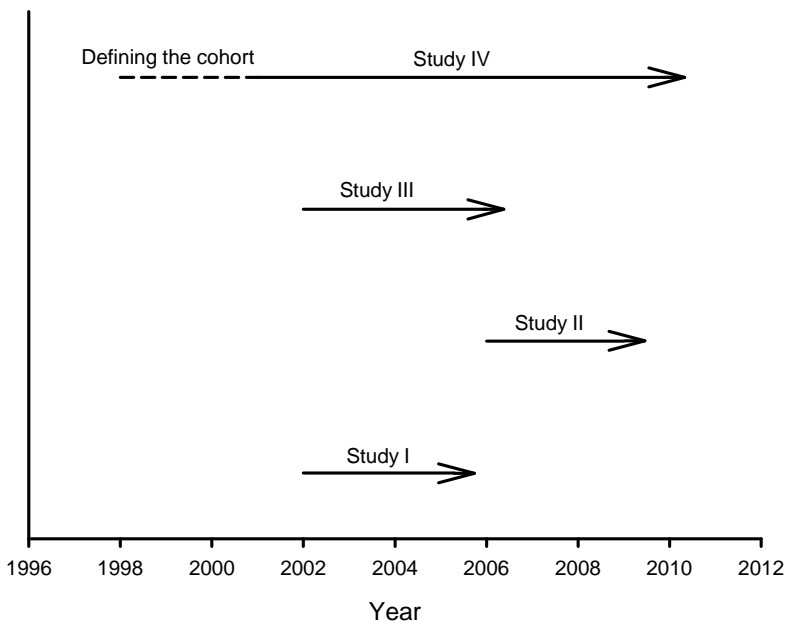


Figure 4. Timeline describing the studied periods in the Studies I, II, III and IV

**Table 3. Relations between the different study cohorts**

Studies	No of patients appearing in two studies	No of patients appearing in three studies	No of patients appearing in four studies
I+II	30		
I+III	175		
II+III	38		
I+IV	80		
II+IV	35		
III+IV	91		
I+II+III		30	
II+III+IV		18	
I+II+III+IV			17

**Table 4. Description patient characteristics in Studies I, II, III and IV**

Study no	No of included patients	Mean age, years (SD)	Diagnosis RA/SpA/PsoA/Uns/JIA %	Female/male %
I	174	51 (12)	54/29/11/3/3	79/21
II	731	54 (14)	59/29/12/0/0	67/33
III	216	50 (12)	55/30/12/0/30	71/29
IV	3977	63 (14)	100/0/0/0/0	74/26

**Table 5. Presentation of outcome measures used in studies I, II and III and description of information retrieval.**

Outcome measure used	EVALUATED IN STUDY			Information retrieval	
	I	II	III	Observed	PRO
NHP emotion	X		X		X
NHP energy	X		X		X
NHP pain	X		X		X
NHP physical	X		X		X
NHP sleep	X		X		X
NHP social	X		X		X
SF-36 PF		X	X		X
SF-36 RP	X	X	X		X
SF-36 BP	X	X	X		X
SF-36 GH	X	X	X		X
SF-36 VT	X	X	X		X
SF-36 SF	X	X	X		X
SF-36 RE	X	X	X		X
SF-36 MH	X	X	X		X
EQ-5D	X	X	X		X
General Health, VAS	X		X		X
Pain, VAS/NRS	X	X	X		X
Fatigue, NRS		X			X
HAQ	X	X	X		X
ASES		X			X
HSCL-25		X			X
BASDAI	X		X		X
BASFI	X		X		X
BAS-G1, BAS-G2			X		X
BASMI			X	X	
Aerobic capacity	X		X	X	
Shoulder arm hand test			X	X	
Grip strength, Grippit			X	X	
SOFI			X	X	



## Methods - Outcome measures

### Outcome measures used for evaluation

#### *The Nottingham Health Profile (NHP)*

part I, was used in Studies I and III to evaluate HRQoL. The 38 items of this generic questionnaire are divided into six subscales: emotional reactions (9 items), energy level (3 items), pain (8 items), physical mobility (8 items), sleep (5 items) and social isolation (5 items). Each question can be answered 'yes' or 'no', and the answer is weighted. Subscale and total scores can vary between 0, 'no problems', and 100, 'all problems listed are present' (Fries et al. 1980; Ekdahl et al. 1988; Wiklund et al. 1988; Wiklund et al. 1990; Houssien et al. 1997).

#### *The Short Form 36 Health Survey (SF-36)*

was used to evaluate HRQoL in Studies II and III. This generic questionnaire of 36 items covers eight dimensions of health: physical functioning (PF, 10 items), physical role limitations (RP, 4 items), bodily pain (BP, 2 items), general health perceptions (GH, 6 items), vitality (VT, 4 items), social functioning (SF, 2 items), emotional role limitations (RE, 3 items) and mental health (MH, 5 items). The scores range from 0 to 100 (worst to best) (Ware et al. 1992; Sullivan et al. 1998).

#### *The Euroqol-5Dimensions (EQ-5D)*

was used to evaluate HRQoL in Studies II and III. The five questions of this generic questionnaire encompass self-care, pain, usual activities and psychological status. The result is a value between 0 and 1 defining health status (0=death, 1=full health) (Hurst et al. 1997).

#### *VAS general health*

Visual analogue scales (VAS) were used to assess global health (0-100 mm/0-10 cm, best to worst) in Studies I, II and III.

#### *VAS pain and VAS fatigue*

Pain was evaluated in Studies I, II and III, using

VAS (0-100 mm/0-10 cm, best to worst) or a numerical rating scale (NRS) (Joos et al. 1991).

The level of fatigue according to definitions given in each language was evaluated using a numeric rating scale (NRS, 0-10, best to worst).

#### *HAQ*

The patient-reported Stanford Health Assessment Questionnaire (HAQ) was used in Studies I, II and III to evaluate physical functioning. HAQ comprises 20 questions covering eight areas of every day activities. The total score ranges from 0 to 3, best to worst (Fries et al. 1980; Ekdahl et al. 1988).

#### *ASES*

The Arthritis Self Efficacy Scale (ASES) was used in study II to evaluate self-efficacy. The total score ranges from 10-100 and in the Dutch version total score ranges from 1 to 5, worst to best (Bloch et al. 1989; Lorig et al. 1998b). The parts for the evaluation of 'pain' (5 items) and of 'other symptoms' (4 items) were used.

#### *HSCL-25*

The Hopkins Symptom CheckList (HSCL-25) was used to evaluate mental wellbeing in Study II. Twenty five items on mental wellbeing and the total scores range from 0-4, best to worse (Nettelbladt et al. 1993).

#### *BAS indices*

In Studies I and III the self-administered disease-specific instrument Bath Ankylosing Spondylitis (BAS) Indices for Function (BASFI) and for Disease Activity (BASDAI) were used to obtain information on functional ability and disease activity in patients with SpA including AS and PsA. The 10 items of the BASFI are answered on a VAS, one for each question. The total score ranges from 0 to 10 (best to worst) (Calin et al. 1994; Garrett et al. 1994; Jones et al. 1996a; Cronstedt et al. 1999; Waldner et al. 1999). In Studies I and III the Bath Indices for Global Health, using a VAS for

each item, measuring global health in the previous week (BASG-1), and global health during the past 6 months (BASG-2) were also used in the SpA group, (0-10, best to worst) (Jones et al. 1996b).

The Bath Ankylosing Spondylitis Metrology Index (BASMI) provides a composite score of observed axial status, and was used exclusively in the SpA group in Studies I and III. A total score ranging from 0 to 10 (best to worst) is derived from five clinical measures on cervical and lumbar ROM (Jones et al. 1995).

#### *Aerobic Capacity*

In Studies I and III the aerobic capacity (maximal oxygen consumption,  $VO_{2max}$ ) was determined using an 8-minute, sub-maximal treadmill walking test. Age, sex, self-selected walking speed (km/h), and working heart rate were used to calculate the individual's oxygen uptake, expressed as ml/kg/min (Ebbeling et al. 1991; Minor et al. 1996). In Study I, the aerobic capacity was classified according to four age groups for women, and five age groups for men, making them comparable to the Astrand fitness categories: 'Low', 'Fair', 'Average', 'Good' and 'High' (Astrand 1960).

#### *The shoulder, arm and hand test*

The shoulder, arm and hand test was used to evaluate the performance of the upper extremities (Bostrom et al. 1991), in Study III. Five different tasks were used to evaluate the ROM, giving a total score ranging from 0 to 60 (worst to best).

#### *Grip strength*

Grip strength was evaluated with the GRIPPIT dynamometer with the patients seated in a standardized position, in Study III. The patients were instructed to press the handle of the instrument for 10 s with each hand. The mean strength of the left and right hand was used (Nordenskiöld et al. 1993; Lagerstrom et al. 1998).

#### *SOFI*

The Signals of Functional Impairment (SOFI) index was used to obtain a composite score of

observed function, in which the performance of upper limbs (8 items) and lower limbs (4 items) were evaluated. The total score ranges from 0 to 48 (best to worst) (Eberhardt et al. 1988). This test was used exclusively in the PA group in Study III.

### **Psychometric properties**

In Study III we wanted to study the validity of a set of instruments in order to determine which outcome measures would provide the best information for multidisciplinary rehabilitation outcome in patients with CIA. We studied the content validity by linking the outcome measures to the ICF components and also assessed construct validity based on predetermined hypotheses and responsiveness to change of the studied outcome measures.

#### *Linkage to the ICF*

We wanted to study and compare the relation to the ICF among the outcome measures used. We identified similarities and dissimilarities in the ability to cover different aspects of health and disease among the studied outcome measures. To aid in the difficult task of describing evaluation and comparing outcome measures, linking rules have been developed to relate outcome measures to the ICF (Cieza et al. 2002; Stamm et al. 2004; Cieza et al. 2005b). All meaningful concepts of the questions, including the response options and examples given in the outcome measure, should be linked to a specific ICF component according to the linking rules (Cieza et al. 2002; Cieza et al. 2005b). Translation and identification of all meaningful concepts of the studied outcome measures were linked to the most precise third-level ICF category. The representation of the categories was then linked to the ICF component(s): body function, body structure activity and participation and environmental factors. Concepts addressing 'health', the overall term defined by the components in the ICF model, were linked to 'health'. One co-author critically reviewed the initial linking and

after discussions and consensus the proposed linking also was thoroughly reviewed by all co-authors. After discussion and revision the finally linking was concluded.

### *Construct Validity*

We also wanted to compare the relationship between outcome measures used to evaluate similar aspects of health and disease. Analysis of construct validity can be used to determine the relationship between outcome instruments. The analysis is based on linking the evaluated attribute or aspect of health to some other attribute(s) by hypothesis. To fully establish construct validity it is necessary to define high correlations (convergent validity) and low correlations (divergent validity). In our analysis convergent validity was defined as  $r_s \geq 0.8$  and divergent validity was defined as  $r_s \leq 0.2$  (Terwee et al. 2007).

If construct validity is high the outcome measures analysed are expected to evaluate similar aspects of health and disease and are thus interchangeable. A high  $r_s$  between outcome measures could probably indicate that the patient should better be spared from the effort with answering or be examined by both questionnaires/outcome measures.

### *Responsiveness*

Analysis of responsiveness evaluates if an outcome measure is sensitive to change (Streiner et al. 1995). We wanted to compare the magnitude of change after the intervention between outcome measures used to evaluate similar aspects of health and disease. Thus we calculated the standardized response mean (SRM) for each instrument or its subscales at the end of rehabilitation and at the 12 month follow-up (Mokkink et al. 2010). Higher SRM scores indicate greater responsiveness to change.

### *Minimal important difference*

Measures for interpreting the improvement at the individual level complementary to the improvement on group level have been promoted by the OMERACT. Minimal important difference (MID) is one suggested measure on clinical relevant change from the patient's perspective (Strand et al. 2011). In Study II the MID was defined as a 0.05 change of EQ-5D (Norman 2003; Strand et al. 2011) and the MID of the SF-36 was calculated for each subscale to be 0.5 of the baseline standard deviation (SD) (Norman 2003).

Another measure for individual improvement is the minimally clinically important difference (MCID), the smallest amount of change considered clinically meaningful (Strand et al. 2011). In Study I MCID in HAQ, BASDAI and BASFI was analysed (Kosinski et al. 2000; Pavy et al. 2005).

## **Health care utilization**

In study IV health care utilization was examined for a closed cohort of RA patients identified as cases by using the SHCR data for the period 1998 to 2001. Using the population register we traced residence status and survival for each identified subject (RA patient and referent) in the period 2001-2010. By using the SHCR we studied the health care utilization for each individual. A subject was censored from the time of eventual death or relocation. We analysed the annual mean number of hospitalizations, in total and at rheumatology, internal medicine or orthopaedic clinics. We also analysed the annual mean number of outpatient clinic visits to physicians, nurses and PTs for each studied calendar year. We further analysed the ratio of the mean number of visits between the RA cohort and reference cohort for each calendar year, to evaluate possible trends.

## Statistics

In Study I, the outcome over time was analysed using paired t-tests, mean ( $\pm$ SD) with 99% CIs, where p-values less than 0.01 were considered significant due to multiple testing. Pearson correlation coefficients were used to assess the association between different outcome measures.

In Study II, we used the analysis of covariance (ANCOVA) to analyse changes in EQ-5D and SF-36. The hypothesized predictors were analysed in 4 different steps of the model according to findings regarding multicollinearity (Pearson correlation analysis). As two different versions of the ASES (10-100 and 1-5) were used in this study, the ASES median score was used to dichotomize the ASES data in all countries before including the results in the ANCOVA. The dependent variables, i.e. the changes in the EQ-5D and the SF-36 subscales, were adjusted for their baseline values. ANCOVA was also used to study the interaction between variables. Regression coefficient  $\beta$ -estimates ( $\beta$ -ests) were presented, with 95% CIs.

In Study III construct validity was analysed by Spearman's correlations ( $r_s$ ). We defined the non-parametric standardized response mean

(SRM<sub>np</sub>) as the median change divided by the interquartile range of change. The SRM<sub>np</sub> is a more robust measure of responsiveness than the original SRM. The SRM<sub>np</sub> can be expected to produce smaller estimates, due to the definition. The magnitude of change due to the intervention (responsiveness) was classified as small (0-0.2), moderate (0.3-0.5) or large (> 0.5) (Cohen 1977; Cohen 1988).

In study IV we calculated the ratio of the mean number of visits between the RA cohort and the reference cohort for each calendar year and performed test for trends across ordered groups. Two tailed p-value of 0.05 or less was considered statistically significant.

## Ethics

Study I, II, III and IV had ethical approval. In the STAR-ETIC ethical approvals were obtained in all participating countries.

## Results

### Health related quality of life

In Study I, HRQoL, as evaluated by the NHP, statistically improved as a result of team rehabilitation and remained statistically improved for 12 months. In Study II, 46% of the patients exhibited MID according to the EQ-5D; this finding being supported by the different SF-36 subscales (positive MID exhibited by 23-47% of the patients on the different subscales). Being female, poorer psychological wellbeing, experiencing more pain or fatigue at admission and the need to change pharmacological treatment during the rehabilitative intervention were found to predict improved HRQoL at discharge.

In Study III the EQ-5D and the SF-36 instruments were found to cover the overall construct of health, according to the ICF. The EQ-5D, NHP and SF-36 outcome measures mainly covered body function, activity and participation. Environmental aspects were only covered by EQ-5D and the NHP (Table 6). The construct validity of the HRQoL outcome measures was moderate ( $r_s$  0.6), however, the subscales of the SF-36 had higher construct validity. The two measures of HRQoL outcome, EQ-5D and NHP, were comparable in responsiveness over time (NHP  $SRM_{np}$  0.6 and 0.3, and EQ-5D  $SRM_{np}$  0.4 and 0.2). Responsiveness of the SF-36 subscales varied between 0 and 0.7.

### Other aspects of health

#### General health

In Study I statistically significant improvement in general health was found at end of rehabilitation and after 12 months. When linking outcome measures to the ICF in Study III VAS general health and other outcome measures or subscales evaluating general health (SF-36 GH, NHP, BAS-G1 and BAS-G2) were linked to the overall construct health (Table 6).

#### Pain

Pain measured by VAS improved significantly after 18 days of rehabilitation. However, the improvement in perceived pain was no longer significant after 4 months in the PA group or after 12 months in the SpA group in Study I. At group level pain measures in 731 patients having participated in rehabilitation programmes in other Northern European countries significant improvements were found, Study II. Using MID analysis for SF-36 BP, 47% of the patients exhibited a positive individual value as a result of rehabilitation, while 16% exhibited a negative MID, in Study II.

When linking pain according to the VAS to the ICF it was found that it could only be linked to the ICF component BF, the 'b280' - pain. Pain measured using other outcome measures, NHP pain, SF-36 pain and BASDAI, was also linked to the ICF component BF. However, NHP pain and SF-36 BP also covered activity and participation (Table 6). Three out of 6 questions of the BASDAI included pain estimated on a VAS, and when analysed correlation to a single measure of VAS pain was  $r_s$  0.8, indicating a strong relationship between these two outcome measures (convergent validity). BASDAI showed a larger  $SRM_{np}$  after 18 days of rehabilitation than did the VAS (0.8 vs. 0.5), while both measures had values of  $SRM_{np}$  close to zero 12 months later ( $SRM_{np}$  0.1 vs. 0.2). BASDAI was found to be superior to a single VAS pain measure in the evaluation of short-term outcome in patients with SpA. No other measures of pain showed convergent validity according to the predefined hypotheses. SF-36BP ( $SRM_{np}$  0.5) and NHP pain ( $SRM_{np}$  0.4) showed more consistent responsiveness than VAS pain.

#### Fatigue

Experiencing more fatigue ( $\beta$ -est 0.02,  $p < 0.001$ ) at admission predicted a positive change in HRQoL according to EQ-5D. This was confirmed by similar findings in the analysis of

the SF-36 subscales in Study II. Higher fatigue at baseline was found to predict an improvement in HRQoL after completion of the rehabilitation programme, as captured by the MH ( $\beta$ -est 0.8,  $p=0.004$ ), SF ( $\beta$ -est 1.4,  $p<0.001$ ), RE ( $\beta$ -est 1.5,  $p=0.038$ ), VT ( $\beta$ -est 1.4,  $p<0.001$ ) and BP ( $\beta$ -est 0.6,  $p=0.033$ ) subscales.

#### *Mental wellbeing*

Poorer mental wellbeing, reflected by the HSCL-25, was found to predict improved HRQoL, according to EQ-5D, Study III. Furthermore, statistically significant interactions were found between HSCL and comorbidities ( $p=0.035$ ), no comorbidities at baseline ( $\beta$ -est -0.13), and comorbidities at baseline ( $\beta$ -est 0.11). In the corresponding analysis of HSCL-25 as a potential predictor of improved HRQoL as captured by the different subscales of the SF-36 HSCL at baseline was found to significantly predict improvement of the MH ( $\beta$ -est 8.9,  $p<0.001$ ), SF ( $\beta$ -est 9.0  $p<0.001$ ), RE ( $\beta$ -est 19.2,  $p<0.001$ ), and VT ( $\beta$ -est 4.6,  $p=0.005$ ) subscales. Interactions were found not to be significant.

#### *Self-efficacy*

Experiencing low self-efficacy (below the median) according to the ASES symptom scale at the start of rehabilitation was found to predict an improvement in the MH ( $\beta$ -est 3.6,  $p=0.004$ ), SF ( $\beta$ -est 4.2,  $p=0.029$ ) and in RE subscales ( $\beta$ -est 6.6,  $p=0.049$ ). Experiencing high self-efficacy (above the median) on the ASES pain scale at the start of rehabilitation was also found to predict improvement on the PF subscale ( $\beta$ -est 4.5,  $p=0.002$ ) in Study II.

### **Physical functioning - patient reported**

Patient-reported outcome measures on physical functioning in Studies I, II and III.

A statistically significant improvement ( $p<0.01$ ) was seen in physical functioning, as measured by the HAQ, in the PA group after 18 days of rehabilitation, but not after 4 and 12 months. The disease-specific instruments, BASDAI and BASFI, both showed statistically

significant changes in physical functioning and reached MCID at 4 months according to BASDAI and at 12 months according to BASFI.

When linking HAQ and BASFI to the ICF they were found to cover similar components: activity, participation and environmental factors, and BASFI could also be linked to the component of body function (Table 6). Furthermore, HAQ and BASFI were found to be measures of related constructs since their correlation coefficient was 0.8. BASFI was the most responsive outcome measure out of the two. HAQ was found not to predict a change in HRQoL resulting from the team rehabilitation intervention when measured by EQ-5D or SF-36.

### **Physical functioning - observed**

In Study III measures of the hand and arm were analysed separately from the measures of spinal/axial mobility. All measures of hand and arm functioning (GRIPPIT, SOFI, Shoulder, hand and arm test) were linked to the ICF component body function (Table 5). Construct validity was not seen between these instruments ( $r_s = 0.3-0.7$ ). The SOFI index was found to be a responsive measure of this type of rehabilitation ( $SRM_{np} 0.7$  and  $0.3$ ) while GRIPPIT and Shoulder, hand and arm test were less responsive ( $SRM_{np} 0.2-0.4$ ).

The measure of axial ROM obtained with BASMI was also linked to the body function component of the ICF (Table 6). We hypothesized that BASMI should have low construct validity, and this hypothesis was confirmed by low correlations with the other outcome measures of observed physical functioning ( $r_s < 0.2$ ). The responsiveness was high:  $SRM_{np} = 0.8$  (at discharge) and  $0.5$  (after 12 months).

#### *Aerobic capacity*

After 18 days of rehabilitation in Study I, the patients had improved their aerobic capacity statistically and clinically significantly. At inclusion, <20% of the tested patients had an

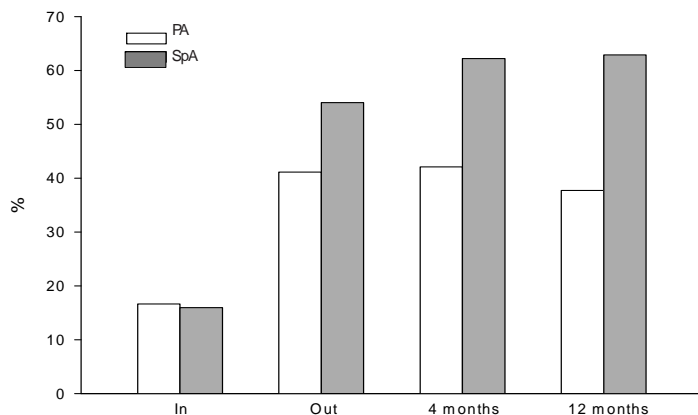


Figure 5. Percentage of patients in PA and SpA groups with aerobic capacity classified as average or more according to Astrand.

**Table 6. Presentation of outcome measures used in studies I, II and III and description of linking to the ICF.**

Outcome measure used:	EVALUATED IN STUDY			BF/BS	ICF		HEALTH
	I	II	III		Activity/ Participation	Environ- mental	
NHP emotion	X		X	X			
NHP energy	X		X	X			
NHP pain	X		X	X	X		
NHP physical	X		X		X	X	
NHP sleep	X		X	X			
NHP social	X		X	X			
SF-36 PF		X	X		X		X
SF-36 RP	X	X	X		X		X
SF-36 BP	X	X	X	X	X		
SF-36 GH	X	X	X				X
SF-36 VT	X	X	X	X			X
SF-36 SF	X	X	X	X	X		X
SF-36 RE	X	X	X	X	X		X
SF-36 MH	X	X	X	X			
EQ-5D	X	X	X	X	X	X	X
General Health, VAS	X		X				X
Pain, VAS/NRS	X	X	X	X			
Fatigue, NRS		X					
HAQ	X	X	X		X	X	
ASES		X					
HSCL-25		X					
BASDAI	X		X				
BASFI	X		X	X	X	X	
BAS-G1, BAS-G2			X				X
BASMI			X	X			
Aerobic capacity	X		X	X			
Shoulder arm hand test			X	X			
Grip strength, GRIPPIT			X	X			
SOFI			X	X	X		



aerobic capacity classified as 'average or better'. Upon completing the rehabilitative intervention, 41% (PA) and 54% (SpA) had an aerobic capacity that could be classified as 'average or better' and the improvement was maintained over 12 months, Figure 5.

Aerobic capacity was linked to ICF body function in Study III (Table 6). Aerobic capacity was found to have divergent validity to the other observed outcome measures ( $r_s \geq 0.2$ ) and it was also found to be a highly responsive observed outcome measure (SRM<sub>np</sub> 1.1 and 1.2).

### Health care utilization

Over the 10 year study period 1417 (35.6%) of the included RA patients had died, and 89 had relocated out of the county. The annual mortality in the RA cohort ranged between 3.0 to 4.3%. Of the 7954 matched referents, 1810 (22.8%) had died by end of the study period and 257 had relocated from Skåne County. The annual mortality of the reference cohort ranged between 2.0 to 2.6%.

The annual mean number of hospitalizations was relatively stable over time in both the RA cohort and the reference cohort, although there was a statistically significant trend for an increase over time in both female and male reference subjects ( $p=0.01$ ).

The mean number of hospitalization at a rheumatology or internal medicine clinic and orthopaedic clinic, respectively, was also relatively stable over time although the number

of hospitalizations to an orthopaedic clinic tended to decrease in both female ( $p=0.01$ ) and male RA patients ( $p=0.06$ ).

The mean number of outpatient visits to a physician decreased during follow-up in female RA patients (from mean 9.9 visits in 2001 to 8.7 visits in 2010,  $p=0.02$ ). Male RA patients had a similar pattern but not statistically significant ( $p=0.19$ ). The number of visits generated by reference subjects remained fairly stable during follow-up.

The mean number of visits to a rheumatologist and/or specialist in internal medicine or orthopaedic specialist, respectively, tended to decline in both female and male RA patients. While the annual mean number of such visits in reference subjects remained fairly stable.

The mean number of visits to a nurse increased for both female ( $p=0.007$ ) and male ( $p=0.04$ ) RA patients, as well as for reference subjects. However, the mean number of visits to a nurse in rheumatology and/or in internal medicine decreased during follow-up in female RA patients, from mean 1.3 in 2001 to 0.9 visits in 2010 ( $p=0.007$ ). The pattern in male RA patients was similar ( $p=0.01$ ).

The number of visits to physiotherapists decreased from annual mean of 5.5 per female RA patient in 2001 to 3.4 in 2010 ( $p=0.003$ ). The pattern in male RA patients was similar ( $p=0.02$ ). The physiotherapy utilization by reference subjects was relatively stable during follow-up.



## General discussion

Multidisciplinary team rehabilitation of patients with CIA was studied in this thesis, with the aim of analysing and presenting the outcome. The psychometrics of established outcome measures and their relation to the ICF were also investigated. Also, a study was carried out using data from health care registers to evaluate changes over time in health care utilization in a closed cohort of RA patients over the past decade.

### **Theoretical frameworks for this thesis – the ICF and the model for structure, process and outcome**

Although the research is clinically based and the implications are for the clinical setting the discourse for the work needs to be discussed.

The ICF was used as a theoretical framework for the work presented in this thesis, together with a model describing rehabilitation in terms of structure (the condition under which care is provided), process (the health care activities conducted) and the outcome (the results from the rehabilitation) (Wade et al. 2000; Donabedian 2003; Wade 2005). Apart from describing the different aspects of the ICF, and having focused on linking the instruments used to measure the outcome of team rehabilitation to the ICF in Study III (Table 6), efforts were made to describe the structure, the process and the outcome. An attempt was made to explain structure and process in a local Swedish rehabilitation programme in Study I where the outcome of team rehabilitation was investigated. In Study II, predictors of change or improvement in HRQoL were investigated in different settings. These two studies were carried out by researchers within the STAR-ETIC project, and the common intention was to apply the structure–process–outcome model to the studies generated from this project as a whole; one subject being analysed in as great detail as possible in each study. In Study III,

the psychometric properties of measures used to evaluate the outcome of the Rheuma Rehab programmes in Lund were analysed. Certain aspects of rheumatological health care were analysed in Study IV by health care utilization analysis in terms of the frequency of visits of a well defined cohort of RA patients.

The ICF puts a focus on the impact of disability on activity and participation as more important to the person affected than their actual medical condition (World Health Organization 2012a). Thus, the ICF was found to be a very useful framework, enabling us to better understand the properties of the outcome measures used in team rehabilitation (Study III).

### **Team rehabilitation**

The results of the studies included in this thesis showed that team rehabilitation was effective in improving HRQoL, aerobic capacity and general health (Study I): three important aspects when living with CIA. It was also found that among patients with CIA referred for rehabilitation in four Northern European countries, women, those experiencing poorer psychological wellbeing, or more pain or fatigue, benefited most in terms of improved HRQoL (Study II). Similar results were seen in EQ-5D and the subscales of SF-36. We also found that 46% (EQ-5D) and 23%–47% (SF-36 subscales) of the patients experienced improved HRQoL and exhibited positive MIDs.

Although our study design was observational, the findings contribute by providing evidence of the important effects of team rehabilitation on aspects highly important to the patient. Observational study design was used in the studies on team rehabilitation (I, II, III).

Rehabilitation has been called ‘the archetypical complex intervention’ (Wade 2005), and the lack of evidence on the benefits

of rehabilitation could be partly related to the difficulties in describing this complexity. The complexity is due to the combination of a number of components in the rehabilitation process which may act independently and interdependently (Campbell et al. 2007). Tailoring the interventions with regard to the needs and goals of each patient also contributes to the complexity (Craig et al. 2008). The value of the information obtained from observational studies has recently been recognized, and has been perceived to provide information from the 'real world' (van Vollenhoven et al. 2011). Team rehabilitation interventions are complex and difficult to apply in randomized controlled trials models. According to PrvuBettger, 'applying carefully designed, non-randomized studies can strengthen the evidence to make more conclusive statements about the effectiveness of rehabilitation services and outcomes' (Prvu Bettger et al. 2007).

Studies on the effects of multidisciplinary team rehabilitation in rheumatology (and on other aspects of rehabilitation) most often include some hundred patients at most. In the rehabilitation context, the cohorts studied in this thesis are large:  $n=174$  (Study I),  $n=731$  (Study II) and  $n=215$  (Study III). The STAR-ETIC cohort of 731 patients, representing different rehabilitation programmes in four Northern European countries is, to the best of our knowledge, a unique example of collaboration within Europe.

#### *The patient's perspective in rheumatological team rehabilitation*

In a recent Norwegian qualitative study, the following conclusions were drawn regarding targeted multidisciplinary rheumatological rehabilitation: (i) it has the potential for outcomes of major personal impact, (ii) interventions should be tailored according to the patient's subjective perception of challenges, and (iii) a secure and supportive environment, where patients are met with respect and interest, is a crucial element (Dager et al. 2012). The findings of the STAR-ETIC project showed that most of the rehabilitation

programmes analysed in this thesis focus on, evaluate and incorporate patients' goals and perceived challenges/impairments in the planning of treatment, and interventions are tailored to the individual patient to varying degrees (Grotle et al. 2012).

Further steps for the development of rheumatological team rehabilitation have been suggested by Li (Li 2005).

1. The evaluation of less well-studied interventions.
2. Improved understanding of the relationships between rehabilitation-related variables and disability.
3. Development and evaluation of innovative care models.
4. Design and evaluation of knowledge transfer innovations.

According to Vliet Vlieland, the use of adequate outcome measures, the enhancement of mutual communication, and further definition and extension of the role of the patient in the team care process should also be included (Vliet Vlieland 2004). We consider that we have tried to target most of these aspects (1-3) in our intention to analyse the outcome of team rehabilitation, albeit with an observational study design. Although team rehabilitation is not the least well-studied area within rehabilitation, it is still hampered by a lack of knowledge. Our finding of positive long-term outcome from a well-described rehabilitation programme (Study I), and information on which patients benefited most from rehabilitation (Study II), can be related to items 1 and 2 above. Our participation in the STAR-ETIC project, where we described the outcome of all participating sites and programmes in parallel to other authors describing the structure and process from the participating sites, can not be regarded as 'development of innovative models' (item 3), but it does provide valuable information on different forms of rehabilitation programmes and their particular advantages. We also analysed outcome measures relevant for the evaluation of team rehabilitation and tried to elucidate their applicability, relevance and validity.

## Health related quality of life

HRQoL was found to improve significantly and to persist over time as a result of multidisciplinary rehabilitation interventions. Among chronic diseases, RA has been rated as one of those with the most serious detrimental effects on HRQoL (Strand et al. 2010). Reports on long-term improvement in HRQoL are rare within rheumatological rehabilitation. Previously in particular short-term improvements from team and rehabilitative interventions had been described (Bulthuis et al. 2007; Breedland et al. 2011) with few exceptions (Tijhuis et al. 2002; Tijhuis et al. 2003).

We also found that rehabilitative interventions were more beneficial in women struggling with more severe consequences of their disease.

It was also found that the instruments used to evaluate HRQoL, i.e. EQ-5D, NHP and SF-36, were not interchangeable, and that the measures studied were not very sensitive to change over time. Interestingly, the short EQ-5D covered more aspects of health and disease than the more comprehensive instruments.

## Physical functioning

Despite previously reported limitations of the sensitivity of the HAQ, the present studies showed an improvement after 18 days of team-based rehabilitation (Study I). HAQ was not found to be predictive of changes in HRQoL (Study II), different from previous report on the ability of HAQ to predict disability after 10 years in cases of early arthritis (Lindqvist et al. 2002). The HAQ and BASFI were comparable measures of functioning, and provide good measures of the specific factors they are intended to evaluate (Study III).

## Aerobic capacity

Aerobic capacity improved as a result of team rehabilitation, and was sustained over 12 months. Improved aerobic capacity after rheumatological team rehabilitation has been

described in one study (Breedland et al. 2011) where the participants (n=24) were randomly assigned to one of two groups, 'exercise' or 'waiting list for control'. The exercise group followed an 8-week programme consisting of 3 hours exercise, 2 days per week. Self-management education, for 60 minutes per week, was also included in the programme. The patients were followed up after 22 weeks. Aerobic capacity was found to improve, while health, self-efficacy and muscle strength did not (Breedland et al. 2011). One contributing factor to the sustained improvement seen in the present work could be the individually tailored plan on how to continue being physically active after the rehabilitation programme. The plan was revised at each follow-up. Furthermore, the role of the follow-ups in motivating the patients seemed important. Improved level of aerobic capacity was maintained indicating an increase in physical activity in daily life. Improved aerobic capacity among CIA patients may also help prevent the development of cardiovascular disease (Turesson et al. 2007).

The psychometric analysis showed that aerobic capacity was not captured by any observed outcome measure on physical function used in Study II. It was also found that increased aerobic capacity was not correlated to energy level as measured by NHP in Study I. We believe that it is of utmost importance to evaluate aerobic capacity in patients with CIA. CIA patients, especially those with low aerobic capacity, should be made more aware of the importance of physical activity, aerobic capacity and general health.

## Psychometrics in the evaluation of team rehabilitation

When outcome measures used for the evaluation of team rehabilitation were linked to the ICF, in Study III, the components most highly represented were body structure and body function. The components of activity and participation were less well represented, while environmental aspects were only

covered by one question in each out of three outcome measures.

When construct validity was evaluated among the outcome measures intended to evaluate similar aspects of health and disease, aerobic capacity was found to represent a different aspect. It was also found that measures of HRQoL are not interchangeable with regard to construct validity.

Aerobic capacity showed the highest responsiveness of all outcome measures analysed.

All HRQoL outcome measures had low to moderate responsiveness, although the shorter EQ-5D was found to cover all ICF components. The BAS indices were found to be of great value and preferable to other comparable measures of disease activity, functioning and mobility when applicable (i.e., in SpA patients).

### **Limitations of the present studies**

We are well aware of the potential selection bias of the participants in Studies I, II and III due to differences in traditions and health care

systems in and between different countries. Patients referred to the Rheuma Rehab programme, and to other rehabilitation programmes and who completed the rehabilitation programmes, could be more motivated than other patients in similar situation which might hamper the generalizability of the results.

Selection bias also adheres to our analysis of health care utilization. In Study IV 3977 RA patients were included, meaning that at the beginning of the study over 10 years not all of the total expected number of RA patients resident in Skåne were included (Englund et al. 2010). Since the cohort was defined by their health care utilization during the inclusion period patients with established mild to moderate disease could be underrepresented. Patients with more severe disease and comorbidities consume more health care for some periods but those with lethal complications will have a lower health care utilization.

## Clinical implications

Pharmacological treatment has changed markedly over recent years with increasing costs for biologic drugs in CIAs. As a consequence in the priority discussions the benefit of complex and costly interventions such as multidisciplinary team rehabilitation has been questioned. However, all patients do not respond to pharmacological treatment, and patients with longstanding disease have special needs not met by drugs only. It is therefore important to identify the patients who will benefit most from this kind of intervention.

- Patients suffering more severe consequences (females with more fatigue, less wellbeing and more pain) of the disease were found to benefit most from team rehabilitation in our studies (I,II). This information could be useful in selecting patients who would benefit from team rehabilitation.

- Aerobic capacity is an important aspect of health in CIA patients and an indicator of the level of physical activity for each individual. In this thesis evidence for improved aerobic capacity maintained over longer time was

presented. Patients with low physical activity improved their physical activity during the rehabilitation program with individual plans for physical activity and also boosting follow ups. Thus, different forms of interventions with individual and tailored planning on physical activity and boosting could be more widely used and evaluated.

- Aerobic capacity was not captured by any other of the outcome measures on observed physical function or self reported energy in this thesis (Study III). Hence aerobic capacity must be evaluated separately when applicable to the intervention performed.

- Outcome measures on evaluation of HRQoL do not seem to be interchangeable in team rehabilitation settings (Study III). Comparisons between outcomes of different study settings should thus be evaluated with this in mind.

- Health care utilization for RA patients seems to decrease over time at least for certain health professionals. This has to be taken into account in the planning of future care within rheumatology.

## Future perspectives

In the future a further development of modern individualised and tailored team based rehabilitation would be an important part of treatment programmes for patients with chronic inflammatory arthritis. Aerobic capacity and physical activity are important aspects of future treatment and rehabilitation. Patients in need for complex interventions yet with individual needs of care should be referred to optimized team rehabilitation programmes. Further evaluation of different

models of team rehabilitation is needed, preferably also adding the societal perspective. This can be done by involving the patients as well as different health care professionals and other stakeholders also from other areas of expertise. Randomized controlled studies will be needed, but for further describing the broader perspective, not usually covered by RCTs also more observational studies will be needed in the future.

## Conclusions

- Patients with CIA improve in HRQoL, aerobic capacity and general health by team based rehabilitation with persisting improvements after twelve months.
- Female patients with more severe impairment in pain, mental well-being and fatigue benefit most from team based rehabilitation.
- Certain aspects of the ICF are well covered (body function and body structure) by the outcome measures used in routine care while the aspects of activity, participation and environmental aspects are less well covered.
- Different patient reported outcome measures such as SF-36, NHP and EQ-5D seem to measure different aspects of HRQoL and are not interchangeable.
- Aerobic capacity is not related to or measured by other measures of physical functioning used in team based rehabilitation.
- During the first decade of the twenty-first century, coinciding with increasing use of earlier and more active RA treatment, including biological treatment, the overall inpatient and outpatient health care utilization among RA patients has decreased compared to the general population.

## Summary in swedish – populärvetenskaplig sammanfattning på svenska

Rehabilitering har sedan länge varit en viktig och naturlig del av behandlingen för personer med reumatiska sjukdomar. I denna doktorsavhandling om teambaserad rehabilitering för personer med kroniska reumatiska ledsjukdomar ges en uppdatering av kunskapsläget liksom en historisk bakgrund. De vetenskapliga resultat som redovisas i avhandlingen visar i korthet på följande:

- Teambaserad reumatologisk specialistrehabilitering ökar välbefinnande mätt som hälsorelaterad livskvalitet samt kondition, både kort- och långsiktigt.

- Med de skillnader och likheter i hur reumatologisk rehabilitering bedrivits i fyra olika länder och på olika centra i Europa har vi funnit att de patienter som genomgått teamrehabilitering avsevärt ökat sitt välbefinnande mätt som hälsorelaterad livskvalitet. De som förbättrades mest var kvinnor som vid rehabiliteringsperiodens början hade mer ont, var tröttare och mådde sämre.

- Välbefinnande mätt som hälsorelaterad livskvalitet bör utvärderas med samma frågeformulär för att kunna jämföras.

- För att studera kondition krävs specifikt mått på syreupptagningsförmåga.

- Sjukvårdskonsumtionen har minskat bland personer med ledgångsreumatism under de senaste 10 åren.

Kronisk reumatisk ledsjukdom kan medföra smärta, stelhet, trötthet, ledförstörelse, minskad funktion i dagligt liv och arbetsliv för den som lever med sjukdomen. För många påverkas fysiskt, psykiskt och socialt välbefinnande och livskvaliteten och den fysiska aktiviteten kan minska. Personer som lever med dessa sjukdomar kan också löpa ökad risk för att drabbas av komplikationer och andra sjukdomar. Under de senaste 20 åren har förståelsen för vad som orsakar och underhåller ledsjukdomen (inflammationen) ökat. Ett flertal nya läkemedel som enskilt eller i kombination effektivt minskar eller till och med bromsar den inflammatoriska aktiviteten har

tagits fram, vilket avsevärt förbättrat livssituation och framtidsutsikter för personer med kronisk reumatisk ledsjukdom. De nya läkemedlen fungerar inte för alla som får dem. De som behandlas kan också ha levt med sin sjukdom under längre tid och/eller haft så hög sjukdomsaktivitet att deras leder och andra organ i kroppen destruerats eller märkts av sjukdomen, vilket inte förbättras lika mycket av läkemedelsbehandling.

Rehabilitering är ett viktigt komplement till den medicinska behandlingen och definieras som "alla åtgärder av medicinsk, psykologisk, social och arbetslivsinriktad art som syftar till att hjälpa den sjuke att återfå bästa möjliga förmåga/funktion". Rehabilitering av olika aspekter av hälsa kan ske som enskild intervention dvs styrketräning, konditionsträning, rörlighetsträning, smärtbehandling, utprovning av hjälpmedel som enskild företeelse, levererad av en eller flera professioner som arbetar enskilt. Då många olika aspekter av hälsa är påverkade eller sjukdomens inverkan är stor kan det uttryckas som att mer komplex problematik föreligger. Teamrehabilitering, dvs rehabilitering som utförs av ett team om fler än 2 personer med olika kompetens som arbetar kring eller tillsammans med varandra och tillsammans med patienten är ett exempel på en sammansatt/komplex intervention. Vid teamrehabilitering inom reumatologin kan läkare, sjuksköterska, sjukgymnast, arbetsterapeut och kurator ingå i teamet. Också ortoped, ortopedtekniker, psykolog samt dietist kan vara med. Teamrehabilitering har visats ha god effekt hos patienter med kronisk reumatologisk ledsjukdom, men kan på grund av sin komplexitet vara svår att utvärdera. Relativt få undersökningar finns och det har också visat sig vara svårt att beskriva rehabiliteringen så att den utifrån studien går att upprepa.

De delarbeten som presenteras i denna avhandling har varit avsedda att studera och beskriva utfall av och utvärderingsmetodik vid



teamrehabilitering av patienter med kronisk reumatisk ledsjukdom (delarbete I, II och III) samt att beskriva hur personer med ledgångsreumatism använt sig av sjukvård under början av 2000 talet (delarbete IV).

Delarbete I är baserat på de 174 patienter som genomfört en rehabiliteringsperiod vid Reuma Rehab i Lund januari 2002 till och med juni 2005. De genomgick 18 dagars rehabilitering för patienter med ledgångsreumatism eller reumatisk ryggsgjukdom och undersöktes/fyllde i frågeformulär vid in- och utskrivning, samt 4 och 12 månader därefter. Patienternas hälsorelaterade livskvalitet, kondition samt skattning av generell hälsa förbättrades och höll sig på en signifikant förbättrad nivå över hela undersökningsperioden, 12 månader. Vid inskrivning visade sig endast 16-17% av patienterna ha medelgod kondition. Vid utskrivning hade 52-54% av patienterna medelgod kondition i relation till kön och ålder. Förbättringen kvarstod under den undersökta perioden, vilket skulle kunna tyda på att patienterna ökat sin fysiska aktivitet.

I delarbete II studeras patientdata från rehabiliteringsprogram inom "Scandinavian Team Arthritis Register-European Team Initiative for Care" (STAR-ETIC projektet). Från Sverige deltog 3 enheter, i Norge behandlade 11 enheter patienter med kronisk reumatisk ledsjukdom, från Danmark och Holland deltog 1 enhet vardera. STAR-ETIC projektet startades för att undersöka *struktur* dvs hur olika teamrehabiliteringsprogram var utformade i de olika sjukvårdssystemen, *process* dvs hur rehabiliteringen utövades samt *utfallet* dvs resultatet av de olika rehabiliteringsprogrammen. Gemensam uppsättning av utvärderingsinstrument samt databas för inrapportering av data togs fram i början av projektet. I delarbete II har 731 patienter med kronisk reumatisk ledsjukdom som avslutat rehabiliteringsperiod inom STAR-ETIC analyserats i försök att utröna vilka patienter som har störst möjlighet att förbättra sin hälsorelaterade livskvalitet genom teamrehabilitering. Vi fann att de patienter som vid inskrivning rapporterat sämst psykologiskt välbefinnande, mer smärta och trötthet och var

kvinnor var de som förbättrades mest i sin hälsorelaterade livskvalitet. Båda de utvärderingsinstrument som använts för skattning av hälsorelaterad livskvalitet visade överensstämmande resultat. Vi undersökte också om patienternas livskvalitet förbättrats så mycket att det påverkade deras vardag, dvs. var "kliniskt relevant" och fann att 46% respektive 23-47% av patienterna upplevde så god förbättring att de uppnådde denna nivå.

I delarbete III studerades undersökningsmetoder och utvärderingsformulär som ofta används vid utvärdering av teamrehabilitering genom studie av information lämnad av 216 patienter som genomfört rehabiliteringsperiod i Lund. Först undersöktes hur undersökningsmetoder och frågeformulär täckte olika aspekter av hälsa genom att länka dem till ett ramverk som tagits fram av WHO. Detta ramverk, International Classification of Functioning, Disability and Health (ICF), har tagits fram för att lättare beskriva och jämföra undersökningsmetoder, frågeformulär, sjukvårdande verksamhet och studier. Sedan studerades hur undersökningsmetoder och frågeformulär som är avsedda att utvärdera liknande aspekter av hälsa och sjukdom överensstämmer med varandra. I en tredje analys undersöktes hur känsliga undersökningsmetoder och utvärderingsformulär är i att fånga förändring. Genom dessa analyser framkom att de studerade undersökningsmetoderna och utvärderingsformulären väl täckte olika aspekter av individens kroppsfunction, att färre frågor rörde aktiviteter i och utanför hemmet och olika sociala sammanhang som arbete och fritid. Minst berördes olika aspekter på miljö, hemma, på arbetet och i samhället. Vidare framkom att kondition inte fångades av någon av de andra utvärderingsmetoder som använts för att testa fysisk funktion, konditionstestet visade sig också vara mycket känsligt för förändring. De särskilda undersökningsmetoder och utvärderingar som användes för att utvärdera reumatisk ryggsgjukdom visade sig fungera mycket bra och visade god känslighet för förändring. Av de frågeformulär som använts för att mäta

hälsorelaterad livskvalitet täckte det kortaste om 5 frågor (EQ-5D) flest aspekter av hälsa, enligt ICF. Då formulären jämfördes framkom att de inte rakt av går att ersätta med varandra, samt att de vid rehabilitering visade sig vara lågt till måttligt känsliga för förändring.

I delarbete IV studerades hur personer med ledgångsreumatism använt sig av sjukvård (sjukvårdskonsumtion) mellan åren 2001 tom 2010. Genom att använda data från Region Skånes Vårddatabaser identifierades patienter som vid två tillfällen diagnostiserats med ledgångsreumatism i samband med läkarbesök mellan 1998 och 2001. Sedan analyserades dessa patienters vårdkonsumtion 2001-2010. Via befolkningsregistret kunde referenspersoner med samma ålders- och köns-sammansättning som patienterna identifieras. Dessa grupper s sjukvårdskonsumtion jämfördes. Totalt sett visade sig sjukvårdskonsumtionen bland patienterna med ledgångsreumatism minska i förhållande till den bland normalbefolkningen. Patienterna med ledgångsreumatism sökte mer vård hos vissa typer av vårdpersonal som sjuksköterska. Vårdsökandet inom den

specialiserade reumatikervården minskade.

Denna avhandling visar således att:

- Teambaserad reumatologisk rehabilitering är fortsatt viktig för vissa personer med kronisk reumatisk ledsjukdom.
- Det är viktigt att fortsättningsvis individualisera också rehabilitering så att de som behöver det får behandling av specialistteam inom reumatologin.
- Test av kondition och träning av kondition är en viktig del som bör ingå i reumatologisk teamrehabilitering och dess utvärdering.
- Hälsorelaterad livskvalitet bör utvärderas med jämförbara formulär också för att underlätta jämförelse med andra typer av behandling.
- Sjukvårdskonsumtionen bland patienter med ledgångsreumatism i Skåne har minskat de senaste 10 åren. Detta gäller både inneliggande sjukhusvård och sjukvårdsbesök, framförallt till den specialiserade vården.

Fortsatt utveckling och utvärdering av den reumatologiska rehabiliteringen är en viktig del i framtidens vård för personer med kronisk reumatisk ledsjukdom.

## Acknowledgements

This thesis is based on work carried out at the Department of Rheumatology, Skåne University Hospital, Lund, at centres participating in the STAR-ETIC project in Sweden, Norway, Denmark and the Netherlands, and at the EPI-CENTRUM (former MORSE-project) in Lund. I greatly appreciate all the efforts put into data collection, retrieval and analysis, and would like to express my gratitude to all those involved in these projects. In particular, I would like to express my sincere gratitude to:

**All the patients**, who generously and with great patience participated in the studies in Sweden, Norway, Denmark and the Netherlands, and who answered all the questionnaires and performed the tests. Then they returned and did it all again... They are one of the cornerstones of this thesis.

The other three cornerstones of this thesis are **Ingemar Petersson**, my main supervisor, and **Elisabet Lindqvist** and **Ann Bremander**, my assistant supervisors – I was fortunate enough to have 3 supervisors along this sometimes bumpy road. Without you my ‘rheumatological life’ would have been poorer and this thesis would not have been written. You are all great advocates for teamwork.

**Ingemar** – You introduced me to the thoughts on writing a thesis, and your encouragement and our fruitful discussions have helped me along the way. You are a visionary with the ability to spread your enthusiasm and share your knowledge. You have helped me focus on the important issues, and your sincere interest and knowledge in teamwork and rehabilitation have been invaluable. Thank you for accompanying me, challenging me and sometimes pushing me forward on this fascinating and developing journey.

**Elisabet** – Thank you for all our fruitful discussions, and for your constructive and

encouraging supervision, not only during my doctoral studies but also as a Master’s student. Your ability to see the positive aspects and to look at things from the opposite perspective has challenged me and pushed me forward.

**Ann** – You have been invaluable in so many ways, whereof one was understanding ‘physiotherapish’. We cogitated over the ICF, outcome measures and also STAR-ETIC data for endless hours. Your gentle but positive encouragement often led me to believe that I had thought of some of the important aspects myself.

**Martin Englund** – my co-author, for your invaluable advice in planning and accomplishing Study IV and writing the paper. Thank you for sharing your extensive epidemiological knowledge with me, and for giving me the opportunity to work with data from the Skåne Health Care Register.

**Jan-Åke Nilsson** – my co-author, for your invaluable statistical advice. You have been my statistical mentor, from my first stumbling steps with SPSS to the last calculations in Study III. Thank you for your patience and for giving me the opportunity to learn by doing, under your watchful supervision.

**Charlotte Bergknut** – my co-author, for invaluable help with the retrieval and analysis of register data in Study IV. Thank you also for sharing my enthusiasm when the results were finally committed to paper.

**All co-authors and co-workers in the STAR-ETIC project.** Thea Vliet Vlieland, Jorit Meesters, Kim Hörslev-Petersen, Inger Henriette Stovgard, Margreth Grotle, Mari Klokkeud, Gerd-Jenny Aanerud, Kåre Birger Hagen, Ida Løchting, Ingvild Kjekken, Britta Strömbeck, Birgitta Smedeby, Susanne Jürgensen, Connie Ziegler, Ann, Elisabet and Ingemar (and all participants at the centres who collected the data) – thank you for fruitful collaboration, and for giving me the opportunity to work with the outcome aspect

of our project. This is teamwork at its best – between professions, patients and countries.

**Ido Leden** – Thank you for persuading me to start working in the field of rheumatology in 1992. Your inspiring lectures and strong belief in teamwork reinforced my reluctantly awakened interest in this speciality that is now so important to me.

**Jan Theander and all former co-workers at the Rheumatology Clinic in Kristianstad:** Inger, Alice, Jenny, Annika, Karin, Ulla, Louis, Susanne, Katarina, Bitte and Majvor. Thanks to your knowledge and enthusiasm I was soon hooked on rheumatology, the speciality that I had previously shied away from.

**Pierre Geborek** – for helping me retrieve data from the Rheuma Rehab programmes, and for encouraging discussions, not least on EQ-5D. You realised the benefits of computerised registers early on, thank you.

**Tore Saxne and Frank Wollheim** – for encouragement and positive support.

**Ingrid Mattsson-Geborek** – for invaluable help with the layout of this thesis and for your patience while working on it.

**Marianne Månsson, Louise Bremander, Anna Lindqvist, Henrik Larsson, Pia Andersson and all others involved,** for patiently and skilfully recording the data from the patients.

**All members of the Rheuma Rehab team:** Malin Lanzinger, Lisa Mogard, Eva Fredriksson, Siv Duckberg, Marie Andersson, Britt Marie Larsson, Kerstin Nived, Iréne Wikström, Marianne Månsson and Catarina Bengtsson – Thank you all for the wonderful atmosphere, and for sharing the joy of work.

**Christina Mo** – for encouraging support during the last part of this work and for sharing my interest in rehabilitation.

**My physiotherapy colleagues at the Clinic of Rheumatology, Skånes Universitetssjukhus,** Lotta K, Lotta R (in remembrance), Eva F, Lisa, Eva O, Maria, and Agneta for loyally sharing increased workload when starting Rheuma Rehab and over the years. I still consider myself as part of the group.

**All co-workers at the EPI-CENTRUM** who are too numerous to mention. Thank you all for your good companionship and interesting

discussions in an inspiring multi-professional spirit.

**My ‘Red Room Comrades’** over the years – Ljuba, Jenny, Anna, Sara, Changchai. We gradually got to know each other through concentrated silence and sometimes lively discussions.

**Everyone at the Spenshult Research and Development Center** – Thank you for inspiring and fruitful discussions and for letting me share your positive scientific atmosphere. Your hospitality made me feel like one of the team.

**Emma Haglund** – for friendship and fruitful discussions on doctoral studies and life.

**Lotte Höjgård, Martin Zedig and Maria Andersson** – for practical assistance and encouragement and for invaluable help with computer related issues.

**Relatives and friends** – for dealing with my absences and for help and support, especially:

Club no. 9, Ladies’ Circle Sweden, all the ‘girls’ in the LA book club and the girls in the ‘EPI-Centrum/RC-Syd’ book club – our meetings forced me to focus on something else and also to be social for a while.

**The Svenssons** – Ann-Sofie, Lasse, Stina and Svante, for all the laughs and improvised and planned suppers over the years.

**Carina and Lars Björk** – for proving that true friendship survives absence, even when we are separated by an ocean.

**Eva and Mikael Kahlström** – through good times and bad we really came to recognise the true values in life.

**Christian, Linda and little Alice** – for reminding me about what is important in life. I can assure you that the distance to Ystad will seem shorter now that I have completed this work.

**Sonja and Bengt Hagel** – my parents, for all your help and support, to me and my family over the years, and for always being there and believing in me.

**Magnus** – my unmarried man, without whose support D-day would never have come. Thank you for your help and belief in me, your encouragement and love.

**Lovisa** – my daughter, for keeping me back on track and being who you are. You and your father are what life is really about!

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