Pain and its relation to participation in valued activities in rheumatoid arthritis

Inger Ahlstrand
In loving memory of Gustav,
who did not get the opportunity to follow this project
Abstract

There has been a dramatic change over the past two decades for persons with rheumatoid arthritis (RA) not only due to early diagnosis, structured treatment, and aggressive medication but also due to an increased demand of participation in work life and society. Despite these treatment changes, RA continues to impact these individuals’ participation in valued daily activities. Participation in valued daily activities provides wellbeing and the opportunity for engagement and participation. By persons with RA pain has been highlighted as one of the most restrictive symptoms. This thesis uses the International Classification of Functioning, Disability, and Health (ICF) as a conceptual framework to describe disability and how participation is related to pain.

Aims: The overall aim of this thesis was to explore and describe the relationship between pain and participation in valued activities, in RA. Paper I compared pain and activity limitations in women and men with contemporary treated early RA with persons who were diagnosed ten years earlier. Paper II described experiences of pain and pain’s relationship with daily activities. Paper III examined difficulties performing valued life activities in relation to pain intensity. Paper IV described personal factors, including self-efficacy and pain acceptance, and studied whether personal factors are mediators of the relation between pain and performance of valued life activities.

Methods: Different methodological approaches were used to provide a comprehensive understanding of pain and participation in valued activities in persons with RA. A prospective longitudinal cohort study was used to compare women and men treated with contemporary treated RA (n=276) with their counterparts ten years earlier (n=373) (Paper I). This study was followed by a focus group study where 33 persons with RA participated in seven focus groups (Paper II). Subsequently, Papers III and IV were conducted based on data from The Swedish Rheumatology Quality Registry (SRQ) and data from a postal questionnaire that gathered data on demographics, pain, personal factors, and participation.
in valued life activities (n=737). In addition, these studies used descriptive and analytical statistics with multiple regression and structural equation modelling (SEM).

**Results:** Pain and activity limitations were still pronounced in women and men with RA despite recent treatment advances (Paper I). The relationship between participation and pain was dynamic and is related to fatigue, stress, and mood, factors that generated difficulties finding a suitable level of activity, resulting in difficulties balancing daily activities (Paper II). Both women and men reported restrictions in participation in valued life activities. Pain was identified as having an important relationship to difficulties performing valued life activities (Paper III). Personal factors were found important as mediators for pain in relation to participation (Paper IV).

**Conclusions:** This thesis found a continued need for multidisciplinary interventions despite current treatments. Pain was identified as related to participation restrictions and had an important relationship to difficulties performing valued life activities. Pain and participation in valued activities needs to be comprehensively analysed and treated in the context of the person’s perspective and needs and demands of persons with RA. The subjective experience of participation, the engagement, must be highlighted. Personal factors mediated the relationship between pain and participation and this finding supports the value of self-management interventions to enable participation in valued activities.
List of Papers

The thesis is based on the following papers, which are referred to by their Roman numerals in the text:

**Paper I**

**Paper II**

**Paper III**

**Paper IV**
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# Contents

Abbreviations ............................................................................................................. 8

Introduction .................................................................................................................. 9

Background .................................................................................................................. 11
  Concepts of participation ......................................................................................... 11
  RA and treatment strategies ................................................................................... 16
  Disability in RA and rehabilitation ....................................................................... 17

Rationale for the thesis ............................................................................................. 25

Overall and specific aims ......................................................................................... 27

Methods ....................................................................................................................... 28
  Design ....................................................................................................................... 28
  Registry based studies ......................................................................................... 30
  Participants ............................................................................................................ 31
  Data collection procedure ................................................................................... 33
  Outcome measures in Paper I, III, and IV ........................................................... 35
  Data analysis .......................................................................................................... 37
  Ethical considerations ......................................................................................... 39

Results ......................................................................................................................... 43
  Pain and activity limitations were still present among persons with RA (Paper I) ......................................................................................................................... 43
  The relationship between pain and daily activities was multidimensional and dynamic (Paper II) ................................................................................................. 45
  Valued life activities were strongly related to pain (Paper III) ......................... 47
  Personal factors were mediators in the relationship between pain and valued life activities (Paper IV) ......................................................................................... 50

Discussion .................................................................................................................... 53
  General discussion of the results ........................................................................ 53
  Methodological considerations ............................................................................ 65

Conclusions .................................................................................................................. 71

Clinical and research implications .......................................................................... 72

Svensk sammanfattning .......................................................................................... 75

Acknowledgements .................................................................................................. 80

References .................................................................................................................... 83
Abbreviations

ACR  American College of Rheumatology
AE   Activity Engagement
ASES  Arthritis Self-Efficacy Scale
BP   Bodily Pain
CMOP-E Canadian Model of Occupational Performance and Engagement
CPAQ  Commitment and Acceptance Questionnaire
DAS28 Disease Activity Score
DMARD Disease-Modifying Anti-Rheumatic Drug
HAQ  Health Assessment Questionnaire
ICF  International Classification of Functioning, Disability and Health
MCID  Minimal clinical important difference
OMERACT  Outcome Measures in Rheumatology
PRO  Patient Reported Outcomes
PROM  Patient Reported Outcome Measures
PW  Pain Willingness
RA  Rheumatoid arthritis
SD  Standard Deviation
SEM  Structural Equation Modelling
SE-pain  Self-Efficacy subscale pain
SE-symptoms  Self-Efficacy subscale other symptoms
SF-36  The Short Form 36 health survey
SOC  Standards of care
SRQ  Swedish Rheumatology Quality Register
TIRA  Swedish acronym for Early Interventions in Rheumatoid Arthritis
VAS  Visual Analogue Scale
VLA  Valued Life Activities
VLA-swe  Valued Life Activities Swedish version
WHO  World Health Organisation
Rheumatoid Arthritis (RA) is a chronic disease often associated with pain and disability (1,2). Over the past two decades, the treatment strategies for RA have changed dramatically with the introduction of early diagnosis and early instituted disease-modifying anti-rheumatic drugs (DMARDs), including biological agents. This strategy has proved effective (2-4) and as a result disease activity and to some extent disability has decreased. Disability has a less favourable course compared to disease activity (1,5). Persons with RA identify pain as the predominant health status impairment and one of the most important symptoms to reduce because of its consequences (6-9). Persons with RA still report difficulties performing daily life activities (10). Additionally, there are some gender differences in RA. More women than men have RA and women are more disabled and have more difficulties performing daily activities than men (5,11-18).

Performing activities of daily living pose a challenge for women and men with RA because there can be considerable variation in pain and other impairments due to their condition, such as fatigue and stress (19). Variations in pain make it challenging for persons with RA to plan their activities. With advancements in RA treatment and thereby expected outcomes, many persons with RA have other expectations for their lives. Therefore, there is a needs to focus on treatment outcomes such as independence and participation in valued activities. Pain relief has traditionally been the first and most prioritized outcome (20). This priority is a cause for concern given the associations between the ability to perform activities rated as an important part of wellbeing (21). Therefore, it is important to understand the activity preferences of persons with RA in order to create opportunities for them to engage in activities that they value despite impairments due to pain. This knowledge will have implications for treatment and rehabilitative interventions.
The belief that one has the ability to effect pain may not only reduce pain perception but also increase wellbeing. However, life does not need not focus only on managing, controlling, and reducing pain if they want to lead an active life as these processes can occur concurrently. Therefore, it is important to determine whether the management strategies used by persons with RA influence their participation in valued activities. To this end, this thesis explores and describes the relationship between pain and participation in valued life activities in women and men with RA. This thesis uses the International Classification of Functioning, Disability, and Health (ICF) as a conceptual framework to describe disability, including how participation is related to pain. This thesis does not intend to cover all aspects of the ICF with regards to the topic of pain in RA. Rather, ICF is used to contextualise the results. The thesis pre-sets a multidimensional picture of the relationship between pain and participation in daily activities based on descriptions and reports from women and men with RA receiving current treatments.
Background

This chapter details a conceptual framework for the thesis and provides an overview of the prevalence, main characteristics, treatment strategies, and rehabilitation for persons with RA. In addition, this chapter describes disability, pain, participation restrictions, and personal factors related to RA.

Concepts of participation

The concept of participation can be described from different perspectives. In this thesis, the concept of participation is related to the International Classification of Functioning, Disability, and Health (ICF) (22) and complemented with concepts from occupational science (23-25) and occupational therapy (26).

International Classification of Functioning, Disability, and Health (ICF)

This thesis uses the International Classification of Functioning, Disability, and Health (ICF) as a conceptual framework to provide a common language (i.e., a language understood across professional disciplines) that describes health and health-related domains (22). The ICF includes a classification of health and health-related states and a bio-psychosocial overall conceptual model of functioning and disability (22). The conceptual model describes health conditions related to functioning in the context of environmental and personal factors (Figure 1). This model comprises the components “Activities and participation”, “Personal factors”, “Environmental factors”, “Body Functions”, and “Body structures”. “Body Functions” are physiological functions of body systems (including psychological functions). “Body Structures” refer to anatomical parts of the body such as organs, limbs, and their components. “Impairments” refer to problems with body functions or structures such
as a significant deviation or loss (e.g., pain). The ICF defines “activity” as the execution of a task or an action by an individual and defines “participation” as the involvement in a life situation. A person's functioning can only be understood in the context of his/her health conditions, personal factors, and the environmental factors. Personal factors include gender, age, management strategies (such as self-efficacy and pain acceptance), social background, education, profession, past and current experiences, overall behaviour pattern, character, and other factors that influence how disability is experienced. Environmental factors consist of the physical, social, and attitudinal environment in which people live and conduct their lives.

![ICF Conceptual model](image)

**Figure 1.** ICF Conceptual model (22)

There is an on-going discussion about the manner in which the ICF conceptualizes disability. The tripartite concept of disability (bodily impairments, activity limitations, and participation restrictions) adopted by the ICF is problematic, as the distinction between activity limitations
and participation restrictions is unclear and is not in accordance with the ICF classification list. In the recently proposed bipartite ICF concepts of functioning and disability (27), participation refers to activities that are actually performed. Bipartite concepts are congruent with the ICF classification and are suitable for multidisciplinary rehabilitation practice and research (27). The valued life activity scale (VLA-swe) used in Papers III and IV applies participation to functioning and disability.

The ICF model can be used to explain participation restrictions in RA (28), which is at the core of occupational therapy (29,30). The ICF emphasises the importance of participation but does not include a subjective experience of meaning (31). It is important to incorporate the personal perspective with the ability to manage and adapt in order to make a relevant statement about participation restrictions (20). An aspect of participation is the subjective experience of engagement. Proponents of the engagement perspective suggest that participation not only should include whether the individual is active and engaged but also should include what happens between the individual and the environment. The environment includes the social actors in different contexts and the physical environment where interaction is likely to occur. In addition, the ICF defines participation using the concept of engagement (“involvement”), defined as “being included”, but not using the subjective experience of engagement (“belonging”) (32).

This thesis uses the ICF as a conceptual framework, complemented with other concepts of participation, to incorporate the subjective experience of engagement and participation in valued activities. The ICF provides an interdisciplinary language that can be integrated in occupational therapy and its theoretical models founded on ecological frameworks that aim to support participation in daily activities (33).
Participation and the concept of occupation

Occupation is a common concept in occupational therapy and occupational science. The word “occupation” is derived from the Latin word *occupatio*, which means “to seize control or occupy”. By performing occupations, people occupy time and space in everyday life (24). Occupation is closely related to the concept of participation. Participation is defined as “[i]nvolve[ment] in any life occupations that may be self- as well as family- or socio-politically initiated” (23). Occupation refers to all things that people do in their lives and their relationship with health. Striving for health from an occupational perspective is associated with engagement (participation) in occupations that meet the needs of *doing*, *being*, *becoming*, and *belonging* (23). The concept of *doing* includes participation in purposeful, goal-oriented activities. *Being* has been defined as time taken to reflect, to discover the self, and to enjoy being with special people and is an important component of living well despite impairment (34). “Living well”, “feeling well”, and “feeling (more) normal” are multidimensional descriptions about important outcomes for persons with RA (35,36). Belonging describes the necessary contribution of social interaction and becoming implies envisioning the future, exploring new opportunities, and experiencing life as worthwhile (34). Occupational performance is a central concept in occupational therapy and in the Canadian Model of Occupational Performance and Engagement (CMOP-E) (26). In the CMOP-E, occupational performance refers to what people do in their current environment, a view that resembles how the ICF understands participation (37). However, the concepts are not synonymous. Participation can be an outcome of occupational performance and the ICF does not refer to the subjective experience of participation (26).

To achieve individual wellbeing, people need to balance activity and recreation (23). Occupational balance is a concept in occupational therapy that can be defined as the individual’s subjective experience of “having the right mix” (i.e., amount and variation) of occupations (38). Occupational balance can enhance the understanding of the link between occupation and health in persons with RA and can be described in three
dimensions: challenging versus relaxing, meaningful for the individual versus meaningful in a socio-cultural context, and caring for oneself versus caring for others (39).

Participation can also be theoretically discussed as a part of occupational science. Occupational science is useful as a theoretical framework in occupational therapy (23,38), particularly when working with people with rheumatological disorders (19,39-41). Participation in everyday occupation is a vital part of human development and lived experience, influencing health and well-being (42). Occupation is a multifaceted phenomenon. As such, it requires a multidimensional approach and both qualitative and quantitative methods (24). When studying occupation, several questions need to be asked. This thesis mainly asks the WHAT question: What activities are the most important for women and men with RA and what difficulties do persons with RA experience? In addition, the thesis asks the WHEN question (as occupational balance can be a challenge for persons with RA): When is RA and its symptoms addressed? The most difficult question according to occupations is WHY they are conducted. Occupational engagement describes people doing occupations in a manner that fully engages their time and attention (24). Engagement in occupations is important for pain acceptance for persons with remaining pain despite medication (43). Occupational engagement contributes to expressing and managing personal identity, staying connected with people, organizing time, and, most importantly, promoting a sense of wellbeing (24). Occupations are not just any kinds of activity; they are activities that provide a sense of purpose and entail meaning. Some occupations are more valued in society than others and some occupations are gendered (44).

Participation in valued activities

Some activities are more important or more meaningful to individuals than others, and the persons’ specific meaning, or “value,” attached to activities may affect participation in persons with RA (45). Participation in valued activities may also be more strongly linked to satisfaction with function and psychological wellbeing than functioning in more basic daily
activities in people with chronic diseases such as RA (46). Individuals’ sustained participation in personally valued activities enhances wellbeing. The type of participation matters, because the strength of the link between participation and wellbeing depends on the activity. Wellbeing is enhanced when people are able to pursue their personal goals. The right way to participate may be different for different individuals depending on what they personally value and find rewarding. There are important individual differences in the types of participation that are most rewarding. Participating in valued activities also provides a structure and meaning to daily life, an outlook that enhances wellbeing. Peoples’ perceptions of wellbeing are influenced by the extent to which they imagine that a given condition, such as pain, would impact their participation in their valued activities. Individuals need to find new ways to participate in order to experience wellbeing (47).

**RA and treatment strategies**

Rheumatoid arthritis is a chronic systematic inflammatory disease with a prevalence of about 0.5% - 0.7% and an annual incidence of 50/100 000 (women = 68/100 000; men = 32/100 000) in the adult Swedish population. RA is three times more common in women than in men (48,49). RA is often associated with disability (1,11) such as pain, fatigue, stiffness, limitations in hand function, difficulties in performing daily activities, as well as participation restrictions (2,15,28,50).

Over the last 20 years, treatment strategies for RA have been dramatically reformed. In the early 1990s, routines for early diagnosis and early use of aggressive DMARDs were aimed at disease remission and reducing joint damage. This new strategy has proven to be highly effective (3,4,51). In the late 1990s, further advances were made by the introduction of tumour necrosis factor alpha inhibiting substances and other “biologic” therapies (52,53). As a result of new regimens in the early 2000s, disease activity decreased in both women and men with early RA, although women with RA had higher disease activity and achieved remission less often than men (54,55). The aim of treatment in early RA is full remission,
reduced disease activity and pain, and maintenance of function in daily activities if full remission is not possible (2,56).

Disability in RA and rehabilitation

In the ICF (Figure 1), functioning (and its components body functions, body structures, activities, and participation) are conceptualised in relation with a health condition (e.g., RA) and contextual factors (i.e., personal and environmental factors). Disability is the negative aspect of functioning, and disability in RA is well known and well described. Contextual factors play an important role in understanding the impact of RA, which is a chronic systematic inflammatory disease that can significantly impact a person’s daily functioning. The inflammatory processes in RA cause impairment due to joint destruction, pain, swelling, stiffness, and fatigue. Although the disability in persons with RA has improved in the last decade as a result of earlier diagnosis and more aggressive treatment strategies, a relatively high proportion of persons with RA still experience problems with daily activities and participation.

Pain in RA

As defined by The International Association for the Study of Pain (IASP), pain refers to an unpleasant sensory and emotional experience associated with actual or potential tissue damage or is described in terms of such damage (57). Pain is a prominent symptom in RA. It is a personal and subjective burden of disease that greatly impacts an individual's overall sense of wellbeing (58). In a Swedish cohort, 67% of persons with RA who reported moderate or severe pain at the time of diagnosis reported a pain intensity >40 mm (VAS) five years after diagnosis. Pain intensity is not related to disease activity in RA (59). This fact is consistent with other studies with long-term follow-up of self-reported disability in RA (60). High pain levels are associated with female gender (2,61). Many people with early RA continue to suffer pain despite aggressive treatment (14). Most people with early RA report incomplete improvement in bodily pain after one year (61). Chronic widespread pain
is common in RA and has been reported to be more closely associated with difficulties in performing daily activities and pain intensity than inflammatory process and was reported more often by women (62).

Pain is expressed by the persons with RA as one of the most important impairments to reduce because of its consequences (6-9,63) and is an issue for research (64). Pain has been described as overwhelming, gnawing, or aching, whereas other reports suggest it is a feeling of stiffness in the joints with burning and shooting sensations (65,66). Pain was sometimes undetectable by others in the social environment and described as closely related to fatigue and stress (66).

A large proportion of persons with high pain at the time of diagnosis still report high pain (above 40 mm, VAS) after five years (59). A majority of persons with RA today continue to report high pain intensity despite well-structured early interventions, including effective medication (63,67). Remaining pain is common in early RA and this has recently been described in Swedish cohorts (68).

Traditionally, pain in RA is studied using quantitative methods and described as pain intensity in millimetres on a visual analogue scale (VAS) (69). Pain can also be reported using the subscale Bodily Pain (BP) in the Swedish version of the Short Form Health Survey (SF-36) (70). The SF-36 BP assesses bodily pain and interference of pain with daily activities and can be used in disease populations, including RA (70-73). Until recently, pain itself had not been an active area of research in rheumatology. Pain can no longer be viewed as an isolated symptom but must take into account fatigue, mood, sleep, and overall quality of life (74). Pain in combination with difficulties in performing daily activities needs to be assessed in a multidimensional way as pain is multi-factorial, requiring a multidimensional perspective of pain (75). The bio-psychosocial model of pain (75) identifies pain as the result of the dynamic interaction between psychological and social factors in the experience of a disease (i.e., RA). Within this model, each individual's pain experience is unique, and the relationship between pain and daily activities is also influenced.
by psychological and socio-economic factors (75). This bio-psychosocial model of pain can be used together with the ICF (22).

Pain is complex and the difference between the person's view and the caregiver's view on what to assess and treat is growing (76,77). The persons’ perspective has been highlighted as an important view in assessments and treatments (78-80). Pain, however, is still expressed by the individual as an impairment not fully understood by caregivers (81). People with severe pain also experience secondary impairments such as fatigue, sleeplessness, and eating difficulties (82). High pain is related to high fatigue and poor quality of life (83). If pain does not improve despite treatment with DMARDs, a multidisciplinary approach is recommended (74). Measures of pain and function can identify persons at an increased risk of severe disability and in need of multidisciplinary treatment (60). Women with more severe pain benefit most from team-based rehabilitation in rheumatology (84).

**Participation restrictions in RA**

The restrictions on participation related to RA are reported in earlier research (28). Substantial gains in disability outcomes after use of aggressive treatments (53) and increased ability to continue work have been reported (85,86). Nonetheless, a wide spectrum of participation restrictions in self-care, domestic life, leisure life, and social life have been described (87). Despite early diagnosis and new treatment, RA still negatively affects individuals (10). Daily activities are a challenge for persons with RA with considerable variation in pain and functional abilities (19). Living with RA is also described as a constant uncertainty due to fluctuating symptoms and the need to find a balance between managing fluctuating RA and activities of daily living (88).

There is a tendency for persons with RA receiving current early interventions to report less disability in basic activities, but they continue to report struggling with different aspects of work and social life (85,87,89), including emotional health (90). They feel the need to manage their activities on a daily basis (88). Changes in one's life balance is valued
differently (40). For example, some persons with RA value the need to be active and independent, performing the activities they enjoyed before the onset of their condition (91). They often experience feelings of insecurity and anxiety as they feel they are no longer able to manage independently. Persons with RA no longer know what and how many activities they can perform (92). Anger and irritation were described in relation to domestic and employed work as well as in relation to social activities, as they felt unable to continue valued activities (88,90). RA often makes people feel that they cannot carry out the activities they have done before and they feel limited (91,93). Work and fatigue makes it more difficult to maintain balance in daily activities. Performance in physical leisure-time activity is related to self-efficacy in persons with RA, and higher levels of engagement in physical leisure-time activities are found to be associated with higher confidence in ability to manage function (94). Although many persons with RA work, many problems are reported that related to acquiring and keeping a job. The efforts to keep employed took most of their energy and time and stress was associated with giving up recreation and leisure activities because they had to rest after work (89). Pain has been reported as the most significant factor predicting satisfaction with performance of main occupation and achieving occupational balance (95).

According the persons with RA, environmental factors, such as other people's attitudes, play a significant role for participation in daily activities. Attitudes (e.g., sharing how pain leads to difficulties in performing daily activities) may facilitate participation. Others in the social environment influence experiences of engaging in occupations in two ways: “Constructive collaboration” and “Insufficient collaboration”. The assisting actions influenced the possibilities to engage in occupations and their experience of engagement (96). The extent of support from the environment might affect a person’s self-esteem and feelings of independence (96,97).

Recommended guidelines suggest that assessment of restrictions in participation should measure what really matters for the person with RA (98,99). Such outcomes are frequently assessed via Patient Reported
Outcome Measures (PROMs), which are typically self-completed questionnaires. Difficulties in performing daily activities caused by RA are often assessed in routine practice using the Health Assessment Questionnaire (HAQ) (1). The HAQ gathers information on subjective experience of the degree of disability in 20 daily activities that correspond primarily to activities of daily living (ADLs) and instrumental activities of daily living (IADLs), such as walking, eating and dressing. Although the HAQ is well known and useful for assessing such basic aspects of daily life (9), it is not exhaustive. Furthermore, it does not capture personal preferences. The Valued Life Activities (VLA) questionnaire focuses on the performance of activities in a social perspective (45). This perspective is quite close to the social perspective of the participation captured in the ICF (22). VLA covers not only the person’s basic daily activities but also covers a comprehensive range of activities across all domains of participation of the ICF (27). Therefore, a person’s perspective, as highlighted in the OMERACT (100) and in the ICF core sets for RA (78), is important in the assessment of the disability. The ability to perform activities rated as important (i.e., valued by a person) has a strong link to wellbeing (21). The Canadian Occupational Performance Measure (COPM) is another client-centred outcome measure where the clients evaluate their occupational performance and satisfaction with performance in daily activities (101). The COPM has been used to describe participation restrictions in persons with arthritis (102,103). The COPM can be seen as a device for ensuring the person participation in the formulation of rehabilitation goals and focusing on what is purposeful occupation to the person with arthritis.

**Personal factors and RA**

Personal factors such as gender, self-efficacy, and pain acceptance must be taken into consideration when analysing the relationships between factors in the ICF such as pain, participation, and valued activities (104). A review has highlighted the importance of understanding the personal factors (e.g., determinants, outcomes, and modifiers of functioning and disability) associated with the ICF component (105). Importantly,
personal factors were linked to the concept of person-centeredness and the strength of the individual’s perspective.

Self-efficacy is strongly related to pain and mood in persons with RA and therefore influences disability (106,107). Self-efficacy is defined as an individual’s belief that he or she will be able to accomplish a specific task. An essential component to accomplishing something is confidence – the belief that success is possible. Bandura (108) referred to self-efficacy as the mind’s self-regulatory function; it tells us when to try and when to stop. If people do not believe something is possible, they are less likely to attempt the task and more likely to give up. Self-efficacy has been reported to be related to ratings of pain, mood, and coping in RA (107). Self-efficacy is thus important to take into consideration when trying to understand RA-related pain (109,110). Pain acceptance is related to participation in valued daily activities among persons with arthritis and others with chronic pain (111-113). Acceptance of pain includes engagement in valued activities and being able to experience on-going pain without attempts to avoid, reduce, or otherwise control it (114). Engagement can be included as a part of personal factors in the ICF (105). There are two components defined in pain acceptance. Pain willingness refers to how prepared people might be to experience an increase in pain so they can accomplish activities they value. Activity engagement refers to how actively involved people are in activities that they consider important (43). The pain acceptance in women living with arthritis has been described as a process of establishing a “new” life in the context of the reality to live with pain (115).

**Differences in disability between women and men with RA**

There are some gender differences in RA. More women than men have RA and women are more disabled by it (5,11-17). Women with RA have a more severe disease course as they are prescribed biologics slightly more often than men (48). Earlier research found no significant differences between women and men in the course of pain intensity during the first five years after diagnosis (59). More than five years after diagnosis some gender differences were found that have implications for future
rehabilitation strategies. The inability to continue with skilled work seemed to be more central in men, whereas the women were more concerned about taking care of their family and home (92). To make it possible to work, men with arthritis adjusted their activity pattern and prioritized work over household activities and leisure activities (116).

**Rehabilitation in RA**

Despite improved medications and new treatment regimens for RA, disability still occurred (mainly in women) and showed a less favourable course compared to disease activity (1,5).

Standards of care for the treatment of RA describe the management of the disease, care, access to information, and support that persons with RA should have access to. These standards also specify that individuals with RA should be provided with opportunities for self-management to enhance functioning in daily life and participation in social roles (80). Persons with RA want to prioritize and get assistance with what they want. Over the last few decades, self-management approaches in rheumatology have been explored (117-122). Person-centred care has strengthened the participation and autonomy of individuals with RA in their relationships with their health professionals (123).

Within the ICF, rehabilitation is defined as a strategy aimed to enable optimal functioning of the individual in interaction with the environment (124,125). The ICF has been applied and endorsed by the network Outcome Measures in Rheumatology (OMERACT) (99,126). Evaluations of modern rheumatologic team rehabilitation (127-130) reveal that the ICF can help rehabilitation teams understand the properties of the outcome measures (131). It has been reported that outcome measures commonly used in rehabilitation practice and research cover the ICF components of body function, activity, and participation. The environmental and personal factors have not achieved much attention in the literature. The currently used rehabilitation tools in rheumatology do not identify what women and men with RA view as important with respect to rehabilitation (132).
Rehabilitation in RA follows a multidisciplinary team approach (129). Team rehabilitation is complex as its effectiveness is often difficult to describe (128). Rehabilitative multidisciplinary interventions aim to reduce disability in persons with RA. There has been a shift from immobilisation, rest, passive movement, and protection to an overall recommendation of activity, active movement, and participation (133-135). The most common traditionally rehabilitative interventions are physical activity, patient education, joint protection, and use of assistive devices and splints (121,136-138). Persons with RA now receive well-structured, early, and effective interventions resulting in less disability. There is a need to expand personal goals beyond basic daily activities in a way that incorporates activities that are of value to the individual and involve participation in society (36,87). Engagement develops through our relationship with other people and requires that we perform activities (doing) that meet the needs of both ourselves (being) and others (belonging) (139).
Rationale for the thesis

Over the last 20 years, treatment strategies in RA have been dramatically reformed. Routines for early diagnosis and early aggressive medication have been established and disease activity has decreased. Although new RA medicines are associated with reduced disability, RA continues to inhibit participation in daily activities.

Pain has been highlighted by persons with RA as one of the most restrictive symptoms of RA. The focus of the current thesis is on the relationship between pain and participation in daily activities in persons with RA. Most people with RA report difficulties performing activities they want to or have to do. How well people with RA accept pain (i.e., their pain acceptance) is related to their ability to participate in valued daily activities. However, it is unclear how a person’s experience and management of pain varies as a function of gender, self-efficacy, and pain acceptance.

Participation in valued daily activities provides wellbeing and the opportunity for engagement. Research on occupation and disability is expansive in the field of occupational science, but this research does not consider RA. This thesis uses several methodological approaches to provide a more comprehensive understanding of pain and participation in valued activities with respect to RA. International recommendations highlight that research should be based on the experience of those who are living with RA, and in standards of care for treatment of RA (including rehabilitation) focus is on the person with RA. Clearly, the personal perspective is important, and research needs to develop better descriptions of pain and better understandings of how pain affects people’s everyday lives. This thesis used a range of Patient Reported Outcome Measures (PROM) and focus group discussions. The participants in this thesis were both women and men as previous research suggests men and women do not experience RA the same way. However, this study does not examine the degree that pain and
participation have been reduced or still exist after the access to biological
drugs. Consequently, there is a need to study pain and the relationship
between pain and participation in daily activities to identify unmet needs
for multidisciplinary interventions in rehabilitation that are directed to
the different needs and demands expressed by the women and men with
RA today. Which means that there is a need to develop knowledge and
methods with respect to rehabilitation. This thesis will contribute to that.
Overall and specific aims

The overall aim of this thesis was to explore and describe the relationship between pain and participation in valued activities in women and men with rheumatoid arthritis (RA).

Specific aims for each paper are listed below:

Paper I To compare pain and activity limitations during the three years after diagnosis in women and men with contemporary treated early RA and with their counterparts who were diagnosed ten years earlier.

Paper II To describe experiences of pain and its relationship with daily activities in persons with RA.

Paper III To examine difficulties performing valued life activities in relation to pain intensity in today’s women and men with RA.

Paper IV To describe personal factors, including self-efficacy and pain acceptance, and to study whether personal factors are mediators in the relationship between pain and performance of valued life activities in women and men with RA.
Methods

Design

This thesis, a collection of three published papers and one unpublished paper, uses an explorative and descriptive design to emphasise the relationship between self-rated pain and participation in activities in daily life in women and men with RA. Paper I, a comparative cohort study, followed persons with RA from diagnosis for three years regarding pain and activities in daily life and compared these findings with a corresponding group diagnosed ten years earlier. Paper II, an explorative design that used focus groups, examined how persons with RA perceived the relationship between pain and daily activities. The results of Paper II generated the questions examined in Papers III and IV. Papers III and IV, cross-sectional register based questionnaire studies, explored the relationships between participation in valued activities and pain. In Paper III pain was identified as a key determinant of valued life activities. Paper IV examined the relationship between pain, personal factors, and valued life activities in persons with RA using advanced modelling techniques. Table 1 details the methodology of each of the involved studies. All four papers include aspects of the components and relationships between the components in the conceptual model ICF. Figure 2 illustrates the papers in the thesis and their relationship to the ICF.
Table 1. Overview of studies in the thesis, design, participants, data collection, and data analyses.

<table>
<thead>
<tr>
<th></th>
<th>I</th>
<th>II</th>
<th>III</th>
<th>IV</th>
</tr>
</thead>
<tbody>
<tr>
<td>Design</td>
<td>Prospective comparative cohort study</td>
<td>Explorative</td>
<td>Cross-sectional</td>
<td>Cross-sectional</td>
</tr>
<tr>
<td>Sample</td>
<td>649 (276+373) persons with RA, 67-69% women</td>
<td>Seven focus groups with 33 women and men, 79% women</td>
<td>737 women and men with RA, 73% women</td>
<td>same as Paper III</td>
</tr>
<tr>
<td>Data collection</td>
<td>Data from TIRA-1 and TIRA-2 registry</td>
<td>Focus group discussions SRQ</td>
<td>Questionnaire and data from SRQ</td>
<td>same as Paper III</td>
</tr>
<tr>
<td>Analyses</td>
<td>Descriptive and repeated measures ANOVA</td>
<td>Qualitative content analysis</td>
<td>Descriptive and multiple regression</td>
<td>Descriptive and multivariate SEM</td>
</tr>
</tbody>
</table>

Figure 2. The papers in the thesis and their relationship to ICF
Registry based studies

SRQ

Quality registries are one of the main drivers of health system improvement in Sweden. The Swedish Rheumatology Quality Registry (SRQ) is a national population-based archive of many aspects of RA. The SRQ lends itself as an important clinical and research repository. The SRQ houses longitudinal records of over 66,000 registered persons with rheumatic diseases (coverage 80%) (140). It contains information on disease activity, disability, health-related quality of life, and prescribed medication from the time of registration. Disability outcomes are captured in the Patient Reported Outcomes (PROs) module where the provider enters clinical data. Because the SRQ data can be connected to other data sources, it lends itself to cost-efficient practice-based real-time research (141).

The TIRA project

The TIRA project (Swedish acronym for Early Interventions in Rheumatoid Arthritis) started in 1995. TIRA cooperates with the rheumatology units in south-eastern Sweden and works in parallel with the nationwide SRQ. As a regional prospective multi-centre project, the TIRA project aims to establish clinical routines for early diagnosis and early multidisciplinary interventions at regular follow-ups by establishing a regional network and a database for research. Data for medication, disease activity, and disability are registered in accordance to the SRQ. In addition, the TIRA collects more data on disability and health-related quality of life (HRQL) than the SRQ (1).

The first TIRA cohort (TIRA-1) was included between 1996 and 1998. The TIRA-1 cohort included 320 patients fulfilling ≥ 4/7 criteria as defined by the 1987 revised American College of Rheumatology Classification criteria (ACR-87) (9) or at least morning stiffness for more than 60 minutes, symmetric arthritis, and arthritis of the small joints at
time of diagnosis. In addition to medication, patients were continuously offered multidisciplinary rehabilitative interventions based on individual needs. Ten years later (2006–2009) and after the introduction of biological agents, 463 patients were enrolled in a second cohort (TIRA-2) by corresponding criteria and routines used for the TIRA-1 cohort.

Participants

**Paper I**

Paper I included a total of 649 persons with RA, 276 participants were from the TIRA-1 database (69% women) and 373 participants were from the TIRA-2 cohort (67% women). Men were significantly older than women in both cohorts (TIRA-1 p=0.025, TIRA-2 p=0.001), but there were no significant gender differences regarding disease activity or medication at inclusion. The mean age at inclusion in TIRA-2 was 59 years (standard deviation, SD=15), which was slightly higher than TIRA-1 (56 years, SD=15) (p=0.013). For both cohorts, the dropouts were significantly older than the study group (TIRA-1: nine years older, p<0.001; TIRA-2: five years older, p=0.004) but no differences were seen at inclusion regarding the Disease Activity Score (DAS-28) (142), Health Assessment Questionnaire (HAQ) (143), and pain reported on a Visual Analogue Scale (VAS).

**Paper II**

The participants were recruited from three Rheumatology Units in south-eastern Sweden. The inclusion criteria were RA ≥4 years duration and pain intensity >40 mm as reported by VAS at the last two clinical visits. People whose Swedish language skills were limited were excluded. The selection process was based on data in the SRQ. Stratified sampling was used to select potential participants based on their age and gender. Initially, 77 people were informed by mail about the study. Subsequently, prospective participants were contacted by phone to confirm their participation.
In total, 33 persons participate. The focus groups (FGs) (Table 2) were homogeneously formed with regards to gender and age (younger, middle aged, and recently retired) to promote discussions in the groups (144). The groups comprised three to seven participants. Both men and women from the different age groups were included in FGs in order to detect possible variations in their experiences (144).

<table>
<thead>
<tr>
<th>FG no.</th>
<th>No. of participants</th>
<th>Ages</th>
<th>Gender</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>4</td>
<td>34-37</td>
<td>Women</td>
</tr>
<tr>
<td>2</td>
<td>6</td>
<td>50-63</td>
<td>Women</td>
</tr>
<tr>
<td>3</td>
<td>7</td>
<td>50-65</td>
<td>Women</td>
</tr>
<tr>
<td>4</td>
<td>4</td>
<td>66-68</td>
<td>Women</td>
</tr>
<tr>
<td>5</td>
<td>5</td>
<td>68-71</td>
<td>Women</td>
</tr>
<tr>
<td>6</td>
<td>3</td>
<td>59-62</td>
<td>Men</td>
</tr>
<tr>
<td>7</td>
<td>4</td>
<td>68-73</td>
<td>Men</td>
</tr>
</tbody>
</table>

**Paper III and IV**

Recruitment was carried out in cooperation with three Rheumatology Units in south-eastern region of Sweden. Five inclusion criteria were identified: satisfying 4 of 7 criteria used by the American College of Rheumatology (ACR) (142,145); being treated at one of the three Rheumatology Units; being between 18 and 80 years old; having RA symptoms for at least four years; and having visited the rheumatology unit at least once during the previous year prior to inclusion into this study with this visit’s data registered in the local quality register, which is part of the SRQ. A total of 1,277 persons met the criteria for inclusion and were approached to complete the questionnaire. A 58% response rate was achieved, resulting in 737 completed questionnaires. Demographic data are presented in Table 3. There were no significant differences between the 737 participants (i.e., responders), and the 540 people in the non-responder group, except for the HAQ scores, were lower among the participants (0.71, SD=0.66) than among the non-responders (0.80, SD=0.66; \(p = 0.029\)).
Table 3. Participants’ characteristics and dropouts (Paper III and IV), mean and SD (percentages when appropriate). P-values for test of differences between groups.

<table>
<thead>
<tr>
<th></th>
<th>Sample n=737</th>
<th>Drop outs n=540</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>63 (12)</td>
<td>62 (13)</td>
<td>ns</td>
</tr>
<tr>
<td>Gender, % women</td>
<td>73.1</td>
<td>73.3</td>
<td>ns</td>
</tr>
<tr>
<td>RA-duration, year</td>
<td>16 (11)</td>
<td>15 (11)</td>
<td>ns</td>
</tr>
<tr>
<td>DAS-28 (0-10)</td>
<td>2.8 (1.3)</td>
<td>2.8 (1.3)</td>
<td>ns</td>
</tr>
<tr>
<td>DMARD, % using</td>
<td>83.9</td>
<td>79.6</td>
<td>ns</td>
</tr>
<tr>
<td>Biologics, % using</td>
<td>36.2</td>
<td>35.0</td>
<td>ns</td>
</tr>
<tr>
<td>Pain* (0-100 mm)</td>
<td>34</td>
<td>34</td>
<td>ns</td>
</tr>
<tr>
<td>HAQ* (0-3)</td>
<td>0.71 (0.66)</td>
<td>0.80 (0.66)</td>
<td>0.029</td>
</tr>
</tbody>
</table>

*at the latest visit to the clinic

Data collection procedure

Paper I

Data were collected at inclusion, after one year (Y1), after two years (Y2), and after three years (Y3). Disease activity was assessed according to Disease Activity Score (DAS28) (142). Data about prescribed medication (traditional DMARDs and/or biologics) were registered at inclusion and at regular follow-ups.

Pain was measured in two ways. RA-related pain intensity over the past week was reported on a VAS in mm from 0 (no pain) to 100 mm (worst possible pain). Pain was also reported by the subscale bodily pain (BP) in the Swedish version of the SF-36 (70). Difficulties in performing daily activities (activity limitations) were reported by the Swedish version of the HAQ (score range 0-3), with 0 corresponding to “no difficulty” and 3 corresponding to “unable to do” (1,143).
**Paper II**

Data were obtained through seven focus group (FG) discussions (144), each focused on pain, activity, occupational balance, and consequences of pain on participation in daily activities. The interview guide was developed in cooperation with a patient research partner from the Swedish Rheumatism Association Patient Participation in Research. The interview guide included questions about consequences of pain in participation in daily activities, balance in activities, environmental factors, and strategies to manage pain in daily activities. The questions were open-ended and formulated to encourage discussions (e.g., “How does the pain affect your activities of daily living?”). The interview guide provided participants with opportunities to express individual thoughts and share experiences in a safe and accepting setting (144,146,147). The FGs were led by a moderator (the thesis author) with the assistance of a second moderator. The moderator led the discussions and created an atmosphere that allowed the participants to express their personal and shared experiences. At the end of the discussion, the assistant moderator briefly summarised the discussions using notes taken during the discussion and gave the participants an opportunity to confirm or clarify the notes (144). Typically, the group sessions lasted about 80 minutes. The focus group discussions were digitally recorded and transcribed verbatim.

**Paper III and IV**

The participants answered a postal questionnaire that provided background data, RA-related pain intensity, RA duration, performance of daily activities, and personal factors. Data were also obtained from the SRQ. Based on the most recent clinical visit, Rheumatology Units’ data in the SRQ were obtained for DAS28 (142) and prescribed DMARDs and/or biologics. Data were analysed with respect to gender. Subgroups with low pain (VAS≤ 40 mm) and high pain (VAS>40 mm) were formed based on previous research (148). An analysis compared the dropouts with the 737 responders with respect to gender, age, disease duration, disease activity, pain intensity, HAQ, and medication (Table 3).
Outcome measures in Paper I, III, and IV

**Pain**

**VAS Pain intensity (I, III, and IV)**
RA-related pain intensity was reported on a VAS in mm from 0 (no pain) to 100 mm (worst possible pain). Pain intensity ratings using VAS have sufficient psychometric strength to be used in chronic pain research, especially research that involves group comparison designs with relatively large sample sizes (149). VAS pain is the best evaluated pain measure in RA (150), and a minimally clinical important change is reported to be between 5 and 11 mm on a 100-mm VAS (151).

**Bodily pain (I)**
In Paper I, pain was also reported by the subscale bodily pain (BP) in the Swedish version of the Short Form Health Survey (SF-36) (70). The SF-36 BP assesses bodily pain and interference of pain with daily activities. It is a generic survey suitable for use in disease populations including RA (70-73). The score ranges from 0 to 100; a higher score indicates lower pain (72).

**Participation**

**HAQ (I, III, and IV)**
Difficulties in performing daily activities were reported by the Swedish version of the HAQ (score range 0-3), with 0 corresponding to “no difficulty” and 3 corresponding to “unable to do”. The HAQ has been found to be valid and reliable (1,143). In the HAQ, a minimally clinical important difference (MCID) is between 0.20 and 0.25 (152-154).
VLA-swe (III and IV)
Performance of valued life activities was reported by the Swedish version of VLA (VLA-swe), which was originally developed and validated in the United States of America (45). VLA measures participation in valued life activities. Activities incorporated into the VLA were selected from RA patient expert panel interviews where individuals were asked to identify activities or activity domains that their condition affected (45). The VLA-swe has been translated and culturally adapted to Swedish based on recommended guidelines for translation of instruments for research purposes (155). The translation and adaptation process included forward/backward translation and cognitive debriefing of persons with RA. The VLA-swe (156) consists of 33 activities of daily living. The VLA-swe scale takes personal value into account. Participants rate each of the 33 activities in terms of whether they were important to perform and perceived difficulty in performance was marked on a four-point scale (0 = no difficulty and 3 = unable to perform). Activities that participants deemed unimportant or did not perform for reasons unrelated to RA were not rated and thus excluded in the scoring. The total VLA-swe score is calculated as the mean difficulty of all rated items (45). The VLA-swe is reported to have excellent internal consistency (α = 0.97) (156). Concurrent validity showed a strong correlation with the HAQ (r = 0.87), moderate with the LiSat11 (r = -0.61), and weak with the DAS28 (r = 0.38).

Personal factors
Self-Efficacy (IV)
The Arthritis Self Efficacy Scale (ASES) was used to measure participants’ confidence in their ability to manage pain, and other symptoms. The self-efficacy subscale for pain (ASES-pain) includes five questions that measure confidence in the ability to control pain due to RA. The second subscale (ASES-symptoms), consisting of six questions, measures participants’ confidence in their own ability to control other symptoms related to the disease. The participants marked their answers on a scale from 10 to 100. Each subscale was scored separately by calculating the mean of the items. Higher scores on the subscale mean higher personal
expectancy of control on that particular subscale (157,158). The Swedish version has shown satisfactory reliability (159) and validity (158) for persons with arthritis. Cronbach’s alpha for the ASES from the current sample was 0.92.

**Pain acceptance (IV)**

Pain acceptance was reported with the Swedish version of Chronic Pain Acceptance Questionnaire (CPAQ) (160). The CPAQ has 20 items and two subscales: Activity Engagement (AE), the degree to which the person engages in activities with pain present (score range 0-66), and Pain Willingness (PW), the degree to which the person refrains from attempts to avoid or control painful experiences (score range 0-54). Higher scores indicate high pain acceptance. All items are rated on a scale from 0 (never true) to 6 (always true). The CPAQ is reliable and valid both in English and Swedish (114,160). Psychometric properties were recently reported in a Swedish chronic pain cohort. Internal consistencies were 0.88 (activity engagement), 0.74 (pain willingness), and 0.86 (total scale) (161). CPAQ is commonly used in persons with chronic pain and in a few studies that examine arthritis (113,162,163). Cronbach’s alpha for the CPAQ scale from current sample was 0.86.

**Data analysis**

**Statistical analyses Paper I, III-IV**

All analyses were performed in the Statistical packages for the social sciences (SPSS) version 19 or 21 and AMOS 21. The critical $\alpha$-value was set to 0.05 for all analyses if not otherwise specified.

**Descriptive analyses**

Descriptive statistics including mean values and standard deviations and proportions were analysed. In Paper III and IV, background data from the SRQ (DAS-28, medication, disease duration, etc.) and age were analysed descriptively based on gender. Data were tested for normal distribution, skewness, and kurtosis using the Kolmogorov Smirnov test.
**Analytic statistics**

Independent sample $t$-tests or Mann-Whitney $U$-tests and Chi-square tests were used to analyse group differences. Differences between follow-ups in Paper I were analysed using repeated measures ANOVA with the Sidak post-hoc test. Correlations were analysed using Pearson's correlation test.

In Paper III, the relationships between performance of valued life activities and pain intensity were analysed based on gender. The participants were grouped by gender and then into two subgroups based on pain intensity, with VAS > 40 set as a cut-off value for high pain intensity, a value used in earlier research (59,164,165).

In Paper III, multiple linear regression analysis was carried out with the total VLA scores as the dependent variable and pain intensity, duration of RA, age, gender, DAS28, and HAQ as independent variables. A forward entry method was used. No multicollinearity across the variables was found to affect the statistical analyses (tolerance values ranging from 0.815 to 0.995 and Variance inflation factor (VIF) ranging from 1.01 to 1.23). To estimate the clinical relevance, effect size was calculated using Rosenthal’s $r$ (large effect ≥ 0.5) (166).

In Paper IV, hierarchical linear regression analyses were performed with the total VLA summary score: difficulties to perform valued life activities was the dependent variable and self-efficacy (ASES subscales “Pain Self-Efficacy” and “Other Symptoms Self-efficacy”) and pain acceptance (CPAQ subscales “Activity Engagement” and “Pain Willingness”) were the independent variables. The mediational role of personal factors on the relationship between pain and valued life activities were estimated using structural equation modelling (SEM) (167,168).
Qualitative content analysis (Paper II)

Based on the aim of the Paper, the transcribed texts were analysed with respect to content (169). This approach is appropriate to use for poorly explored multi-faceted phenomena in healthcare research (170). Meaning units were identified, condensed, abstracted, and coded. The coded meaning units were sorted into sub-categories and exhaustive and mutually exclusive categories. The meaning units and the categories were reviewed by the co-authors and a patient research partner from the Swedish Rheumatism Association Patient Participation in Research examined the findings and confirmed that the categories were credible. Quotations were used to illustrate the categories and to present a link to the FGs from which they originated.

Ethical considerations

All studies were carried out in compliance with the Helsinki Declaration (171) and the Swedish Research Council guidelines and ethical principles. The study protocol for Paper I was approved by the local ethics committee in Linköping, Sweden. Paper I was based on data from the TIRA projects. The TIRA-1 project was approved by the local ethics committee associated with the participating rheumatologic units in Sweden (Dnr 96035) and the TIRA-2 was approved by the Regional Ethical Review Board in Linköping (Dnr M168-05). Studies II, III, and IV were approved by the Regional Ethical Review Board in Linköping, (Dnr 2010/42-31 and Dnr 2011/452-31).

Respect for people and the Autonomy Principle

Paper I was based on data from the TIRA project. All participants gave their written informed consent to participate in the study. Paper II was aimed to describe people’s experiences of pain and its impact on their daily activities. Recruitment of persons with RA for the focus group discussions was made using the SRQ. Participants were informed about the study and they provided informed consent before participation.
All eligible participants were sent an invitation and information sheet. The letter informed participants that they would receive a phone call within a week of receiving the letter to ask if they would be interested in participating in the study. The letter provided clearly written information about the purposes of the study and how the data would be treated. The letter notified participants of their ability to withdraw from the study at any point without justification or prejudice. Participants were informed that all information obtained through the study would be treated confidentially, with all identifiable information removed from reports or scientific publications. The letter made it clear that the decision to participate in the study would not affect their on-going treatment at the clinic. Participants were also reminded of these ethical principles verbally before the interviews. Thus efforts were undertaken to ensure that participants made an autonomous decision to participate in the study.

Paper III and IV used data from the quality register SRQ. When people were included in the SRQ, they were informed that the data collected could be used for research. When the data from the register is used for research studies, approval from an ethical board is required.

**Goodness Principle, beneficence, and non-maleficence**

The goodness principle was met using research based on the people's perspectives and giving participants the opportunity to share their experiences with others (Paper II) (172). There is a small risk that the group dynamics might influence group participation. There is also a small risk that participants could perceive focus groups and interviews as an intrusion on their privacy as some of the questions concern personal experiences. Efforts were made to mitigate each of these risks: a) informing all participants of their right to avoid answering questions that were uncomfortable; b) involving experienced moderators who created an atmosphere that allowed participants to express their personal and shared experiences in a safe and accepting setting; c) using a well-designed interview guide; and d) making arrangements to refer
participants to the regular care at each rheumatology unit if a need of care or support emerged. Since focus interviews allow each participant to choose what they want to talk about, the risk of privacy violations was small. Experience suggests that persons with RA have limited opportunity to talk about their experiences and consequences of pain with healthcare professionals, so a focus group with people in the same situation and with a competent leader could actually provide some benefits for the participants. Benefits for participants are an important aspect to take into consideration (173). No perceived risks were identified in Papers I, III, and IV. The findings of each of these studies will inform practice guidelines for persons with RA.

The principle of justice

The principle of fairness was taken into account by affording all who met the criteria for inclusion into the study equal opportunity to participate (174). Within a focus group setting, the moderator ensured that everyone had the opportunity to be heard. Since the focus group discussions required good communicative skills, people who were unable to communicate in Swedish were unfortunately not able to participate. A Patient Research Partner of the Swedish Rheumatism Association has participated in planning and execution of the studies. Collaboration between patients and research professionals is recommended (175). Because people living with chronic illness have unique knowledge about living with their disease, their perspectives should be included in research and therefore, along with a desire to increase user influence in research, a research partner was involved in the studies.
Results

Pain and activity limitations were still present among persons with RA (Paper I)

Pain and activity limitations in the cohorts over time
Pain and activity limitations were pronounced at inclusion for both genders in both cohorts. For the first three years after inclusion, overall improvement was statistically significant for pain intensity, bodily pain, and activity limitations in all groups regardless of cohort or gender ($p < 0.001$), with the exception of pain intensity in women in TIRA-1. Pain intensity in both cohorts was reduced from inclusion to Y1 (follow-up one year after diagnose) and thereafter stable ($p < 0.001$), with the exception of pain intensity in women in TIRA-1, which did not differ between inclusion and Y1. In both cohorts, bodily pain and difficulties in performing daily activities across genders were reduced from inclusion to Y1 ($p < 0.001$), but thereafter stable (Figure 3).

Differences in pain and activity limitations between cohorts
Persons with contemporary treated early RA (TIRA-2) reported lower pain and activity limitations at all follow-ups. At all follow-ups, men reported lower pain than women. Women reported significantly higher difficulties performing daily activities at all time-points. In TIRA-1, no differences in pain and difficulties in performing daily activities between women and men were seen at any time points except for women reporting significantly more difficulties performing daily activities than men at all follow-ups. Pain and difficulties performing daily activities were still pronounced in persons with contemporary treated early RA (TIRA-2), especially in women.
Figure 3. Time course for pain intensity (VAS Pain, 0-100), bodily pain (SF-36 BP, 0-100), and difficulties performing daily activities (HAQ, 0-3) in TIRA-1 and TIRA-2 for women and men. Mean values and 95% confidence intervals are displayed. TIRA, Early interventions in RA; VAS, Visual Analogue Scale; HAQ, Health Assessment Questionnaire; SF-36, Short Form Health Survey; BP, Bodily pain.
The relationship between pain and daily activities was multidimensional and dynamic (Paper II)

The focus group discussions resulted in five categories supported by ten sub-categories (Figure 4). The relationship between pain and daily activities in RA was dynamic as pain affected everyday life and was perceived as a barrier to performing valued activities. The pain per se, or in combination with poorly adapted environments, prevented the participants from engaging in desired activities such as attending dinner parties. Pain caused participants to stop engaging in some activities (e.g., some older women and men stopped driving because of the pain) or required them to devote more time and effort to complete activities. Pain in the feet limited many activities and restricted social participation such as walking or shopping with friends. Participants also modified activities with friends and grandchildren so the activities were less physically demanding.

Finding the right balance of activity was difficult for participants as participants found it easy to be so active that their pain increased. Certain activities were carried out anyway and were described as so important that to carry them out was worth the pain and exhaustion that followed. Activities, however, seemed to mediate pain and enhance wellbeing by shifting the focus away from the pain. Some participants shifted their focus away from their pain by engaging in professional work and in activities with their friends and their children.

Personal factors and the social environment influenced the effect pain had on participation and independence. The participants were frustrated because they could not do what they wanted or needed to do. Attitudes of employers, colleagues, friends, and relatives were perceived to affect the consequences of pain in daily activities, both positively and negatively. Support from family and friends created opportunities for participation. Other people’s thoughtfulness contributed to wellbeing at times when the RA patients were experiencing severe pain. Colleagues’ support was perceived as important. Lack of support from colleagues, family, and
friends contributed to participation restrictions. Poor understanding of the pain or friends ignoring the pain obstructed participation in social contexts. Participants described having to ask for help or to hand over activities at home, which created a feeling of dependence. This feeling of dependence was perceived as annoying and inconvenient.

Figure 4. Categories and subcategories of relation between pain and daily activities in RA
Valued life activities were strongly related to pain (Paper III)

Paper III examined the activities persons with RA valued and how the participation in valued activities was related to pain across gender. While women and men valued different activities, both reported pain-related restrictions in carrying out valued life activities. Women rated their pain intensity higher than men, but some participants reported restrictions even when pain was low. Close to half of the participants reported at least one valued activity as being difficult, or even impossible, to carry out.

The most frequently affected activities were gardening, minor repairs, hobbies, activities with children, and physically strenuous leisure activities. Women also reported that pain affected their ability to do heavy housework, to take care of children, and to shop. More women than men encountered difficulties performing cooking, heavy housework, minor repairs, gardening, community mobility, shopping, child care, having others visit, volunteer work, study, sleeping, and meeting new people. No valued life activities were identified in which men reported more difficulties than women (Table 4).

Regardless of gender, 58% had low pain (VAS<40) and 42% had high pain (VAS ≥ 40). Women reported higher pain intensity (35 mm) than men (31 mm). Almost all 33 difficulty ratings for valued life activities were significantly higher in the high-pain group than in the low-pain group. There were significant correlations (rho ranging from 0.19 to 0.68) with respect to difficulty ratings for valued life activities and pain in the low-pain group. In the high-pain group, however, difficulty ratings for the 33 valued life activities were not correlated with the degree of pain.

Pain had strong links to the total VLA score. A multiple linear regression model with the variables that were significantly correlated with VLA summary score explained 34% of the variance. Pain was identified as having the most important relation to difficulties performing valued life activities. RA duration, disease activity (DAS28), and age explained a
further 4.2%. Although gender correlated with the total VLA score, gender did not explain more of the variance. VLA assisted in identifying that low levels of pain were positively correlated with difficulties to perform VLA.
Table 4 Difficulty ratings for valued life activities by gender. Proportions of participants reporting respective activity as valuable and proportions reporting difficulty (score 1-3) performing each valuable activity (affected). Mean value and standard error (SE) of performance (score 0-3) in each activity. Compared means between women and men (n= 737).

<table>
<thead>
<tr>
<th>VLA activity</th>
<th>Valued n (%)†</th>
<th>Affected (%)</th>
<th>Performance</th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Women (W)</td>
<td>Men (M)</td>
<td></td>
<td>W</td>
<td>M</td>
<td>p-value</td>
<td>W Mean (SE)</td>
<td>M</td>
<td>Mean (SE)</td>
<td>p-value</td>
</tr>
<tr>
<td>Basic needs</td>
<td>471 (87)</td>
<td>178 (90)</td>
<td>48 52</td>
<td>ns</td>
<td>0.53 0.028</td>
<td>0.56 0.044</td>
<td>ns</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Meals/cook</td>
<td>454 (84)</td>
<td>159 (80)</td>
<td>43 35</td>
<td>ns</td>
<td>0.47 0.027</td>
<td>0.36 0.041</td>
<td>0.042*</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Light housework</td>
<td>449 (83)</td>
<td>150 (76)</td>
<td>45 42</td>
<td>ns</td>
<td>0.52 0.030</td>
<td>0.48 0.050</td>
<td>ns</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Heavy housework</td>
<td>413 (77)</td>
<td>157 (79)</td>
<td>71 54</td>
<td>&lt;0.001*</td>
<td>0.95 0.038</td>
<td>0.69 0.061</td>
<td>&lt;0.001*</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Minor repairs</td>
<td>223 (41)</td>
<td>155 (78)</td>
<td>75 63</td>
<td>0.015*</td>
<td>1.17 0.062</td>
<td>0.76 0.055</td>
<td>&lt;0.001*</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gardening</td>
<td>295 (55)</td>
<td>136 (67)</td>
<td>80 71</td>
<td>0.031*</td>
<td>1.09 0.046</td>
<td>0.89 0.061</td>
<td>0.015*</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Administration/</td>
<td>402 (75)</td>
<td>160 (81)</td>
<td>16 13</td>
<td>ns</td>
<td>0.19 0.025</td>
<td>0.13 0.027</td>
<td>ns</td>
<td></td>
<td></td>
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<tr>
<td>Household business</td>
<td></td>
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<td></td>
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</tr>
<tr>
<td>Walking inside</td>
<td>472 (88)</td>
<td>184 (93)</td>
<td>36 41</td>
<td>ns</td>
<td>0.40 0.026</td>
<td>0.46 0.044</td>
<td>ns</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Walking outside</td>
<td>452 (84)</td>
<td>171 (86)</td>
<td>48 51</td>
<td>ns</td>
<td>0.58 0.032</td>
<td>0.61 0.052</td>
<td>ns</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Getting around your</td>
<td>419 (78)</td>
<td>173 (87)</td>
<td>35 25</td>
<td>0.029*</td>
<td>0.41 0.031</td>
<td>0.29 0.043</td>
<td>0.028*</td>
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<tr>
<td>community</td>
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<td></td>
<td></td>
<td></td>
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<tr>
<td>Going to appointments</td>
<td>453 (84)</td>
<td>175 (88)</td>
<td>28 29</td>
<td>ns</td>
<td>0.35 0.029</td>
<td>0.30 0.038</td>
<td>ns</td>
<td></td>
<td></td>
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<tr>
<td>Shopping</td>
<td>437 (81)</td>
<td>169 (85)</td>
<td>59 40</td>
<td>&lt;0.001*</td>
<td>0.71 0.033</td>
<td>0.46 0.049</td>
<td>&lt;0.001*</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Child care</td>
<td>210 (39)</td>
<td>63 (35)</td>
<td>60 44</td>
<td>0.024*</td>
<td>0.76 0.051</td>
<td>0.54 0.084</td>
<td>0.032*</td>
<td></td>
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<tr>
<td>Activities with children</td>
<td>308 (57)</td>
<td>110 (56)</td>
<td>61 61</td>
<td>ns</td>
<td>0.77 0.043</td>
<td>0.72 0.063</td>
<td>ns</td>
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<td></td>
</tr>
<tr>
<td>Other family care</td>
<td>265 (47)</td>
<td>112 (57)</td>
<td>52 40</td>
<td>0.041*</td>
<td>0.61 0.043</td>
<td>0.48 0.062</td>
<td>ns</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Social events</td>
<td>414 (77)</td>
<td>153 (77)</td>
<td>41 34</td>
<td>ns</td>
<td>0.47 0.031</td>
<td>0.39 0.047</td>
<td>ns</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Social communication</td>
<td>449 (83)</td>
<td>162 (82)</td>
<td>20 15</td>
<td>ns</td>
<td>0.21 0.021</td>
<td>0.18 0.035</td>
<td>ns</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Visit others</td>
<td>453 (84)</td>
<td>167 (84)</td>
<td>31 30</td>
<td>ns</td>
<td>0.37 0.028</td>
<td>0.34 0.044</td>
<td>ns</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Having others visit</td>
<td>440 (82)</td>
<td>169 (85)</td>
<td>37 31</td>
<td>&lt;0.001*</td>
<td>0.41 0.027</td>
<td>0.21 0.035</td>
<td>&lt;0.001*</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hobbies</td>
<td>348 (65)</td>
<td>122 (62)</td>
<td>69 62</td>
<td>ns</td>
<td>0.91 0.042</td>
<td>0.76 0.066</td>
<td>ns</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Leisure in home</td>
<td>449 (83)</td>
<td>171 (86)</td>
<td>9 11</td>
<td>ns</td>
<td>0.10 0.016</td>
<td>0.14 0.034</td>
<td>ns</td>
<td></td>
<td></td>
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<tr>
<td>Leisure activities out of</td>
<td>401 (74)</td>
<td>142 (72)</td>
<td>33 27</td>
<td>ns</td>
<td>0.40 0.032</td>
<td>0.30 0.044</td>
<td>ns</td>
<td></td>
<td></td>
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<tr>
<td>home</td>
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</tr>
<tr>
<td>Physical activities</td>
<td>393 (73)</td>
<td>142 (71)</td>
<td>74 68</td>
<td>ns</td>
<td>0.92 0.036</td>
<td>0.89 0.067</td>
<td>ns</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Travel</td>
<td>396 (73)</td>
<td>148 (75)</td>
<td>41 32</td>
<td>ns</td>
<td>0.46 0.047</td>
<td>0.36 0.047</td>
<td>ns</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Religious/spiritual</td>
<td>120 (22)</td>
<td>31 (16)</td>
<td>29 23</td>
<td>ns</td>
<td>0.29 0.042</td>
<td>0.26 0.092</td>
<td>ns</td>
<td></td>
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<tr>
<td>activities</td>
<td></td>
<td></td>
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<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Volunteer work</td>
<td>144 (27)</td>
<td>58 (29)</td>
<td>50 33</td>
<td>0.026*</td>
<td>0.63 0.062</td>
<td>0.34 0.068</td>
<td>0.015*</td>
<td></td>
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<tr>
<td>Study</td>
<td>155 (29)</td>
<td>61 (31)</td>
<td>39 20</td>
<td>0.008*</td>
<td>0.45 0.052</td>
<td>0.23 0.064</td>
<td>0.009*</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Working</td>
<td>195 (36)</td>
<td>73 (37)</td>
<td>58 51</td>
<td>ns</td>
<td>0.70 0.052</td>
<td>0.68 0.097</td>
<td>ns</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sleeping</td>
<td>454 (84)</td>
<td>173 (87)</td>
<td>55 36</td>
<td>&lt;0.001*</td>
<td>0.65 0.031</td>
<td>0.42 0.046</td>
<td>&lt;0.001*</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Eating</td>
<td>447 (83)</td>
<td>174 (88)</td>
<td>19 16</td>
<td>ns</td>
<td>0.21 0.021</td>
<td>0.16 0.029</td>
<td>ns</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Intimate relations</td>
<td>314 (58)</td>
<td>138 (70)</td>
<td>49 44</td>
<td>ns</td>
<td>0.59 0.039</td>
<td>0.59 0.067</td>
<td>ns</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Meet new people</td>
<td>411 (76)</td>
<td>159 (80)</td>
<td>20 11</td>
<td>0.006*</td>
<td>0.23 0.023</td>
<td>0.13 0.031</td>
<td>0.007*</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Care for pets</td>
<td>220 (41)</td>
<td>81 (41)</td>
<td>43 35</td>
<td>ns</td>
<td>0.51 0.046</td>
<td>0.36 0.056</td>
<td>ns</td>
<td></td>
<td></td>
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</tr>
</tbody>
</table>

VLA, Valued Life Activities; W, Women; M, Men
*significant at the 0.05 level
†Response frequencies vary because data were missing or because responders reported that the activity was neither important nor applicable.
Personal factors were mediators in the relationship between pain and valued life activities (Paper IV)

Women reported higher pain intensity than men ($p<0.036$). Gender was not associated with activity engagement, pain willingness scores, and certainty about being able to control pain. Compared to women, men, tended to be more confident about managing symptoms (SE-symptom) ($p = 0.05$). The VLA scores (VLA summary) did not vary by gender ($p = 0.056$).

Results of univariate regression analyses revealed that all pain acceptance and self-efficacy constructs were significantly associated with VLA ($p <0.001$). The final hierarchical linear regression model explained 46.5% of variability in perceived difficulties performing valued life activities. Participants with low intensity RA pain continued to report fewer difficulties performing valued life activities ($p <0.001$). Participants with lower activity engagement and lower self-efficacy in managing RA symptoms were more likely to have increased difficulties performing valued life activities. Participants’ pain willingness scores and their self-efficacy in managing pain did not significantly contribute to the prediction of their valued life activity scores.

A possible mediating effect of the personal factors – i.e., activity engagement (CPAQ-AE), self-efficacy in managing arthritis symptoms (SE-symptoms), and managing pain (SE-pain) – that influence how pain interferes with performing valued life activities (VLA) was examined through structural equation modelling. Figure 5 presents the most parsimonious model that best fitted the data. The direct effect of pain on valued life activity scores was significant ($Beta = 0.34$, $p <0.001$). Significant positive associations between pain and personal factors were found ($Beta = -0.48$, $p <0.001$). Personal factors were also found to be significantly and negatively associated with their valued life activity scores ($Beta = -0.45$, $p <0.001$). There was an indirect effect of pain on valued life activities through personal factors ($p <0.001$) (Standardized
indirect effect, \( \beta = 0.22 \)). Personal factors mediated the relationship between pain and valued life activity score.

**Figure 5.** Structural equation model of the associations (beta weights) among Pain, Personal factors, and Valued life activity score. Pain had a significant direct effect on valued life activities and a significant indirect effect on valued life activities mediated by Personal factors.
Discussion

General discussion of the results

The present thesis explores and describes pain in relation to participation in women and men with RA. Pain and activity limitation were still pronounced in women and men with RA despite recent treatment advances. The relationship between pain and participation was multidimensional and dynamic. Pain was related to fatigue, stress, and mood, all factors that generated difficulties in finding a suitable level of activity, affecting the balance of daily activities. Participation in valued activities was also used as distraction of pain. Both women and men reported restrictions in participation in valued life activities. Pain was identified as having an essential relation to difficulties performing valued life activities. Personal factors as well as the social environment were found important as mediators for pain in relation to participation.

This thesis uses the ICF as a conceptual framework to describe disability and how participation is related to pain. The findings in the thesis are discussed in relation to the components in the ICF and relations between components: pain as impairment, activities, participation, personal factors, and environmental factors. This thesis analyses the significance of these findings and what these findings suggest for future RA rehabilitation.

Pain is complex and still present among today’s persons with RA

Paper I described pain and restriction in participation in persons with RA receiving current treatments. At the follow-ups, both women and men in the TIRA-2 cohort (i.e., persons with RA treated with current protocols) reported lower pain after being diagnosed with RA than their counterparts treated a decade earlier. In accordance with recent studies on individuals with early RA (53,176-179), the largest improvement in pain occurred the first year of the treatment in both cohorts. In persons
with RA, minimal clinically significant changes in pain assessments have been estimated to be 11 mm on a 100-mm scale (71,151). In the comparative cohort study (Paper I), the pain intensity was scored with a reduced mean difference from inclusion to the follow-up after one year: 24 mm for women and 25 mm for men in the TIRA-2 cohort. This difference is quite large compared to their counterparts, and this can be seen as a distinct clinical change over time. However, pain was still pronounced. Pain intensity plateaued for persons receiving current treatments (Paper I). Because this remaining pain may not have been caused by inflammation, early identification and early multidisciplinary rehabilitation may be needed (62). It is important to recognize persons with high pain at disease onset to predict severe disability later in the disease process (60). Some persons with RA can have an enhanced pain regulation and develop a generalized pain that needs to be addressed individually with person-centred rehabilitation (74). Non-pharmacologic pain management strategies, based on pain acceptance and self-efficacy, can provide important relief for persons with RA (65).

Pain was described by the participants in the focus group study (Paper II) as related to fatigue, stress and mood. Depressed mood and increased stress manifested as muscle tension were perceived to further increase pain, a phenomenon previously described (66). In fact, pain has a strong documented positive correlation with fatigue, further limiting activity (180). The complexity of pain in RA has been identified earlier (59) and this complexity highlights the importance of considering the individual’s pain in a bio-psychosocial context (22,75). Previous research confirms that it is easy to become irritated and extra sensitive during times when the pain is at its worst (19). Pain also caused issues with performing daily activities and affected mood (92).

**Being able to participate**

Despite improved medications and new treatment regimes, the TIRA-2 cohort’s abilities to perform daily activities were significantly reduced and still evident two and three years after diagnosis (Paper I). At the follow-ups, the mean HAQ scores varied between 0.5 and 0.6 in women
and between 0.3 and 0.4 in men, with significant differences between genders. In comparison with Swedish reference HAQ scores (0.07 in women and 0.05 in men), difficulties performing daily activities were pronounced (15). In Paper III, 85% reported at least one valued life activity affected by RA and about half of the participants reported severe difficulty or unable to perform at least one activity they valued as important, although previous studies have reported slightly higher proportions (45).

In addition, previous studies have reported a wide spectrum of participation restrictions in self-care, domestic life, leisure, and social life (87). The described dilemmas largely correspond with the finding in Paper III that valued activities (e.g., gardening, minor repairs, and leisure activities) were difficult to perform. The well-structured early instituted and effective interventions have indeed brought on dramatic changes that have enabled activity in all areas in daily life. However, this has not been the case for all persons with RA (10). Furthermore, greater expectations on participation in daily activities will arise as improvements occur in the disease (87). Paradoxically, feeling better entails the risk of overstraining oneself. In fact, in Paper II and in previous studies, participants found it difficult to find suitable levels of activity as this required adjusting their activity patterns to carefully balance their daily activities (10,116,181). The focus group discussions (Paper II) show that the participants were frustrated because they could not do what they wanted or needed to do, were dependent on others, had reduced opportunities for participation, in the social context and were dependent on family and friends for everyday functioning. Support from the social environment might affect how a person with RA understands independence and the subjective experience of engagement (“belonging”), which is important for participation (32,96).

In Paper III, participants reported difficulties performing valued activities such as leisure activities, physical activities, and “social demanding” activities. There is a tendency for persons with RA to report less disability in basic activities even though they struggle with different aspects of work and social life (85,87,89). The ability to perform valued
life activities that individuals find meaningful or pleasurable influences wellbeing. Indeed, this link has been reported to be even stronger than functional limitations and disability in basic activities of daily living (21).

**Pain and participation have a dynamic relation**

Restrictions of participation in valued life activities were common (Paper II, III, IV). The participants reported that their pain restricted and, in some cases, inhibited their ability to perform activities. Activities they did before their disease onset were no longer possible to do or they needed to adapt the activities. Pain affected participants’ ability to partake in daily activities (Paper II). Difficulties in adjusting the level of activity resulted in a pattern of overdoing in “good days”. That is, when pain levels were reduced, they often were overly active and this resulted in increased pain and a feeling of inadequacy. The results in Paper III also confirmed previous research (45) regarding the relation between pain and participation restrictions in RA. However, the finding that relatively low levels of pain were correlated with participation restrictions is a novel finding. This may mean that higher demands today on a pain that persons with RA may require more and better pain relief.

However, the participants also described activity as a distraction for pain and an opportunity for feeling well despite pain. Social activities like playing with the grandchildren or going to work shifted their focus away from the pain. Thus the pain had a multidimensional impact and affected the whole life situation, which is also evident in studies on people with chronic pain (182). Paper III revealed that RA-related pain was the main reason for restricting activities such as gardening, minor house repairs, hobbies, activities with children, and leisure activities. Previous research has indicated the same pattern. That is, more basic functions were less affected, as they were carried out anyhow, whereas leisure and social activities are the first activities to be given less priority due to pain intensity (45,183,184).

In Paper II, the participants also reported that participation in valued activities was used as a distraction of pain. Leisure and social activities
have been proven to decrease pain levels and improve quality of life (74). Participating in leisure, social, or other valued activities may be a way to cope with the restriction of basic activities, so persons with RA might need rehabilitation professionals to help them prioritise their activities (185).

Valued activities, mostly leisure or work-related, were sacrificed because it was not worthwhile doing them when they caused pain, findings that are consistent with another study focusing on the impact of RA on daily life (92). Therefore, it seems important to assess performance of valued activities as they appear to be linked to wellbeing more strongly than limitations in general function (21,45). The VLA-swe covers a comprehensive range of activities across all domains of participation of the ICF, which was classified and described earlier in the same sample (156). VLA measures participation using the bipartite concepts of functioning and disability, a distinction also found in the ICF (27). Since both the persons preferences and ICF concepts of disability are taken into account, it is a useful complement to traditional measures (156).

**Personal factors as mediators between pain and participation**

The participants in the focus group discussions (Paper II) describe the significance of management strategies and awareness of functional limitations in performance of daily activities. Focus group discussions provided interesting reflections when the participants described and discussed ways to manage concrete situations in daily activities, for example, in household and work situations. These reflections constituted the basis for the planning of the Paper IV. This finding indicates the importance of considering personal factors to promote participation. According to Paper IV, self-efficacy and pain acceptance, defined in the ICF (22) as personal factors, have a strong relationship with the valued life activity score in women and men with RA. Participants with lower activity engagement and those with lower self-efficacy in managing RA symptoms were more likely to have increased difficulties performing valued life activities. Furthermore, personal factors (represented here by pain acceptance and self-efficacy) worked as mediators on performance
of valued life activities and facilitated participation across genders in RA-related pain. To my knowledge, Paper IV is the first paper in which this mediating influence is described in women and men diagnosed with RA.

Gender and the subscale of pain willingness from the CPAQ did not have a strong relationship with how pain affected valued life activities (Paper IV). Instead, self-efficacy was much more important, which was also found in the focus group study (Paper II). Active management promotes a sense of confidence, or self-efficacy, in dealing with pain that is associated with improved participation in daily activities and wellbeing. Low self-efficacy gives a feeling that pain is uncontrollable and unmanageable in daily life (186). Paper IV indicates that lower levels of pain implies higher self-efficacy and higher pain acceptance. Increased focus on self-efficacy may be particularly valuable in persons with RA who continue to experience pain despite optimal medical treatment. Persons with RA who have low levels of self-efficacy may therefore benefit from multidisciplinary interventions that can increase self-efficacy (110). Self-efficacy may identify an additional route for improving outcomes for these persons (i.e., educational or psychosocial interventions to increase arthritis self-efficacy). Self-management programs are reported to lead to increased self-efficacy, which has been related to improvements in pain management and health (109,187). The results in Paper IV suggest that self-efficacy is a key factor when it comes to predicting the impact of pain on VLA. Learning effective self-management strategies to regain a sense of control, to facilitate participation, and to learn how to best manage the pain significantly helped the pain acceptance process. Self-management and education are also described as facilitators for pain acceptance (115). Standards of care for the treatment of RA emphasize self-management as a way to enhance functioning in daily life and participation in social roles (80).

Although pain management strategies can be helpful in persons with persistent pain, research findings suggest that their lives sometimes can be dominated by efforts to control pain rather than being active despite pain (109). Pain acceptance changes the focus from pain control to a more flexible engagement in valued activities, which may include pain as a part
of the engagement, without struggling for pain control (188). In Paper IV, participants with higher pain acceptance reported less pain, a finding that agrees with a previous study of early RA (162). Acceptance is a valuable concept on how persons with long term pain adapt to pain (112,114). Acceptance entails “doing with pain”: an individual may participate in daily activities even while continuously experiencing pain (189). Of the two components of pain acceptance, engagement in activities while pain is being experienced was most important for the participants. The importance of engagement in valued activities is critical to maintaining wellbeing (190). This finding is also consistent with previous cross-sectional studies, suggesting the importance of acceptance-based approaches in several chronic pain conditions (111,112,191) and in RA (162). Higher pain acceptance is associated with less pain intensity, lower levels of disability, greater reported daily activity (191), and higher wellbeing (112). Facilitators of acceptance, including self-management and education, have been described in women living with arthritis. Barriers to acceptance include a lack of support and lack of acceptance by others (115). The significance of attitudes for participation was reported in Paper II. Friends and family support, however, can encourage persons with RA to participate in activities. Participants in the focus groups (Paper II) emphasized that attitudes of family, employers, and friends could be facilitators or barriers to participation.

**Differences in pain and participation between women and men with RA**

In this thesis the differences have mainly been analysed with respect to biological gender. Some gender differences were found. Women in the TIRA-2 cohort (Paper I) experienced more pain and reported more difficulties performing daily activities than men, a finding that is consistent with other cohort studies (5,13,54,55,61). Maybe this disparity can be explained by higher pain sensitivity and less muscular strength in women, but it might also be explained by the fact that men sometimes over-estimate their functional ability (55).
Significantly more women than men encountered difficulties cooking, doing heavy housework, doing minor repairs, gardening, community mobility, shopping, taking care of children, hosting visitors, volunteering for work, studying, sleeping, and meeting new people. No valued life activities were identified in which men reported more difficulties than women. The difference between men and women regarding which activities, and to which extent these activities were affected (Paper III), may be reflected by the fact that women reported higher pain than men (5). Lower manual strength (16) will likely further contribute to this finding (18). In addition, more women in Paper III reported sleeping distractions, which are known to indirectly affect participation (192).

Interestingly, women reported more pain and difficulties performing valued life activities than men. These results draw attention to the importance of addressing valued activities especially among women with low levels of pain, since their pain may impact their activities in daily life that they identify as important. No gender differences were identified in the model for mediating pain in performance of valued life activities in Paper IV. Only some trends of differences in self-efficacy and pain acceptance between women and men were found. Further research is required to examine possible difference in personal factors between genders and their significance for rehabilitation strategies.

Men with RA generally report lower pain (54,55,193) and participation restrictions than women and their prognosis of disability is also generally better than the women’s (5,13,54,55,194). Hence, women need to be treated differently in order to optimize rehabilitation (16,18,55). Previous research, however, has demonstrated that arthritis rehabilitation seems to be most beneficial for people with more severe consequences of their disease (128).
Need for rehabilitation in RA today

The results from this thesis and previous literature suggest a need for developing “modern” rehabilitation strategies for women and men with RA today. The findings in this thesis indicate a continued need for multidisciplinary interventions despite more effective medication. Pain in RA needs to be comprehensively treated from the individual’s perspective and needs (9,50,81,195). To improve function and ability to participate in valued activities, multidisciplinary teams should address pain management by providing education about the values of goal-setting, pain acceptance, and self-management strategies (74). Such intervention strategies address pain from a bio-psychosocial perspective (75), taking into account the individual’s perspective and needs. The results show that even low levels of pain affect everyday life and may be a barrier to performing valued activities. Treatment should focus on functional adaptation – “learning to live with pain” – in order to facilitate participation in an active life (115,186). Contemporary approaches in pain management used in rehabilitation in chronic pain, such as pain acceptance, might be useful in pain management for persons with remaining pain in RA (196). Access to allied health professionals in rheumatologic rehabilitation would help promote the pain acceptance process (115).

Living with chronic pain can disrupt everyday life in different ways and occupational therapy can benefit people who experience an imbalance between rest, work, and leisure or a pattern of either under-activity or over-activity (185). Previous research indicates a strong association between self-efficacy and occupational balance and suggests that this finding may influence how rehabilitation can enable persons with RA to achieve a balanced life, including occupational balance (95). Higher levels of engagement in physical leisure-time activities are associated with self-efficacy (94). Today, persons with RA continue to work, placing greater demands on functioning (85), affecting how they balance activities (89). The lack of leisure-work balance emerges when a person with RA is unable to engage in valued activities after work. The efforts to go on working take most of the energy and time of the day. That is, persons with
RA often find that their pain prevents them from participating in recreational activities after work. (Paper II).

From an ICF perspective, and according to the model in Paper IV, personal factors may have an important role for participation in women and men with RA. The results provide a greater understanding of how valued activities are related to the various components of the ICF, including pain (impairment), personal factors, and environmental factors. Outcome rehabilitation instruments have shown that personal factors do not receive as much attention as pain and environmental factors (131). Outcomes must be developed that complement established outcome measures (20,35). Recent research reports pain, daily activities, management strategies, and participation as among the domains selected to be the most central for rehabilitation (197).

The primary focus of rehabilitation research has been physical and functional outcomes and quality of life measures, but personal factors need more attention. Well-targeted rehabilitation has the potential to create desirable outcomes (198). Recent RA treatment research has begun to evaluate multidisciplinary rehabilitation interventions, including physical activity and self-management interventions (199). Recent structured RA rehabilitation programmes focus on self-management strategies and goal-attainment as a complement to the traditional rehabilitation programmes (130). This research underlines the value of the results of this thesis. Self-management interventions are person-centred and are acknowledged as a key element of quality care, including rehabilitation in rheumatology (80,121).

As this thesis found that ICF was a useful framework (131), ICF could be seen as a first step towards a general theory of functioning that could be used in rehabilitation and disability research (200). The on-going discussion about how the ICF conceptualizes functioning and disability, where participation refers to activities that are actually performed (27), is not clearly established in this thesis. These discussions have to be continued and the concept of occupation (23,24,34) needs to be introduced in the discussion.
The findings that personal factors can work as mediators between pain and performance of valued life activities are consistent with the ICF’s assumptions. The ICF includes some assumptions about human functioning; it hypothesizes that the impact of the health condition on function is mediated by contextual factors that can be empirically tested (e.g., environmental factors can hinder or facilitate participation and personal factors include how barriers are overcome or avoided). The ICF can also be used to explain participation restrictions in RA (28). The subjective experience of participation, something that is absent in the ICF (31,32), is crucial for capturing the personal value of participation (33).

Patient-reported outcomes are important in rheumatology (50), but these outcomes must reflect the personal perspective on what is relevant and important in RA. Moreover, currently used assessments do not emphasise personal perspectives. Unlike traditional tools, the VLA captures the personal perspective by providing better insights into participation restrictions (156). Occupational therapy interventions include analysing personal and environmental influences that impact engagement in occupation. Opportunities for participation in work rely on strengthening the person, establishing a person-centred focus (26).

That is, valued activities should inform rehabilitation strategies. The person's engagement and subjective experience of participation is a key factor and focus in occupational therapy (31). ICF includes the concept of engagement (“involvement”), defined as “being included”, but not the subjective experience of engagement, defined as “belonging” (32). Engagement in occupation requires that people perform occupations (doing) that are valued for ourselves (being) and to others (belonging) (139). Therefore, engagement has to be highlighted in addition to the ICF in RA rehabilitation.

The dynamic relationship between pain and valued activities implies the need for multidisciplinary rehabilitation. Even low levels of pain may impact activities in daily life, persons with RA identify as important. Environmental factors can facilitate or hinder the ability to participate in valued activities. As a component of ICF, personal factors reflect the individual’s needs and strengths, important for rehabilitation. Thus,
consider the personal factors is an important step of implementing person-centeredness care (105). Person-centred care strengthens the participation and independence of the person with RA as well as strengths their relationship with health professionals (123). The relationship between health professionals and the person with RA is essential because the needs of the individual are required to be identified and met in order to achieve wellbeing. A person-centred approach requires that personal factors (including gender) be taken into account.

The findings in this thesis can be used to help develop rehabilitative interventions specifically designed for individuals to manage pain and facilitate participation in valued activities and thereby increase wellbeing in women and men with RA.
Methodological considerations

External validity addresses whether results can be generalized to other people, groups or settings (201). A clearly defined group of participants facilitates generalizability of a study’s findings (201). The participants in these studies lived in a major city, urban areas, and rural areas in southeastern Sweden and represent incidence rates, age at onset, and gender distribution.

Because relatively fewer men than women are diagnosed with RA, RA research does not always include men. In this thesis, both men and women participated in all the studies. In Papers II, III, and IV, the participants were recruited from SRQ, a clinically based quality register that links PRO and clinical data from regular clinic visits. Paper I used the data from the regional RA project TIRA (TIRA-1 and TIRA-2). Compared to the TIRA-1 participants, the TIRA-2 participants at inclusion were slightly older, had higher HAQ scores, and had more pain as measured by VAS. Mean HAQ scores increases with age (0.01 unit per year in persons with RA) as well as in control subjects (202). Some of the differences in the HAQ scores can be explained by this phenomenon.

In focus group discussions (Paper II), the selection of participants through purposive sampling is crucial for the study’s credibility and transferability. Both men and women of different ages were included in the study (166) to increase credibility. Loss of participants due to acute illness symptoms meant that certain groups were on the verge of being too small to provide a creative environment for discussions (147). With respect to young men with RA, lack of time and energy was mentioned as the main reason for not participating in the focus groups. These limitations may influence the transferability of results.

In Papers III and IV, the response rate was 58%. In the first mailing, those who chose not to participate were asked to mail their blank questionnaire to avoid a reminder. This strategy lowered the response rate. In the second mailing (i.e., the first reminder), this option was removed. Exactly
how this affected the response rate is hard to estimate, apart from the fact that 265 blank questionnaires were returned. The response rate constitutes a limitation that may affect the generalizability of the findings. However, the drop-out analysis showed that the only significant difference between the responders and the non-responders was in the HAQ measurements. Otherwise, the two groups were not significantly different. The use of patient reported HAQ data from SRQ, even from those who did not participate in the study, could be questioned on ethical grounds; however, the regional ethical review board approved the study that included the non-respond analysis.

Using data from a quality registry meant the data were stable, and the participants and outcomes were well-defined (140). A strength of the data obtained from SRQ and TIRA is that the data were collected during regular visits to the rheumatology clinics. As a standard procedure in these clinics, patients are asked to rate their pain using a VAS. The VAS is used because it is simple and adaptable to a broad range of populations, including persons with RA (68,71,151). In addition the SF-36 BP was used to assess bodily pain intensity and its interference with normal activities (71). SF-36 BP can be regarded as estimating the relative burden of different diseases, including RA (203). In the entire study group in Paper I (i.e., the TIRA-1 and the TIRA-2 group), the correlation between VAS pain and SF-36 BP was $r = -0.50$ (p<0.001), indicating that VAS pain and SF-36 BP subscale do not measure the same aspects of pain. VAS pain assumes that the pain is a linear phenomenon, which may not be the case. An alternative measurement scale could have been the Borg CR10 rating scale (204), which is a verbally level-anchored ratio scale, also called a category rating scale, but it does not assume linearity as a feature of pain.

Difficulties performing daily activities were reported by the Swedish version of the HAQ in Paper I in which the concept “activity limitation” (22) is used. The HAQ is clinically relevant (1) and commonly used in research studies (60,62,128). However, the distinction between “activity” and “participation” in the ICF is a matter of debate (27), so HAQ was used to report participation restrictions in Papers III and IV.
VLA-swe has recently been validated for Swedish conditions (156), and it has been demonstrated that the VLA-swe can capture participation restrictions also for those with low levels of pain. Further research with this tool is needed to determine its reliability.

The Arthritis self-efficacy scale (ASES) (Paper IV) is commonly used in rheumatology, which is a strength of this theses. The Swedish version has shown satisfactory reliability (159) and validity (158) for persons with arthritis. Internal consistency for both subscales used in this study, ASES-pain and ASES-other symptoms, was 0.90 (159). The pain acceptance related questionnaire (CPAQ) is commonly used in persons with chronic pain, but only a few studies have used this instrument with respect to arthritis (113,162,163). Therefore, it is necessary that future studies use CPAQ when studying persons with RA-related pain. Furthermore, the CPAQ did not measure barriers to pain acceptance, such as lack of support and acceptance of others (115), nor did it consider the role of other environmental factors. Hence, there could be models other than those presented in this thesis that better represent this issue.

Using a mailed questionnaire (Papers III and IV) could be an invalid source of data, as only 58% of the target population completed the questionnaire. The response rate is comparable, or even somewhat higher, depending on the mode of administration, to other RA surveys (205). However, these participants had experience completing questionnaires, given the standard procedures at the clinics, and the patient research partner was involved in the design and selection of questionnaires. Hence, this procedure should not have affected the validity of these studies. Furthermore, a pilot study reported no difficulties with respect to participants understanding or completing the questionnaire.

Pain intensity was measured using a VAS (i.e., a linear scale measurement) in order to compare results with other studies. Previous research used the same cut-off value for high pain intensity (high pain >40 mm) (59,164,165), but there are no established distinctions between pain levels. Perhaps this cut-off for high pain could be lower with respect
to changing demands on the ability to participate in society. In these papers, the VAS means for pain were 26.4 mm for the TIRA-2 cohort (three years after diagnosis) (Paper I), 35.6 mm for the TIRA-1 cohort (Paper I), and 37 mm in Papers III and IV. All these mean values were below the cut-off. The use of only one or some of the subscales in the SF-36 is possible and the use of the subscale bodily pain is common (71). Given that there is no consensus on whether pain is normally distributed, descriptive statistics included mean values, and SDs were complemented with median and IQR (Interquartile Range) values for the analyses in Paper I and Paper III. However, these values were not reported because there were no differences in the results between non-parametric and parametric analyses. Corrections of critical alpha values to prevent type I error at multiple analyses have been made (Paper I), which, in turn, may increase the risk of type II errors. However, the risk of type II errors in the studies must be considered low given the large sample sizes. Based on the smallest sample (66 men with high pain in Paper III), a critical $\alpha$-value of 0.05, and a $1-\beta$ of 0.2 (i.e., a power of 80%), a standardized difference (Cohen’s $d$) of 0.5 or larger was possible to detect. A Cohen’s $d$ of that magnitude is considered to be a medium size, which suggests that all other tests were able to detect even smaller differences between groups. The choice of statistical tests (Table 1) were based on the assumption of normal distribution, which was checked using Kolmogorov Smirnov tests, identifying adequate distribution to carry out these tests (201,206). Alternative statistical methods could have been used, such as in Paper I, where t-tests have been used previously in the corresponding cohort studies (1,5). The repeated ANOVA also shows the changes over the time period, in this case from time for diagnosis and during the three years thereafter. In Paper IV the mediation effect could have been done with multiple regression, however the SEM modeling is based on multiple regression and factor analysis, but also a graphical model is used in the analysis which facilitates understanding of the analysis (167).

Pain in RA is a relatively unexplored area from a patient perspective. Therefore, focus group discussions were used to gather information, focusing on pain related to daily activities, and to respond to the study’s research questions (169). Through focus group discussions, it was
possible to broadly describe and catch various aspects of how pain affects daily activities (144,170). Pain intensity >40 mm as reported by VAS was used as an inclusion criterion in focus group discussions (Study II). This high cut-off meant that descriptions were missed that reflected how lower levels of pain affect participation in valued activities. The groups were divided based on age and gender to create a more comfortable environment for participants to share their experiences (144), but this segregation may have led to limitations in the discussions. To increase dependability, an interview guide was used. The content of the interview guide was developed based on previous knowledge about living with long-term pain. Independent experts of the method as well as people with experience of living with RA and pain commented on the interview guide. As a member-check (9), at the end of every focus group the assistant moderator summarised the discussions and provided an opportunity for the participants to add or adjust the information gathered.

To be credible, a focus group researcher has to have a broad perspective and be open to new interpretations when analysing focus-group discussions (147). Another important issue for credibility is to select the most suitable meaning unit (169). Meaning units focusing only on pain and activity were selected, and the information describing the disease in general was left out. The discussions were lively and it was sometimes difficult for the respondents to separate pain from general disease factors that affect daily activities, which obviously may have affected results. Throughout the analysis, it was necessary to keep the research question in mind and to go back to the data to check the dependability of the categories to secure consistency between data and findings (170). The first author did the first steps in these analyses. Later, other members of the research group checked the categories to increase dependability. Persons who were familiar with the study and content analysis reviewed the codes and categories to ensure that they were consistent with the content of the transcribed verbatim (169). The confirmability of the Paper II was strengthened by external audit of the focus groups' questions. This audit was done with assistance from the research partner from the Swedish Rheumatism Association Patient Participation in Research. This partner also reviewed the findings and confirmed the
identified categories. There is a possible bias when working with a research partner that the observations were solely based on their own experiences. The research partner, however, was an experienced researcher and had completed a training course. In Paper II, the analysis was substantially manifest and lead to identifying categories and subcategories (169). No overarching themes emerged through the analysis. The credibility was further strengthened using quotations from the focus groups.
Conclusions

- Pain was identified as related to participation restrictions and had an important relationship to difficulties performing valued life activities. Pain and participation in valued activities needs to be comprehensively analysed and treated in the context of the person's perspective and needs and demands of persons with RA.
- As pain was related to fatigue, stress, and mood, the complexity of pain and its relation to participation in daily activities need to be emphasised.
- Activities were used as distractions of pain, which means that management strategies for pain relief can be used based on participation in activities selected as important by the person.
- Even among persons with lower levels of pain, the ability to participate in valued life activities was affected, which highlights the importance of addressing pain, since pain may impact on the possibility to participate in important activities.
- Some gender differences were found. Women reported more pain and difficulties performing valued life activities than men. There were differences in which activities were valued and in which activities women and men reported participation restrictions, findings that further demonstrate the importance of person-centred rehabilitation interventions.
- Personal factors influence the relationship between pain and participation which supports the value of person-centered interventions, to facilitate participation in the activities of persons with RA perceive as important to them.
- Personal factors, in this case self-efficacy and pain acceptance, work as mediators between pain and participation in valued activities and are important to take into account when planning of interventions.
- The findings in the thesis demonstrates a continued need for multidisciplinary rehabilitation interventions despite advances in treatment.
Clinical and research implications

Clinical implications of the findings in this thesis:

The extent of pain and participation restriction in valued activities in early RA, despite early interventions, implies that multidisciplinary rehabilitation is still needed.

The VLA questionnaire is appropriate for problem solving and intervention planning in rheumatologic rehabilitation and research, as it includes personal preferences regarding valued activities as well as traditional rating of difficulties performing activities.

The findings indicate that pain and participation restrictions need to be treated with an awareness of personal factors. A person-centred approach improves the identification of individual needs and demands in rheumatologic rehabilitation.

Self-management and activity-based methods can be used in rheumatologic rehabilitation to strengthen personal factors and thereby facilitate participation, distract pain, support balance in daily activities, and enhance pain relief.

The use of the theoretical framework and terminology found in the ICF improves the ability to identify disabilities, measure outcomes, and describe rehabilitation in rheumatology.
Implications for further research of the findings in this thesis:

There is need to study the personal factors in persons with RA and still remaining pain. In addition, it is important to identify these individuals soon after diagnosis to prevent later participation restrictions.

Outcomes for participation relevant for persons with RA treated with current treatment strategies need to be developed that complement established outcome measures. VLA-swe was shown to capture participation restrictions. Further research with this tool is needed to determine its reliability.

In addition, there is a need to study the personal factors from a broader perspective (not just CPAQ and ASES) and their impact on the relationship of pain and activity.

Further research should examine possible differences between genders, and their significant for rehabilitation strategies. Further research is also needed to describe occupational balance in persons with current treated RA and explore factors associated with good occupational balance.

Management strategies based on self-efficacy and pain acceptance appropriate for persons with RA need to be developed and evaluated in collaboration with clinics and researchers (i.e., RCT) to generate better evidence.

This thesis used ICF as framework and explored and described pain, participation, and personal factors in persons with RA, but further studies are needed to explore the relationship between components in the ICF.
Svensk sammanfattning

Smärta och dess relation till delaktighet i viktiga aktiviteter för personer med reumatoid artrit

Under de senaste 20 åren har behandlingsresultaten vid Reumatoid Artrit (RA) förbättrats avsevärt som en följd av tidig diagnos, strukturerat omhändertagande och tidigt insatta sjukdomsmodifierande läkemedel (Disease Modyfying Anti Rheumatic Drugs=DMARD) samt tillgång till nya biologiska läkemedel. De förbättrade behandlingsresultaten innefattar såväl minskad sjukdomsaktivitet som minskade funktionshinder men också upplevda ökade krav på att kunna arbeta och vara delaktig i samhället. Trots dagens rutiner med tidiga insatser för personer med RA rapporterar många personer med RA fortfarande omfattande funktionshinder som smärta och svårigheter i de aktiviteter som värderas som viktiga att kunna utföra.

Att vara involverad i viktiga aktiviteter ger välbefinnande och möjlighet till engagemang och delaktighet. Personer med RA har lyft fram smärta som ett av de mest begränsande symtomen vid RA. Då smärtan ofta varierar över tid och beskrivs som oförutsägbar ställs det stora krav på personer med RA att hantera smärta för att kunna vara delaktiga. Ökad kunskap om hur smärta är relaterad till delaktighet i viktiga aktiviteter är betydelsefullt för att utveckla hanteringsstrategier för smärta med målet att öka delaktigheten hos personer med RA. I denna avhandling användes International Classification of Functioning, Disability and Health (ICF), som en begreppsmodell för beskrivning av funktionshinder och med speciellt fokus på hur delaktighet är relaterat till smärta.
Syfte

Det övergripande syftet med avhandlingen var att utforska och beskriva relationen mellan smärta och delaktighet i viktiga aktiviteter vid RA. Syftet i den första studien (Paper I) var att beskriva smärta och aktivitetsbegränsningar under de tre första åren efter diagnos bland en grupp kvinnor och män med RA omhändertagna med dagens behandlingsstrategier, jämfört med motsvarande grupp personer med RA som diagnostiserades 10 år tidigare. I den andra studien (Paper II) var syftet att beskriva upplevelser av smärta och dess relation till dagliga aktiviteter hos personer med RA. I den tredje studien (Paper III) undersöktes svårigheter att utföra viktiga aktiviteter i relation till smärtintensitet. I den fjärde studien (Paper IV) beskrivs personliga faktorer (enligt ICF), representerat av self-efficacy och smärtacceptans. I fjärde artikeln studerades även om personliga faktorer fungerar som mediatörer (medlare) i relationen mellan smärta och delaktighet i viktiga aktiviteter.

Metod

Olika metodologiska tillvägagångssätt användes för att ge en övergripande förståelse för smärta och delaktighet i viktiga aktiviteter för personer med RA. En prospektiv kohortstudie där kvinnor och män med RA, omhändertagna med dagens behandlingsstrategier (n = 276), jämfördes med motsvarande grupp personer med RA som diagnostiserades 10 år tidigare (n = 373) (Paper I), följdes av en fokusgruppsstudie där sammanlagt 33 personer med RA deltog i totalt sju fokusgrupper (Paper II). Tredje och fjärde artiklarna (Paper III och IV) genomfördes baserat på data från Svensk Reumatologis Kvalitetsregister (SRQ), i kombination med data från en utskickad enkät om sociodemografska data, smärta, personliga faktorer och delaktighet i viktiga livsaktiviteter. Enkäten besvarades av 737 personer med RA (svarsfrekvens 58 %). Beskrivande och analyserande statistik med multikel regression och strukturell ekvationsmodellering (SEM) användes i artikel I, III och IV. I artikel II användes innehållsanalys.
Alla studier genomfördes i enlighet med Helsingforsdeklarationen samt Vetenskapsrådets riktlinjer för etisk värdering av medicinsk humanforskning. Samtliga studier har godkänts av Regionala etikprövningsnämnden i Linköping.

**Resultat**

Studie I visade att dagens personer med RA rapporterar betydligt lägre smärta och aktivitetsbegränsningar än personer som diagnostiserats tio år tidigare. Även om de senaste framstegen inom reumatologin, med utveckling av strukturerat omhändertagande och behandlingsstrategier minskat funktionshindren så var såväl smärta som aktivitetsbegränsningar fortfarande uttalade bland kvinnor och män med RA. Kvinnor rapporterade genomgående mer smärta och mer aktivitetsbegränsningar än män.


Studie III visade att 85 % av personer med RA har minst en delaktighetsinskränkning i viktiga livsaktiviteter. Svårigheterna var mer uttalade hos kvinnor jämfört med hos män. Smärta var starkt relaterat till svårigheter att utföra viktiga aktiviteter. Studie IV visade att personliga faktorer, representerat av "self-efficacy" och smärtacceptans, är relaterade till delaktighet i viktiga livsaktiviteter hos såväl män och kvinnor med RA. Dessa personliga faktorer visade även på en medierande effekt i relationen mellan smärta och delaktighet i viktiga livsaktiviteter.
Avhandlingens slutsatser

- Smärta identifierades att ha en betydelsefull relation till svårigheter att utföra viktiga aktiviteter för personer med RA. Smärta och delaktighet i viktiga aktiviteter behöver analyseras och behandlas omsorgsfullt inom ramen för den unika personens behov och önskemål.
- Smärta var relaterad till trötthet, stress och sinnesstämning. Detta indikerar behovet av att i kliniskt arbete uppmärksamma komplexiteten av smärta och dess relation till delaktighet i viktiga livsaktiviteter.
- Aktiviteter användes som distraktion av smärta, vilket innebär att hanteringsstrategier för smärtlindring kan baseras på aktiviteter som valts ut som viktiga av personen.
- Smärta vid RA är komplex och ett angeläget område att ta hänsyn till, eftersom även låga nivåer av smärta påverkar vardagen och kan vara ett hinder för att utföra viktiga aktiviteter.
- Personliga faktorer inverkar på relationen mellan smärta och delaktighet vilket stödjer värdet av personcentrerade insatser, för att möjliggöra delaktighet i de aktiviteter som personer med RA uppfattar som viktiga för dem.
- Personliga faktorer, i det här fallet self-efficacy och smärtacceptans, fungerar som medlare i relationen mellan smärta och delaktighet i viktiga aktiviteter och bör tas hänsyn till i planeringen av rehabiliteringsinsatser.
- Resultaten i avhandlingen visar ett fortsatt behov av multidisciplinära rehabiliteringsinsatser trots nuvarande omhändertagande och behandlingsstrategier.
**Kliniska tillämpningar av avhandlingens resultat**

Omfattningen av smärta och delaktighetsinskränkningar i viktiga aktiviteter hos män och kvinnor med RA som erhållit dagens moderna behandlingsstrategier, understryker att det fortfarande behövs multidisciplinär rehabilitering.

Frågeformuläret VLA, som innehåller personens preferenser gällande identifiering av viktiga livsaktiviteter, är användbart för att inkludera den unika individens perspektiv vid bedömning och behandling inom reumatologisk rehabilitering och även vid forskning.

Resultaten tyder på att smärta och delaktighetsbegränsningar bör behandlas med en medvetenhet om personliga faktorer för att uppnå ett optimalt resultat. En personcentrerad strategi förbättrar processen vid identifiering av individuella behov och krav i reumatologisk rehabilitering.

Utveckling av hanteringsstrategier för smärta och aktivitetsbaserade metoder bör användas i reumatologisk rehabilitering i syfte att stärka personliga faktorer och därigenom underlätta delaktighet, distrahera smärta, stödja balans i dagliga aktiviteter och förbättra smärtlindring.

Användning av den teoretiska ramen och begrepp i ICF stödjer tydlighet i kommunikation om funktionshinder, inklusive hur delaktighet är relaterat till smärta vid rehabilitering i reumatologi.
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87


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