FROM THE DEPARTMENT OF CLINICAL SCIENCE
AND EDUCATION, SÖDERSJUKHUSET
Karolinska Institutet,
Stockholm, Sweden
and
Sophiahemmet University
Stockholm, Sweden

PAIN, FATIGUE AND FEAR-AVOIDANCE BELIEFS IN RELATION TO PHYSICAL ACTIVITY AND BODY AWARENESS IN PERSONS DIAGNOSED WITH RHEUMATOID ARTHRITIS

Helena Lööf

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Av
Helena Lööf
Leg. sjuksköterska

Huvudhandledare:
Professor Unn-Britt Johansson
Sophiahemmet Högskola
och Karolinska Institutet,
Institutionen för klinisk forskning och utbildning,
Södersjukhuset

Bihandledare:
Docent Elisabet Welin Henriksson
Karolinska Institutet,
Institutionen för neurobiologi, vårdvetenskap och samhälle,
Sektionen för omvårdnad

Professor Staffan Lindblad
Karolinska Institutet,
Institutionen för lärande, informatik, management och etik,
Medical Management Centrum

Fakultetsopponent:
Professor Siv Söderberg
Mittuniversitetet, Campus Östersund,
Institutionen för Folkhälsovetenskap
Sektionen för omvårdnad

Betygsnämnd:
Professor Barbro Arvidsson
Högskolan Halmstad,
Sektionen för hälsa och samhälle

Docent Mari Lundberg
Göteborgs Universitet,
Avdelningen för ortopedi,
Lundberglaboratoriet för ortopedisk forskning

Professor Per Wretenberg
Karolinska Institutet,
Institutionen för molekylär medicin
och kirurgi,
Sektionen för Ortopedi

Stockholm 2015

My lovely children♡

"The whole world is a series of miracles. But we are so used to them, we call them ordinary things."

(Hans Christian Andersen)

“Yes, one week ago I was enjoying my life. I stayed up and watched the midnight sun. In X city, I went up to the mountains and stood there looking, fascinated by the view of the mountains, at sunset at twelve o'clock at night. So, this is something that enhances life a bit. That, despite everything, you do get there, that you've seen it! That one has experienced this! Then I thought afterwards that during this time I didn’t think at all about my ailments. One doesn’t think about that then. So, that was a past experience that was exceptional in my mind.”

(Participant, Study IV).

ABSTRACT

Introduction: Pain and fatigue are highly common and a major concern for persons diagnosed with rheumatoid arthritis (RA). Having physical limitations, which have a significant effect on daily life, is also described as a major problem for persons with RA. Research findings show that a minority of persons with RA perform maintained health-enhancing physical activity (HEPA), and that psychosocial factors seem to be the most salient and consistent factors to explain variations in HEPA. Furthermore, fear of physical activity and exercise has been described as major barriers for persons with chronic pain. The ability to notice bodily inner sensations and stimuli (body awareness, BA) is described in the literature as having either a positive or a negative impact on a person's health and well-being. However, the concept of BA is complex and therefore greater insight into this phenomenon is needed. **Aim:** The overall aim of this thesis was to investigate pain, fatigue and fear-avoidance beliefs in relation to physical activity and their correlates in persons with RA. A further overall aim was to develop a psychometric measurement of BA. A final overall aim was to deepen our understanding of BA in persons with RA. **Methods:** Study I was a psychometric evaluation of a Swedish version of the Body Awareness Questionnaire (BAQ) in a student population and in adults with RA. Studies II - III were a cross-sectional survey studies in adults with RA. Study IV was a phenomenological study using the empirical phenomenological psychological (EPP) method in adults with RA. **Results:** In study I, the value of Cronbach's alpha coefficients for the total score in the Swedish version of the BAQ was satisfactory. According to confirmatory factor analysis (CFA), neither a one-factor model nor a four-factor model tested in this study fulfilled the pre-specified criteria. In study II, pain was significantly associated with health-related quality of life (HRQoL) and disease activity. Fatigue was significantly associated with disease activity, BA and positive affect. The adjusted R^2 was 28.6% for fatigue and 50.0% for pain. Study III showed that, for socio-demographic factors, being male and having a below average income were associated with an increased risk of high fear-avoidance beliefs about physical activity (mFABQ high). Moreover, the two disease-specific factors, which are most indicative of mFABQ high, were high level of pain and poor health. Concerning psychosocial factors, low HRQoL and low exercise self-efficacy were significantly associated with mFABQ high. The model fit was 0.27 (Nagelkerkés R^2). In study IV, some general characteristics were found, which had to do with the disease giving rise to a higher degree of negatively toned BA. BA was a reactive process of searching or controlling for disease-related symptoms, or a reactive process that was triggered by emotions. In addition, BA was an active process in the sense of taking an inventory of abilities. All the participants had the ability to shift focus from BA to the outside world. **Conclusions:** This thesis showed that pain, fatigue and fear-avoidance beliefs about physical activity in persons with RA have several potential correlates, including socio-demographic, disease-specific and psychosocial factors for the variables investigated. The Swedish version of the BAQ is simple to administer and should be used as a tool to measure self-reported attentiveness to normal body processes. Cronbach's alpha coefficient for the total score was satisfactory; nevertheless, since neither of the models fulfilled the pre-specified criteria further testing of the Swedish version of the BAQ is required. BA was found to be both positively and negatively toned in persons with RA, though RA resulted in a higher degree of negatively toned BA. Thus, the ability to shift attention, from BA to activities in the outside world, could sometimes be beneficial for the person's general health and well-being. Having the opportunity to participate in meaningful and purposeful daily real-world activities keeps the mind busy (and distracted) and can decrease the negative BA.

Keywords: Rheumatoid Arthritis, Body Awareness, Pain, Fatigue, Fear-avoidance beliefs about physical activity, Physical activity, Coping strategies, Cross-cultural adaptation, Concurrent think-aloud interviews, Narrative interviews, Phenomenological, Cross-sectional, Psychometrics.

LIST OF SCIENTIFIC PUBLICATIONS

I. **Lööf, H.,** Johansson, U.-B., Welin Henriksson, E., Lindblad, S., & Saboonchi, F. (2013). Development and psychometric testing of the Swedish version of the Body Awareness Questionnaire. *Journal of Advanced Nursing, 69*(7), 1643-1651. doi: 10.1111/jan.12020

II. **Lööf, H.,** Johansson, U.-B., Welin Henriksson, E., Lindblad, S., & Saboonchi, F. (2013). Pain and fatigue in adult patients with rheumatoid arthritis: Association with body awareness, demographic, disease-related, emotional and psychosocial factors. *Open Journal of Nursing*, *3*(2), 293-300. doi: 10.4236/ojn.2013.32040

III. **Lööf, H.,** Demmelmaier, I., Welin Henriksson, E., Lindblad, S., Nordgren, B., Opava, H.C., & Johansson, U.-B. (2015). Fear-avoidance beliefs about physical activity in adults with rheumatoid arthritis. *Scandinavian Journal of Rheumatology, 44*(2), 93-99. doi:10. 3109/ 03009742.2014.932432

IV. **Lööf, H.,** Johansson, U.-B., Welin Henriksson, E., Lindblad, S., & Bullington, J. (2014). Body awareness in persons diagnosed with rheumatoid arthritis. *International Journal of Qualitative Studies on Health and Well-being, 31;9*: 24670. doi: 10.3402/qhw.v9.24670

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CONTENTS

LIST OF ABBREVIATIONS

ANOVA	Analysis of variance
BA	Body awareness
BAQ	Body awareness questionnaire
CBT	Cognitive-behavioral therapy
CFA	Confirmatory factor analysis
CFI	Comparative fit index
CFS	Chronic fatigue syndrome
CST	Cognitive-behavioral coping skills training
DAS	Disease activity score
EPP method	Empirical phenomenological psychological method
ESE	Exercise self-efficacy
EULAR	European League Against Rheumatism
FM	Fibromyalgia
HEPA	Health-enhancing physical activity
IASP	International Association for the Study of Pain
mFABQ	modified Fear-avoidance beliefs about physical activity questionnaire
NA	Negative affect
PA	Positive affect
PCC	Person-centered care
QoL	Quality of life
RA	Rheumatoid arthritis
RMSEA	Root mean square of approximation
SBU	Swedish Council on Health Technology Assessment
SRMR	Standardized root mean squared residual

INTRODUCTION

Within health care activities, the Swedish Code of Statutes (2014:821) aim to strengthen and clarify the status of patients and to promote patient privacy, self-determination and participation. In quality terms, health care should be patient-focused and knowledge-based (Swedish Code of Statutes, 2014:821). Health care professionals are responsible for promoting health and preventing illness, restoring health, relieving suffering and restoring dignity. For health care professionals to meet these responsibilities, it is essential to adopt a humanistic and holistic perspective (International Council of Nurses, 2012).

RA is an autoimmune disease characterized by joint pain, swelling, tenderness and deformity. RA occurs when your immune system mistakenly attacks your own body's tissues (Frostegård, 2012). Untreated RA leads to destruction and loss of function in bone, cartilage, muscle and other tissues, but it can also include vital organs such as the kidneys and heart (Hochberg, Silman, Smolen, Weinblatt & Weisman, 2011). Persons with RA report moderate to severe pain (Taylor et al., 2010) and both fatigue and pain are a major concern in persons with RA (Carr et al., 2003; Heiberg, Finset, Uhlig & Kvien, 2005; Hewlett et al., 2005; Lee et al., 2014; Verstappen, 2013). Studies have found that significant fatigue occurs in up to 70% of persons with RA and that fatigue is a complex emotion to cope with (Hewlett et al., 2005). Pain and fatigue generally occur early in the course of RA. Reduction of body function, muscle strength and aerobic capacity may follow (van den Ende, Vliet Vlieland, Munneke & Hazes, 1998). Although aggressive treatment strategies exist today, persons with RA (and clinicans) continue to report pain, fatigue and loss of function as major problems associated with the disease (Lee et al., 2014; Taylor et al., 2010; Verstappen, 2013; Walsh & McWilliam, 2014). Lee et al. (2014) found that persons with RA and with minimal signs of inflammation still had high levels of pain catastrophizing and fatigue. Furthermore, Verstappen (2013) reported that a relatively high proportion of persons with RA take sick leave or become work-disabled, and that this appears to happen within the first few years of the RA disease. Persons with RA often experience diminished HRQoL (Nas et al., 2011), anxiety (Dirik & Karanci, 2010) and depression (Matcham, Rayner, Steer & Hotopf, 2013). In a review, the categories helplessness and avoidance were found to be prognostically associated with increased general psychological distress in persons with RA (Vriezekolk, van Lankveld, Geenen & van den Ende, 2011). A meta-analysis showed that persons with RA have an overall reduced HRQoL in comparison with persons with other physical illnesses (Matcham et al., 2014).

Some evidence (reviews and meta-analysis) suggests that properly designed exercise can reduce pain and fatigue. Physical activity and exercise can also improve the psychological well-being and QoL in persons with RA (Baillet et al., 2010; Cooney et al., 2011). Cooney et al. (2011) i.e. aimed to demonstrate the multitude of beneficial effects, that properly designed exercise training has in persons with RA. Cooney et al. (2011) moreover conclude that exercise can reduce morning stiffness, improve functional ability and that properly designed exercise has not been shown to exacerbate RA disease activity (Cooney et al., 2011). A higher level of self-reported physical activity and exercise in persons with RA is associated with a lower level of arterial dysfunction, independent of other cardiovascular events and rheumatologic factors (Crilly & Wallace, 2013). Research has shown, however, that a minority of persons with RA perform HEPA (Demmelmaier, Bergman, Nordgren, Jensen & Opava, 2013). Psychosocial factors seem to be the most salient and consistent factors to explain HEPA variation (Demmelmaier et al., 2013).

Research findings have shown the advantages of the ability to notice subtile bodily sensations and that such awareness (BA) may be useful in the management of various chronic diseases (Mehling et al., 2009), such as congestive heart failure (Baas, Berry, Allen, Wizer & Wagoner, 2004), chronic renal failure (Christensen, Wiebe, Edwards, Micheles & Lawton, 1996) and chronic lower back pain (Mehling, Hamel, Acree, Byl & Hecht, 2005). BA involves attentional focus on and awareness of internal bodily sensations (Cioffi, 1991). However, a growing body of literature suggests that BA could have either a positive or a negative impact on a person's health and well-being. The concept of BA is complex and greater understanding is needed about the phenomenon (Mehling et al., 2009). There still exists today little knowledge about the meaning of the concept of BA in persons with RA. Because studies have not focused specifically on BA in persons with RA, there is a need to explore this phenomenon.

The overall aim of this thesis was to investigate pain, fatigue and fear-avoidance beliefs in relation to physical activity and their correlates in persons with RA. A further overall aim was to develop a psychometric measurement of BA. A final overall aim was to deepen our understanding of BA in persons with RA.

BACKGROUND

Theoretical framework

At the beginning of 2009, at the starting point of this doctoral thesis, the biopsychosocial model was chosen as the framework. However, when writing this thesis, I have also found value in the framework of person-centered care (PCC) as described by Ekman et al. (2011).

The biopsychosocial model

In concordance with a humanistic and holistic perspective, is the biopsychosocial model (Engel, 1977) and the overarching theoretical framework chosen for this thesis. Engel (1977) believed that to understand and respond adequately to patients' suffering and to give them a sense of being understood, clinicians must follow a holistic perspective.

The biopsychosocial model was developed by George Engel in 1977. Engel described the value of simultaneously looking at biological, psychological and social domains, as well as to take into account existential dimensions of illness.

Philosophically, Frankel, Quill and McDaniel (2003) express that the biopsychosocial model is a way of understanding how suffering, disease and illness are affected by multiple levels of organization. At the practical level, it is a way of understanding the patient's subjective experience. In essence, it is an essential contributor to accurate diagnosis, health outcomes and human care. Frankel et al. (2003) also felt that, to apply the biopsychosocial approach to clinical practice, it is essential that health care professionals know the patient's history in the context of life circumstances (Frankel et al., 2003).

According to a biopsychosocial approach, psychological factors are not only affected by the course of the disease but are also important for the patient's general health and well-being (Keefe et al., 2002). In this approach (Engel, 1977; Engel, 1980), health care professionals should determine which aspects of biological, psychological and social domains are the most important in relation to the person (Engel, 1977; Engel, 1980).

Person-centered care

The concept of PCC originates in psychology. During the 1960s a psychologist articulated the importance of the person's perspective and experience of his or her situation (Rogers, 1961). PCC can be described as care that strives to make visible the whole person (holistic care) from a humanistic approach (sets the person's perceptions in focus) (Ekman et al., 2011; McCormack & McCance, 2010), which concurs with the biopsychosocial model (Engel, 1977).

The PCC approach to care sets the person's views about his or her life situation and condition at the center of care (Ekman et al., 2011; McCormack & McCance, 2010). In a PCC approach, the patient narrative constitutes the starting point, and lays the foundation for a partnership in care (Ekman et al., 2011).

The patient narrative is the sick person's personal account of his or her illness, symptoms and their impact on his or her life (Ekman et al., 2011). The PCC approach prioritizes spiritual, existential, social and psychological needs to the same extent as physical needs (McCormack & McCance, 2010). PCC care (Ekman et al., 2011; McCormack & McCance, 2010) emphasizes that people's identity is created to some extent in the encounter with others.

Rheumatoid arthritis

Classification of rheumatic diseases is usually done in four main groups. One group consists of inflammatory joint diseases (i.e. arthritic diseases). RA is the most common arthritic disease. RA is a disease that goes way back in time and skeletal findings from Indians show that the disease existed over 3000 years ago in North America. However, the first secure clinical finding from Europe dates from the 1800s (Klareskog, Saxne & Enman, 2011).

Epidemiology

RA is present in all populations. The disease affects all ages and both sexes. The prevalence and incidence of RA, however, are higher in women than in men (overall RA is 2-3 times more common in women). The disease increases with age and peaks at about 70-79 years and then declines (for both women and men) (Eriksson et al., 2013; Symmons, 2002). Older age and being female are considered risk factors for the development of RA, as well as for a less favorable outcome (Symmons, 2002). In addition, the association between high socioeconomic status and lower risk of RA has been reported (Bengtsson et al., 2005).

The incidence and prevalence of RA appear to have fallen in Europe, North America and Japan in the past 50 years. The prevalence of RA in most industrialized countries varies between 0.3 and 1% (Symmons, Mathers & Pfleger, 2000). Scandinavia has a prevalence of 0.7% (Klareskog et al., 2011). Eriksson et al. (2013) found that the overall incidence in Sweden was 41 per 100 000 (56 for women, 25 for men). Furthermore, the age- and sex-standardized incidences were lower in densely populated areas and in individuals with a high educational level (Eriksson et al., 2013). The highest incidence has been seen in some North American Indian groups, with up to 5%. The explanation for these differences is the presence of various risk genes (HLA genes), although environmental and lifestyle factors are also involved (Klareskog et al., 2011).

Etiology and pathogenesis

The causes of RA are not fully known and over the years a number of hypotheses have been offered. A strong hypothesis is that RA is due to autoimmunity, i.e. the immune system attacks its own tissues (Frostegård, 2012). The etiology of RA is a mixture of genetic and environmental factors. Genetic predisposition to develop RA is estimated to be as much as 50% (Klareskog, Catrina & Paget, 2009). Smoking, in combination with different gene variants, especially HLA, leads to higher disease risk (Klareskog et al., 2009). Multiple risk factors are occupational related (e.g., working with asphalt and asbestos) (Klareskog et al., 2011). Risk factors for the development of RA also include adverse pregnancy outcome, obesity, recent infections, autoimmune states, psychological stress and hormone interactions (Hochberg et al., 2011; Klareskog et al., 2011).

The disease can present with systemic manifestations, including subcutaneous nodules, pleuritis, pericarditis and vasculitis, which contribute to morbidity and mortality (Turesson, O´Fallon, Crowson, Gabriel & Matteson, 2003). Most persons with RA also suffer from an accelerated loss of muscle mass (known as rheumatoid cachexia). Particularly, the amount of fat and lean mass located in the arms and legs is strongly associated with disability in persons with RA (Giles, Bartlett, Andersen, Fontaine & Bathon, 2008). Persons with RA have an increased risk of premature death, which is due to cardiovascular disease, possibly related to inflammation (Akrout et al., 2012) and other factors (Pereira & Borba, 2008). In an overview, Puttevils, De Vuuser, Geusens and Dens (2014) found that persons with established RA have a higher cardiovascular morbidity and mortality in comparison with the general population. It is considered to be an independent risk factor for cardiovascular disease (Puttevils et al., 2014). Moreover, Sandberg et al. (2014) has shown that persons with regular physical activity before onset of RA seem to present with milder RA disease.

Classification criteria for RA

In this thesis, the following diagnostic criteria were chosen according to Arnett et al. (1987). Diagnosis is established based on careful investigation that includes medical history, x-ray examinations, general physical examination and different blood tests. The following criteria should be investigated for diagnosis of RA: morning stiffness lasting more than an hour, arthritis in more than three joints, the hands joints and finger joints are affected, the presence of rheumatoid factor (RF), rheumatic nodules and symmetric distribution of symptoms and skeletal changes seen in an X-ray (Arnett et al., 1987). See table 1.

Table 1. Criteria (developed by the ACR 1987) to diagnose RA. (MCP=Metacarpophalangeal joints, MTP = Metatarsophalangeal joints and PIP=Proximal interphalangeal joints.)

At least four of these seven criteria must be present to confirm a diagnosis of RA. Symptoms of criteria (1, 4) must have been present for at least six weeks.

1) Morning stiffness
In and around the joints with a minimum of one hour duration before they are pain-relieved.

2) Arthritis in at least three groups of joints
The patient must have had soft tissue swelling or fluid observed by doctors. The possible areas are the hands PIP, MCP, elbow, knee, ankle and MTP joints.

3) Arthritis of hand joints
Swelling of at least one area (as defined above) in wrist, MCP or PIP joints.

4) Symmetric arthritis
Involvement of areas (as defined in criterion 2) on both sides of the body (bilateral involvement of PIP, MCP or MTP joints, point accepted without absolute symmetry).

5) Rheumatic nodules
Subcutaneous nodules observed by a physician.

6) Rheumatoid factor
Blood tests.

7) Radiographic change
X-ray examinations.

However, since 2010, classification criteria for RA are developed by Aletaha et al. (2010). These classification criteria for RA (Aletaha et al., 2010) are based on the confirmed presence of synovitis in at least one joint, and absence of an alternative diagnosis (better explaining the synovitis). Classification is based on achievement of a total score of 6 or greater (of possible 10) from the individual scores, in the four domains;

- Number and site of involved joints (range 0-5)
- Serological abnormality (range 0-3)
- Elevated acute-phase response (range 0-1)
- Symptom duration (two levels; range 0-1) (Aletaha et al., 2010).

Clinical manifestations

In some cases, the course of RA is short and limited, but RA is usually a progressive disease. Arthritis typically begins in the small joints of the hands and feet that subsequently spreads to the larger joints, causing joint deformity and progressive physical disability. Symmetrical inflammatory polyarthritis is the primary clinical manifestation. A classic symptom of RA is morning stiffness that usually lasts for more than an hour. Symptoms can also include feeling generally unwell with low grade fever and weight loss (Hochberg et al., 2011; Klareskog et al., 2011). Persons with RA exhibit reduced joint flexibility, muscle function, and aerobic fitness early in the course of the RA disease (Eurenius et al., 2005). The disease is manifested by periods of flare-ups in disease activity. The varied disease progression makes it most difficult to establish individual prognoses (Hochberg et al., 2011; Klareskog et al., 2011).

Treatments

In most untreated cases, RA is likely to have an unfavorable outcome with joint deterioration and functional disability (Turesson et al., 2003). However, even though aggressive pharmacotherapy treatment strategies are currently available, persons with RA continue to experience pain, fatigue and loss of function (Lee et al., 2014; Verstappen, 2013; Walsh & McWilliam, 2014). A relatively high proportion of persons are forced to take sick leave or become work disabled already within the first few years of the disease (Verstappen, 2013). Many persons still perceive high levels of sleep disturbances in relation to pain problems (Lee et al., 2014).

According to Leirisalo-Repo (2013), treatment of RA must be started early, i.e. six months or less after onset of symptoms. Treatment goals are to reduce mortality, relieve/reduce suffering and prevent loss of function (Baecklund, Baecklund, Forsblad & Turesson, 2013; The National Board of Health and Welfare, 2012). Patients should be given personalized information about their health status, as well as information about available investigations and treatments (Scott, Wolfe & Huizinga, 2010).

In consultation with the patient, a primary objective is to rapidly slow down and gain control over the inflammatory process. This has become possible through progress in immunomodulating therapy (including biological drugs) during the past decades (Baecklund et al., 2013; van der Heijde et al., 2006).

However, pharmacotherapy may cause both trivial and serious adverse effects. It should be noted that not all patients achieve clinical remission (Askling & Dixon, 2008; Verstappen & Symmons, 2011).

The treatment includes (Scott et al., 2010) overall;

- Pharmacotherapy
- Surgery
- Rehabilitation
- Education
- Physical activity (Scott et al., 2010).

The European League Against Rheumatism [EULAR] recommendations (Van Eijk-Hustings et al., 2012) include self-management support. Nurses should promote self-management skills in order that persons with chronic inflammatory arthritis might achieve a greater; sense of control, self-efficacy and empowerment (Van Eijk-Hustings et al., 2012).

Chronic pain

The International Association for the Study of Pain (IASP) (2012) *defines pain* as an unpleasant sensory and emotional experience associated with actual or potential tissue damage. In this definition, pain is known to possess a strong emotional component (IASP, 2012). Fear, which is considered a natural response to pain, is a vital response to physical and emotional danger in a person (Swedish Council on Health Technology Assessment [SBU], 2006).

The biopsychosocial model attempts to integrate the mind and body complex (Engel, 1977; Engel, 1980) and observe chronic pain from a multifactorial perspective (SBU, 2006).

Chronic pain is described as a highly diverse and complex phenomenon. Anxiety, stress, depression and anger interact in a complex, dynamic manner in chronic pain (SBU, 2006; Turk & Monarch, 2002). Psychological factors also affect the experience and behavior of persons with chronic pain. A high degree of comorbidity has also been found between chronic pain and various psychological problems. Strong evidence indicates that depression, which often occurs simultaneously with chronic pain, is the result rather than the cause of depression (SBU, 2006). From a biosychosocial approach, Turk and Monarch (2002) describe the importance of considering biological, psychological and social components of chronic pain, and that this approach is essential if we wish to achieve better pain control (Turk & Monarch, 2002).

Kool, van Middendorp, Boeije and Geenen (2009) illustrate that persons with chronic pain believe that others do not understand their pain (Kool et al., 2009). Hadjistavropoulos et al. (2011) describe that pain communication is important, and the way that persons (eg, partners and health care providers) respond to patients sharing their pain-related thoughts (and feelings) may have significant implications for pain-related outcomes (Hadjistavropoulos et al., 2011).

Edmond and Keefe (2015) found in their review that in couples where the partner provided higher levels of validation (a process in which a listener communicates that a person's thoughts and feelings are understandable and legitimate, e.g. pain symptoms), patients were much more likely to engage in disclosure. The results showed that participants in the validation condition maintained their positive affect. Participants in the validation condition also reported a significant decrease in worry (Edmond & Keefe, 2015).

Chronic pain is often accompanied by other symptoms, including limitations and difficulties in daily living (SBU, 2006). Based on the biopsychosocial model (Engel, 1977), a multimodal rehabilitation of persons with chronic pain conditions may include various combinations of interventions: physiotherapeutic, social, educational and psychological (SBU, 2006).

Pain in RA

Persons with RA and clinicians have often reported pain as a key outcome measure in RA (Minnock, FitzGerald & Bresnihan, 2003). Persons with RA have reported moderate to severe pain (Taylor et al., 2010) that affect life in different ways (Carr et al., 2003). In reviews, Lee et al. (2014), Verstappen (2013) and Walsh and McWilliam (2014) report that persons with RA still identify pain as problematic and a major concern in their life. Furthermore, Lee et al. (2014) found that pain symptoms often persist despite minimal signs of RA inflammation. Even though aggressive treatment strategies exist today, persons with RA continue to experience pain (Lee et al., 2014; Verstappen, 2013; Walsh & McWilliam, 2014). Pain catastrophizing and sleep disturbance are suggested to be indicative of a chronic widespread pain syndrome in persons with RA (Lee et al., 2014).

Walsh and McWilliam (2014) noted that RA pain arises from multiple mechanisms. This involving RA inflammation, peripheral and central pain processing and, with disease progression, structural change within the joint. Furthermore, RA pain can vary, being; *constant or intermittent*; *localized or spread out*. The pain, that is experienced, is predominantly of a *nociceptive character* and related to the RA disease inflammatory tissue process. *Neurogenic pain* is also experienced by persons with RA. The pain is then associated with central, or peripheral, nerve damage. Another pain condition in patients with RA is a *widespread pain* throughout the body (Walsh & McWilliam, 2014).

Anderson, Forslind and Hafström (2015) aimed to compare disease characteristics over the first five years of disease in persons with RA, with disease onset in 1990s and 2000s, respectively. The results showed that persons included in the 2000s achieved higher frequency of remission at the five year follow-up, compared with those included in the 1990s (suggested to reflect the more active medical treatment). However, improvement in pain and health assesment did not differ between the two cohorts (Anderson et al., 2015).

RA pain is often associated with psychological distress and fatigue (Walsh & McWilliam, 2014) and pain in general impacts overall QoL in persons with RA (Read, McEachern & Mitchell, 2001). Pain is a dominant problem that often prevents a person with RA to participate in pleasurable activities (Ahlstrand, Björk, Thyberg, Börsbo & Falkmer, 2012). Moreover, environmental factors could be either barriers or supportive for participation in activities (Ahlstrand et al., 2012). Björk, Gerdle, Thyberg and Peolsson (2008) found that performance of daily activities is dependent on the level of pain intensity (Björk et al., 2008). Ahlstrand, Björk, Thyberg and Falkmer (2015) aimed to examine the difficulties with performing valued life activities in relation to pain intensity in women and men with RA. Women reported more pain and difficulties in performing valued life activities than men (Ahlstrand et al., 2015) and more disability in daily activity (Thyberg, Hass, Nordenskiöld, Gerdle & Skogh, 2005). Thyberg et al., (2005) conclude that their results indicate that the more pronounced activity limitations seen in women with RA, as compared with men, may be explained by lower grip force rather than sex (Thyberg et al., 2005).

Lee et al. (2014) found that persons with RA had high levels of pain catastrophizing (pain catastrophizing, see page 16) (Lee et al., 2014), pain catastrophizing plays an important role in persons with RA (Perrot, Dieudé, Pérocheau & Allanore, 2013). Depression and catastrophizing are important variables in understanding the experience of pain in persons with rheumatologic disorders. A review by Edwards, Cahalan, Mensing, Smith and Haythornthwaite (2011) found that depression and catastrophizing are consistently associated with pain severity, sensitivity to pain, poor treatment outcomes, physical disability and potentially early mortality. A variety of pathways (cognitive to behavioral to neurophysiological) seem to mediate these deleterious effects (Edwards et al., 2011). Moreover, Nicassio et al. (2012) found that pain and depression play a major role in self-reported sleep disturbances in persons with RA.

Kojima et al. (2014) found an association between alexithymia (a personality trait characterized by deficits in cognitive processing and regulation of emotions) and depression, inflammation, and pain in persons with RA. Among those without alexithymia, pain severity increased linearly with C-reactive protein (CRP) tertile levels, regardless of the presence of depression. However, no linear association between pain severity and CRP level was observed among those with alexithymia. Moreover, depressed patients with alexithymia reported severe pain, even at low CRP levels (Kojima et al., 2014).

Pain in persons with rheumatic diseases has several correlates (Edwards et al., 2011), including personality traits (Kojima et al., 2014). Increasing evidence in support of a biopsychosocial model of pain suggests that cognitive and emotional processes are crucial contributors to inter-individual differences in the perception and impact of pain. Pain, depression and catastrophizing might all be uniquely important therapeutic targets in the multimodal management of chronic pain in rheumatic diseases (Edwards et al., 2011). According to Feldthusen, Björk, Forsblad-d´Elia, Mannerkorpi and University of Gothenburg Centre for Person-Centered Care (2013) a complex relationship between pain, fatigue and mood exists.

Several correlates to pain in RA have been reported in the literature i.e.

Pain intensity: high pain intensity has been shown to be strongly related to fear-avoidance beliefs and to beliefs about relationships between pain and impairment in long-standing RA (Lundgren, Olausson, Bergström & Stenström, 2005).

Fatigue: problems associated with chronic pain in persons with RA include fatigue problems (Garip, Eser, Aktenkin & Bodur, 2011).

Sleep problems: Lee et al. (2013) showed that persons with RA have impaired conditioned pain modulation (CPM), and suggested that low CPM levels might be attributed in part to sleep disturbance.

Disturbed mood and catastrophizing: pain in RA is related to mood (including fear and depression). Anxiety and depression can enhance the perception of pain (Korkmaz et al., 2009) and pain intensity is associated with psychological distress in RA (Bai et al., 2009; Kosinski, Zhao, Dedhiya, Osterhaus & Ware, 2000). Collectively, depression and catastrophizing are critically important in understanding the experience of pain in persons with rheumatologic disorders (Edwards et al., 2011).

Disability/activity: properly designed exercise can reduce pain (Baillet et al., 2010; Cooney et al., 2011). Cardiorespiratory aerobic conditioning (in stable RA) i.e. appears to be safe, and improves some of the most important outcome measures (Baillet et al., 2010).

Disease activity: pain in RA is associated with disease activity (Garip et al., 2011).

Fatigue

Fatigue *is a subjective feeling*, and appears to be quite complex symptom (Repping-Wuts, Van Riel & van Achterberg, 2008) and thought to have several correlates (Nikolaus & van de Laar, 2011).

Fatigue has several dimensions, such as; peripheral, physical, mental, intellectual and emotional. Norheim, Jonsson and Omdal (2010) have pointed out that central fatigue is sometimes named “general fatigue”.

Central fatigue is the subjective self-reported feeling of fatigue. This is the experience persons generally report when they seek medical treatment (Berrios, 1990; Staud, 2012). Central fatigue is depicted as abnormalities in neurotransmitter pathways within the central nervous system. It often co-exists with psychological complaints (such as depression or anxiety) (Staud, 2012). *Peripheral fatigue* is an expression originally used to describe muscle fatigability, which is due to disorders of the muscle and neuromuscular junction transmission (Chaudhuri

& Behan, 2004). Neuromuscular dysfunction relates to impaired neurotransmission in peripheral nerves, defects in muscular contraction, or both (Staud, 2012).

However, fatigue is complex and difficult to describe (Rasker, 2009), and whether it is correct and appropriate to subdivide it into distinct dimensions (i.e. peripheral, physical and central/mental fatigue, etc.) is debatable. Moreover, there is no universal agreement regarding the dimensions of fatigue, which makes the phenomenon even more complex (Norheim et al., 2010).

The meaning of fatigue, from a person with chronic illness and her or his perspective, has been investigated in numerous studies. Olsson, Stafström and Söderberg (2013) i.e. investigated the meaning of fatigue in persons with Parkinson's disease. The authors described the familiar daily routines of the women, noting that these routines had changed in the sense that their bodily attachment to the world had been altered. The body served as a barrier to daily living and the person's body no longer provided access to the surrounding world (Olsson et al., 2013).

Söderberg, Lundman and Norberg (2002), in investigating the meaning of fatigue and tiredness in women with fibromyalgi (FM), found the body as a burden and an absent presence. For healthy women, however, the major theme presented was the need for recovery. The study found that healthy women reported tiredness as a natural phenomenon. However, women with FM reported fatigue as "I have a body, instead of I am my body", and that the lived body becomes urgently present as an *'it'* (Söderberg et al., 2002).

Fatigue in RA

Fatigue in persons with RA is most likely under-recognized and undertreated (Hewlett et al., 2005). Feldthusen, et al. (2013) describe that during medical consultation, fatigue was perceived as a factor not given much consideration, and the participants expressed taking responsibility for managing their fatigue symptoms themselves (Feldthusen et al., 2013).

In their overview, Stebbings and Treharne (2010) found that the persons felt that fatigue is a very negative aspect of their life. Persons with RA see fatigue as a major concern and just as troublesome as pain. Fatigue, in persons with RA, is a problem that is often unmanageable to cope with and commonly ignored by health care professionals (Minnock & Bresnihan, 2008). It has been recognized by persons with RA as the most annoying symptom (Repping-Wuts, Uitterhoeve, van Riel & van Achterberg, 2008a). Studies have found that persons with RA feel worried about their fatigue (Repping-Wuts et al., 2008a; Nikolaus, Bode, Taal & van de Laar, 2010a). Fatigue is an important cause of decreased QoL in persons with RA (Repping-Wuts et al., 2008a; Rupp, Boshuizen, Jacobi, Dinant & van den Bos, 2004).

Fatigue (supplementary to RA-related pain and depressive symptoms) appears to be a feasible and treatable target in the clinical management of RA to increase HRQoL (Rupp et al., 2004). Clinically significant fatigue is common in persons with RA (Carr et al., 2003; Hewlett et al., 2005; Repping-Wuts, van Riel & van Achterberg, 2009; Wolfe, Hawley & Wilson, 1996). The prevalence rate of fatigue in persons with RA is quite high, ranging from 42 to 80% (Repping-Wuts et al., 2009). Fatigue in persons with RA can remain stable from days to months (Repping-Wuts et al., 2008b), making daily life difficult (Stebbings, Herbison, Doyle, Treharne & Highton, 2010; Stebbings & Trehane, 2010).

Hewlett et al. (2011) reported a conceptual model for fatigue in RA. This model includes disease-related factors (i.e. physical consequences of inflammation and physical treatment), cognitive and behavioral factors (interactions between thoughts, feelings, behaviors and symptoms) and personal factors (social support and personal responsibilities). Stebbings and Treharne (2010) reported the following factors associated with fatigue in RA: disease activity, pain, disturbed mood, self-efficacy, disability, coping and sleep disturbance. However, the direction of causality between the concepts in relation to fatigue in RA is multi-causal (Dickens & Creed, 2001; Nikolaus & van De Laar, 2011; Novaes, Perez, Beraldo, Pinto, & Gianini, 2011; Stebbings &Treharne, 2010).

Feldthusen et al. (2013) aimed to investigate how persons with RA (of working age) experience and handle their fatigue in everyday life. The analyses resulted in four categories; perception of fatigue, consequences due to fatigue, communicating fatigue and strategies to handle fatigue. Fatigue caused considerable health problems for persons with RA of working age: negative emotions, imbalance in daily life due to increased need for rest, and difficulties gaining understanding (Feldthusen et al., 2013).

Several correlates to fatigue in RA have been reported in the literature i.e.

Sex: women report higher levels of fatigue than men (Nikolaus, Bode, Taal & van de Laar, 2013; Thyberg, Dahlström & Thyberg, 2009).

Sleep disturbance: fatigue in RA is related to sleep disturbance (Thyberg et al., 2009).

Chronic pain: pain in persons with RA include fatigue problems (Garip et al., 2011).

Disturbed mood and self-efficacy: associations between depression, anxiety and fatigue have been observed in persons with RA (Belza, Henke, Yelin, Epstein & Gilliss, 1993; Huyser et al., 1998; Mancuso, Rincon, Sayles & Paget, 2006). A review by Dickens and Creed (2001) demonstrated that research consistently confirms an association between fatigue, depression and RA (Dickens & Creed, 2001). Anxiety has also been linked to fatigue. It has been suggested that ongoing anxiety may be fatiguing (Stebbings & Treharne, 2010).

Social support: fatigue in RA can be worsened by inadequate (low) social support (Huyser et al., 1998).

Disability/activity: in persons with RA, a higher level of daily physical activity was associated with reduced levels of fatigue (Rongen-van Dartel et al., 2014). Moreover, fatigue is associated with increased functional disability. Some evidence suggests that fatigue can be used both as a main measure in RA and as a good predictor of physical activity (Balsamo, Diniz, dos Santos-Neto & da Mota, 2014).

Disease activity: fatigue in RA is associated with disease activity (Stebbings & Treharne, 2010). .

However, findings also indicate that fatigue in RA does not seem to be related to inflammation as measured by CRP and ESR (van Hoogmoed, Fransen, Bleiienberg & van Riel, 2010).

Positive affect and negative affect

Psychosocial risk factors have been found to be closely linked to depressive symptoms and function over time in persons with RA (Morris, Yelin, Wong & Katz, 2008). The EULAR recommendations (Van Eijk-Hustings et al., 2012) include that nurses should identify, assess and address psychosocial issues to minimise the chance of patients' anxiety and depression.

Negative affect (NA) is manifested in decreased arousal, energy and activity, as well as in the absence of positive feelings (Gross & John, 2003). *Positive affect* (PA) facilitates approach behavior (Davidson, 1993) or continued action (Carver & Scheier, 1990a), i.e. individuals engage more actively with their environment and are more willing to take part in different activities. A person with PA feels more enthusiastic, active and alert (Carver & Scheier, 1990b; Gross & John, 2003).

A threat to the person of an illness may produce an emotional response. This emotional response may increase or decrease the experience of the illness symptoms. It could also lead to the possibility; that a person experiences and concentrates on the most negative consequences of the illness (Leventhal, Nerenz & Steele, 1984).

Self-efficacy belief

According to Albert Bandura (1977, 1992, 1995), and his social cognitive theory, the *self-efficacy* is a person’s belief in his or her ability to succeed in a particular situation.

A person with a weak sense of self-efficacy, fast lose self-belief in his or her personal abilities, and therefore *avoid* challenging tasks. The person with a weak sense of self-efficacy believe that difficult situations are outside his or her capabilities (Bandura, 1977, 1992, 1995).Thus, a *strong* sense of self-efficacy belief is important (See figure 1.)

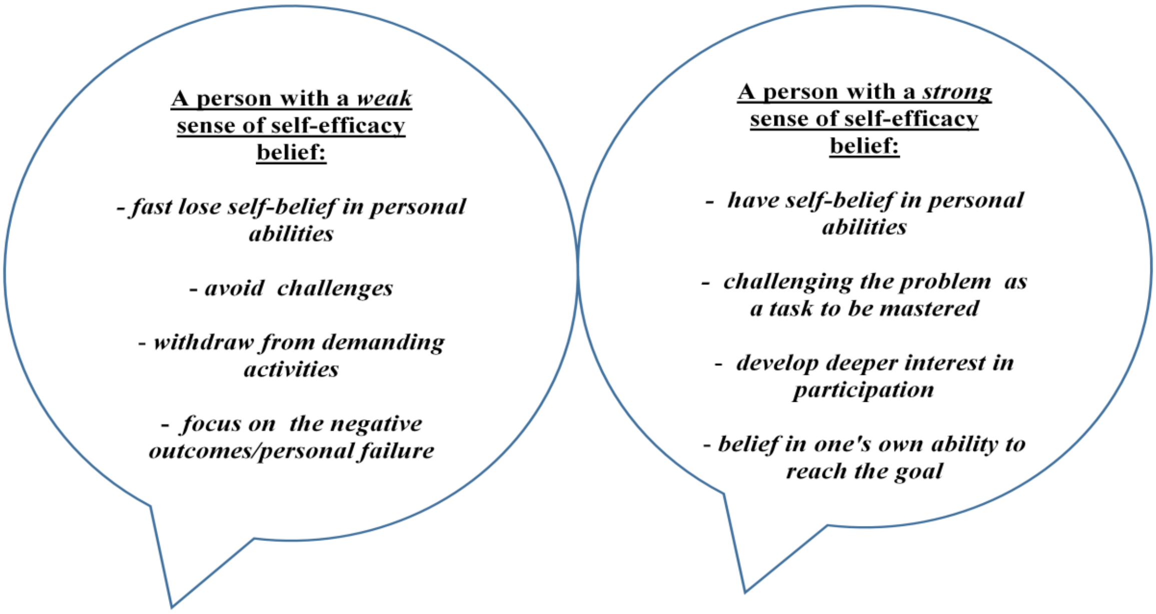

Figure 1. *A strong and weak sense of self-efficacy belief* - according to Bandura (1977, 1992, 1995).

A persons self-efficacy continues to develop, throughout life, as the person gain new experiences, and new understanding in life (Bandura, 1977).

Positive affect and negative affect in persons with RA

Psychological well-being of an individual with RA is significantly affected by fundamental life changes and the complexity of the disease process (Davis, Wagner & Groves, 2000; Husted, Gladman, Farewell & Cook, 2001). Negative emotionality and stress are two major psychological factors that have been associated with RA; emotions play a crucial role in how persons adjust to having RA and in the context of chronic pain in general (Dickens, Jackson, Tomenson, Hay & Creed, 2003; Hamilton, Karoly & Kitzman, 2004; Hamilton, Zautra & Reich, 2005).

Persons with RA and with psychosocial problems experience a more negative impact of the RA disease. For instance, persons with psychosocial problems had higher scores on depression and more frequently expected that the RA would negatively affect their future (Gåfvels, Hägerström, Nordmark & Wändell, 2011).

Persons with RA can be limited in their ability to perform activities of daily living and to maintain their roles as spouses, parents or workers (Östlund et al., 2014). Östlund et al. (2014) found that persons with RA reported sadness when trying to perform daily activities (such as getting up in the mornings and getting dressed), or not being able to perform duties at work. Sadness was experienced in relation to not being able to continue leisure activities or caring for children. In addition, anger and irritation were described in relation to domestic and employed work, but also in social relations in which individuals felt that they were unable to continue valued activities (Östlund et al., 2014).

Gåfvels et al. (2011) investigated what factors predict negative effects of RA. Their results showed that one third of the individual had problems directly related to RA. The rest of the individual had problems with their overall life situation (without or reinforced by RA). The results also showed that persons with psychosocial problems lived under more strained social situations than persons without psychosocial problems (Gåfvels et al., 2011).

Coping with chronic illness

Lazarus and Folkman (1984) reason that coping involves great effort to manage stressful situations: whether or not those efforts are effective. Furthermore, *coping changes over time and across situations*. It is differentiated between two major functions: problem-focused and emotion-focused coping. Problem-focused coping refers to the management of the changed person-environment relationship (that is the source of stress). Emotion-focused coping refers to the regulation of stressful emotions that arise in response to the problem (Lazarus & Folkman, 1984). Psychological factors (particular cognitive representations, coping efforts and appraisal of coping efforts) play a key role in adapting to chronic diseases (Pimm & Weinman, 1998). *Over* *the years,* researchers have revealed that persons with chronic illness have problems with a number of fundamental changes in their life. Charmaz (1983) suggests that living with a chronic illness often leads to a more restricted life (Charmaz, 1983). In addition, it can lead to loss of control and social isolation and can be a threat to the person's identity (Conrad, 1987). This involves experiencing the body in different ways, dealing with uncertainty (Bury, 1982) and a reconstruction process of the self (Corbin & Strauss, 1991). McCormack and McCance (2010) reason that illness and disease can be thought of as a threat to the self, because illness and disease can increase the distance between what we want to manage and what we really can manage in daily life. The disease symptoms can have a negative effect on daily life in different ways. However, life is about being a whole person (expressing our self) and therefore it is important to find ways to balance daily life in the face of a chronic illness (Jeon et al., 2010).

Coping strategies in persons with RA

Living with RA requires using various strategies in everyday life to cope with a host of emotions. Mental requirements and an overall need for coping management strategies are important (Engelbrecht, Wendler & Alten, 2012; Engelbrecht, Kruckow, Araujo, Rech & Schett, 2013; Grønning, Lomundal, Koksvik & Steinsbekk, 2011; Shariff et al., 2009).

Individuals who used resting and inactivity (helplessness category) experienced negative outcomes. Avoidance (escape) was the most common category associated with negative outcomes in persons with RA (Ramjeet, Smith & Adams, 2008). Individuals with RA and psychosocial problems are more anxious, show a lower sense of coherence and use more emotion-based coping strategies (such as resignation, protest, isolation and intrusion) (Gåfvels et al., 2011). The use of helplessness (inactivity and passive coping) and escape/avoidant coping strategies (including denial and wishful thinking) can be identified and dealt with by health care professionals to reduce associated negative outcomes (Ramjeet et al., 2008).

Furthermore, persons with RA that are under greater perceived stress and those who do not use active coping strategies appear to be at risk of psychological comorbidity. Therefore, these persons may benefit from interventions that include specific active coping strategies (Treharne, Lyons, Booth & Kitas, 2007). Medical health care workers (skilled in RA care) should offer individuals with psychosocial problems psychosocial support and assistance (Gåfvels et al., 2011).

Engelbrecht et al. (2013) reported that persons with RA with moderate to high impaired physical function and emotional well-being reported significantly higher disease activity and a more frequent use of distancing and active problem-solving coping strategies than patients with low impairment. These individuals also reported experiencing significantly higher levels of helplessness. Thus, encouraging and educating patients on how to cognitively reframe their current situation might play a major role in reducing the level of helplessness that results from impairment of physical function and emotional well-being (Engelbrecht et al., 2013).

Mcdonald et al. (2012) found that persons with RA have good days and bad days and that the persons must take advantage of the former. By coping strategies, it is meant not to plan too much in advance as well as thinking positively and to participate in fun activities (Ahlstrand et al., 2012; Kowalski & Chung, 2012). Tak (2006) found three major strategies that persons with arthritis used to cope with daily stress; cognitive efforts (seeking peace of mind), diversional activities (getting out, doing or looking) and assertive actions (talking and seeking). Pierre-Auguste Renoir, the famous French artist who was a leading painter in the development of the Impressionist style, suffered from debilitating RA. Despite his arthritis, he was able to maintain an incredible level of precision and efficiency in his work. Renoir remained positive and did not let his condition affect his passion for painting. He applied a wide variety of coping mechanisms, using creativity to devise different ways to continue his passion for painting (Kowalski & Chung, 2012).

In a study, Bergsten, Bergman, Fridlund and Arvidsson (2011) found that in the management of RA (as experienced by individuals with RA) individuals incorporated the use of personal resources and sought support from others. Four dimensions emerged characterizing person's different ways of managing RA; mastering, relying, struggling and being resigned. Both self-management strategies and person's need of support were important in managing RA (Bergsten et al., 2011).

Sinclair and Blackburns (2008) reported the value of “reclaiming control” over one´s life. This reclaiming process was made possible, for persons with RA, by changing priorities, pacing themselves, being flexible, delegating to others and establishing appropriate boundaries. Reframing a situation enabled persons to change their perspective and minimize threats from RA. It also enabled individuals to re-prioritize their values and find meaning and positive changes. Sinclair and Blackburn (2008) moreover showed that participants used a variety of sources of encouragement to bolster courage. The sources included; confidence from past successes, inspiring role models and different social support systems (Sinclair & Blackburn, 2008).

Studies have demonstrated that cognitive behavioral therapy (CBT), relaxation response training, meditation and education (exercise programs) are beneficial to persons with RA *in terms of coping with the psychological burden* (Barsky et al., 2010; Gettings, 2010).

Moreover, Lumley et al. (2014) investigated the effects of written emotional disclosure, and coping skills training, in persons with RA. Findings indicate that cognitive-behavioral coping skills training (CST) is recommended for individuals with RA, and has been shown to improve the health status (Lumley et al., 2014).

General recommendations regarding physical activity and exercise

From a systematic review, evidence exist that an active lifestyle is associated with reduced risk of developing disease (e.g., cardiovascular disease, type 2 diabetes, osteoporosis and cancer) (SBU, 2007). Studies (e.g., Andersen, Schnohr, Schroll & Hein, 2000; Crespo et al., 2002; Gregg et al., 2003) reported that the risk of *all-cause mortality* is reduced in persons who participate in regular physical activities, when compared with those who have an inactive lifestyle. Research has also revealed that properly designed exercise has an analgesic effect comparable to analgesic medication (The National Board of Health and Welfare, 2012).

Byberg et al. (2009) moreover found that increased physical activity in middle age is eventually followed by a reduction in mortality, and to the same level as seen among men with constantly high physical activity (Byberg et al., 2009). However, according to research findings people generally move too little, and especially those who would most benefit from it (SBU, 2007).

Physical activity has various dimensions such as; *intensity, duration and frequency*. According to the health-enhancing recommendations in Sweden the physical activity intensity should be moderate (or more) to achieve positive health effects. Moreover, according to the health-enhancing recommendations the duration is given as minutes, and the frequency is given per week/or day. Thus, adults in Sweden are recommended to be physically active, at least 150 minutes a week (moderate-intensity) or (at least) 75 minutes a week (high-intensity) (The National Board of Health and Welfare in Sweden, 2011). This recommendation, however, describes nothing of remaining "awake time". It should be noted that a person can be both highly active (according to the general health recommendations) but also have much time per day sedentary (Mattsson et al., 2015).

Physical activity

Physical activity can refer to all bodily movement as a result of bone or muscular contraction that results in an increased level of energy consumption. The concept of physical activity thus includes; body movement during (both) work and leisure, as well as all forms of physical exercise; e.g. gymnastics, outdoor activities, etc. (Pate et al., 1995; Shephard & Balady, 1999).

Exercise

Exercise can be defined as a subset of physical activity that is; planned, purposeful, structured and repetitive. The goal is to improve, or maintain, of physical fitness (Pate et al., 1995; Shephard & Balady, 1999).

Health-enhancing physical activity

For healthy adults aged 18-65 years, Haskell et al. (2007) recommend that moderate-intensity aerobic physical activity be performed regularly. Here, *regularly* means that the activity should be performed to promote and maintain health, and consists of moderate-intensity aerobic (endurance) activity for a minimum of 30 minutes for five days each week *or* vigorous-intensity aerobic activity for a minimum of 20 minutes for three days each week. *In addition*, adults should perform muscular strength training activities at least twice a week. Combinations of moderate- and high-intensity activity can be performed to meet this recommendation (Haskell et al., 2007).

Physical activity and exercise recommendations in persons with chronic conditions

Recommendations for adults >65 years, or for adults 50 to 64 years with chronic conditions and/or functional limitations are described by Nelson et al. (2007). Nelson et al. (2007) recommend;

- that the individual´s aerobic fitness should be considered when recommending intensity of aerobic activity
- the activities that improve or maintain flexibility need to be taken into account (e.g., balancing exercises for older patients with high risk for falls)
- an individual activity plan for achieving recommended activity
  (Nelson et al., 2007).

Physical activity and exercise in persons with RA

Because of the unpredictable progress (of the RA disease) it is recommended that every organized physical exercise should be adapted to the person. Thus, *an individual activity plan* for achieving recommended activity is important. Need for health checks (e.g. as screening for cardiovascular disease, and the degree of joint destruction etc.) should be assessed before dosing of physical exercise begins (Bremander, 2015). To reduce the risk of aggravated symptoms, in connection with increased physical activity in persons with RA, Bremander (2015) and Brodin and Swärdh (2015) additionally underscore that the physical activity should be; *slowly introduced and gradually increased*.

Physical activity has a *therapeutic and/or secondary preventive effect* when the disease has already occurred (SBU, 2007) and regular properly designed physical activity in persons with RA is associated with better physical condition, and improved mental health (Andersen et al., 2000; Crespo et al., 2002; Gregg et al., 2003). Thus, there are several benefits of being physically active. *However,* research shows that in many countries a relatively low proportion of individuals with RA exercise (Sokka, Krishnan, Häkkinen & Hannonen, 2003). Regular physical activity is paramount because a reduction in muscular strength is common in persons with RA, causing reduced activity and participation restriction in daily life (Eurenius & Stenström, 2005; Sokka et al., 2008). Decreased aerobic capacities, and reduced muscular strength, are common in persons with RA (Eurenius & Stenström, 2005; Sokka et al., 2003). Persons are therefore recommended to be physically active to maintain muscle function and reduce the risk of additional health problems (Stenström & Minor, 2003), including the increased risk of premature death because of cardiovascular disease (Akrout et al., 2012; Crilly & Wallace, 2013).

There is an indication that regular, moderate-intensity physical activity, results in improved muscle function and QoL in individuals with early RA (Brodin et al., 2008). Hurkmans, van der Giesen, Vliet Vlieland, Schoones and van den Ende (2009) and Cooney et al. (2011) moreover found that physical activity and exercise (performed with sufficient intensity and duration) result in increased aerobic capacity and muscular strength.

Results indicated that high physical activity level at baseline was the only predictor of high physical activity one year later. Low pain, high physical activity and good lower extremity function were identified as predictors of good general health perception (Eurenius, Brodin, Lindblad, Opava & Para Study Group, 2007).

Because many individuals with RA have experienced hand dysfunctions, hand exercises are also a part of standard treatment. In a review, Bergstra, Murgia, Te Velde and Caljouw (2014) describe the effectiveness of hand exercise theraphy in the treatment of hand and finger RA. The authors suggest that hand exercises may have positive effects on hand strength, as well as some aspects of daily functioning, without aggravating disease activity or pain. The authors note that *caution* should be taken for persons in the exacerbation period (Bergstra et al., 2014). Lamb et al. (2014) investigasted tailored strengthening and a stretching hand exercise program to improve the function of the hand of persons with RA. The authors found that tailored hand exercises might provide additional improvements. The tailored hand exercise program is a low-cost intervention in addition to various drug regimens (Lamb et al., 2014).

Physical activity maintenance

Loeppenthin et al. (2014) summarized the essential meaning of the phenomenon of physical activity maintenance in individuals with RA as; striving for a transparent body and participation.

Striving for a transparent body and participation points to experiences of sensations of well-being, liberation from restrictions and social participation on equal terms with the normal (i.e. non-arthritic) population. The study reported that physical activity in persons with RA may be understood as a resource to resist disability, as well as to feel and stay healthy while creating and sustaining meaningfulness in life (Loeppenthin et al., 2014).

Ways of understanding how to determine the intensity

The authors (Brodin, Swärdh, Biguet & Opava, 2009) suggest that it might be a discrepancy between health professionals and persons with RA regarding the understanding of physical activity intensity. In a study four qualitatively different ways of understanding how to determine the intensity of physical activity were reported in Brodin et al. (2009). The different ways were describes as; focus on alterations of bodily features, focus on will-power and awareness, focus on type and performance of activity and focus on the consequences of the disease (Brodin et al., 2009).

Health professionals should reach a common understanding of evidence-based ways of determining physical activity intensity with each patient in order to prescribe accurately and assess physical activity (Brodin et al., 2009).

Promotion against physical activity

To emphasize a health-oriented and salutogenic theoretical perspective each persons health-relevant pattern of goals, their resources and social needs, need to be systematically addressed (Engel, 1977; Engel, 1980; Frankel et al., 2003). A persons self-efficacy plays a major role in *how* goals and challenges are approached, according to Bandura (1977).

Sources, that strengthen sense of self-efficacy *i.e:*

- learning how to elevate mood (when facing demanding tasks)
- observing people (similar to oneself) succeed by persistent effort
- performing a task successfully (Bandura, 1977, 1992, 1995).

According to Bandura (1977) *encouragement* helps people overcome self-doubt, and is a key role in promotion participation in activity (Bandura, 1977, 1992, 1995). Lehman et al. (2011) for example show that persons with RA experienced more problematic spousal support when their partner underestimated (or overestimated) their physical limitation level. Moreover, of significance, according to Bandura (1977) a person can improve the sense of self-efficacy.

A person need to be motivated to find activities that they enjoy and to communicate training benefits: increased sense of control, better physical status and the joy in participating in activities (Eyler, 2003; Hootman, Macera, Ham, Helmick & Sniezek, 2003).

Patient education programs, for the promotion of health-enhancing physical activity, has moreover been recommended in studies (i.e. Foresteir et al., 2009; Hurkmans et al., 2011).

From the Council on Health Technology Assessment in Sweden (2007), there is evidence indicating that the advice patients receive in an everyday clinical environment leads to increased physical activity in 12-50% of the patients. Furthermore, counseling patients in an everyday clinical environment resulted in increased physical activity six months or longer after the counseling session (SBU, 2007).

Recommendations for physical activity in persons with RA

Recommendations for physical activity in persons with RA are recently published (in March 2015) (Brodin & Swärdh, 2015). In these recommendations the authors Brodin and Swärdh (2015) *concludes* that: land-based exercise improves aerobic capacity and reduces pain. Additionally, water-based exercise can improve aerobic capacity in persons with RA. Combined training (to improve both aerobic capacity and muscle strength) is recommended. *Thus,* persons with RA, and with low to moderate disease severity, should be recommended land or water-based exercise and strength training (Brodin & Swärdh, 2015). For details see moreover in Brodin and Swärdh (2015).

Persons with RA and with complications need specific attention

The potential risks of physical activity, for persons with RA, are due to increased risks, for e.g. fractures etc., and caution should also be observed in connection with interactions with medical treatments (e.g. cortisone treatment) (Bremander, 2015).

In addition, *caution* should also be observed in connection for persons with e.g. large joint destruction, in the event of joint replacement surgery, and during RA flare-ups (Brodin & Swärdh, 2015).

Persons with RA and with *complications need specific attention* from health-care professionals, and specially designed physical training that are supervised by skilled health professionals (see moreover in Brodin & Swärdh, 2015).

Correlates of physical activity for the general population

For the general population, some *positive correlates* related to physical activity have been identified. These correlates are: being male, self-efficacy, reported health, intention to exercise and previous history of physical activity (Bauman et al., 2012).

Correlates of physical inactivity/activity in persons with RA

Positive correlates of physical activity in persons with RA have also been reported, including: previous history of physical activity, perceived health, motivation and self-efficacy. *Negative associations* were found for: fatigue, regulation style and psychosocial variables (Larkin & Kenney, 2014).

In both men and women with arthritis, *inactivity* was associated with: older age, lower education, and having functional limitations. In addition, *among women*, inactivity was also associated with: having frequent anxiety/depression, social limitations, not receiving physical activity counseling, and needing special equipment. *Among men*, inactivity was also associated with: severe joint pain (Shih, Hootman, Kruger & Helmick, 2002). Sokka et al. (2008) found that physical inactivity, in individuals with RA, is associated with: being female, lower education, older age, comorbidity, obesity, low functional capacity, higher levels of RA disease activity and also with higher pain and fatigue levels (Sokka et al., 2008).

Fear-avoidance beliefs about physical activity

Pain catastrophizing and avoidance behavior

High pain intensity is in itself a threatening experience, which drives escape and avoidance (Eccleston & Crombez, 1999).

However, the term *catastrophizing* was first coined by Ellis (1962). It described the process in which persons with anxiety focus on the most extreme negative consequences conceivable. *Pain catastrophizing* refers to the process during which pain is interpreted as being extremely threatening.

Avoidance behavior refers to behavior aimed at postponing, or preventing, an aversive situation (i.e. activity) from occurring (Kanfer & Philips, 1970). Vlaeyen and Linton (2000) presented an overview of studies demonstrating that in the case of chronic pain, the avoidance aimed to keep away from the perceived threat (the situations/activities that are assumed to i.e. increase pain).

Pain-related fear has been found to be associated with catastrophic misinterpretations of pain, hyper vigilance and increased escape and avoidance behaviors along with intensified pain intensity and functional disability (Asmundson, Vlaeyen & Crombez, 2004; Vlaeyen & Linton, 2000).

Fear-avoidance beliefs about physical activity in chronic illness

The maladaptive negative beliefs can reinforce inactivity, while decreased physical activity can lead to increased pain perception, negative expectations and increased avoidance. Proper beliefs assessment is therefore advocated (Asmundson et al., 2004; Vlaeyen & Linton, 2000).

Most studies have focused on patients with non-specific medical diagnoses, but the pain-related fear process is suggested to be applicable to specific pain problems as well (Leeuw et al., 2007). In a study of persons with chronic venous disease, fear of avoidance beliefs was associated with low physical activity (Roaldsen, Elfving, Stanghelle, Talme & Mattsson, 2009). Moreover, that the information on the importance of the benefits of physical activity as a treatment strategy was not given as routine (Roaldsen, Biguet & Elfving, 2011).

Persons with chronic fatigue syndrome (CFS) have reduced daily physical activity levels (Nijs et al., 2011; van Weering, Vollenbroek-Hutten, Kotte & Hermens, 2007). Ickmans et al. (2013) found that part of the cause of this deteriorated physical exercise capacity can possibly be seen in the entailed downward spiral of physical inactivity and avoidance behavior towards physical activity (Ickmans et al, 2013). Severe exacerbation of symptoms following physical activity is characteristic of CFS and fibromyalgia (FM). These exacerbations of symptoms make it understandable for people with CFS and FM to develop fear of performing physical activity, and consequently, facilitation of avoidance behavior towards physical activity (Nijs et al., 2013).

Nijs et al. (2013) (state of the art and implications for clinical practice) show that individually tailored CBT in combination with exercise training (depending on the patient’s classification as avoiding or persisting) appears to be the most promising strategy for treating fear of movement and avoidance behavior towards physical activity in patients with CFS and FM.

Avoidance of physical activity results not only in negative physical consequences (such as loss of muscle strength and impaired mobility) but also in psychological change, depression and anxiety. It may also result in decreased social activities (Turk & Monarch, 2002).

Fear-avoidance beliefs about physical activity in persons with RA

Fear of pain, fear of work-related activities, fear of movement and fear of being reinjured are often described in patients who suffer from chronic pain (SBU, 2006). Pain catastrophizing has also been seen to play an important role in persons with RA (Perrot et al., 2013).

High pain intensity was strongly related to fear-avoidance beliefs, as well as to beliefs about relationships between pain and impairment in long-standing RA (Lundgren et al., 2005).

Body capacity and body limitations

Melanson and Downe-Wamboldt (2003) found that physical limitations in daily life cause the largest disease-related concerns in persons diagnosed with RA. Pain affects the everyday life of individuals, and may be a physical barrier to performing valued activities. It is apparently difficult to choose the right activity level, i.e. it is easy to be overactive; triggering subsequent elevation of pain levels (Melson & Downe-Wamboldt, 2003).

Lempp, Scott and Kingsley (2006) noted that having RA leads to changes in the body, and that these changes limit daily activities. Additionally, the identity was affected in e.g. relation to perceived change of physical appearance.

Moreover, fear descriptions have been reported in a study on deteriorating health and fumble fear in patients with RA, which made the individuals withdraw from activities as a result of mistrusting their own body's capacity (Östlund et al., 2014).

Body Awareness

Definitions and the concept of body awareness

Mehling et al. (2009) argued that a a clear definition of the concept of BA is rarely provided in the literature.
A multidisciplinary group of researchers interested in the concept of BA developed a working *definition* of BA (Mehling et al., 2009):

Body awareness is the perception of bodily states, processes and actions that is presumed to originate from sensory proprioceptive and interoceptive afferents and that an individual has the capacity to be aware of. Body awareness includes the perception of specific physical sensations (e.g., awareness of heart activity; proprioception of limb position) as well as complex syndromes (e.g., pain; sense of relaxation; 'somatic markers' of emotions). Body awareness is hypothesized as the product of an interactive and dynamic, emergent process that a) reflects complex afferent, efferent, forward and back-projecting neural activities, b) includes cognitive appraisal and unconscious gating, and c) is shaped by the person's attitudes, beliefs, experience and learning in a social and cultural context (Mehling et al., 2009).

Based on a conceptual review, a theoretical model for BA that includes four domains of BA was developed by Mehling et al. (2009): Perceived body sensation, Quality of attention, Attitude of body awareness and Awareness of mind-body integration.

Self-reporting instrument for body awareness

The authors remakred that the self-reporting instruments for BA do not attend to important domains of the construct of BA and are unable to discern between its adaptive and maladaptive aspects. The authors also noted that the domain "Awareness of mind-body integration" was missing from most of self-reporting instruments measuring BA (Mehling et al., 2009).

Chronic illness and body awareness

The concept of BA, as well as self-reported measures within the concept, is used for a wide range of diseases (Mehling et al., 2009).

Research shows that improved BA may change the attitude to one's own body, enhance the ability to listen to bodily symptoms and increase sense of control. Improved BA may also provide an understanding in the ability to manage chronic pain (Gard, 2005; Gustafsson, Ekholm & Broman, 2002; Lundvik Gyllensten & Gard, 2008). Other studies have indicated the advantages in the ability to notice subtile body sensations and that it may be useful in the management of chronic diseases, including congestive heart failure (Baas et al., 2004), chronic renal failure (Christensen et al., 1996) and chronic low back pain (Mehling et al., 2005). Eriksson, Möller, Söderberg, Eriksson and Kurlberg (2007) showed that somatic symptoms decreased in parallel with the depressive symptoms in persons with iritable bowel syndrome (IBS). Body awareness therapy (BAT) gave relief of somatic complaints and psychological symptoms and normalized body tension (Eriksson et al., 2007). *However*, research has also shown (e.g., Abramowitz, Schwartz & Whiteside, 2002) that BA may lead to excessive dwelling on different bodily functions in some persons. Efforts to focus awareness and attention to one´s own body can subsequently create somaticizing, with anxiety and depression (Abramowitz et al., 2002; Kirmayer & Looper, 2006).

Understanding BA is applied to studies of pain by using distraction. Attentional focus is then directed away from the pain sensations and towards mental tasks. By using a pain-inducing activity, certain benefits would be expected (e.g., reduced pain perception while attention is distracted away from noxious stimuli) (Bantick et al., 2002; Johnson, 2005). Some supplementary evidence suggests that it should be used with caution in that findings show that distraction from chronic pain (during a pain-inducing activity) is associated with greater post-activity pain (Goubert, Crombez, Eccleston & Devulder, 2004).

BA may be used to monitor physical cues associated with stress and provide a start to begin stress reduction interventions (Baas et al., 2004). Severeal therapeutic approaches used throughout the world claim to enhance BA. In their review, Mehling et al. (2009) discussed a variety of therapeutic approches: yoga, tai chi, massage, body-oriented psychotherapy, mindfulness-based therapies, meditation (Mehling et al., 2009) and in addition, Body Awareness Therapy (BAT) (Ryding, Rudebeck & Roxendal, 2002) and Body Awareness Program (BAP) (Landsman-Dijkstra, van Wijck & Groothoff, 2006).

All these therapeutic approaches (above-named) is decribed to seek to cultivate *a particular quality of BA*. BA is not characterized by intensity (exaggerated or ignored) but by non-judgmental ‘mindfulness’. Moreover, the aims of these approaches are to achieve a quality of non-elaborative awareness to current experience and a quality of relating to one's experience with an orientation towards curiosity, experiential openness and acceptance (Mehling et al., 2009).

Theoretically, an increase in BA may help individuals recognize symptoms of worsening RA. *However*, it is not known whether increased BA in persons with RA leads to somatization. Because many symptoms of RA (e.g., pain and fatigue) are generally evocative of negative emotional responses, elevated BA may be associated with poorer emotion regulation and worse perceived health. The body, which might previously have been relatively quiet and unreflective, becomes continuously reminded of the various disease symptoms.

A number of phenomenological studies have been carried out (i.e. Hwang, Kim & Jun, 2004; Iaquinta & Larabee, 2004; Mitton, Treharne, Hale, Williams & Kitas, 2007; Ryan, 1996; Söderberg et al., 2002), and the most common issues investigated in the phenomenological studies are lived experiences, fatigue and specific populations. A phenomenological study, on the experience of BA in persons with RA, can complement purely medical and psychological perspectives with a holistic understanding. Moreover, because no studies have focused specifically on BA in persons with RA, there is an urgent need to explore this phenomenon.

AIMS OF THE THESIS

The overall aim

The overall aim of this thesis was to investigate pain, fatigue and fear-avoidance beliefs in relation to physical activity and their correlates in persons with RA. A further overall aim was to develop a psychometric measurement of BA. A final overall aim was to deepen our understanding of BA in persons with RA.

The specific aims (study I-IV):

Study I The aim was to develop and test the psychometric properties of a Swedish version of the BAQ to measure bodily focus of attention.

Study II The aim was to examine fatigue and pain in adult patients with RA and to investigate the association between pain and fatigue with body awareness, demographic, disease-related, emotional and psychosocial factors.

Study III The aim was to describe fear-avoidance beliefs about physical activity and explore how they correlate with socio-demographic, disease-specific and psychosocial factors in adults with RA.

Study IV The aim was to obtain rich descriptions of lived experiences of BA in persons with RA in accordance with a phenomenological understanding of the body.

METHODS

A general description of the focus of the study, design, data collection and participants of the studies is given in table 2.

Table 2. Description of study I-IV - Overview.

Study	**I**	**II**	**III**	**IV**
Focus of the study	The body awareness questionnaire	Pain and fatigue in persons with RA	Fear-avoidance beliefs about physical activity in persons with RA	Body awareness in persons with RA
Design	Cross-sectional Cross-cultural adaption and psychometric evaluation	Cross-sectional	Cross-sectional	Phenomenological
Data collection	2009- 2011 Concurrent think-aloud interviews and protocols Questionnaires	2009-2011 Questionnaires	2010 Questionnaires	2013 Narrative interviews
Participants	10 patients 120 nursing students and 120 patients	120 patients	2351 patients	18 patients

Design

The study designs used were a cross-sectional and an empirical phenomenological psychological design.

Inclusion and exclusion criteria

Study I

Participants (n=10) in the concurrent think-aloud interviews *in study I* comprised a sample of patients diagnosed with RA. The participants were selected by rheumatologists at a university hospital in Stockholm. The patients were chosen by the rheumatologists because they were assumed to be able to communicate valuable information about BA from their own perspective. Eligible for inclusion in the study were patients aged 20-80 years with a confirmed diagnosis of RA according to the American College of Rheumatology (ACR) criteria for RA (Arnett et al., 1987). Patients with language difficulties or other problems that could interfere with participating in a interview were excluded.

An information letter was initially given to the patients by the rheumatologists; in some cases (in agreement with the participants) the letter was sent home. A few days later, after the patients had been given information about the study, the first author (HL) telephoned and offered additional information and later asked the patients for their consent to participate.

Participants included in the think-aloud interviews (n=10) had a mean age 62 years and 80% were women. Thirty percent had compulsory school education, 20% upper secondary education and 50% higher education. In addition, 40% had a full-time job, 50% part-time work and 10% were retired.

The study sample *in study I* also included n=120 patients diagnosed with RA. These participants were consecutively recruited. Eligible for inclusion were those aged 20-80 years with a confirmed diagnosis of RA according to ACR criteria (Arnett et al., 1987). The patients received their diagnosis of RA at least six months before the start of the study, had adequate knowledge of the Swedish language and were able to read and understand study instructions. The exclusion criterion was any comorbidity that could affect the outcome of the study. The rheumatologists selected the study participants based on the above-mentioned criteria. Within two weeks after the patients had received the written study information (and communicated a verbal interest to the rheumatologist), the questionnaires, a written consent form, a study information letter and a postage-paid reply envelope were sent home to each patient. No reminder was sent. The response rate was 78%.

Demographic and clinical characteristics of the patients were collected from computerized medical records during 2009-2011. These data included age and sex. A disease activity score (DAS) was also computed to measure the level of disease activity in patients with RA (Prevoo et al., 1995). All questionnaires were coded.

In the final sample, 22.5% of the patients were aged <45 years, 42.5% aged 46-65 years and 35% aged >65 years. The majority of the patients were female (86%). The participants mean age was 59.5 (± 12.6 SD). The mean DAS was 3.2 (± 1.2 SD).

Moreover, *study I* also included a sample of n=120 students from two programs at one university in Sweden. Sixty students were enrolled in a Nursing Program and another 60 enrolled in a Bachelor´s Program in Nursing Science (for complete details, see the original study). The nursing students' demographic data (sex, age and level of education) were obtained on the same day the participants participated in the study. The first (HL) and second author (U-BJ) collected the questionnaires. The response rate for the questionnaires among the nursing students was 95%.

The student sample consisted of 94% females aged 37.2 ± 11.4 years (mean ± SD).

Students who wanted to participate in the study received a letter containing written information about the study and the questionnaires. Those who consented to participate in the study stayed inside the classroom and filled in the questionnaires. The students' responses were put in a sealed envelope addressed to HL or U-BJ. However, some participants (n=20) wanted to fill in the questionnaires later and then place their responses in HL or U-BJ's mailbox at the university. All questionnaires were coded.

Study II

See above, the participants (n=120 patients diagnosed with RA) included in study I.

Study III

Participants (n=2351) included *in study III* were patients diagnosed with RA, according to the 1987 ACR criteria (Arnett et al., 1987). The participants were consecutively recruited.

This cross-sectional study is part of the PARA (Physical Activity in Rheumatoid Arthritis) 2010 study. The selection procedure has been described elsewhere (Nordgren, Fridén, Demmelmaier, Bergström & Opava, 2012; Nordgren, Fridén, Demmelmaier & Opava, 2014).

In all, 3152 (of 5391) potentially eligible patients with RA responded to the questionnaire. A detailed description of differences between responders (n = 3152) and non-responders (n = 2239) is available elsewhere (Demmelmaier et al., 2013).

Of the 3152 (59%) returned questionnaires (in the PARA 2010 study), 2351 (75%) had observations for all the variables. These 2351 patients constitute the present study sample (for detailed demographic data, the reader is referred to Lööf et al., 2015). Descriptive statistics of the excluded and included groups in the primary analysis are presented in Table 1 in the article (Lööf et al., 2015). A larger proportion of those excluded were older, lived alone, had lower education and income, higher comorbidity, more symptoms, poorer HRQoL, lower ESES and higher mFABQ scores.

Initially, the SRQ registries were searched for potentially eligible participants. Six rheumatology clinics were chosen to represent university and county hospitals, rural and urban areas and different regions of Sweden. To identify a population that would be at target for a physical activity intervention, only those ≤ 75 years and with a Health Assessment Questionnaire Disability Index (HAQ-DI) score of ≤ 2 (measured by the Stanford HAQ-DI) were included.

Study IV

Patients (n=18, diagnosed with RA according to the 1987 ACR criteria) were consecutively recruited *in study IV*. The participants were selected by rheumatologists at a university hospital in Stockholm. The participants were chosen by the rheumatologists because they were assumed to be able to communicate valuable information about BA from their own perspective. The selection included a heterogeneous group. Patients with language difficulties or other issues that could cause problems to participate in a narrative interview were excluded. Eligible for inclusion were patients aged 20-100 years with a confirmed diagnosis of RA. About two to three days later, after the participants had been given information about the study from their rheumatologist, the first author (HL) telephoned and offered additional information and subsequently asked potential participants for their consent to join the study. Eighteen narrative interviews were performed from June-October 2013. The interviews took place in a private quiet room. The participants chose the place for the interview.

Two participants (men) who had been booked for an interview later declined to participate. The final sample included 18 patients (2 males and 16 females aged 23-78 years) with RA. Disease duration ranged from 6-34 years. Two participants had basic education, eight had college education and eight had university education. Seven patients were living alone and 11 were cohabiting. (For more details see page 38).

Questionnaires

In this thesis a combination of generic and disease-specific questionnaires were used. See table 3.

Table 3. Questionnaires used in study I-III –Overview.

Questionnaires	**Study I**	**Study II**	**Study III**
Generic			
BAQ	X	X	
ESES-S			X
ERQ		X	
ISSI		X	
MAF		X	
mFABQ			X
PANAS		X	
PSS4		X	
EQ-5D	X	X	X
Disease-specific			
DAS-28	X	X	X
VAS* *(*investigating RA pain, RA fatigue, RA and general health)*	X	X	X

Pre-testing questions

The procedure follows that recommended for cross-cultural adaptation of self-reporting measures for use in a different country and language (Beaton, Bombardier, Guillemin & Ferraz, 2000).

Cognitive concurrent think-aloud method

Cognitive interviews (think-aloud) is used to measure content validity (Collins, 2003; Drennan, 2003).

One major problem in survey research is non-response or non-completion of questionnaire items, which leads to incomplete data sets and makes data analysis difficult. Incomplete data could affect the generalizability of the findings (Drennan, 2003).

Questionnaire completion can fail for several reasons, including participant non-response, irrelevance of questions or questionnaires to respondents, inability of respondents to complete questions involving memory, the use of intrusive or sensitive questions about i.e. health history, or complex questionnaire design (Dillman, 2007).

Conrad and Blair (1996) have developed a classification of possible response problems that may occur with questionnaire completion. This classification is made up of *five categories* of problems:

- lexical, inclusion/exclusion, temporal, logical and computational (Conrad & Blair, 1996).

Haberlandt (1997) describe that *cognitive interviewing* uses cognitive theory to understand human information processing. The cognitive theory includes;

- attention span
- word recognition
- action
- memory
- language processing
- problem solving and reasoning
- as well as the exploration of how knowledge is organized in memory, and how memory is retrieved in relation to completing questionnaires (Haberlandt, 1997).

Drennan (2003) points out that problem with questionnaire responses are multifactorial and need to be identified before administering the questionnaires. Pre-testing questions in their questionnaire context helps establish whether respondents can understand the question concept. Of importance here is that the participants understand the questions in a consistent way and in a way the researcher intended (Collins, 2003).

Therefore, the concurrent think-aloud method (Collins 2003) was chosen and used *in study I* to investigate the usability of the Swedish BAQ and how the patients perceived and interpreted the questions.

Study I

Demographic data

Demographic data were collected *in study I*. These data included sex, age (year) and educational status (compulsory school, upper secondary school, higher education and other education).

Disease activity score-28 joints

Disease activity was evaluated *in study I* using the Disease activity score-28 joints (DAS-28). DAS-28 is based on the erythrocyte sedimentation rate (ESR, mm/h), number of swollen (n = 28) and tender (n = 28) joints and on the patients perceived general health (visual analogue scale,VAS, 0 - 100 mm). A score below 3.2 indicates low disease activity and a score above 5.1 indicates high disease activity (Prevoo et al., 1995).

Body awareness questionnaire

The BAQ, which was used in *study I and II,* is designed to assess self-reported attentiveness to normal none-motive body processes, such as sensitivity to body cycles and rhythms, the ability to detect small changes in normal functioning and the ability to anticipate bodily reactions (Shields, Mallory & Simon, 1989).

The BAQ is a one-dimensional 18-item instrument in which the underlying structure is described by four factors: (i) "note response or changes in body process" (items 1, 4, 10, 13, 14, 16), (ii) "predict body reactions" (items 2, 3, 8, 11, 12, 15, 16), (iii) "sleep-wake cycle" (items 7, 8, 9, 15, 17, 18) and (iv) "onset of illness" (items 5, 6, 7, 10). Respondents are instructed to read each statement and then in the space to the left of the item write the number that best described how true the statement was for them on a seven-point scale (1= "not at all true" 4= "neutral" and 7= "very true").

The BAQ has been found to be suitable for use with college students and non-student adults in measuring self-focused BA (Shields et al., 1989). In previous studies Cronbach's alpha has been shown to range from 0.80-0.88 (Baas et al., 2004; Shields et al., 1989).

Study II

Demographic data

Demographic data were collected *in study II* and included sex, age (year), smoking (yes or no), educational status (compulsory school, upper secondary school, higher education and other education) and marital status (single or common-law). Physical activity per week was categorized into yes = ≥7 days of physical activity per week and no = <7 days of physical activity per week. Working status was categorized into yes = working and no = not working, retired and sick leave.

Multidimensional assessment of fatigue

There are several scales to assess fatigue, but only a few have been validated. Hewlett and colleagues (Hewlett, Heir & Kirwan, 2007) conducted a systematic review of the scales used to measure fatigue in RA. Six scales showed reasonable evidence of validation. One of these six scales was the the multidimensional assessment of fatigue (MAF) scale (Belza et al., 1993).

MAF measures *four dimensions* of fatigue. 1.) The degree and severity of fatigue, 2.) distress that fatigue causes, 3.) timing of fatigue ("over the past week, when it occurred and any changes"), 4.) and also fatigues impact on various activities of daily living ("household chores, cooking, bathing, dressing, working, socializing, sexual activity, leisure and recreation, shopping, walking, and exercising") (Belza et al., 1993).

MAF include 16 items. Respondents are asked to reflect on any patterns of fatigue that have occurred over the past week. The MAF items are used to calculate scores for each of the four dimensions, and 15 of the 16 items are used to calculate the global fatigue index (GFI) (Belza et al., 1993). The Swedish version of the MAF has been tested in patients with rheumatic disease (Sandqvist, Archenholtz, Scheja & Hesselstrand, 2011) and was used in this thesis *in study II.*

Visual analogue scale

The VAS was used *in study II* to assess components of pain that occurred over the past week. The patients were asked one question about pain: "*How much pain did you have during the past week because of your rheumatic disease*?" (Dixon & Bird, 1981). Pain perception was rated on a 100-mm VAS from 0 (totally fine) to 100 (worst imaginable pain). This scale is considered valid and reliable in RA (Huskisson, 1982; Felson et al., 1993).

The EuroQol 5 dimension

The The EuroQol 5 dimension (EQ-5D) was used to assess HRQoL. This questionnaire, used *in study II*, includes five questions covering *five domains*: mobility, hygiene, daily activities, pain/discomfort and anxiety/depression. The EQ-5D score is reported on a scale from 0 to 1, where 0 refers to death and 1 to full health. Each dimension is scored from 1 (no problems) to 3 (extreme problems). To rate health on the actual day a line is drawn from a box to the appropriate point on a vertical thermometer from "worst imaginable health state" to "best imaginable health state". It is considered a valid measure of HRQoL in patients with RA (Hurst, Kind, Ruta, Hunter & Stubbings, 1997). The instrument has previously been used in a general population in Sweden and is seen as useful in measuring perceived health in RA together with condition-specific instruments (EuroQol, 1990).

Emotion regulation questionnaire

The emotion regulation questionnaire (ERQ) (Gross & John, 2003) was used *in study II*. ERQ is designed to assess individual differences in the habitual use of two emotion regulation strategies: *cognitive reappraisal and expressive suppression.* The questions in ERQ is about the emotional life; one is about the emotional experience (or what a person feel like inside), and one is about the emotional expression (or how a person show emotions, talk, gesture, or behave). The respondents are instructed to read each statement, and then in the space to the left of the item write the number on a seven-point scale (1= "strongly disagree" 4= "neutral" and 7= "strongly agree"). In a previous study on these two emotion regulation processes, the value of Cronbach's alpha was 0.79 for reappraisal and 0.73 for suppression (Gross & John, 2003).

Perceived stress scale 4

The perceived stress scale 4 (PSS4) was employed *in study II* to assess components of perceived stress. The scale ranges from 0-16, with higher scores indicating a higher degree of perceived stress. The questions in PSS4 asks about feelings and thoughts during the last month. The participants are instructured to answer the questions on the scale; 0=never, 1=almost never, 2=sometimes, 3=fairly often or 4=very often. Cronbach's alpha for the PSS4 was 0.72 (Cohen, Kamarck, & Mermelstein, 1983). In *study II*, a Swedish version of the PSS4 was included and in a previous study Cronbach's alpha was 0.82 (Eskin & Parr, 1996).

Positive and negative affect scale

The positive and negative affect scale (PANAS) was applied in *study II* to assess components of mood. PANAS includes items relating to positive affect (PA) domain and to a negative affect (NA) domain. A higher score on the PA domain indicates greater PA, or the extent to which an individual feels enthusiastic, active and alert. A higher score on the NA domain represents a greater negative affect or the extent to which the individual feels aversive mood states and general distress. Participants in the PANAS are required to respond to a 20-item test using 5-point scale that ranges from very slightly or not at all (1) to extremely (5). This measure has been validated in a previous study, where Cronbach's alpha was 0.86 to 0.90 for the PA domain and 0.84 to 0.87 for the NA domain (Watson, Clark & Tellegen, 1988). In a Swedish study, Cronbach's alpha was 0.86 for PA and 0.85 for NA (Nahlén & Saboonchi, 2010).

Interview schedule for social interaction

The interview schedule for social interaction (ISSI) was first developed by Henderson, Duncan-Jones, Byrne and Scott (1980). *In this thesis*, the abbreviated Swedish version of ISSI were used (Undén & Orth-Gomér, 1989) to measure components of social interaction and support. The ISSI measure the availability of deep emotional relationships and attachments, and the availability of more peripheral contacts of social networks and integration. It is a self-report instrument, with 30 items. Each item in ISSI give 0 or 1 points (depending on how the person respond), and the total score in the abbreviated version is thus 30 points. In previous work, Cronbach's alpha was 0.77 for the Availability of Social Integration (AVSI) scale, and Cronbach's alpha was 0.80 for the Availability of Attachment (AVAT) scale (Undén & Orth-Gomér, 1989).

In addition, the **DAS-28 joints** and the **BAQ** were also included in *study II*. (For details see study I).

Study III

Demographic data

Socio-demographic data on sex, age (years), members of household, education and income were collected in *study III.*

The Visual analogue scale

General health perception was rated in *study III* on a 100 mm VAS from 0 (totally fine) to 100 (worst imaginable health). Perceived pain was rated on a 100 mm VAS from 0 (no pain) to 100 (maximal pain). This scale is considered valid and reliable in RA (Felson et al., 1993; Huskisson, 1982). Fatigue was rated on a 100 mm VAS from 0 (no fatigue) to 100 (maximal fatigue). The scale has good face validity and is sensitive to changes in RA (Tack, 1990; Wolfe, 2004).

Exercise self-efficacy scale

Psychosocial data were collected in *study III* using the exercise self-efficacy scale (ESES-S). The scale contains six items covering common barriers to exercise. Ratings are made on a six-point scale from 1 (not at all confident) to 6 (very confident). The ESES-S has been determined as a valid instrument (internal consistency and concurrent validity) for measuring barriers to exercise. A recent study (Nessen, Demmelmaier, Nordgren & Opava, 2015) found that the Swedish version of the ESES-S has moderate test-retest reliability and respectable internal consistency in individuals with RA. Construct validity was partially supported in the present sample (Nessen et al., 2015). The original version of the ESES-S employs a 0-100 scale (Dzewaltowski, 1989), but the Swedish version is from 1 (not certain) to 10 (very certain). Although the number of scale points differ between the Swedish and original version, the Swedish version manages to retain a similar scale structure as the original (Nessen et al., 2015).

Fear-avoidance beliefs questionnaire

Fear-avoidance beliefs were measured in *study III* by a modified version of the fear-avoidance beliefs questionnaire (mFABQ). The modified instrument consists of four items on beliefs about physical activity that causes pain and injury. The items are rated on a seven-point scale from 0 (do not agree at all) to 6 (agree completely). The validity and reliability of the questionnaire have been reported in patients with chronic muscular pain (Wadell et al., 1993). The mFABQ has also been used in a general population in Sweden (Buer & Linton, 2002). Concerning psychometric properties, the FABQ appears to be the best available measure to assess fear-avoidance beliefs. However, evidence supporting the psychometric properties of FABQ to measure fear of pain is still incomplete. Therefore, future research on the validity of this tool seems warranted (Lundberg et al., 2011).

Study IV

Demographic data

Demographic data in *study IV* were collected by sex, age (year), disease duration (year), educational status (basic education, college education and university education) and civil status (living alone or co-habiting).

Narrative interviews

The purpose of choosing narrative interviews was that they can provide valuable information about the phenomenon of BA from the patient’s perspective. The life world perspective includes the world in which we live and to which we ascribe meaning, which means that our experience is always subjective and relative, where the focus is on human experience (Spiegelberg, 1982).

Phenomenology, which is rooted in the philosophical tradition, was developed by Husserl (Husserl, 1962) to explore and understand people's experiences of their life-world. In empirical studies, this implies that the researcher aims to determine the essence and constituents of various human phenomena (Karlsson, 1993).

The empirical phenomenological psychological (EPP) method was used in *study IV* (Karlsson, 1993). According to the EPP method, the researcher does not attempt to validate a hypothesis. Nor does the researcher seek to prove theoretical constructions. Rather, importance is placed on openness, i.e. that which shows itself through the participants’ experiences (Karlsson, 1993).

Interviews took place according to the participants’ wishes at the following places:

- four interviews were conducted in the participants’ private office
- one interview was conducted in HL’s private office
- thirteen interviews were conducted at the rheumatology clinics

The intention, with that the participants would choose the place of the interview, was that the particiapants should feel safe in the environment.

Research questions

To penetrate the phenomenon of BA, the following questions were asked:

- *Can you tell me when you are aware of your own body?*
- *How do you pay attention to your body?*
- *What parts of your body do you recognize?*
- *Can you remember a situation when you noticed that your body felt comfortable and without problems?*
- *Can you remember a situation when you noticed that your body felt uncomfortable and disturbing?*
- *In what situations do you not pay attention to your body and in what situations will body awareness disappear altogether?*
- *What does it mean for you to pay attention to your body?*

DATA ANALYSIS

Data analyses in study I-IV, se table 4.

Table 4. Data analyses in study I-IV (Overview).

Study	**I**	**II**	**III**	**IV**
Descriptive statistics	X	X	X	X
Cronbach´s alpha coefficient	X	X	X	
Chi-square test	X		X	
Confirmatory factor analysis	X			
Cross-cultural adaptation of self-reporting measures	X			
Univariate analysis of variance and backwards stepwise multiple regression		X		
Univariate analysis of variance and backwards stepwise logistic regression			X	
Empirical phenomenological psychological method				X

Cross-cultural adaptation of self-reporting measures

Study I

The procedure follows that recommended for cross-cultural adaptation of self-reporting measures for use in a different country and language (Beaton et al., 2000).

The process in this thesis was to identify overall problems with the BAQ questionnaire. A deeper understanding from the respondent's perspective can lead to useful information about the response process respondents employ when answering the BAQ questionnaire items.

Stage I: translation process

The 18 items in the original BAQ (Shields et al., 1989) were initially translated in *study I* from English into Swedish by three of the authors (HL, FS & U-BJ). A preliminary Swedish version was developed by synthesis of the translations by these authors. Next, a bilingual authorized translator translated the Swedish version of the BAQ back into English (back translation). A four-member back-translation committee (HL, EWH, FS & U-BJ) and the authorized bilingual translator then examined discrepancies between the original English version and the Swedish version of the BAQ. From this examination, a final Swedish version was approved.

Stage II: usability testing

The data collected from the think-aloud interviews were analyzed to reveal any problems in respondents' verbal and written reports (Collins, 2003). The transcribed interviews and the study protocol for each participant were analyzed under the headings *understanding, retrieval, judgment and response* (Tourangeau, 1984; Tourangeau, Rips & Raisinki, 2000). The "question-and-answer model" was used in the analysis. The question-and-answer model is a useful and commonly cited representation of how respondents answer survey questions. In its simplest form, the model suggests that there are four actions* that respondents have to complete to answer a question (Tourangeau, 1984).

*1. The participants must comprehend the question**

The key issue in comprehend, is whether the respondents interpreted the questions as the researcher intended (Collins, 2003; Tourangeau, 1984).

*2. The participants must retrieve the necessary information from long-term store**

Already in the 1970s, Tulving and Thomson (1973) argued that having comprehended the question the respondent then (usually) has to retrieve the relevant information from the long-term storage system. In designing questions, it is important to assess *how easily* respondents will be able to retrieve the information required (Collins, 2003; Tourangeau, 1984).

A number of factors may affect the retrieval process. Tulving and Thomson (1973) to begin with described that if the retrieval context is different to the original encoding context, the respondent may not be able to recognize that the event took place, or i.e. be able to recall the correct event (Tulving & Thomson, 1973).

*3. The participants have to make a judgment about the information needed to answer the question**

In designing a survey question, the researcher assumes that the respondent can provide the information being requested (Collins, 2003; Tourangeau, 1984).

Judgment forms an important part of the question-and-answer process because the information being sought is often difficult to recall accurately (such as dates or frequencies). What can be recalled may be incomplete (such as recalling the details of a particular event) (Collins, 2003; Tourangeau, 1984).

Or, in the case of attitude or opinion questions, the question asks the respondents to express a view or opinion on something that they may not have thought about (for some time) or in that particular context (Collins, 2003; Tourangeau, 1984).

*4. The participants need to respond to the question**

The final task described by the question-and-answer model is the response stage (Collins, 2003; Tourangeau, 1984).

Schwarz and Hippler (1991) note that there are two components involved in responding to the question: 1.) “formatting” and 2.) “editing the response”. The researcher’s choice of response alternatives may affect the way the respondent decides to answer the question (which may affect the survey findings). Having formed a judgment, the respondents then have to fit their answer into one of the pre-specified answers being offered (Schwarz & Hippler, 1991).

Tourangeau et al. (1984; 2000) suggests that the respondents may want to edit their answers before they communicate it because of the desire to conform to notions of social desirability and self-presentation. Collins (2003) describes that these effects may be more profound in face-to-face interviews, than in telephone or self-completion data collection methods. See figure 2.

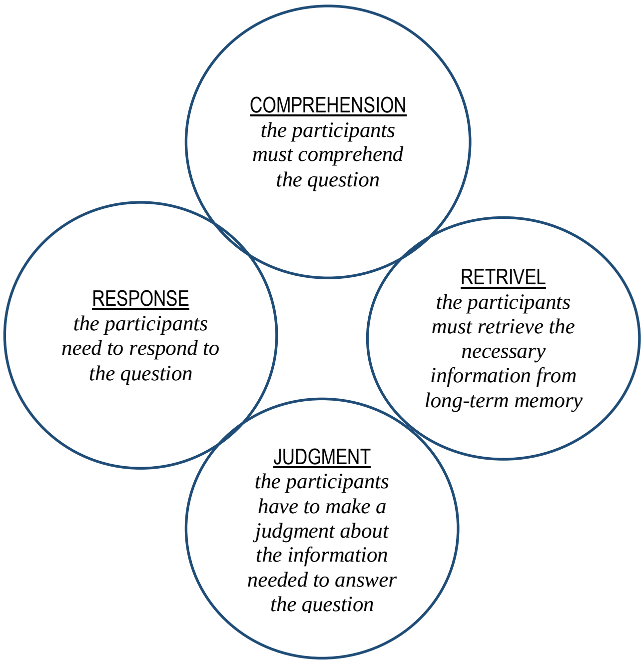

Figure 2. The four stages of Tourangeau’s model (1984).

In reality, the question-and-answer process is probably not linear, but involves numerous iterations of and interactions between the different phases (Collins, 2003).

Confirmatory factor analysis

Construct validity and internal consistency

Construct validity

CFA of the data was conducted using the SEM package in R to test the factor structure. Maximum-likelihood estimates were obtained for both the one- and four-factor model depicted by Shields et al. (1989).

To assess the overall goodness-of-fit, the chi-square test was used. The comparative fit index (CFI), the standardized root mean squared residual (SRMR) and the root mean square error of approximation (RMSEA) were also estimated.

The criterion values of the CFI are in the range of 0-1; Hu and Bentler (1999) suggest goodness-of-fit values of 0.90 are acceptable and > 0.95 excellent. A model showing a good fit will have a RMSEA index between 0.00 and 0.05 (Browne & Cudeck, 1993) and a value of SRMR close to or below 0.08 (Hu & Bentler, 1999).

The input correlation matrices for the CFAs were based on Pearson correlation coefficients, where missing values were dealt with by pairwise deletion.

Reliability

Cronbach's alpha coefficient was obtained to test reliability in terms of internal consistency. A value of 0.70 is generally considered sufficient (Nunnally & Bernstein, 1994).

Statistical analysis was performed using SPSS statistics 20 for Windows (IBM SPSS, NY, USA) and R 2.14.1 (R Foundation for Statistical Computing, Vienna, Austria).

Univariate analysis of variance and backwards stepwise multiple regression

Study II

To evaluate factors related to fatigue and pain, stepwise multiple regression analyses were performed in *study II.* The analyses were done in two separate models, with both performed in two steps.

In the first step, univariate analysis of variance (ANOVA) was conducted on all relevant independent factors. Based on the ANOVA, all factors with a p-value < 0.2 were entered into the second step.

In the second step, backwards stepwise regression was applied with model selection based on the Akaike information criterion.

Model fit

When the final model was obtained, the model assumptions were evaluated based on the residual diagnosis. The model fit was estimated using Adjusted R^2.

The statistical analyses were carried out using R version 2.14.1 (R Foundation for Statistical Computing, Vienna, Austria) and IBM SPSS Statistics 20 for Windows (IBM SPSS, NY, USA).

Univariate analysis of variance and backwards stepwise logistic regression

Study III

The statistical analysis, performed in two steps in *study III*, was aimed to evaluate factors associated with fear-avoidance beliefs.

In step one, univariate logistic regression was performed for all independent factors. Based on the univariate analysis, all factors with a p-value < 0.2 were selected into step two.

In step two, backwards stepwise logistic regression was used in which the model selection was based on the Akaike information criterion.

The dependent variable, mFABQ, was dichotomized as low (0-6) or high (7-24) according to median values, where the model estimates the odds ratio (OR) of having a high value.

The independent variables (age, sex, children and adults in the household, education, health, pain, fatigue and ESES) were grouped into the same categories as those adopted by Demmelmaier et al. (2013).

EQ-5D and EQ-5D VAS were dichotomized based on median values in the present sample.

Model fit

The model fit was estimated using Nagelkerkés R^2.

Descriptive statistics are presented as numbers and proportions (%). Differences between the two groups of participants (excluded versus included) in the analysis and of those with high and low mFABQ scores were analyzed with the chi-square test. Statistical significance was set at $p < 0.05$.

The statistical analysis was performed in R version 2.14.1 (R Foundation for Statistical Computing, Vienna Austria).

Empirical phenomenological psychological method

Study IV

The analysis in *study IV* was conducted using the EPP method (Karlsson, 1993) as applied to the phenomenon of BA. The method involves five steps. Data analysis was based on the following steps:

Step 1: A reading focused on gaining an initial understanding of the text at a level of everyday understanding. The first author (HL) read through the entire transcribed interviews and on several occasions listened to the tape recording for each participant separately.

Step 2: Interview texts were divided into meaning units, carefully marking (directly in the text) where a change in meaning had occurred in the text.

Step 3: Meaning units were then transformed into the researcher's language with focus on the significance of the meaning in light of the phenomenon in question, namely BA.

Step 4: The transformed meaningful units were assembled as an individual structure (situated structure) in terms of a synopsis, with one structure for each individual interview.

Step 5: Including *two parts:*

In step one - the condensed structures of each interview were eventually synthesized into a general characteristic common to all the (n=18) narrative accounts.

In step two - the variations of the phenomenon were interpreted in terms of typological structures (Karlsson, 1993).

Note: During the analysis process; through the use of reflection and through carrying out numerous critical discussions within the research group; the aim was to strive for openness and flexibility in relation to the data. The analysis (step 1-5) lasted for several months, due to rich amount of data from the 18 narrative interviews.

ETHICAL CONSIDERATIONS AND APPROVALS

The four studies were all approved by the Regional Ethical Review Board at the Karolinska Institutet in Stockholm. **Study I:** Dnr. 2010/734-32 and 2009/1795-31/3. **Study II:** Dnr. 2010/734-32 and Dnr. 2009/1795-31/3, **Study III:** Dnr: 2010/1232-31/1 and **Study IV:** Dnr. 2013/718-31/2.

The written information given to the participants (I-IV) included the aim of the study, what it meant to participate in the study (answering a questionnaire or participating in an interview), and assurance of confidentiality. The individuals were also informed that participation was voluntary and that they could withdraw from the study at any time. The studies (I-IV) were carried out in accordance with the ethical principles of the World Medical Association Declaration of Helsinki: ethical principles for medical research involving human subjects (2013).

FINDINGS

Usability of the instrument, construct validity and internal consistency reliability

Study I

Only one participant had some difficulties in following the study instructions and in thinking aloud. The interviewer sometimes had to remind this participant to think-aloud. All the participants scored each statement in the BAQ using a scale from 1-7 (1= “not at all true of me”, 4= “neutral” and 7= “very true of me”).

The majority of the participants (8 of 10) were able to comprehend (understanding) all the items in the BAQ, retrieve (retrieval) all the necessary information from their long-term store, make a judgment (judgment) about the information needed to answer the questions in the BAQ and respond (responding) to the statements in the BAQ. However, two participants expressed some problems in understanding the Swedish words “årtidsbundna rytmer (seasonal rhythms) och cykler” (cycles) in item 10, “specifika kroppsliga reaktioner” (specific body reactions) in item 13 and “alltför hungrig” (too hungry) in item 18.

Model fit

Neither of the models fulfilled the pre-specified criteria with respect to CFI, RMSEA or SRMR.

Cronbach’s alpha coefficients

Cronbach’s alpha coefficient for the total score was satisfactory. Cronbach’s alpha coefficients for the total score, and for the four subscales, are shown in table 5.

Table 5. Cronbach alpha coefficients, in students and RA patients.

	Students	**RA patients**
Onset of illness	0.25	0.62
Note response or changes in body process	0.52	0.71
Predict body reaction	0.63	0.79
Sleep-wake cycle	0.65	0.89
All questions	0.74	0.90

In the data from the student sample, item 6 (onset of illness, concerning item *fever)* was deleted in the four-factor model because of non-convergence of the statistical model and a factor loading above 1.

Fit indices for the confirmatory factor analysis (CFA) are shown in table 6 and table 7.

Table 6. Fit indices for CFA. RA patients.

Population	**Model**	**X^2**	**df**	**CFI**	**SRMR**	**RMSEA**
RA patients	*Single-factor* model	274.65	135	0.759	0.084	0.094
RA patients	*Four-factor* model	339.37	130	0.638	0.211	0.118

Table 7. Fit indices for CFA. Students.

Population	**Model**	**X2**	**df**	**CFI**	**SRMR**	**RMSEA**
Students	*Single-factor* model	224.29	135	0.689	0.084	0.079
Students	*Four-factor* model*	234.15	114	0.589	0.137	0.094

**Without question 6 for factor 4.*

Univariate analysis

Study II

Pain

The univariate analysis identified 3 of 17 independent factors as significant with a *p*-value of < 0.2 in relation to *pain*. The factors identified were EQ-5D (*p* = <0.001), DAS-28 (*p* = <0.001) and PSS4 (*p* = 0.001).

Stepwise multiple regression analysis

Pain

The results from the stepwise multiple regression analysis for pain show that *pain* was significantly associated with the EQ-5D (*p* = 0.008) and DAS-28 (*p* = <0.001). The adjusted R^2 was 50.0%.

Univariate analysis

Fatigue

The univariate analysis identified 7 of 17 independent factors in relation to *fatigue* with a *p*-value of < 0.2. These independent factors were no smoking (*p* = 0.104), no physical activity (*p* = 0.146), DAS-28 (*p* = 0.002), BAQ (*p* = 0.056), PA (*p* = 0.001), NA (*p* = 0.071) and PSS4 (*p* = <0.001).

Stepwise multiple regression analysis

Fatigue

The results from the stepwise multiple regression analysis for *fatigue* show that fatigue was significantly associated with no smoking (*p* = 0.021), DAS-28 (*p* = 0.049), BAQ (*p* = 0.006) and PA (*p* = 0.008). The adjusted R^2 was 28.6%.

The final models

The model for *pain* (50.0%) and the model for *fatigue* (28.6%) were considered acceptable (adjusted R^2).

Internal consistency

Cronbach’s alpha coefficients for the different instruments in study II ranged from 0.40-0.90. See table 8.

Table 8. Cronbach's alpha coefficients.

Instrument	Cronbach's alpha
BAQ	0.86
ERQ	
Reappraisal	0.76
Suppression	0.68
ISSI	
AVSI	0.76
AVAT	0.40
PANAS	
PA	0.90
NA	0.89
PSS4	0.74

Univariate and backwards stepwise logistic regression

Study III

Socio-demographic factors

The stepwise logistic regression showed that for the socio-demographic factors being male (OR 1.55, 95% CI 1.26 - 1.91) and earning a below average income (OR 1.35, 95% CI 1.12 - 1.63) were associated with an increased risk of high mFABQ.

**Excluded persons in the analyses for socio-demographic factors:*
A larger proportion of those excluded were older, lived alone had lower education and lower income than those not excluded.

Disease-specific factors

The two disease-specific factors most indicative of high mFABQ were high level of pain (OR 1.99 95%, CI 1.40 - 2.84) and poor health (OR 1.59, 95% CI 1.10 - 2.29).

**Excluded persons in the analyses for disease-specific factors:*
A larger proportion of those excluded had higher comorbidity and more RA symptoms.

Psychosocial factors

For psychosocial factors, low HRQoL (OR 0.44, 95% CI 0.35 - 0.55) and low ESES (OR 0.66, 95% CI 0.52 - 0.82) were significantly associated with high mFABQ.

**Excluded persons in the analyses for psychosocial factors:*
A larger proportion of those excluded had lower ESES and more mFABQ.

Significant overall correlations

The logistic regression model demonstrated significant overall correlations between all the independent variables and fear-avoidance beliefs (Nagelkerkés R^2 0.27). Overall, the model correctly classified 60.6% of the cases as high or low mFABQ.

Empirical phenomenological psychological method

Study IV

For descriptive statistics see table 9.

Table 9. Descriptive statistics, participants included in study IV.

Sex	**Age**	**Marital status**	**Children in household**	**Education**	**Diagnosed RA (year)**
Female	23	Cohabiting	No	Basic education	2007
Female	50	Cohabiting	Yes	University education	2004
Male	59	Cohabiting	No	University education	2006
Female	60	Living alone	No	University education	2004
Female	61	Cohabiting	No	University education	2004
Male	63	Living alone	No	College education	2012
Female	66	Cohabiting	No	College education	2003
Female	66	Living alone	No	College education	1999
Female	67	Cohabiting	No	Basic education	1992
Female	67	Cohabiting	No	College education	1996
Female	67	Living alone	No	College education	1999
Female	No information	Cohabiting	Yes	College education	2000
Female	No information	Living alone	No	University education	2007
Female	70	Living alone	No	College education	2007
Female	75	Living alone	No	University education	2006
Female	74	Cohabiting	No information	University education	2006
Female	75	Cohabiting	No	University education	1980
Female	78	Cohabiting	No	College education	2008

Information about the phenomenon of BA, from the patient's perspective, were obtained in study IV.

No general structure was found, due to all the various meanings contained in the 18 interviews.

However, general characteristics were present in the 18 interviews. The condensed structures of each interview were synthesized into **a general characteristic**, common to all the narrative accounts;

- BA can be understood in terms of a searching for, or the controlling of different symptoms. The disease symptoms triggered negatively toned BA.
- Heightened BA was also resulting from different emotional triggers. These emotional triggers gave either heightened positively toned BA, or negatively toned BA.
- BA was initiated through the participants taking an inventory of their abilities.
- The ability to change focus from BA to the outside world. This change in focus seemed to occur when the participants experienced an enjoyable, interesting, or meaningful environment.

A REACTIVE PROCESS*:*

React on bodily sensations, and stimuli's; react on symptoms emerging from the RA disease; and react on different emotional triggers. The symptoms of the disease called for the person's attention. Pain and fatigue were often in focus. Some persons mostly focused on their pain, whereas others mostly focused on fatigue. For some, this process occurred most often during the early mornings, but the body could also exhibit greatest symptoms in the evenings. Some participants explained that their body felt heavy, whereas others experienced their body as strained, and out of balance.

Participants also reported that heightened BA was triggered by different emotions.

Negatively toned; The body was not to be trusted, and as though they were constantly trapped inside a disabling body. Other participants described having strong feelings (i.e. fury and rage), and also grief over not having a normal functioning body. *A comparative process;* this form of reactive BA sometimes involved a comparative process (i.e., a comparison with either a younger body or the healthy body).

Positively toned; BA was also connected to awareness of bodily strength. Some participants experienced a positively toned BA to take part in physical activities or physical training, or to participate in alternative treatments, which could relieve their pain and discomfort. Positive BA was also experienced through living in a community with others, from feelings of acceptance, and feelings of being cared for by others.

AN ACTIVE PROCESS:

An active process on *taking an inventory* of one's abilities. This form of active BA was a process aiming at determining the body's current status, and abilities. It was a process to *check* bodily priorities, and the daily status. The participants mentioned that heightened BA was initiated by limited physical abilities. The participants tried to check, and control their body's abilities, and some investigated the energy level.

A SHIFTING PROCESS:

A chancing process; "between being body aware - or being in the outside world." The participants remarked that their attention was directed towards the world, and away from BA, i.e., they were no longer mindful of their own body. For some participants; the shift (from the body to the outside world) was often initiated, *active* by the participants themselves. For others, it was often a more *passive* process. They felt that the shift was the result of the world intruding on their life. BA in persons with RA (see figure 3).

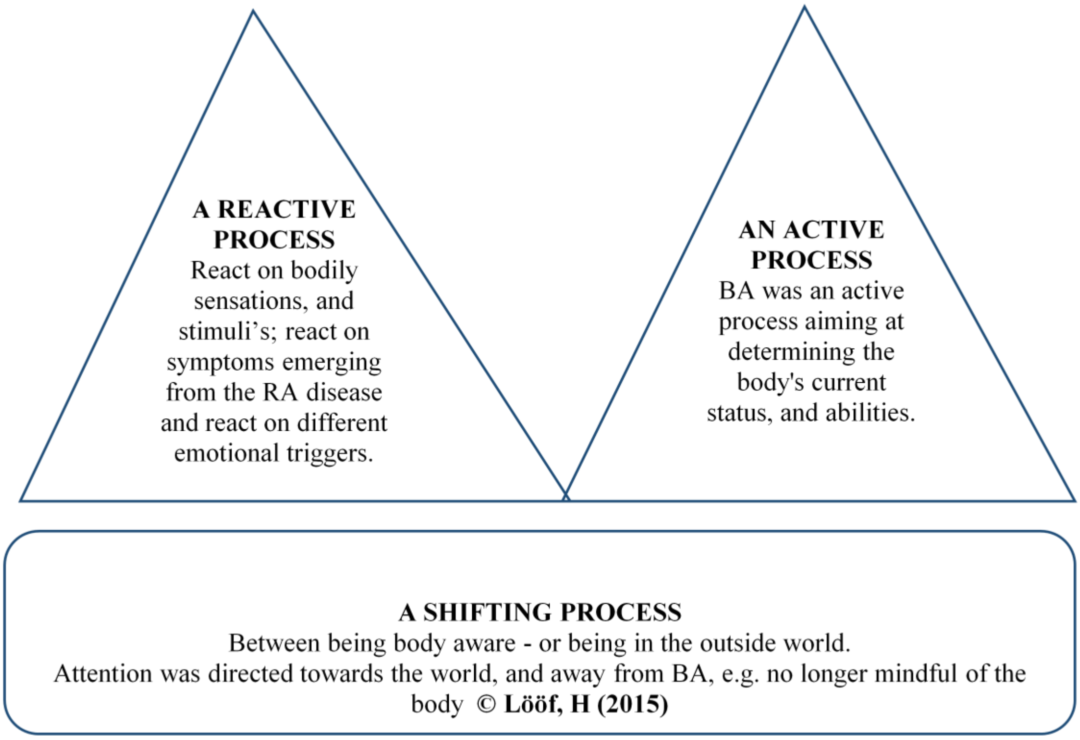

Figure 3. BA in persons with RA. Reactive and Active – A shifting process.

There were, however, differences in the interview descriptions. The variations of the phenomenon were interpreted in terms of typological structures. The typologies are exemplified by the participants' own descriptions in table 10.

Table 10. Typologies. Differences in the interview descriptions, the participants' own descriptions.
.

A reactive process on symptoms: *"When I do not get reminded of it myself, so to say. And it's then when I have pain in a joint, of course, and when I, it depends a bit on how much pain I have. I am most reminded of the pain in the morning and at night. In the morning it is a bit slow to get started, and in the evening one is simply tired from an exhausting day."* Participant in study IV.

A reactive process on emotional triggers: "*So, now I go to a physical training center. I go once a week to a physical therapist, which I think is very good. I've never gone before to any physical therapy or anything throughout my sickness. But since I broke my shoulder in January, I have a really good physiotherapist. And she has taken me in a group and she has a location in the X center. There are some Italian machines, it's called something like "X line," or something like that. Then, I think it feels good. I can do the movements. So, it is actually very good; so, it's positive and you feel happy when you leave."* Participant in study IV.

An active process on taking an inventory of abilities: "*...think for sure that if I manage to do the right things, meet some people or do something fun outdoors. But it's just that it gives a bit of energy. But one has to keep it up! This takes energy, too. If I would go to the cinema and watch a good movie, this requires energy as well. It becomes a catch-22 situation."* Participant in study IV.

A shifting from BA to the outside world: "*I can forget about myself when I am with, for example, my grandchildren. You go into their world and play with them. If, because I can be very childish then, and play with them. And then I think why not. I'll do it. I completely forget myself once I enter the game and get really childish. Then I can have fun and play with them."* Participant in study IV.

DISCUSSION

The overall aim of this thesis was threefold: to investigate pain, fatigue and fear-avoidance beliefs in relation to physical activity and their correlates in persons with RA; to develop a psychometric test to measure BA; and to obtain a deeper understanding of BA in persons with RA.

Chronic pain

Study II demonstrated that pain in persons with RA appears to be associated with decreased HRQoL and increased disease activity. The final models for pain (Adjusted R^2, 50%) were fairly high, suggesting that the model is of moderately to high predictive value.

Strand and Khanna (2010) demonstrated that RA can affect QoL and the individual's ability to work (paid or unpaid work). In addition, a systematic review and meta-analysis by Matcham et al. (2014) found that, in comparison with other physical illnesses, individuals with RA have a substantially reduced HRQoL.

Van Hoogmoed et al. (2010) and Walsh and McWilliam (2014) showed that pain severity is strongly associated with level of fatigue. Studies have also observed that properly designed exercise can reduce pain and fatigue. Baillet et al. (2010) and Cooney et al. (2011) reported that physical activity and physical exercise can improve psychological well-being and QoL in persons with RA. These findings are important to keep in mind when caring for persons with RA.

To summarize, over the years, patients and clinicians have consistently reported pain as a key outcome measure in RA that negatively affects life in different ways and therefore should be prioritized (i.e. Carr et al., 2003; Felson et al., 1993; Heiberg et al., 2005; Minnock et al., 2003). Although aggressive pharmacotherapy treatment strategies exist today, pain and loss of function continue to be reported by persons with RA and clinicans alike (Lee et al., 2014; Taylor et al., 2010; Verstappen, 2013; Walsh & McWilliam, 2014). Lee et al. (2014) found that persons with RA with only minimal signs of inflammation still had high levels of pain catastrophizing. Furhter, improvement in pain and health assesment did not differ between the two cohorts (with disease onset in 1990s and 2000s, respectively) in Anderson et als. studie (2015).

Chronic pain is often accompanied by limitations and difficulties in daily living. Anxiety, stress, depression and anger all interact in a complex network of chronic pain (SBU, 2006). In a review study, RA pain was often found to be associated with psychological distress (Walsh & McWilliam, 2014). Studies have reported that anxiety and depression can enhance the perception of pain (Korkmaz et al., 2009) and that pain intensity is associated with psychological distress in RA (Bai et al., 2009; Kosinski et al., 2000). A high degree of comorbidity has also been observed between chronic pain and various types of psychological problem. There is also strong eveidence to indicate that depression, which often occurs simultaneously with chronic pain, is the result rather than the cause of pain (SBU, 2006). Unfortunately, there is no data about the participants comorbidity (that could explain level of pain). Comorbidity should be included in studies investigating pain and its correlates. This fact limits the generalizability of the results in *study II.*

In the EULAR recommendations for the role of the rheumatology nurse, overall disease management involves monitoring the disease and common disease symptoms (i.e. pain) (Van Eijk-Hustings et al., 2012). Because persons with RA have been found to have a substantially reduced HRQoL (Matcham et al., 2014), it is important to study chronic pain using a multimodal approach. Based on the biopsychosocial model (Engel, 1977; Engel, 1980), a multimodal rehabilitation of patients with chronic pain conditions may include various combinations of physiotherapeutic, social, educational and psychological interventions (SBU, 2006).

Fatigue

Study II showed that fatigue was significantly associated with disease activity. Bergman et al. (2009) found that fatigue is multidimensional and that it is highly correlated with disease activity in RA. However, in their study, Bergman et al. (2009) found that it is not thought to be linked to classical inflammatory parameters (such as the ESR or concentrations of CRP, or to swollen or tender joint counts) (Bergman et al., 2009).

Because it is a subjective feeling, fatigue as a symptom appears to be quite complex (Repping-Wuts et al., 2008). Clinically significant fatigue is common in persons with RA (Carr et al., 2003), occurring in up to 70% in this group (Hewlett et al., 2005). Persons with RA report fatigue as their most disabling symptom (Gendelman & Amital, 2012; Perandini et al., 2012), and persons with RA feel that it is hard to cope with fatigue (Hewlett et al., 2005). Rupp et al. (2004) found that fatigue is an important cause of decreased QoL in individuals with RA. Fatigue (supplementary to RA-related pain and depressive symptoms) appears to be a feasible and treatable target in the clinical management of RA (Rupp et al., 2004).

Based on my knowledge from the literature investigating fatigue in persons with RA (i.e. Bergman et al., 2009; Carr et al., 2003; Garip et al., 2011; Hewlett et al., 2005; Hewlett et al., 2007; Nikolaus, Bode, Taal & van de Laar, 2010a; Nikolaus, Bode, Taal & van de Laar, 2010b; Nikolaus et al., 2013; Perandini et al., 2012; Thyberg et al., 2009; Wolfe et al., 1996), the concept and correlates of fatigue in RA seem to be highly complex. However, some factors were more often described than others in the literature (e.g., pain level, disability, anxiety and depression). In their overview, Stebbings and Treharne (2010) suggest that fatigue is influenced by disability levels, which may increase an individual's effort to perform day-to-day tasks. Stebbing and Treharne (2010) also discuss fatigue in relation to motivation and mood. Psychological mood and distress seem to be central (versus peripheral) factors in fatigue. The analysis for fatigue in study (Lööf et al., 2013b) shows that fatigue was significantly associated with BA and PA.

In Feldthusen et al. (2013) study fatigue was associated with negative emotions, changed self-image, and fears. Feelings of frustration and shame were central when the persons were forced to exclude valued life activities. Further, fatigue caused changes in cognitive ability, ability to act, and overall activity pattern (where the increased need for rest and sleep caused an imbalance in daily life). Fatigue was difficult to gain understanding for, and the participants adjusted their communication accordingly, it was important to keep up appearances. Coping strategies comprised; conscious self-care, mental strategies, planning, and prioritizing (Feldthusen et al., 2013). Based on findings, in *study II and IV*, concerning BA and PA, these results are also important to keep in mind, when caring for persons with RA.

In *study II*, the choice was made to not investigate sleep variables, in retrospect, such investigations should be included in future work. Moreover, the choice was made to not include the patient's comorbidity (that could explain level of fatigue). In retrospect, because depression is highly prevalent in RA (Matcham et al., 2013), comorbidity should be included in studies investigating fatigue and its correlates. Depression was one of the factors that had the highest link to the complicated process of fatigue in persons with RA (Nikolaus et al., 2013).

In summarize, research has shown that fatigue is related to mental health (Thyberg et al., 2009). In a study by Van Hoogmoed et al. (2010), depressive mood, self-efficacy for fatigue, helplessness and worrying were factors strongly associated with level of fatigue. Moreover, evidence suggests that fatigue can be used as a good predictor of physical activity (Balsamo et al., 2014). In individuals with RA, a higher level of daily physical activity was associated with reduced levels of fatigue (Rongen-van Dartelet et al., 2014). The literature indicates that there are many factors related to fatigue in RA, which makes it even more important to study fatigue, its correlates and lived experiences of fatigue in persons with RA.

The adjusted R^2 for fatigue (28.6% of the model) was low to fairly high in *Study II*, suggesting that the model is of moderate predictive value. However, more research is needed to enhance the models predictive value.

Fear-avoidance beliefs about physical activity

For socio-demographic factors most indicative of high mFABQ, below average income was associated with an increased risk of high mFABQ (study III).

Harisson et al. (2005) pointed out the importance of recording socioeconomic status in clinical trials because patients with lower socioeconomic status are more likely to experience higher disease activity, lower physical functions, poorer emotional aspects of mental health, lower QoL and greater pain (Harrison et al., 2005).

For the general population, positive correlates have previously been identified concerning physical activity. Among these correlates were being male (Bauman et al., 2012). *Nevertheless*, our results in *study III* showed that being male was associated with an increased risk of high mFABQ. Thus, it is important to study RA among men and the concept of fear-avoidance beliefs related to physical activity.

In both men and women with arthritis Shih et al. (2002) found that inactivity was associated with older age, lower education, and having functional limitations. *Among men*, inactivity was also associated with severe joint pain (Shih et al., 2002).

Research on denial and well-being in persons with RA shows that individuals with early RA report greater future denial than individuals with established RA. Moreover, younger patients report more hostility than older patients (Treharne Lyons, Booth, Mason & Kitas, 2004).

Nevertheless, in *study III*, the excluded groups comprised older persons, those who lived alone and those with a lower education and income. This fact limits the generalizability of the results.

Disease-specific factors, which are most indicative of high mFABQ, were high level of pain and poor health.

Pain severity appears to have an important role in disability. Ahlstrand et al. (2015) found that women reported higher pain intensity than men (Ahlstrand et al., 2015).

Physical inactivity has been found to be associated with pain, fatigue comorbidity, low functional capacity and higher levels of disease activity (Sokka et al., 2008). Correlates of physical activity reported in persons with RA include perceived health (Larkin & Kennedy, 2014).

In persons with chronic back pain, pain-related fear is reportedly associated with impaired physical performance (Al-Obaidi, Nelson, Al-Awadhi & Al-Shuwaie, 2000; van den Hout, Vlaeyen, Houben, Soeters & Peters, 2001; Vlaeyen & Crombez, 1999). Most studies have focused on patients with non-specific medical diagnoses, but the pain-related fear process is applicable to specific pain problems as well (Leuuw et al., 2007). Pain affects everyday life and may prevent the individual from performing valued activities. It could be a considerable challenge to choose the right activity level because it is easy to be overactive, triggering subsequent elevation of pain levels (Melanson & Downe-Wamboldt, 2003).

Persons with RA often experience increased levels of pain when participating in physical activity and exercise. This *temporary pain increase* can bee seen as a harmless tenderness, and is not a hinder to continued activity. To help persons reduce pain-related fear they need to be told that pain is a common symptom in RA that, particulary in the *chronic stage*, is not indicative of hurt or damage. An individual activity plan for achieving recommended activity is important. Bremander (2015) and Brodin and Swärdh (2015) additionally underscore that the physical activity should be *slowly introduced and gradually increased*. Moreover, a persons self-efficacy plays a major role in *how* goals and challenges are approached, according to Bandura (1977). The sense of self-efficacy can be strengthen by learning how to elevate mood (when facing demanding tasks) and by performing a task successfully (Bandura, 1977, 1992, 1995). Thus, suitable forms of exercise should be planed in relation to the person, it could be: *i.e.* biking, cross country skiing and walking etc. (Westby, 2001).

Melanson and Downe-Wamboldt (2003) found that physical limitations in daily life are the most significant disease-related concern in persons diagnosed with RA. Lempp et al. (2006) demonstrated that having RA leads to changes in the body, which limit an individual’s daily activities (Lempp et al., 2006). Eurenius et al. (2007) reported that a high level of physical activity in persons with RA at baseline was the only predictor of high physical activity one year later. Low pain, high physical activity and good lower extremity function were identified as predictors of good general health perception in persons with RA (Eurenius et al., 2007).

In patients with chronic back pain, pain-related fear has been reported to be associated with an increased self-reported disability (Asmundson, Norton & Allerdings, 1997). In another study perceived disability was significantly predicted by pain intensity and fear-avoidance beliefs (Ilse et al., 2006).

Ahlstrand et al. (2015) found that women reported more difficulties in performing valued life activities than men (Ahlstrand et al., 2015). The ability to perform valued life activities (i.e. that individuals find meaningful or pleasurable) has strong links to well-being (Katz, 2004).

In *study III*, the excluded groups in the analysis for disease-specific factors had higher comorbidity, more symptoms and poorer HRQoL. This limits the generalizability of the results.

In the present study, for psychosocial factors, low HRQoL and low ESES were significantly associated with high mFABQ.

Disaster thoughts and behaviors seem to function as a means to maintain factors for chronic pain and its consequences (Geertzen, van Wilgen, Schrier & Dijkstra, 2007). Avoidance (escape) is the most common coping category in persons with RA and one that is associated with predominantly negative outcomes (Ramjeet et al., 2008).

For the general population, some correlates have been identified for physical inactivity: intention to exercise, self-efficacy and previous physical activity behavior (Bauman et al., 2012). Additional correlates reported in persons with RA were perceived health, self-efficacy and motivation (Larkin & Kennedy, 2014). Negative social exchanges, stressors in the environment, lack of social support are factors that can influence a person's health (Gatchel, Peng, Peters, Fuchs & Turk, 2007). PA facilitates approach behavior (Davidson, 1993) or continued action (Carver, & Scheier, 1990a), i.e. individuals engage more with their environment and are willing to take part in different activities to a great extent. A person with PA feels more enthusiastic, active and alert. NA is manifested in decreased arousal, energy and activity, as well as the absence of positive feelings (e.g., sadness, lethargy and boredom) (Carver, & Scheier, 1990b; Gross & John, 2003). Results show that physical activity in persons with RA may be understood as a resource to resist disability, as well as to feel and stay healthy while creating and sustaining meaningfulness in life (Loeppenthin et al., 2014). Positive associations with PA were found to motivate physical activity, self-efficacy, health perception and previous PA levels in persons with RA (Larkin & Kennedy, 2014). Read et al. (2001) showed that lack of self-confidence was common in individuals with RA. These results are also important to keep in mind, when caring for persons with RA.

Persons with CFS exhibited reduced daily physical activity levels (Nijs et al., 2011; van Weering et al., 2007). Ickmans et al. (2013) believes that part of the cause of this deteriorated physical exercise capacity can be found in the entailed downward spiral of physical inactivity, as well as in avoidance behavior towards physical activity.

Severe exacerbation of symptoms following physical activity is characteristic of CFS and FM. These exacerbations of symptoms make it understandable for people with CFS and FM to develop fear of performing body movement or physical activity, and consequently, the development of avoidance behavior towards physical activity (Nijs et al., 2013). Fear descriptions were reported in a study on deteriorating health and fumble fear in individuals with RA. Because of their condition, these persons withdrew as a result of mistrusting the body (Östlund et al., 2014). In *study IV* some participants mentioned a lack of control over their physical condition, which was likely related to the continually unpredictable fluctuations of the RA disease process. During disease flare-ups, some participants expressed a fear about their changing body, which led to an increased negatively toned BA. Catastrophizing thoughts and fear-avoidance beliefs about physical activity can be addressed as negatively toned emotions and negatively toned bodily attention. Negatively toned self-focused bodily attention has been linked to less effective decision-making strategies and worse adherence (e.g., Christensen et al, 1996).

Behavioral interventions and gradual exposure to activity are necessary (i.e. to desensitize the patients' fear). Nijs et al. (2013) findings show that individually tailored CBT, in combination with exercise training (depending on the patient's classification as avoiding or persisting), appears to be the most promising strategy for treating fear of movement and avoidance behavior towards physical activity in persons with CFS and FM.

Van Eijk-Hustings et al. (2012) recommendations promote self-management skills in order that persons with chronic inflammatory arthritis might achieve a greater; sense of control, self-efficacy and empowerment (Van Eijk-Hustings et al., 2012). A systematic review and meta-analysis of studies (including psychological interventions for increasing physical activity in RA) indicate that techniques derived from self-regulation theory appear to play a role in reducing depressive symptoms and anxiety in individuals with RA (Knittle et al., 2010). A person's self-efficacy continues to develop, throughout life, as the person gain new experiences, and new understanding in life (Bandura, 1977). A source to strengthen the sense of self-efficacy can i.e. be observing people (similar to oneself) succeed by persistent effort. These results are additionally of value to keep in mind, when caring for persons with RA.

In *study III*, the excluded groups in the analysis were more fear-avoidant than the group included in the study. In addition, the excluded groups had a lower ESES. This limits the generalizability of the results.

The logistic regression model demonstrated significant overall correlations between all the independent variables included in the study and fear-avoidance beliefs (Nagelkerkés R^2 0.27). Overall, the model correctly classified 60.6% of the cases as high or low mFABQ.

Body awareness questionnaire

In study I, the choice was made to use cognitive interviews because think-aloud interviews have been suggested as a method to measure content validity (Drennan, 2003). Using the think-aloud method, the researcher can provide a better understanding of the questionnaire (in our case BAQ) from the respondents' perspective. Therefore, the concurrent think-aloud method (Collins, 2003) was used in the present study to investigate the usability of the Swedish version of the BAQ and to determine how the patients perceived and interpreted the questions. The low frequency of missing data in *study I* indicates that the Swedish BAQ was easy to complete. The majority of participants were able to understand all the items (1-18), retrieve all the necessary information, make a judgment about the information needed to answer the items and respond to each of the statements in the BAQ. Nevertheless, two participants expressed some problems in understanding a few Swedish words. Perhaps, another translation should have been done (especially for item 10, "årtidsbundna rytmer och cykler") in the Swedish version of BAQ. However, it remains the best translation, according to my knowledge.

Pre-testing questions in their questionnaire context enables the researcher to establish whether respondents can understand the question concept. Of particular importance is that the respondents do so in a consistent way and in a way the researcher intended (Collins, 2003). According to Fowler (1995), questions must be sensitive enough to measure important real differences or changes and that they cover all the dimensions of the topic under investigation. A fuller understanding from the respondents' perspective can lead to useful information about the response process respondent's use when answering the BAQ questions. The concurrent interviews gave valuable information from the participants' perspective.

The BAQ is designed to assess self-reported attentiveness to normal none-motive body processes, such as sensitivity to body cycles and rhythms, the ability to detect small changes in normal functioning and the ability to anticipate bodily reactions (Shields et al., 1989). The BAQ is a one-dimensional 18-item instrument in which the underlying structure is described by four factors. Respondents are instructed to read each statement and then, in the space to the left of the item, write the number that best described how true the statement was for them on a seven-point scale. All the participants in our study scored each statement in the BAQ using the same seven-point scale as mentioned above (Shields et al., 1989). Cronbach's alpha coefficient was obtained in *Study I* to test reliability in terms of internal consistency; a value of 0.70 is generally considered sufficient (Nunnally & Bernstein, 1994). Cronbach's alpha coefficient for the total score was satisfactory (0.86) for the Swedish version of the BAQ.

Neither of the models fulfilled the pre-specified criteria with respect to CFI, RMSEA or SRMR. Therefore, further testing of the Swedish version of BAQ, preferably with a larger sample, is recommended.

Lived experiences of body awareness

The symptomatic body out of synch

In *study IV,* one of the findings was that heightened BA was a reactive process for RA symptoms. All participants remarked that BA was a reactive process emerging from their pain, fatigue and other disease symptoms. The disease symptoms triggered negatively toned BA. The body, which might have previously been relatively quiet and unreflective, was now sick and continuously reminded of the disease symptoms that intruded on the person's life world. *Study IV* showed a change in the persons lived body, i.e. some participants felt as though they were constantly trapped inside a disabling, fatigued and painful body.

From a phenomenological perspective (Merleau-Ponty, 1997), having undergone a significant change in the body can have a radical change in a person's life. Awareness of one's perceptual field, which is transforming to the uncomfortable and problematic body (the symptomatic body), was the main focus for the participants in our study. According to Merleau-Ponty, access to the world is through our lived bodies. With this in mind, the participants experienced a lived life with unpredictable daily (stressful) symptoms that were a consequence of the RA disease. The reduced capacity to perform in life's activities is interesting to compare with Merleau-Ponty (1997) meaning that the subject and the world are inseparable.

In *study IV,* it emerged that the sick body fails to do what the person expects it to do. These findings are consistent with those of Bullington (2005). In Bullington's (2005) study, the participants' body disobeyed and the body was described as an alien. Our participants, *in study IV,* reported similar experiences. Attention was found against the former young or healthy body (body memories), as well as attention to one's limited capacity (body boundaries). In Bullington (2005) study the persons showed diminished strength and control over their bodies (Bullington, 2005), which was confirmed in our findings. The participants in our study felt that their body could no longer be trusted to perform as they wished. Uncertainty about day-to-day conditions in the symptomatic body was described in Nyman and Lütze (1999). The RA disease is manifested by periods of flare-ups in disease activity (Hochberg et al., 2011). The unpredictability of the disease and the disease flare-ups made it extremely difficult to make plans ahead of time (Iaquinta & Larabee, 2004). These results are also important to keep in mind, when caring for persons with RA.

Pain in persons with RA was commonly reported and affected the individual's QoL (Read et al., 2001). Researchers have shown that individuals with a chronic illness have a number of problems regarding fundamental changes in their life. This involves experiencing the body in different ways, i.e. dealing with uncertainty (Bury, 1982) and reconstructing the self (Corbin & Strauss, 1991). Illness can be a threat to the person's identity (Conrad, 1987). McCormack and McCance (2010) believe that illness and disease can be described as a threat to the self because illness and disease tend to increase the distance between what we want to manage and what we can manage (McCormack & McCance, 2010). Facing a large number of disease symptoms can make an individual become dependent on support and protection from the surroundings. Such a condition also places high demands on a person's coping skills (Sharif et al., 2009).

Positive and negative affect

Heightened BA was found in *study IV* in terms of a reactive process that likely resulted from different emotional triggers. These emotional triggers gave either heightened positively toned BA or negatively toned BA.

Persons with chronic illness suffer not only from the physical aspects of pain and discomfort but also from a loss of identity, whereby one feels alienated and detached from things that used to have meaning (Bullington, 2009). RA requires using different strategies in everyday life to cope with various emotions. Mental requirements and an overall need for coping management strategies are important for the person's health (Engelbrecht et al., 2012; Gronning et al., 2011; Shariff et al., 2009). The participants in Lütze and Archenholtz (2007) expressed fear of losing their independence. Some of the participants in *study IV* expressed fear about their changing body, that their body degenerated and that the body could no longer perform life's activities, all of which led to an increased negatively toned BA. Read et al. (2001) reported that their participants felt fearful about losing their independence and worried about the future (Read et al., 2001).

Feelings of guilt for those who had to take care of them, learning to cope with frustration and negative thoughts of the future were expressed by persons with RA (Ryan, 1996). In *study IV*, it emerged feelings of sadness or grief about the disease process. Moreover, some participants were concerned about the loss of ability that was caused by a diseased and degenerated body. The participants in *study IV* reported that they did not want to become a burden on their family, friends and community. In Stephens and Yoshida (1999), participants expressed feelings of anger and helplessness. The negative feelings of being a burden on others and the will of wanting to be in control of one's life were central to these participants (Stephens & Yoshida, 1999). In *study IV*, some participants expressed hatred towards their own body and they felt they were no longer " friends" with their body because of the constant reminder of their reduced ability to experience themselves in a positive way. These same participants expressed strong (negative) feelings (such as fury, anger, indignation and rage). These feelings were expressed as though the self was constantly trapped inside a disabling body. Not surprisingly, these feelings of being trapped (with no means of escape) inside a sick and aching body can affect the person's general health and well-being (Lööf et al., 2014), i.e. Lyrra and Hekkinen's (2006) participants with RA expressed good health in terms of having "freedom to choose in life". These results are also important to keep in mind, when caring for persons with RA. Iaquinta and Larabee (2004) found that RA strongly influenced mood and social life. Feelings of helplessness and uncertainty led to anger and depression. When activities could no longer be maintained, role positioning in the family also changed (Iaquinta & Larabee, 2004). The participants tried to adapt to illness by using new strategies (Lütze & Archenholtz, 2007).

The positively toned BA observed in *study IV* implied reinforcement of a positive emotion (e.g., hope, happiness, tranquility in body signals and curiosity). Most participants in Plach, Stevens and Moss (2004) found ways to enhance their adaptive capacity, to cope with symptoms of RA. These participants also made an effort to maintain as much normalcy in their life as possible (Plach et al., 2004). A positive engagement meant fulfilling roles, planning and meeting life goals and having a sense of well-being. The participants chose to accept uncertainty in their future and to live life on a day-to-day basis in their own design. The participants had to become more creative and had to let go of usual ways of doing things. By doing so, their energy could be devoted to important things in life. It was crucial to get support from others, yet still maintain independence (Schmidt, Brauer & Peden-McAlpine, 2003). Both self-management strategies and individuals need for support were essential in managing RA (Bergsten et al., 2011).

Hwang et al. (2004) found that positive support from families and others was important as a means to strengthen the will to live. Positive BA in *study IV* was also experienced through living in a community with others, feelings of acceptance from others and spending quality time with family and friends. For some participants *(study IV)*, positive BA was linked to feelings of being cared for by others (Lööf et al., 2014). Strategies for maintaining a positive attitude were setting realistic goals, using humor, being with family and friends, helping others as much as possible and refusing to surrender to the condition. By learning to recognize negative feelings, they could better deal with them (Shaul, 1997). Learning to live with RA was characterized by periods of uncertainty, of learning about the illness and discovering strategies that allowed the establishment of new patterns of daily life (Shaul, 1995). Not to plan too much in advance, thinking positively and participating in activities that are experienced as fun have previously been described as important (Ahlstrand et al., 2012; Kowalski & Chung, 2012).

Some participants (*study IV)* experienced a positively toned BA, i.e. they expressed a positive attitude to take part in physical activities or physical training. Positively toned BA meant that BA was connected to awareness of bodily strength, enjoyment and peace or tranquility in body signals.

Individuals who used resting and inactivity (helplessness category) experienced negative outcomes. Avoidance (escape) was the most common behaviour associated with negative outcomes in persons with RA (Ramjeet et al., 2008). Persons with RA and psychosocial problems are more anxious and show a lower sense of coherence. These persons also use more emotion-based coping strategies (such as resignation, protest, isolation and intrusion) (Gåfvels et al., 2011). The use of helplessness (inactivity and passive coping) and escape/avoidant coping strategies (including denial and wishful thinking) can be identified and dealt with by health care professionals to reduce the associated negative outcomes (Ramjeet et al., 2008). Medical health care workers (skilled in RA care) should offer psychosocial support to patients with psychosocial problems (Gåfvels et al., 2011). Individuals with RA who are under greater perceived stress and who do not use active coping strategies appear to be at risk for psychological comorbidity. Therefore, these persons may benefit from interventions that contain specific, active coping strategies (Treharne et al., 2007). These results are moreover of value to keep in mind, when caring for persons with RA.

Activity in daily life

In *study IV*, one of the findings was that BA was an active process that was initiated by participants taking an inventory of their abilities. This heightened BA was performed as a means to examine the abilities of the body in relation to different planned activities. Studies point out negative impact on daily life, especially in the way the participants perform their physical activities. Participants had negative perceptions that could be attributed directly to their physical limitations (Lütze & Archenholtz, 2007; Ryan, 1996). Our participants had heightened BA as an active process of taking an inventory of their abilities.

Read et al. (2001) identified activity and mobility as a hinder for persons with RA. Decreased physical activity gave a feeling of non-participation in leisure activities, which resulted in losses regarding participating in different life activities (Stephens & Yokshida, 1999).

The participants attempted to take an inventory of their abilities by adapting to the illness, by increasing their activities and using new strategies or stretching their physical limits (Lütze & Archenholtz, 2007). In *study IV* some of the participants tried to increase their activities, and stretching their physical limits.

Shiftning focus of attention

In *study IV,* turning attention away from BA would sometimes be beneficial for the person’s general health and well-being because disease symptoms are all too often the center of attention. These results are moreover important to keep in mind, when caring for persons with RA. Women reported different strategies for maintaining a positive attitude in Shauls (1997) study: setting realistic goals, using humor, being with family and friends, doing things they enjoyed, helping others as much as possible, praying and refusing to give in to the condition (Shaul, 1997). The motivation to continue to concentrate and undertake daily activities was believed to be important in the desire to feel “normal” (Hooper, Ryan & Hassell, 2004). Of central importence is to participate in activities that are experienced as fun (Ahlstrand et al., 2012; Kowalski & Chung, 2012). A shifting of focus from BA to the outside world could be done so that the individual could participate in joyful, meaningful or interesting activities. All the participants in *study IV* had the ability to shift focus from BA to the outside world. Ekman et al. (2011) noted that, in contrast to medical narratives (that reflect the process of diagnosing and treating the disease), the PCC approach captures a person's suffering in an everyday context (Ekman et al., 2011). McCormack & McCance, 2010) emphasizes that people's identity is created to some extent in the encounter with others.

Lorimer Moseley and Vlaeyen (2015) point out that a imprecision hypothesis posits pain as a conditioned response to multisensory and meaningful events that routinely coincide with, or preempt, nociceptive input. Furthermore, imprecise encoding of multisensory and meaningful events leads to overgeneralization of the response, such that an adaptive and protective process becomes maladaptive, distressing and disabling chronic pain. The authors suggest that more research be conducted to help open up new possibilities for the treatment of people with acute pain, focusing on the precise encoding of the painful event (Lorimer Moseley & Vlaeyen, 2015). This thinking is in line with the biopsychosocial model (Engel, 1977). Frankel et als. (2003), in applying the biopsychosocial approach to clinical practice, assert that it is important that health care professionals obtain the patient’s history in the context of life circumstances. Encouraging and educating individuals on how to cognitively reframe their current situation might play a key role in reducing the level of helplessness resulting from impairments of physical function and emotional well-being (Engelbrecht et al., 2013).

Alternative therapies/methods were deleniated in *study IV* that could give the possibility to access awareness of the comfortable and unproblematic body. The alternative therapies and methods could serve towards a better health experience in life. BAT has demonstrated good efficacy in both psychological and psychosomatic conditions, as well as in chronic pain (Lundvik Gyllensten & Gard., 2008). Evans, et al. (2013) examined the effect of a six-week program of yoga in young women with RA. Iyengar yoga increased quality of life and decreased RA-related pain, RA-related fatigue and depression. These positive effects persisted two months after completing the program (Evans et al., 2013).

Participating in meanigful, interesting or joful activities in the outside world was positive for the general health and well-being, according to the participants in *study IV*. Moreover, a good social support system can lead to better adaptation to illness (Hooper et al., 2004; Iaquinta & Larrabee, 2004). Social interactions were described by the participants as an important coping strategy (Lyrra & Hekkinen, 2006).

In their review, Hausteiner-Wiehle and Henningsen (2014) present conceptual and clinical relations between IBS, other functional somatoform disorders and mental disorders. These authors put forward that all mental and bodily symptoms, including those beyond the IBS core symptoms (as well as psychosocial strain, the level of functioning/participation and QoL) should be asked for (by the health care professionals) early in the course of the illness, regardless of the examiner's subspecialty (Hausteiner-Wiehle & Henningsen, 2014).

The multidimensionality approach addresses awareness of additional extraintestinal and psychobehavioral symptoms in patients with IBS, general and collaborative care (rather than specialist and separated care and implementation of "interface disorders"). This is of importance for abandon the dualistic classification of purely organic or purely mental disorders (Hausteiner-Wiehle & Henningsen, 2014).

The multidimensionality concept supports general and collaborative care rather than specialist and separated care (Hausteiner-Wiehle & Henningsen, 2014).

METHODOLOGICAL CONSIDERATIONS

The studies have some methodological limitations that must be addressed.

A cross-sectional design *(Study I-III)* is limited. Inherent limitations of a cross-sectional design are that it is difficult to make causal inference, the design deals only with survivors and measures parameters at a single point of time. Results from a cross-sectional design do not provide evidence for a causal relationship between the variables under investigation, i.e. it is impossible to infer causality (Bland, 2000).

Drennan (2003) posits that because the problems with questions and questionnaire responses are multifactorial, they need to be identified prior to the administration of the questionnaire. An enhaustive study plan was performed for the studies *I-IV*. However, self-reported questionnaires *(Study I-III)* could have some validity problems.

The four studies of this thesis included persons diagnosed with RA. All participants were diagnosed with RA according to the ACR criteria (Arnett et al., 1997). One strength of the research is that the same diagnosis criteria were used in all four studies. The exclusion criterion was any comorbidity *(Study I, II, IV)* that could affect the outcome of the study. However, enforcing this criterion could affect the generazibility of the results.

In *Study I*, *II* and *IV* a sample from only one geographical region was used. However, the sample was demographically comparable to the sample in a population study carried out in southern Sweden (Englund et al., 2010). In Sweden, differences in samples in different regions of the country might not be so large, but one should keep that in mind when making international comparisons.

Harisson et al. (2005) described the importance of recording socioeconomic status in clinical trials because patients with lower socioeconomic status are more likely to experience higher disease activity, lower physical function, poorer emotional aspects of mental health, lower QoL and greater pain. Thus, socioeconomic factors should be considered in the planning of future studies. In *study III*, caution with regard to generalizability should be taken into regards because of the differences between excluded and included groups.

A sample consisting of nursing students from a university college in Sweden was used in *study I*. All nursing students within a class were asked to participate. A sample of 120 students from two programs (Nursing program and Bridging program) were included in the study. The representativeness (in terms of generalizability) of the nursing students, who served as the control group (representing the public), can be discussed. How these nursing students represent the normal population on the basis of gender composition and training needs to be addressed. Nursing students, can be more body aware than the general population, and students are more likely to be able to participate in a study and answer the questionnaires correctly. Another parameter of concern is that the nursing students were younger then the included persons with RA.

In *study I* and *II*, no information is given about the the non-respondents (22%). Still, the response rate of 78% can be considered fairly high for this kind of study. In *study III*, the response rate was 59%, but no information about the non-respondents (39%) is given. For this kind of study, the response rate can be considered reasonable (and comparable to other similar studies).

In *study I and II*, Cronbach's alpha coefficient was obtained to test internal consistency reliability, i.e to measure how well the items in the questionnaire measure the same construct or idea. According to Nunnally and

Bernstein (1994), a value of 0.70 is generally considered sufficient (Nunnally & Bernstein (1994). Cronhach's alpha for the different measures in *study II* was: 0.86 (BAQ), 0.76 (ERQ-Reappraisal), 0.68 (ERQ-Suppression), 0.90 (PA), 0.89 (NA), 0.76 (AVSI), 0.40 (AVAT) and 0.74 (PSS4). The measurments that tested below 0.70 were AVAT and ERQ-Reappraisal, which is a weakness. This because low reliability means much of the observed test variance in measurement error.

Graneheim and Lundman (2004) describes that qualitative research results should be as trustworthy as possible. To achieve good *trustworthiness*, the following should be addressed: the *credibility* (in preference to internal validity), the *transferability* (in preference to external validity/generalisability), the *dependability* (in preference to reliability), and *confirmability* (in preference to objectivity) (Graneheim & Lundman, 2004; Guba, 1981). A qualitative research requires a well thought out and described approach. It is essential to describe how the research progressed, so the reader can follow the research flow (in each step) in the data method (Graneheim & Lundman, 2004). *However*, it is ultimately the reader who must assess whether the study showed good trustworthiness.

In phenomenology studies *(study IV)*, ideas are generated from a rich amount of data by means of induction and human interests. "*Phenomenology advocates the scientific study of immediate experiences and focuses on events, occurrences and happenings as one experiences them, with a minimum of regard for the external, physical reality*" (Fellows & Liu, 2008, p.70). Data gathering, however, can take up a great deal of time and resources. Further, the analysis and interpretation of a large body of data may be difficult (Fellows & Li, 2008). The EPP method (Karlsson, 1993) requires flexibility on the part of the researcher. For researchers, it is important to reflect on their own attitudes and preconceptions of the phenomenon in question. We aimed at openness and flexibility in the research process through the use of reflection and carrying out numerous critical discussions within the research group. However, because the researchers had considerable knowledge about the phenomenon under investigation, there could be a problem with openness in relation to the phenomenon (BA) at issue.

PRACTICAL IMPLICATIONS

Pain and fatigue are major concerns in persons with RA. Moreover, high BA and high fear-avoidance beliefs about physical activity in persons with RA have been associated with increased somatic and emotional distress. Negatively toned self-focused BA has been linked to less effective coping strategies, adherence, and affecting the person's general health and well-being. These results are important to keep in mind, when caring for persons with RA.

Moreover, it is also important to identify at an early stage those persons at risk for high negatively toned BA, and those groups at risk for high fear-avoidance beliefs in connection with physical activity. The treatment approaches in care should acknowledge its variability and multi-dimensionality.

The findings in this thesis indicate that it is important to encourage and support persons with RA to participate in adequate and meaningful health-enhancing physical activities and exercise. It is important to support how physical activities can be integrated into the daily life of the persons.

Moreover, health care professionals must have a more nuanced understanding of when BA is positive and when it is negative in relation to the person. By gaining more knowledge about the complex concept of BA, both maladaptive and adaptive BA can be addressed with greater understanding.

BA was found to be both positively and negatively toned in persons with RA though RA resulted in a higher degree of negatively toned BA.

The comfortable and unproblematic body, a positively toned BA, was experienced by taking part in physical activities and/or exercise, and to participate in alternative treatments, which could relieve their pain and discomfort. Positive BA was also experienced through living in a community with others, from feelings of acceptance, and feelings of being cared for by others. Positively toned BA meant that BA was connected to awareness of bodily strength, enjoyment and peace or tranquility in body process. These results are also important to keep in mind, when caring for persons with RA.

At last, from a biopsychosocial approach, different actors in the care of persons with RA are needed to improve the understanding of these issues.

CONCLUSIONS AND SUMMARY

- Pain, fatigue and fear-avoidance beliefs about physical activity in persons with RA have several potential correlates. The study revealed numerous correlations for socio-demographic, disease-specific and psychosocial factors for the variables investigated.

- The Swedish version of the BAQ is simple to administer and should be used as a tool to measure self-reported attentiveness to normal body processes. However, further testing of the Swedish version of the BAQ is required.

- BA was found to be both positively and negatively toned in persons with RA, though RA resulted in a higher degree of negatively toned BA. It is important to aim for a more nuanced understanding of when BA is positive and when it is negative in relation to the person.

- Having the opportunity to participate in meaningful and purposeful daily real-world activities keeps the mind busy (and distracted) and off the negative, and is therefore of great value for a person’s general health and well-being. Aiming for reframing is of great importence, because persons who use inactivity as coping strategies experience more negative outcomes and adherence.

FUTURE RESEARCH

Pain and fatigue are major concerns for patients with RA. Fatigue is an enigma that is hard to explain and control. Therefore, further studies designed to describe and explore the complex concept of fatigue in persons with RA are needed. Prospective longitudinal studies are called for to find out more about the multicausal pathways of fatigue in RA.

Some participants' initiated a shifting from the body to the outside world, but for others the world presented the meaningful and enjoyable activities. Studies have shown that improved BA may change people's attitude towards their own body, as well as the ability to participate in the outside world. It would be worthwhile to investigate the meaning of participating in the outside world using individual narrative interviews. Of further interest would be to investigate the process (*reactive or active – a shifting process*).

It would also be of interest to investigate whether there are gender differences in experiencing BA. Furthermore, testing of the Swedish version of the BAQ in a larger sample is recommended. In addition, of particular value would be to develop self-reporting instruments for BA that address important domains of BA and that discern between its adaptive and maladaptive aspects.

It might also be worthwhile to examine in greater depth fear-avoidance beliefs towards physical activity. The concept of fear-avoidance beliefs towards physical activity is multifaceted, and an understanding of what it means from individuals with RA and their perspective is needed.

To incorporate the persons perspective in relation to fear-avoidance beliefs research should be performed using a qualitative research approach. A phenomenological approch, as well as a focus group approach, could be used to investigate the phenomenon of fear-avoidance beliefs about physical activity in persons with RA.

Moreover, agreeing on conceptual and operational definitions of the various constructs for fear-avoidance beliefs must be addressed in future work.

Finally, intervention researchs (i.e. randomized controlled studies), are also of course needed for e.g. evaluating (the many) various therapies (aiming for treating) in relation to BA, and in relation to fear-avoidance beliefs about physical activity.

SVENSK SAMMANFATTNING

Bakgrund: Personer med diagnostiserad reumatoid artrit (RA) konfronteras dagligen med en mängd olika stressfaktorer, som innebär olika fysiologiska, psykologiska och sociala krav på personen. Smärta och svår trötthet är ett stort problem bland personer med RA, såväl som fysiska begränsningar. Rädsla för smärta, och rädsla-undvikande för fysisk aktivitet, beskrivs ofta som ett problem hos personer med kronisk smärtproblematik. Forskningsresultat visar vidare att en minoritet av personer med RA utför hälsofrämjande fysisk aktivitet (HEPA), och att psykosociala faktorer tycks vara de mest framträdande faktorerna för att förklara variationer i HEPA. Förmågan att varsebli kroppsliga inre förnimmelser och stimuli, kroppsmedvetande, beskrivs kunna ge antingen en positiv eller negativ inverkan på en persons hälsa och välbefinnande. Dock är begreppet kroppsmedvetande komplext, och mer förståelse behövs om begreppet från personer med RA och deras perspektiv. **Syfte:** Det övergripande syftet med denna avhandling var att undersöka smärta, svår trötthet, rädsla-undvikande för fysisk aktivitet och deras korrelat hos personer med RA. Vidare var syftet att översätta och psykometriskt utvärdera ett frågeformulär som mäter kroppsmedvetande, samt fördjupa förståelsen för kroppsmedvetande hos personer med RA. **Metod och resultat**: *Studie I* var en psykometrisk utvärdering av en svensk version av Body Awareness Questionnaire (BAQ), med en population av högskolestudenter samt vuxna personer med diagnostiserad RA. BAQ är ett självskattningsinstrument, som är utformat för att bedöma självrapporterad uppmärksamhet till normala kroppsliga inre sensationer och stimuli. Resultatet påvisar att värdet på Cronbachs alfa koefficienten, för den totala poängen i den svenska versionen av BAQ, var tillfredsställande. Enligt den konfirmatoriska faktoranalysen, uppfylldes dock inte de i förväg specificerade kriterierna. *Studie II* var en cross-sectionell studie med vuxna med diagnostiserad RA. Resultatet påvisar att smärta var signifikant associerat med hälsorelaterad livskvalitet, och sjukdomsaktivitet. Vidare att svår trötthet var signifikant associerat med sjukdomsaktivitet, kroppsmedvetande och positiv affekt. Den justerade R-faktorn var 28,6 procent för svår trötthet, och för smärta var den 50 procent. *Studie III* var en cross-sectionell studie med vuxna med diagnostiserad RA. Resultatet för socio-demografiska faktorer påvisar att män, samt personer som har en lägre medelinkomst var associerade med en ökad risk för hög rädsla undvikande för fysisk aktivitet (mFABQ var hög). Dessutom, de två sjukdomsspecifika faktorerna (för en hög mFABQ) var hög nivå av smärta och dålig generell hälsa. När det gäller psyko-sociala faktorer, så var låg hälsorelaterad livskvalitet, och låg självkänsla för fysisk aktivitet signifikant associerade med hög mFABQ. Modellens passform var 0,27 procent (Nagelkerkés R^2). *Studie IV* var en fenomenologisk studie, med Empirisk Fenomenologisk Psykologisk metod (EPP), hos vuxna personer diagnostiserade med RA. Studiens resultat visar på en generell karaktär, som har att göra med det faktum att RA hade gett upphov till högre grad av negativt tonat kroppsmedvetande. Kroppsmedvetande var en reaktiv process, för att söka efter eller kontrolla sjukdomsrelaterade symtom, eller en reaktiv process som utlöstes av olika emotioner. Vidare, kroppsmedvetande var en aktiv process, för inventering av ens kroppsliga förmågor. Alla deltagare i studien hade möjlighet att skifta fokus från kroppsmedvetande till den yttre omvärlden. **Slutsatser:** Avhandlingen visar att smärta, svår trötthet och rädsla-undvikande för fysisk aktivitet hos personer med RA är komplexa med flertalet korrelat inom socio-demografiska, sjukdomsspecifika samt psyko-sociala faktorer. BAQ är enkel att administrera, och skall användas som ett självskattningsinstrument som mäter självrapporterad uppmärksamhet till normala inre kroppsliga processer och förnimmelser. Reliabiliteten (intern konsistens) för den svenska versionen av BAQ var tillfredsställande, men ytterligare testning och utvärdering av modellstrukturens lämplighet behövs. Avhandlingen visar vidare att kroppsmedvetande upplevdes vara både positivt och negativt tonat hos personer med RA, men att RA resulterade i en högre grad av negativt tonat kroppsmedvetande. Förmågan att kunna skifta uppmärksamhetsfokus, från den egna kroppen till uppmärksamhet och aktivitet i den yttre omvärlden, kan vara betydelsefullt för personer med RA för deras generella hälsa och välbefinnande. Uppmärksamhetsfokus och delaktighet i den yttre omvärlden, genom för personen meningsfulla dagliga aktiviteter, kan minska ett negativt tonat kroppsmedvetande.

Nyckelord: Reumatoid artrit, Smärta, Svår trötthet, Kroppsmedvetande, Rädsla-undvikande för fysisk aktivitet, Fysisk aktivitet, Coping strategier, Intervjuer, Fenomenologi, Cross-sectionell, Psykometri.

APPENDIX

DEN SVENSKA ÖVERSÄTTNINGEN AV ”THE BODY AWARENESS QUESTIONNAIRE” (BAQ) (Shields et al., 1989).

BAQ enkäten mäter uppmärksamhet av inre kroppsliga sensationer (Shields et al., 1989). Den svenska översatta och validerade versionen av BAQ (Lööf et al., 2013) inkluderar 18 frågor, indelade inom följande fyra områden:

1.) Uppmärksamhet eller förändringar i kroppsliga processer

”note response or changes in body process" Fråga: 1, 4, 10, 13, 14, 16

2.) Förutsäga kroppsliga reaktioner

"predict body reaction" Fråga: 2, 3, 8, 11, 12, 15, 16

3.) Uppmärksamhet av ohälsa

"onset of illness" Fråga: 5, 6, 7, 10

4.) Sömn/vakenhets rytm/cykler

"sleep-wake cycle" Fråga**:** 7, 8, 9, 15, 17, 18.

Vid användande av den svenska validerade versionen av BAQ (Lööf et al., 2013) ska tillstånd om användande inhämtas hos Helena Lööf: helena.loof@shh.se som därefter skickar kopia av originalenkäten till forskaren/lärosätet.

Helena Lööf
Lecturer in Nursing Science, RN, MSc, PhD student KI and Sophiahemmet University
www.sophiahemmethogskola.se Stockholm, Sweden Phone (+46 8) 406 28 75 Mobile (+46) 073-990 6 995
helena.loof@sophiahemmethogskola.se

Följande referenser skall anges vid användandet av den svenska BAQ:

Shields, S.A., Mallory, M.E., & Simon, A. (1989). The body awareness questionnaire: reliability and validity. *Journal of Personality*, *53*(4), 802-815.

Lööf, H., Johansson, U-B., Welin Henriksson, E., Lindblad, S., & Saboonchi, F. (2013). Development and psychometric testing of the Swedish version of the Body Awareness Questionnaire. *Journal of Advanced Nursing*, *69*(7), 1643–1651**.**doi: 10.1111/jan.12020.

BAQ

Ett antal påståenden som människor kan känna mer eller mindre sanna om sig själva anges nedan. Läs varje påstående och ange sedan, i utrymmet till vänster, den siffra som bäst beskriver hur sant påståendet är för dig. Det finns inga rätt eller fel svar. Det bästa svaret är det som ärligt speglar i vilken utsträckning påståendet passar din egen erfarenhet. Använd följande skala:

1 2 3 4 5 6 7

Inte alls sant om mig Neutral Väldigt sant om mig

______1. Jag uppmärksammar skillnader i hur min kropp reagerar för olika sorters mat.

______2. Jag kan alltid förutsäga när jag slår mig om det blir ett blåmärke eller ej.

______3. Jag vet alltid när jag överansträngt mig så mycket att jag kommer att vara öm i kroppen nästa dag.

______4. Jag är alltid medveten om förändringar i min energinivå när jag äter viss mat.

______5. Jag vet i förväg när jag får influensan.

______6. Jag vet om när jag har feber utan att ta min temperatur.

______7. Jag kan urskilja mellan trötthet som beror av hunger och trötthet som beror av sömnbrist.

______8. Jag kan exakt förutsäga vilken tid på dagen brist på sömn kommer att hinna ifatt mig.

______9. Jag är medveten om cykler i min aktivitetsnivå under dagen.

______10. Jag uppmärksammar *inte* årtidsbundna rytmer och cykler i hur min kropp fungerar.

______11. Så fort jag vaknar på morgonen vet jag hur mycket energi jag kommer att ha under dagen.

______12. Jag kan säga när jag går till sängs hur bra jag kommer att sova den natten.

______13. Jag uppmärksammar tydliga kroppsliga reaktioner när jag är uttröttad.

______14. Jag uppmärksammar särskilda kroppsliga gensvar vid förändringar i vädret.

______15. Jag kan förutsäga hur mycket sömn jag behöver till natten för att vakna upp utsövd.

______16. När mina motionsvanor ändras kan jag förutsäga mycket exakt hur förändringen kommer att påverka min energinivå.

______17. Det tycks finnas en bästa tid för mig att gå och sova för natten.

______18. Jag uppmärksammar specifika kroppsliga reaktioner till att bli alltför hungrig.

References: Original version of BAQ: Shields, S.A., Mallroy, M.E., & Simon, A. (1989). The body awareness questionnaire: reliability and validity. *Journal of Personality Assessment, 53*, 802-815. Swedish translated version of BAQ: Lööf, H., Johansson, U-B., Welin Henriksson, E., Lindblad, S., & Saboonchi, F. (2013). Development and psychometric testing of the Swedish version of the Body Awareness Questionnaire. *Journal of Advanced Nursing 69*(7), 1643–1651.doi: 10.1111/jan.12020.

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Foto: *Lars Lööf, Sunflower.*

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