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Musculoskeletal pain rehabilitation

A one-year follow-up of occupational performance, psychosocial functioning and disability

Elisabeth Persson



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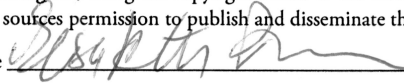
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Abstract <p>Multidisciplinary pain rehabilitation programmes are found decreasing pain and improve back-to-work rates. There is, however, a lack of knowledge in several respects. The overall aim of this thesis was to study outcomes in terms of occupational performance, satisfaction with performance, psychosocial functioning, disability, and coping profiles at a one-year follow-up after a musculoskeletal pain rehabilitation programme. Part of the aim was to evaluate differences among subgroups of participants based on baseline characteristics and pain-related severities, regarding the above described outcomes. Better psychosocial functioning and less severe disability were in a sample of 509 individuals (Paper I) associated with: older age, being at work prior admission, being Nordic born, longer education, a diagnosis of fibromyalgia (compared with neck disorder or low back pain). At a one-year follow-up psychosocial functioning was significantly improved whereas less improvement was found in physical disability. Improvements at one-year follow-up were independently of participants' characteristics. The participants' prioritized occupational problems in all sorts of occupations pertaining to looking after one self (self-care), enjoying life (leisure), and contributing to the social and economic fabric of a community (productivity). The most prioritized subcategory of occupations to be improved on was household management (Paper II). The most frequently reported occupations were reported as: working, sitting and cleaning the house. Occupational performance and satisfaction with performance improved significantly at discharge and at the follow-up (Paper III). Improvements on occupational performance at follow-up were significantly associated with the following factors: female gender, less physical disability, less life interference and more life control at baseline. However, participants with most perceived severities to perform their prioritized occupations had significantly higher chance to be improved. The pain coping profiles of Adaptive Copers significantly increased at the follow-up, whereas the Dysfunctional profiles significantly decreased (Paper IV). Having an Adaptive Coper profile at follow-up was associated with improvement on occupational performance and was significantly associated with: being Nordic born, having a longer education and an Adaptive Coper profile and higher scores on satisfaction with occupational performance at baseline. Having an Adaptive Coper profile at follow-up was significantly associated with improvements on occupational performance and satisfaction with performance.</p>		
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A one-year follow-up of occupational performance, psychosocial functioning and disability

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*Causes of happiness come rarely,
and many are the seeds of suffering.
But if I have not had pain,
I never longed for freedom,
and therefore o my mind, be steadfast.*

*Shantideva
quoted by
Chödrön, P. (1997).*

In memory to
Thyra-Lis, Seth, Olle and Motti

To my family

Erik and Mattias
Johanna with family
Lotta and Rebecka

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Abstract

Multidisciplinary pain rehabilitation programmes are found decreasing pain and improve back-to-work rates. There is, however, a lack of knowledge in several respects. The overall aim of this thesis was to study outcomes in terms of occupational performance, satisfaction with performance, psychosocial functioning, disability, and coping profiles at a one-year follow-up after a musculoskeletal pain rehabilitation programme. Part of the aim was to evaluate differences among subgroups of participants based on baseline characteristics and pain-related severities, regarding the above described outcomes. Better psychosocial functioning and less severe disability were in a sample of 509 individuals (Paper I) associated with: older age, being at work prior admission, being Nordic born, longer education, a diagnosis of fibromyalgia (compared with neck disorder or low back pain). At a one-year follow-up psychosocial functioning was significantly improved whereas less improvement was found in physical disability. Improvements at one-year follow-up were independently of participants' characteristics. The participants' prioritized occupational problems in all sorts of occupations pertaining to looking after one self (self-care), enjoying life (leisure), and contributing to the social and economic fabric of a community (productivity). The most prioritized subcategory of occupations to be improved on was household management (Paper II). The most frequently reported occupations were reported as: working, sitting and cleaning the house. Occupational performance and satisfaction with performance improved significantly at discharge and at the follow-up (Paper III). Improvements on occupational performance at follow-up were significantly associated with the following factors: female gender, less physical disability, less life interference and more life control at baseline. However, participants with most perceived severities to perform their prioritized occupations had significantly higher chance to be improved. The pain coping profiles of Adaptive Copers significantly increased at the follow-up, whereas the Dysfunctional profiles significantly decreased (Paper IV). Having an Adaptive Coper profile at follow-up was associated with improvement on occupational performance and was significantly associated with: being Nordic born, having a longer education and an Adaptive Coper profile and higher scores on satisfaction with occupational performance at baseline. Having an Adaptive Coper profile at follow-up was significantly associated with improvements on occupational performance and satisfaction with performance.

List of papers

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

- I. Persson, E., Lexell, J., Eklund, M. & Rivano-Fischer, M. Positive effects of a Musculoskeletal Pain Rehabilitation Program Regardless of Pain Duration or Diagnosis. *PM R* 2012; 4: 355-366.
- II. Persson, E., Rivano-Fischer, M., Lexell, J., & Eklund, M. Everyday occupational problems perceived by participants in a musculoskeletal pain rehabilitation program. *Scan J Occup Ther* 2013; 20: 306-314.
- III. Persson, E., Rivano-Fischer, M., Lexell, J., & Eklund, M. Occupational performance and factors associated with outcomes in patients participating in a musculoskeletal pain rehabilitation programme. Accepted for publication in *J Rehabil Med*.
- IV. Persson, E., Lexell, J., Eklund, M. & Rivano-Fischer, M. Changes in psychosocial coping profiles after pain rehabilitation: Associations with occupational performance and patient characteristics. Submitted.

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Abbreviations

AC Adaptive Copers

BPS Biopsychosocial

CARF Commission on the Accreditation of Rehabilitation Facilities

CBT Cognitive Behavioural Therapy

COPM Canadian Occupational Performance Measure

DRI Disability Rating Index

DYS Dysfunctional

IASP International Association for the Study of Pain

ICF International Classification of Functioning, Disability, and Health

ID Interpersonally Distressed

IMMPACT Initiative on Methods, Measurements, and Pain Assessment in Clinical Trials

IRP Interdisciplinary Rehabilitation Programme

MdPR Multidisciplinary Pain Rehabilitation

MIC Minimal (clinically) Important Change

MPI Multidimensional Pain Inventory

OT Occupational Therapist

P Physician

PS Psychologist

PT Physical Therapist

SALAR Swedish Association of Local Authorities and Regions

SW Social Worker

SQRP Swedish Quality Registry for Pain Rehabilitation

WHO World Health Organization

Definitions of central concepts used in the thesis

Activity

Defined as a more general, culturally shared idea about a category of action (Pierce, 2001).

Coping

Conceptualized as a stabilizing factor that can help people to maintain psychosocial adaptation during stressful periods; it encompasses cognitive and behavioural efforts to reduce or eliminate stressful conditions and associated emotional distress (Lazarus & Folkman, 1984; Moos & Schaefer, 1993).

Disability

Used to describe individuals' subjective ability to perform physical activities captured by the Disability Rating Index (Salén, Spangfort, Nygren & Nordemar 1994); therefore disability in this thesis denotes "physical disability".

Interdisciplinary team

This team constellation is most common in pain rehabilitation programmes. The different therapists contribute with strategies from their occupational roles and skills. Goals for the specific patient or patient groups are shared and coordinated and jointly set up together by all therapists and the patients involved (King, Nelson, Heye, Turturro & Titus, 1998; SoS, 2000; Lundgren & Molander, 2008). In this thesis used when referred to the programme under investigation.

Musculoskeletal pain

Musculoskeletal pain affects the bones, muscles, ligaments, tendons, and nerves. Musculoskeletal pain can be located in one area or be widespread (Vicenzino, Souvlis & Wright, 2002).

Multidisciplinary team

The work involvement of the different therapists is less coordinated, in comparison with that of interdisciplinary teams (King et al., 1998; SoS, 2000; Lundgren & Molander, 2008).

Pain Coping strategies

Refers to coping strategies described by the three pain coping profiles derived from the Multidimensional Pain Inventory (MPI) (Rudy, 1989; Kerns, Turk & Rudy, 1985).

Occupation

The definition of occupation used in the present thesis is:

“Occupation refers to groups of activities and tasks of everyday life, named, organized, and given value and meaning by individuals and a culture. Occupation is everything people do to occupy themselves, including looking after themselves (self-care), enjoying life (leisure), and contributing to the social and economic fabric of their communities (productivity)” (Law, Polatajko, Baptiste & Townsend, 1997, pp. 34).

The term occupation refers not only to work, but to all manners of human doing. Occupations are in the literature also defined as a person’s personally constructed one-time experience within a unique context (Pierce, 2001).

Occupational performance

Defined by the Canadian Association of Occupational Therapists as:

“The result of a dynamic, interwoven relationship between persons, environment, and occupation over a person’s lifespan; the ability to choose, organize, and satisfactorily perform meaningful occupations that are culturally defined and age appropriate for looking after oneself, enjoying life, and contributing to the social and economic fabric of a community” (Townsend, 1997, pp. 181).

Pain management

All actions, procedures and behaviours aimed at minimizing negative consequences of pain and providing long-term self-management of pain and its consequences (Main, Sullivan & Watson, 2008).

Psychosocial functioning

Refers to psychosocial factors related to pain and as defined by pain severity, life interference, life control, affective distress and social support (Kerns *et al.*, 1985).

Rehabilitation

Rehabilitation is a process aimed at reaching and maintaining optimal physical, sensory, intellectual, psychological and social functional levels for people with disabilities. Initiatives aimed to provide a person with acquired disabilities, based on their needs and circumstances, recover or retain the best possible function and create favourable conditions for independent living and active participation in community life. (WHO, 2013; Socialstyrelsen, 2007).

Preface

Several persons and circumstances have inspired me during the years I have worked with pain rehabilitation. I have learnt a lot by working together with skilled colleagues but most of all I have learnt from patients. During my first years as an occupational therapist I worked in a team with G. Nordström-Björverud who started the first group-based pain rehabilitation programme at the clinic, December 1989. The good results were later published (Nordström-Björverud & Mortiz, 1998). Effects on improved quality-of-life and long term effects (follow-up of 2-4 years and use of a comparison group) on return to work were found. In the 1990s a project focusing on a “doing” perspective in an occupational therapy group at the clinic was inspiring (Persson, 1996; Persson, 2001). In the 1990s an OT colleague E-K. Einarsson validated an early version of the Canadian Occupational Performance Measure (COPM), a client-centered measure that the occupational therapists in the clinic have mostly used since then. In the 1990s Professor B. Sjölund invited Fordyce and his team from the Seattle Pain Clinic to teach us about cognitive behavioural approaches. Our team visited J. Vlayen’s pain-team in the Netherlands some years later. In 1998 our team went to an IASP Congress. A PT colleague I. Lindström and I presented posters made with a lot of help from M. Rivano Fischer. In 2002 M. Eklund supervised me on a paper (Persson, Rivano-Fischer, Eklund, 2004). During studies on ergonomics and work-related rehabilitation at the Karolinska Institute and former Institute for Work-related Research I learned a lot. In recent years I have worked part-time at the Swedish Quality Registry for Pain Rehabilitation. Meetings with pain colleagues in Sweden have been inspiring. In 2006 I was offered a PhD employment at Jönköping University, however, in November 2006, J. Lexell and M. Rivano-Fischer, offered me the opportunity to begin part-time PhD studies in Lund. I started this project, which was first supervised by M. Eklund and then by J. Lexell and M. Rivano-Fischer in September 2008.

Having this possibility to investigate some of the aspects incurred from clinical interests, practice and research is a unique chance. I am very grateful for having this chance and for being able to take it. During these years research on pain has increased enormously, however, pain research focusing everyday occupations is still rare. This situation made me specifically interested to focus on everyday occupations, psychosocial functioning, physical disability and coping behaviours in the process of recovery for patients with persistent pain. Hopefully, this thesis will contribute with more knowledge in this field.

Introduction

Pain has throughout history accompanied the human race as a necessary factor for survival but also as a source of fear and threats (Andersson, 1998). Several complex factors are involved in both pain development, risk for having persistent pain and which pain-related consequences are most prominent. Persistent pain tends to vary over time, being worse in periods and decrease in other periods. Most people with persistent musculoskeletal pain live normal lives, stay active and participate actively in society. Nevertheless, some become disabled with varying degrees of suffering and consequences. In worse cases people may become unable to work and to manage normal everyday activities such as doing self-care, homework and leisure activities. Sometimes their social lives with friends and family diminish to a minimum and some of them seek health care. Interventions offered to them differ in both scope and intensity, not always in relation to their main problems. A smaller group of them are enrolled in cognitive behavioural interdisciplinary pain programmes at specialized tertiary centers, such as the one in focus in this thesis. Most of them have repeatedly received “treatment-as-usual” at primary health care centers, which generally entails consultation with physicians (59%) and physiotherapist (53%). Only 3% have been found to have had contact with a nurse or an occupational therapist (Marhold, Linton & Melin, 2001).

Pain

During the 1960s pain research was focused on a new theory of pain mechanisms (Melzak & Wall, 1965) which provided input to the definition of pain. The International Association for the Study of Pain (IASP) defines it as: “Pain is an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage” (Merskey, 1979). Pain is thus always a subjective and complex experience. Pain that persists over time has been described as chronic pain, intermittent pain, long-term pain and persistent pain. Chronic pain has by Smith and Gribbin (2001) been defined as, “pain that persists 6 months after an injury and beyond the usual recovery time of a comparable injury; this pain may continue in the presence or absence of demonstrable pathology” (pp. S1). Others use a time frame of three to six months (Norrbrink & Lundeborg, 2010). However, Manchikanti, Singh, Caraway and

Benyamin (2011) recently stated that the literature for chronic non-cancer pain including its terminology, prevalence, relevance, characteristics, and treatments, has been poorly described and continuously needs to be debated. In this thesis as well as in most publications the former term chronic pain will be substituted for the term persistent pain further used and referred to as musculoskeletal persistent pain that has persisted beyond expected time.

The “gate control theory of pain” model is commonly used to describe the brain’s active and dynamic role in modulation of pain in the spinal cord (Melzak & Wall, 1965). Pain should be understood as a complex experience including sensory-discriminator, affective-motivational and cognitive-evaluative aspects or dimensions (Melzak & Wall, 1965). The sensory-discriminative dimension delivers information about pain intensity, localization and duration. This information is a consequence of activity in the somatosensory cortex of the brain. The affective dimension (perceived as discomfort) is processed in limbic structures, amygdala and hippocampus. These brain structures are also processing emotional and memory functions. The cognitive dimension, components of thoughts and actions, are analyzed in the prefrontal and frontal cortex of the brain (Norrbrink & Lundeberg, 2010). The pathways in these processes are constructed as a “neuromatrix” of pain that provides a framework for explaining the role of central nervous system structures in the physiology of pain. This “neuromatrix” address the complexity of persistent pain and its diverse consequences for people having it.

A usual description of pain is in terms of its causal physiological mechanism, as nociceptive or as neuropathic/neurogenic pain. Nociceptive pain occurs through activation of nociceptors and neuropathic pain is evoked through activation in the somato-sensory nervous system (Norrbrink & Lundeberg, 2010). Sensory stimulation can adapt or modulate pain activities and the experience of pain on several different levels in the nerve system (Norrbrink & Lundeberg, 2010). Normal plastic phenomena intended to modulate peripheral and central processes when painful stimuli have been activated, occur in the nervous system in response to tissue injury or inflammation (Gerdle & Sandberg, 2006). These processes are conceptualized as peripheral and central sensitizations. Peripheral and central sensitizations are involved in the transition from acute to persistent pain (Gerdle & Sandberg, 2006). One process is the “wind-up” phenomenon described as increased incoming of nerve signals, and increased neurotransmitter activity and thus increased pain perception (Gracely, Grant & Giesecke, 2003). Reduced inhibition of pain signals is yet another mechanism in the downward control of pain (Gerdle & Sandberg, 2006).

Acute versus persistent pain

All people, with the exception of a few individuals with genetic deviation, experience pain. Pain is a fundamental experience. An example of acute pain is hammering on the thumb or pain coming from other injuries, or from pathological processes that affect the nervous system. Normal, acute pain is a warning signal aimed at protecting the person and usually decreases or disappears with time, within minutes, hours or days. However, pain may also be recurrent. Low back pain relapse incidences tend to come more and more often and remain for longer time (Linton, 2005). Acute pain is thus recognized as a signal that something has to be done to fix it. However, as the definition of pain indicates, pain is more than a specific acute sensation, it is a complex phenomenon. It is therefore important to understand the difference between acute and persistent pain. Acute pain may give information that is essential for human survival, by generating relevant escape behaviour in response to actual or potential tissue injury (Yaksh, 2008). However, such escape behaviours may be disastrous for a person with persistent pain as the situation then becomes even worse with time. Life may involve fewer and fewer meaningful contents.

It is argued that acute and persistent pains are different phenomena. The biological value of acute pain is lost when pain becomes persistent. The areas of the brain activated in acute pain differ from those activated during persistent pain (Apkarian, Hashmi & Baliki, 2011). In addition to the pain processes involved in the transition of acute to chronic pain it is important to focus on those from regional to widespread pain as well. Andersson (2004) described, in a general population follow-up study, that 85% of those with chronic pain at baseline still had chronic pain 12 years later. The number of painful areas at baseline has been found as a strong predictor for pain at a follow-up (Bergman, Herrström, Jacobsson & Petersson, 2002).

It has been maintained that some people are more prone to develop persistent pain due to an inherent vulnerability (Clauw & Ablin, 2008). Psychosocial and cognitive variables are found to be clearly linked with the transition from acute to chronic pain disability (Linton, 2000). In the transition from acute to chronic low back pain psychological factors such as distress, depressive mood, and somatization have been found to be involved (Pincus, Burton, Vogel & Field, 2002). Other risk factors associated with transitioning from regional to chronic widespread musculoskeletal pains are having higher age, family histories of pain, and number of pain sites at baseline and being women (Larsson, Björk, Börsbo & Gerdle, 2012; SBU, 2006). A further factor of note is comorbidity. Depression and other physical symptoms than pain are common in the group of people with persistent pain (Borg, Gerdle & Stibrant Sunnerhagen, 2006). This description of factors relevant for transition of pain indicates the heterogeneity of factors involved in persistent pain.

Persistent pain

Pain is in this thesis defined as pain remaining beyond the time expected, after an injury or even with no known tissue damage. Research on persistent pain has focused on its prevalence, the risk factors involved and the kinds of consequences it implies. A better understanding of pain mechanisms and pain management for people seeking health care due to persistent pain is required (Varrassi et al., 2010). During recent years opioid therapy has been found to escalate and in a review the use and misuse of opioids were critically evaluated (Manchikanti et al, 2011). In spite of the inherent differences, pharmacological treatments are used for both acute and persistent pain. Pharmaceuticals are firstly aimed at inhibiting pain, and when used together with multidisciplinary interventions both at inhibiting peaks of pain and inhibiting pain-related functional consequences (SBU, 2006). Other treatments such as psychological, social and occupational therapy treatments are mostly used a long time after the pain has become persistent and are focused on decreasing pain-related consequences, not in treating pain itself. These therapies are not primarily pain inhibitory (Rivano-Fischer, 2006).

The lack of explanations of why the pain has become persistent has been found stressful for those having persistent muscular pain. They report feeling rejected, misunderstood, and disbelieved. Such situations may prevent them from dealing with their situation constructively. Long investigation periods may also provoke anxiety and therefore a confirmation of a pain diagnosis is often a relief (Henriksson, 1995). However, in a recently performed review it was stated that there still seem to be a lack of knowledge and agreement on how to diagnose and treat acute low back pain among physicians (Fullen et al., 2008). Persistent pain may be combined with and sometimes confused with suffering. Individuals with pain are often described in the literature as “pain sufferers” or as people “suffering from pain”. Turk and Wilson (2009), however, propose a stop in referring to individuals with pain as sufferers and instead describe them as people with a painful condition. A person can indeed suffer without having a painful condition, and having a pain condition is not automatically linked to suffering. Pain-related disability can be significant, even with low levels of noxious stimulation, but for others higher levels of noxious stimuli are needed for reporting pain. If the person believes the pain is beyond their control they tend to report higher pain levels (Kahn & Steeves, 1996; Morse & Carter, 1996). The experience of control has been maintained as being important in qualifying the extent to which persistent pain is linked to suffering. In Figure 1 factors involved in the human processing of pain-related consequences are described: nociception, pain, suffering and pain behaviour. These concepts are commonly, described in the literature as being of relevance for understanding persistent pain consequences (Loeser, 2005; Turk & Wilson, 2009).

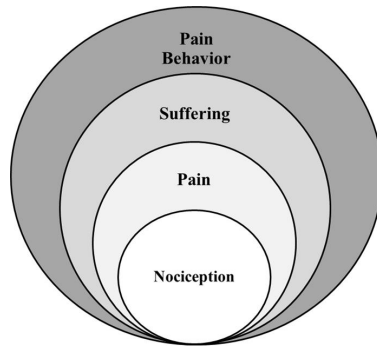


Figure 1.

The four components that are necessary and sufficient for describing the phenomenon of pain (Loeser, 2005, pp.21).

All pain and suffering is related to social interactions in the ascribed legitimacy of pain complaints (Lasch, 2005). However, suffering is probably a motive that makes people with persistent pain seek health care. It may not be the nociception or even the pain itself that makes people seek health care but the pain-related consequences from which they suffer (Loeser, 2005). In order to ease suffering it is thus important to not only focus on analgesia, but also on treating factors important for each individual person's suffering if this is possible (Body, Kaide, Kendal & Foex, 2013). Even if the pain itself can be a generator of suffering, other factors may be as important. Suffering may lead to pain behaviours, and health care providers should not question patients' complaints, but investigate what is behind the complaints, nociception, pain, suffering, or pain behaviour (Loeser, 2005).

Prevalence of and risk factors for persistent pain

Persistent pain is common and prevalence rates in western societies are described in several studies (Bergman et al., 2001; Verhaak, Kerssens, Dekker, Sorbi & Bensing, 1998; Breivik, Collett, Ventafridda, Cohen & Gallacher, 2006; Oslund et al., 2009; Freburger et al., 2009). Approximately 19% of adults in Europe report moderate to severe persistent pain (Breivik et al., 2006) whereas 15% of the population of the US report chronic pain (Oslund et al., 2009). The 19% reporting persistent pain in Europe included people reporting pain with the criteria that pain had remained six months or more and with a pain intensity of 5 or more on a 10-point scale (Breivik et al., 2006). The prevalence of low back pain was found to increase in the US during a period of 14 years, and the proportion of persons seeking health care also increased, from 73% 1992 to 84% 2006, while the mean number of visits to all health care providers was similar (Freburger et al., 2009).

No recent study that addressed an increasing prevalence among Europeans has been found. However, the rising prevalence and the increased proportion of pain patients worldwide indicate that of all people seeking healthcare those with persistent pain constitute a larger proportion (Freburger et al., 2009).

Literature has highlighted several risk factors for developing pain and pain-related disability. Risk factors are found in domains such as, injuries, work or activity-related risks, demography, psychological, biological (sex and age differences) and social factors (SBU, 2006; SBU 2012).

Injuries related to accidents, falls, and sports give rise to a high incidence of neck-related pain, often in terms of so-called whiplash injuries (Sterner, Toolanen, Gerdle & Hildingsson, 2003; Holm et al., 2009). Work-related factors are also found to have relevance for the development of musculoskeletal pain (SBU, 2012; Larsson, 2006; Holtermann, Clausen, Aust, Steen Mortensen & Andersen, 2013). Other risk factors described include a previous history of neck pain or low back pain, poor self-assessed health, number of children and poor psychological health (Croft et al., 2001). Physiological mechanisms and psychosocial factors are relevant for the development and maintenance of persistent pain (Bradley & McKendree-Smith, 2001). Psychological risk factors are described by Linton and Skevington (1999), later summarized by Linton (2005) and organized in groups of: behavioural, cognitive, emotional and social risk factors. Depression, anxiety and related emotions have been studied as factors strongly related to pain and disability (Linton, 2000). One psychological factor being relevant for increased risk of more severe disabilities after a chronic disease or injury is reduced ability to cope with new situations (Burell & Stensman, 2006). Low self-efficacy, yet another psychological factor, is related to higher pain-related disability (Richard, Dionne & Nouwen, 2011). Important evidence regarding the potential clinical relevance of a number of pain coping responses is hypothesized to influence future pain and functions in persons with arthritis (Alschuler, Molton, Jensen & Riddle, 2013).

Social factors should also be mentioned in addition to psychological factors. Social determinants have through convincing evidence been established as the most important gradients in health (Marmot & Wilkinson, 2006). One aspect of social determinants is social support that has also been found to be associated with the development of back pain and found to protect against developing chronic widespread pain (Linton, 2001; Ariens et al., 2001). Socio-demographic and psychosocial factors have been found by several authors to be important for pain-related disability (Hoogendoorn, van Poppel, Bongers, Koes & Bouter, 2000; Blyth, MacFarlane & Nicholas, 2007). Having a family history of chronic pain, having lower education and belonging to lower socio-economic groups, being an immigrant, living in a deprived housing areas are more associated with chronic widespread pain or fibromyalgia compared with no pain or regional pain (Bergman, 2005). Further proof of the relevance of social determinants for pain

prevalence is that apart from age, ethnicity, education, previous pain conditions, and marital status are also found to be risk factors for persistent pain (SBU, 2006; Edwards, Doleys, Fillingim & Lowery, 2001; Klaber Moeffett, Underwood & Gardiner, 2009; Wittink et al., 2006; Hunter, 2001; SBU, 2000). Women are found to be at greater risk than men for developing persistent pain (Fillingim, King, Ribeiro-Dasilva, Rahim-Williams & Riley, 2009; Gerdle, Björk, Henriksson & Bengtsson, 2004; Bergman et al., 2001). Higher mean numbers of pain sites are seen among: women, separated or divorced persons, those having a disability pension, smokers, persons with less physical activity and a higher body mass index, worse overall health and sleep quality (Kamaleri, Natvig, Ihlebaek, Benth & Brussgarrd, 2008).

Consequences of persistent pain

Persistent musculoskeletal pain might bring about severe negative consequences with regard to activity limitations and reduced participation in society (SBU, 2006). People with persistent pain have been shown to have lower life satisfaction as compared to a reference group from the normal population (Silvemark, Källmén, Portala & Molander, 2008a), indicating that persistent pain has consequences on several aspects of life. Reduced participation in society has negative consequences for society as well as for the individual. Loss of employment and income, mood disturbances, change in marital relationships and reduction of social and leisure activities are some of the consequences described (SBU, 2006; Hitchcock, Ferell & McCaffery, 1994). Persistent pain is thus associated with socioeconomic costs as well as with disability for the individual. In 2009 the cost of musculoskeletal disorders represented 31% of the total health insurance costs in Sweden (Försäkringskassan, 2011). The indirect costs (mainly productivity losses because of lost work days) appear to be substantially higher than the direct costs (pharmaceuticals, medical visits, physiotherapy, and hospitalizations) (Ekman, Jönhagen, Hunsche & Jönsson, 2005; van Tulder, Koes & Bouter, 1995). In a systematic analysis of the global burden of diseases it was found that pain conditions caused 21% of all years lived with disabilities (Vos et al., 2012). Persistent pain is common health problem and undertreated (Harker et al., 2012)

The negative effects on peoples' ability and participation in activities of daily life such as self-care, physical activities, social/recreational activities, family life and work are common pain-related consequences (Turk et al., 2008; SBU, 2006). Those with high levels of disability and limitations in their daily life also have higher levels of health care consumption (Becker et al., 2010). The more problems that those with pain have in performing everyday occupations the more they seem to consume healthcare (Müllersdorf, 2002). As daily routines may be disrupted and conflicts between life roles can lead to stress (Henriksson, 1995) such consequences probably force people to seek health care. Over and above problems

with everyday occupational performances, deteriorated psychosocial functioning and increased physical disability are highlighted and described as usual pain-related consequences (SBU, 2006; Salén et al., 1994; Turk et al., 2008; Stubbs et al., 2010). The concepts of occupational performance, psychosocial and behavioural functioning, and disability are specifically focused here and is described below in more detail.

Occupational performance

People with persistent pain experience loss of ability to perform valued occupations in everyday life and they also have reported loss of future opportunities (Henriksson, 1995). A reduced capability to be active and to perform everyday occupations is described as a common negative pain-related consequence (SBU, 2006; Müllersdorf & Söderback, 2000; Walsh, Kelly, Johnson, Rajkumar & Bennetts, 2004; Henriksson, 1995). Improved occupational performance is reported as one of three domains that strongest relates to treatment satisfaction after pain rehabilitation (McCracken, Evon & Karapas, 2002) thus implying that occupational functioning is an important consequence to focus on. Keponen and Kielhofner (2006) examined how women with persistent pain experienced their everyday occupations and the meaning of occupations in their lives. These authors found that the experiences of performing occupations differed in the women's histories. The meaning they ascribed to occupation, how they viewed other people in relation to their doing, and how they envisioned the future were relevant for how they experienced their everyday occupational performance. One conclusion from that study was that the experience of everyday occupations and the ability to perform occupations is heterogeneous and depends on the underlying meaning of how the participants interpreted their occupational life. Some of the experiences and the themes found (in brackets below) in the analyses were described as "occupation is a source of enjoyment" (=moving forward), "doing requires slowing down" (=slowing down), ".obligation without expecting enjoyment:" (=fighting) or "satisfying doing is impossible." (=standing still). Trying to understand the relevance of occupational performance, the meaning of and the strategies used to deal with everyday occupational problems that the participants attribute to their pain are issues to focus on. Some meanings and beliefs about occupational performance are described as "to be ready for" rehabilitation and whether acceptance or non-acceptance of the long term nature of their pain was perceived (van Huet, Innes & Whitford, 2009).

When evaluating occupational performances among people with persistent pain it is not just a question of whether an occupation is performed or not. There are often several issues to pay attention to, such as the quality of performance, barriers in the environment or habits in the way the performance is carried out. Some people with persistent pain are found to interrupt their performance and they give up activities and stop due to pain (Müllersdorf, 2002) or other unknown reasons. An

occupation is generally given up when pain becomes worse, except when the occupations are enjoyed, and then the pain may be ignored (Persson, Andersson & Eklund, 2011). People with musculoskeletal pain are found to report differences between performed occupations and what they want to do and most often among leisure occupations (Eriksson, Jonsson, Tham & Eriksson, 2012).

Occupational performance is closely connected to the concept of participation as it is used in the International Classification of Functioning, Disability, and Health (ICF) (Polatajko et al., 2007a). “People participate in and experience occupation individually and also through interactions with and for other people in a highly contextualized way” (Borell, Asaba, Rosenberg, Schult & Townsend, 2006, p. 84). The meaning of losing the ability to actively participate in family life and in society, based on the loss of the capabilities needed for performing occupations that should fulfill life roles and goals, impacts on the person’s whole self-identity. Experiencing and defining the impairment, making assessments and identity trade-offs and relinquishing control over illness is a process that may take time (Charmaz, 1995).

Psychosocial and behavioural factors

Behaviour is commonly associated with the field of cognitive behaviourism and broadly addressed within psychological pain research. Behaviour in psychology is defined as a person’s interaction with environmental factors and the person and the environment are influenced by the former’s behaviour (Smith, 1993). Behavioural consequences in pain may originate from automatically recalled defense mechanisms, such as flying or fighting reactions (Linton, 2005). Which of the responses, flying or fighting, that emerges, is determined by complex patterns of individual functioning and by several environmental factors. Fordyce (1968) originally termed pain behaviour as being of significant relevance for negative pain-related consequences. Pain behaviour is thus a pain consequence frequently focused among pain rehabilitation clinicians and researchers since the 1970s. Pain behaviours were usually when a person with persistent pain ceased to carry out everyday activities, reclined in the bed or couch, took too much pain medications or cried until the pain subsided (Fordyce, 1968; Fordyce, Fowler, Lehmann & DeLateur, 1968). One of the major criticisms of behaviourism is that it is mechanistic and does not account for the wholeness of human experiences and creativity (Ikiugu & Ciaravino, 2007).

The concept of pain-related psychosocial functioning goes beyond behavioural issues and involves relevant psychological and social factors including distinct affective dimensions of pain, life control and social support (Turk & Okifuji, 2002; Blyth et al., 2007). Psychological aspects of persistent pain and their relations to pain are then highlighted as being important pain-related consequences (Linton, 2000; Keefe, Rumble, Scipio, Giorano & Perri, 2004; SBU, 2006; Gatchel, Bo Peng, Peters, Fuchs & Turk, 2007). As persistent pain is a subjective

perception it is filtered by the persons' current psychological status and modulated in the "body-self neuromatrix" (Gatchel et al., 2007; Melzack, 2001, 2005). In the context of this "neuromatrix", psychosocial factors, however, should be viewed on both as risk factors for developing persistent pain and as consequences of pain. Psychological consequences can be derived from living with persistent pain, which in turn restricts everyday life, provokes anxiety and create conflicts between life roles (Henriksson, 1995). Stress, distress, or anxiety are reported as being related to pain (Linton, 2000). The degree of depression is seen to be one of the most important factors for lower levels of self-perceived health and quality of life among those with persistent pain, which is also strongly associated with catastrophizing among patients with neck-related pain (Börsbo, Peolsson & Gerdle, 2008). Pain catastrophizing, pain-related anxiety and fear, and helplessness are other psychological factors associated with pain and physical disability (Keefe et al., 2004). Pain catastrophic thoughts that have a negative impact for the patients' actual situations are specifically important as a pain consequence. These thoughts may be associated with patients' social goals (Sullivan et al., 2001), fear avoidance behaviour (Vlaeyen & Linton, 2000), and over-activity also known as "endurance" (Philips, 1998; Birkholtz, Aylwin & Harmann, 2004a; Hasenbring & Verbunt, 2010) and have impact on pain management in turn. The complexities of the consequences make it difficult to assess and understand pain. Some people known to demonstrate "endurance", also termed over-doers, have difficulties in stopping during occupational performances when they need to and they do not "listen" to when their body signals the need to take a break. However, the same person may in another situation act as though influenced by with fear and avoid occupational performances, cease occupations and evade participation due to fear of causing pain.

Physical Disability

Pain is often accompanied by changes in physical, emotional and social functioning (Turk & Wilson, 2009). In the pain literature physical disabilities are not always well-defined and this makes it difficult to compare studies describing physical disability. Physical functioning and disabilities are sometimes combined with occupational functioning, activities of daily living, and then defined as the ability to perform housework, work and travelling (Dworkin et al., 2005; SBU, 2010). According to the ICF model (ICF, 2003) physical functioning should, however, be related to aerobic capacity, physical fitness, and physical endurance fatigue. In the pain literature physical disabilities are mostly understood as a person's capability or ability to perform specific actions or activities (Salén et al., 1994), and then evaluated by using items that specify different activities (Dworkin et al., 2005). Physical disability due to pain is usually considered to be impaired for persons with persistent pain (SBU, 2010). It is thus important to assess patients' movements and mobility, muscle functions, sensory functions and muscle reflexes in order to identify eventual specific physical problems related to muscle-

bone functioning for evaluating whether these functions can be improved or even treated. Furthermore, physical disability is recommended to be seen as a core domain of pain-related consequences and to be focused when describing pain-related consequences (Dworkin et al., 2008). Physical disability is therefore often focused in pain research and often used as an outcome variable (Merrick & Sjölund, 2009; Norrefalk, Littwold Pöljö, Ryhle & Jensen, 2010; Grotle, Brox & Kjøppke Vøllestad, 2004; Sjöström, Alricsson, Asplund & Nordenmark, 2009; Salen et al., 1994). As chronic pain interferes with daily activities it has been assumed that relief of pain is accompanied with improved functioning (Dworkin et al., 2008), even though pain intensity and physical functioning are found to be only modestly associated (Turk, 2002). Recently it was also shown that improved aerobic capacity was not covered in self-report measures on physical function, used in rehabilitation focused on arthritis patients (Hagel, 2012). Therefore, if physical functioning, aerobic capacity, muscle strength or body movements are important aspects of physical disability these aspects should be evaluated by other measures than self-reports.

Pain rehabilitation

Rehabilitation refers to initiatives that will help a person with disabilities, based on the person's needs and circumstances, to recover or retain her/his/best possible capacity. Rehabilitation should thus create the most favourable conditions for independent living and active participation in community life for people with disabilities (Socialstyrelsen, 2007). Rehabilitation contains an educational process that is time-limited, goal-oriented and consists of various coordinated actions (Borg et al., 2006). Rehabilitation thus provides people with disabilities with the tools to attain independence and self-determination. Since persistent pain is complex with multifaceted origins and consequences it is best treated by multi- or interdisciplinary rehabilitation teams, including different professional competences and mixed medical interventions (SBU, 2006; Borg et al., 2006; SALAR, 2013). Studies of rehabilitation are included in university programs for occupational therapists, physiotherapists and physicians (Borg et al., 2006; Lundgren & Molander, 2008). Multimodal rehabilitation is a type of rehabilitation formed by several professions (at least three different professions) working in a team with planned and coordinated actions for a specific time and with a specific goal as defined together with the patient (SALAR, 2013; SBU, 2006).

Rehabilitation is an educational process in which coping and empowerment are central concepts. Coping is generally conceptualized as a stabilizing factor that can help people to maintain psychosocial adaptation during stressful periods (Lazarus & Folkman, 1984; Moos & Schaefer, 1993). Furthermore coping is conceptualized

as helping people to maintain adaptation and may also be a mediator between specific disease-related stressors and outcomes (Maes, Leventhal & deRidder, 1996). Haythornwaite & Heinberg (1999) have stated that it is not fully known when coping works, in what way it works and for whom. The ability to cope with a new situation when having a chronic disease and to cope with pain is important (Burell & Stensman, 2006; Alschuler et al., 2013).

It is of interest to evaluate which coping strategies that participants entering pain rehabilitation programmes use. Patients with chronic diseases have to deal with several challenges such as uncertainty, dependency, physical disability, pain, fatigue and the stigma and negative stereotypes imposed by others that introduce coping demands for people with chronic physical illnesses (Devins & Benik, 1996). The social support that persons with chronic diseases have access to is also essential for the ability to cope with illness and in what way significant others react or support will impact on how a person copes with persistent pain. Keefe, Salley and Lefebvre (1992) thus emphasized that it is important to consider the effects that spouses have on patients' pain coping styles, beliefs and coping efforts.

Appraisal of responses to illness in terms of coping appears to be essential, not only to understand responses to illness, but also in biopsychosocial treatment planning and for improving outcomes (Main, Richards & Fortune, 2000). Differences in the use of pain coping strategies across pain diagnostic groups have been described (Keefe et al., 1991). Peolsson & Gerdle (2004) examined gender differences and subgroups based on coping strategies. They found that pain, depression and coping in form of catastrophizing were interwoven and explained patients' health-related quality of life. Pain-coping relates to pain and disability and self-efficacy, beneficial pain coping strategies, readiness to change and acceptance are related to decreased pain and physical disability (Keefe et al., 2004). It is thus important to determine the unique contributions that coping strategies provide for the understanding of pain and pain adjustment in chronic pain patients (Keefe, et al., 1992).

Pain rehabilitation programmes

It was in the early 1950s that pain itself became a legitimate target for clinics and for research. Fordyce (1968) described in an early article on pain rehabilitation a case story of Mrs Y who was rehabilitated based on a behavioural approach provided by a rehabilitation team. An occupational and a physical therapy programme were designed as the main treatments. The intervention was based on practical learning, graded activity and behavioural approach. Mrs Y improved and dramatically increased her levels of activity during the treatment. These first pain programmes were mainly focusing on reducing negative pain-related behaviours and increasing activity levels (Anderson, Cole, Gullicksen, Hudgens & Roberts,

1977; Roberts & Reinhardt, 1980). Since the 1970s the multidisciplinary pain programmes and the research on pain rehabilitation has dramatically increased in most western societies. Goals, structures and methods used in these pain programmes have changed over time. There are still no official national guidelines in Sweden of the indicators of the need for rehabilitation. A proposal of indicators for unimodal and multimodal rehabilitation has been described (Samarbetsprojekt, 2011). In a national survey in Sweden it was found that professionals mostly used tacit knowledge to assess patients' needs for pain rehabilitation (Skjutar, Christensson & Müllersdorf, 2009). Important patient indicators described by therapists as being important for inclusion in rehabilitation were: activity level, catastrophizing, coping, existential problems, fear avoidance, high pain ratings, medications, motivation and reduced physical function (Skjutar et al., 2009).

Two models commonly used in pain rehabilitation

A biopsychosocial model (BPS) focused on both disease and illness is important in a context of complex interactions of biological, psychological, and social factors such as in pain (Engels, 1977; Gatchel, 2005). Another framework of disability is the ICF model (ICF, 2003). Both these models are used in pain rehabilitation. The BPS model questions the traditional approach within medicine that embraces a dualistic viewpoint that conceptualizes the mind and the body as separate and independent entities. The BPS model is widely accepted and used as a problem solving approach to chronic pain (Engels, 1977; Gatchel et al., 2007). With this model in mind Gatchel et al. (2007) reviewed the basic neuroscience processes of pain (the bio part of biopsychosocial), as well as the psychosocial factors of relevance. This research on how psychological and social factors can interact with brain processes to influence health and illness has provided new insights into brain-pain mechanisms. A BPS design has been adopted at rehabilitation medicine clinics in Sweden since the 1980s (Borg et al., 2006).

While the BPS model helps professionals understand the complexity of pain the ICF model should facilitate communication between professionals and organizations. It is used to describe the several factors involved in health (ICF, 2003). It has been shown to support the team during the assessment procedure (Schult & Ekholm, 2006; Löfgren, Ekholm, Broman, Njoo & Schult, 2013; Cieza et al., 2004). The use of a modified brief pain-specific core set protocol based on the ICF has been found beneficial (Löfgren et al., 2013).

Structures and goals of pain rehabilitation programmes

The structure of multidisciplinary pain programmes include how the team coordinates, plans and follows up the rehabilitation (Gerdle & Gullacksen, 2006). Rehabilitation programmes are designed to follow a designed process described to capture: a first assessment and diagnostics, writing a treatment plan together with the patient, inclusion in the multidisciplinary pain programme, follow-up and

evaluation of outcomes (Gerdle & Gullacksen, 2006). The length, duration and contents of both assessments and programmes vary widely (Unruh, Strong & Wright, 2002; Norrefalk, 2006; Löfgren et al., 2013; Ehrenborg, Gustafsson & Archenholtz, 2013). A recent review of interdisciplinary pain rehabilitation programmes stated that these programmes are usually 3-6 weeks in duration and 6-8 hours per day (Stanos, 2012). The team often monitors a performance assessment to adjust and modify the interventions due to the progress or deterioration during the programme (Borg et al., 2006). The focus of the process in rehabilitation is based on the individual rehabilitation plan that the team write together with each patient (Lexell, 2007). Regular meetings, when the team follow up patients' progresses or further needs, are recommended (SALAR, 2013).

Three structures or levels of pain rehabilitation based on patients' needs are described in Sweden. These are: unimodal, intermediary and multimodal rehabilitation (Gerdle & Sandberg, 2006). Before inclusion in any intervention an analysis of patient's needs must be done in order to find the right level of care. Unimodal rehabilitation is based on single actions/profession interventions. Intermediary interventions include several actions and contacts with physician, physiotherapist, psychologist, occupational therapist, social worker or any other health care professional can be included here. The professions do not work in regular teams and the actions occur without regularity. Multimodal team rehabilitation is offered for patients having large and complex needs. These teams work more coordinated and synchronized. They mostly work for several weeks with patients actively involved in full-time programmes. Unimodal and intermediary rehabilitations are of primary care interest and multimodal, multidisciplinary or interdisciplinary rehabilitation teams are often situated at specialized rehabilitation clinics.

Careful selection of patients, close monitoring, and flexibility in treatment approaches have been suggested as helping factors for overall improved treatment successes (Stanos, 2012). However, the most important may be having shared attributes and a successful communication between the patient and the team. In an interdisciplinary rehabilitation programme for patients with late effects of polio, the goal-oriented rehabilitation was seen to be a "turning point" in their lives and patients established new habits and acceptance of life (Larsson Lund & Lexell, 2010). A statement that is confirmed by clients enrolled in goal-oriented pain rehabilitation programme (Rydstad, Schult & Löfgren, 2010).

Since 2008, the government and the Swedish Association of Local Authorities and Regions [SALAR] introduced a guarantee for citizens in Sweden named "Rehabiliteringsgarantin" [Rehabilitation guarantee]. This initiative was intended as a guarantee for citizens to be able to receive rehabilitation when needed. The main purpose was that the diagnoses that accounted for most sick leave was to be offered additional services in terms of medical rehabilitation. The aim was to prevent sickness or to facilitate a return to work. The major diagnostic groups,

under the umbrella of this rehabilitation guarantee, were non-specific back and neck problems, and minor or moderate mental illness (SOU, 2011).

Patients referred to pain rehabilitation clinics have often already visited several health care professionals at primary care units, mostly physicians and physiotherapists (Marhold et al., 2001). When pain persists or treatment fails to produce desired effects referrals to specialist care, rehabilitation medicine clinics are recommended (Socialstyrelsen, 1994; SBU, 2006). It is important to focus on the two questions: ‘What is wrong?’ and ‘What can be done about it?’ as if the patient does not receive answers to these and then may not be motivated for further actions (Walsh et al., 2008; Matthias et al., 2010). The pain diagnoses should first be confirmed, further need of examinations or unimodal treatments should be precluded, and the complexity of the pain-related consequences are to be evaluated as being of such a nature that the pain programme is needed. This is to be established at an assessment prior to inclusion in a pain programme (SBU, 2006). At the initial encounter an effective communication with respect to the patient’s goals is fundamental to a successful outcome (Stanos, 2012). Successful interventions for patients with persistent pain should lead to important gains for the individuals in terms of improved health and for the society in fewer costs.

Key successful outcomes lie in shared attributes of the treating teams, focusing on helping patients reduce eventual maladaptive behaviour, foster optimism, combat demoralization, and promote a self-management approach (Stanos, 2012). The goals may, however, vary some in different pain treatments. An overall focus on different strategies that help patients to increase their participation in society and in an active and meaningful everyday life is thus the overall goal for most pain programmes. Minimizing “doctor shopping” behaviours (von Korff, Wagner, Dworking & Saunders, 1991; SBU, 2006) and motivating the use of self-management strategies are often other important goals. A decrease of non-effective analgesic medications or minimizing opioid-use is yet another common goal (Anderson et al., 1977; Manchikanti et al., 2011). A recently found increasing use of opioids has been criticized, and instead use of appropriate pain management therapies are proposed by Manchikanti et al. (2011). Prescription of opioids has recently also been described associated with people having higher levels of “overactivity” (Andrews, Strong, Meredith & Fleming, 2013) indicating a need to assess client’s occupational patterns, “overactivity”. Three issues are found to be of main importance for patients’ satisfaction with treatment outcomes during pain rehabilitation. These are patients feeling that their evaluation was complete, that they received an explanation for clinical procedures used, and that treatment helped them to improve on their daily occupations (McCracken et al., 2002).

Professions working in pain rehabilitation and team work

Team collaboration is a key when working in health and social care. In order to face the biopsychosocial approach multidisciplinary treatments are needed.

Different professions have different knowledge bases, paradigms, treatment goals and treatment strategies (Lundberg & Molander, 2008). The challenge is to find a way of co-operating with others while it at the same time it being clear for all team-members what each profession contributes with (Finlay, 2004). Interdisciplinary pain rehabilitation clinics mostly include physicians, nurses, occupational therapists, physiotherapists, psychologists and vocational counsellors or social workers (Stanos, 2012; SALAR, 2013). Physicians, physiotherapists and psychologists are mainly trained and educated to assess and focus physical or psychological functioning, whereas occupational therapists and social workers have methods to assess and focus everyday occupational functioning, participation and environmental factors. A sustainable balance between generic and specialist roles that works for a team and its service users are needed in order to develop beneficial team-based work. In team work the professionals and their specific knowledge form the contents and methods used in pain programmes. Description checklists for professional competence and work duties, according to national recommendations, have been established in Sweden and internationally (SALAR, 2013; Stanos & Houle, 2006). It is important that these professionals are skilled in team work as the outcome of rehabilitation is dependent on attitudes, thoughts and motivation regarding the rehabilitation process. The rehabilitation process in itself also builds on social interaction (Öhman, 2005). Therapists' abilities to bring about a therapeutic alliance with patients are therefore of most importance (Ferreira et al., 2013).

Pain curriculum, international guidelines on education and practice for the professions involved in pain treatment have been established (Watt-Watson et al., 2004). The IASP organization has accurately described teaching courses on chronic pain at both undergraduate and graduate level, last updated in May 2012 (IASP, 2012). Specific information about: dentistry, medical schools, nursing, occupational therapy, pharmacy, psychology, physiotherapy and inter-professional issues are included in these courses. However, a need for a pain-related curriculum in health science programs at least including medicine, dentistry, pharmacy, physiotherapy, occupational therapy, has also been presented (Watt-Watson et al., 2009).

Finally, there is no organization that is the best for all cases. Team work has been criticized for being expensive, difficult to organize in order to fit in with health care reimbursement systems, unclear responsibility and requiring good leaders. The advantages with teams are, however, found to be their effectiveness when the medical problem is complex and when problems need to be solved by different methods. Other advantages with team work are that this approach is shown to generate good outcomes, have impact when several people give the patient the same information and be effective when different competencies are needed during rehabilitation (Lundgren & Molander, 2008). However, it is not known which specific process, content or structure, professional method or skill that is the most

beneficial in pain rehabilitation. It is assumed that it is the total and interactive part that is the best with team work. The team constellations and methods used by different professionals simultaneously are mostly based on clinical evidence. All components included needs to be further evaluated. Some processes and methods are evaluated in several studies whereas others are not evaluated at all.

Methods used in pain programmes

Pain programmes are mostly designed to include different interventions aimed at teaching patients to use self-management techniques (Unruh & Harman, 2002; SBU, 2006; Strong & Unruh, 2002). Attention to psychological management of pain, often with a cognitive behavioural approach, is generally recommended in addition to physical and activity-related managements (Unruh & Harman, 2002; SBU, 2006; Strong, Unruh, Wright & Baxter 2002). Scheduled sessions for occupational therapy and physiotherapy groups, group therapy sessions lead by a psychologist or social workers, medical information and group-based information from the professions included seem to be the other usual contents (Loeser & Egan, 1989; Rydstad et al., 2010; SBU, 2006; Samuelsson, Carlberg, Hesselstrand, Ölander & Wressle, 2011; Unruh & Harman, 2002). Fitness training, relaxation, biofeedback, manipulation, acupuncture, physiotherapy, occupational therapy, video-feedback, workplace visits, and activity training focusing both avoidance and over-activity patterns, time-use strategies, graded-activity training, are methods that are usually described in the literature (SBU, 2006; Nordström-Björverud & Mortiz, 1998; Unruh & Harman, 2002; Gerdle & Gullacksen., 2006; Norrefalk, 2006, IASP, 2012). However, it should always be the patients' need that determines which interventions that are to be used. Based on the patients' needs it should also be defined which professions are to be included, which in turn depends on the patients' main problems. If one profession is needed but not available this missing profession should be consulted (SALAR, 2013).

Learning and educational strategies contribute with important knowledge for professionals in these pain programmes in order to facilitate the process on how to teach strategies for best pain management (McGrath & Hillier, 2001). Two questions are found relevant when assessing the learning of new skills in pain management. These questions are focused on humans' values and their behaviours. How much do the patients want the reward (ability for adopting new behaviours) and how much do they want to avoid discomfort (accept pain as being persistent)? Pain-related prediction and decision-making, the core components of pain motivation, is a particular class of learning algorithm called Reinforcement Learning (Seymour; 2013).

Operant behavioural-graded activity training and problem-solving training are focused in programmes that are strictly behavioural and exposure-based for those with fear-avoidance behaviours (Fordyce, 1976; Vlaeyen, Linton, Boersma & de Jong, 2012). Skilled therapists then focus on time-contingent increase or pacing of

activities that are important and relevant for the patient's personal situation. Problem-solving training is still described as a useful ingredient for pain management programmes (van den Hout Vlaeyen, Heuts, Zijlema & Wijnen., 2003). Morley (2011) has described the development of cognitive behavioural therapy and the author starts with Buddhism 1000 BCE, probably as focus on the benefit of mediation, yoga or mindfulness training has been emphasized during the last decades, techniques with roots from ancient philosophies. The development of cognitive behavioural therapies has been described in a timeline as follows: operant behaviour analysis and operant therapy (1960s), bio-feedback and stress management (1970s), cognitive therapy, mindfulness-based stress reduction (1980s), fear avoidance model (1990s) to acceptance-based approaches (ACT) (2000th) (quoted by Vlayen, Linton, Boersma & de Jong, 2012). ACT focuses on training and assessing patients to Accept, Choose and Take action. The main focus in ACT therapy is not to control the pain but to focus on life roles, thoughts and mindfulness interventions (Harris, 2009; Kabat-Zinn, 1990; Dahl & Lundgren, 2006; McCracken, 2005). Suffering and its link with emotional pain emphasizes working with the knowledge that the suffering "is not you", and such emotion-focused coping is a part of an ACT concept (Kabat-Zinn, 1990). The CBT or ACT techniques, based on psychological and philosophical theories, can be used in individual therapies. When used in interdisciplinary rehabilitation these approaches should be known by the whole team, often with a skilled therapist as a guiding supervisor (Unruh & Harman, 2002).

Essential elements for enabling occupational performances

Engagement in occupation is considered to be an important factor for general health and well-being (Townsend & Polatajko, 2007; Kielhofner, 2008; Hasselkus, 2002). The link between occupation and well-being has been established by several authors (Law, Steinwender & Leclair, 1998a; Eklund & Leufstadius, 2007). Schult, Söderback and Jacobs (2000) found a relationship between performance of everyday occupations and sense of coherence among persons with persistent pain.

Occupational therapists have the main responsibility for providing support in performing everyday occupations (IASP, 2014). Occupational therapy has its origin in the Moral Treatment movement, founded in the early 1800s, and its connection to the Arts and Crafts movement. Rehabilitation according to the Moral Treatment movement encourages the patients to engage in purposeful everyday occupations. This was seen as central and aimed at diversion from morbid thoughts and was regarded an avenue for altering patients' emotional

excesses (Mattingly, 1994). The basic Moral Treatment principles are found in today's occupational therapy as well. For example, Kielhofner et al. (2008a) argued that an active life that involves a sustained pattern of meaningful occupations and participation in the society reflects a person's identity. Use of occupational theories and occupation-based practice models enable occupational therapists in their therapeutic reasoning, and in planning, implementing, and evaluating the outcomes of therapy. Occupational therapy is aimed at enabling performance of the occupations the patient needs or wants to perform to fulfil her or his life roles (Kielhofner & Forsyth, 2008). In this sense, occupation is both the means and the ends of occupational therapy (Hasselkus, 2000).

The ICF model uses the constructs of activity and participation. Participation is sometimes seen as being the equivalent of everyday occupations' although participation does not refer to the subjective experience. The distinction between activity and participation has not been defined (Polatajko et al., 2007a). In occupational therapy "participation is imbedded with occupation – individual meaning and social roles are part of participation" (Polatajko et al., 2007a, pp. 36). The understanding of participation and its relation to occupation thus needs to be developed and deepened. For example, the knowledge about underlying social forces influencing occupations should be acknowledged (Borell et al., 2006). Enablement of occupational performance thus emphasizes the person's skills, abilities, habits and life roles, but also the environmental context, which should be known by the therapist. The main aims of occupational therapy interventions are to enable peoples' engagement in occupations connected to their interests, wishes and values; what they find worth doing and what they think contributes to family life and society (Kielhofner et al., 2008a). Occupational therapists employ a client-centered and process-oriented approach for assessments and interventions (Wressle, Eeg-Olofsson, Marcusson & Henriksson, 2002; Townsend et al., 2007c). The process of coping with persistent pain and its negative consequences may be related to how people are able to adjust their occupational performance. Such an adaptation process is described by Schkade & Schultz (1992) in a model that includes the following pathways: Person (a desire for mastery and an adaptation response), Interaction (the press for mastery, occupational challenges, occupational role expectations and occupational responses) and Demands for mastery (occupational environment and incorporation into occupational environment). This process of enabling and managing occupational challenges is referred to as occupational adaptation. This model may be helpful to therapists as a guide for their intervention planning and implementation (Schkade & McClung, 2001).

The role of occupational therapists in pain programmes

Chronic illness disrupts the self-concept and challenges taken-for-granted ways of thinking, feeling, and acting. It is important to emphasize the interaction between a person's self-concepts and occupations as being the means and ends of occupational therapy. There is an important relationship between identity, occupations, and meaning, in the sense that occupations constitute the mechanism that enables people to develop and express their identities (Christansen, 1999). The self-concept of a human being is thus characteristic and specific for that individual and distinguishes him or her from other people (Charmaz, 2002). The biopsychosocial model describes elements that are important in pain rehabilitation and emphasizes not only medical issues but also psychological and social elements (Gatchel et al., 2007; Wall, 2002). New discoveries in pain pathways, techniques of brain images, and use of the biopsychosocial model, question the traditional separation of sensory and motor mechanisms as pain caused either by anatomical, pathological or physiological changes (Gatchel et al., 2007). "The pain is not simply a mechanical response to the presence of tissue damage but is also affected by the mood and the attitude of the one who suffers" (Wall, 2002, pp XII foreword). It is thus reasonable that therapies directed at active movement planning, posture and active participation in daily life influence perceived sensations. The new knowledge of pain pathways has tremendous implications for occupational therapists, it provides a conceptual rationale for understanding how participating in activities that are meaningful to the patient might influence the perception of pain and in turn decrease disability and improve function in daily life (Wall, 2002). Persons with persistent pain have continuously been found to need help to enable everyday occupations and this need is widely confirmed (Henriksson, 1995; Skjutar & Müllersdorf, 2010; Schult et al., 2000; Müllersdorf, 2002). Assessments and interventions aimed at improving occupational performance therefore seem valuable in pain rehabilitation.

The role of the occupational therapist in pain rehabilitation programmes is to provide assessments and interventions targeting balance between various everyday occupations, occupational performance issues and occupational patterns, including leisure, everyday life and work/study occupations (Fordyce, 1968; Loeser & Egan, 1989; Kielhofner, 2008; Townsend & Polatajko, 2007; Andrews et al., 2012). Following the onset of disability most people initially experience a gap between the identity reflected in their personal occupational histories and what they are presently able to enact (Kielhofner, Mallinson, Forssyth & Lai, 2001; Mallinson, Mahaffey & Kielhofner, 1998). As a change of focus from body functions to activity and participation is proposed in rehabilitation (SBU, 2006), client-centered assessments and interventions with a focus on occupational performance contribute with important information (Walsh et al., 2004; Samuelsson et al., 2011). The questions occupational therapists use at assessment interviews focus on: what is done and when, and why and where it is done (Christiansen & Baum,

2005). Occupational therapists' main goals and their interventions are addressed at meeting the needs of patients' in pain management and focusing on assisting them to increase their knowledge of how to handle daily occupations. The purpose is to decrease pain, maintain competence, improve performance, and to increase knowledge of how to handle negative pain-related consequences (Müllersdorf, 2001).

Observations and analyses of patients' performance skills, use of discussion groups, video-feedback, graded-activity training, focusing adaptation strategies, EMG-biofeedback training, workplace analyses and use of creative activities are useful occupational therapy methods and strategies (Stanos, 2012; Luk et al, 2010; Norrefalk, 2006; Nordström-Björverud & Mortiz, 1998; Unruh et al., 2002; Loeser & Egan, 1989; Charmaz, 2002; Gunnarsson & Björklund, 2013; Pincus & Henderson, 2013; Ehrenborg & Archenholtz, 2010). The use of pacing techniques in activity training has been proposed to be beneficial as well (Birkholtz, Aylwin & Harman, 2004b), but there is a need to define the basic components of these methods (Andrews et al., 2012).

A recent presentation found preliminary results on the association between over-activity and the likelihood of frequently using opioids (Andrews et al., 2013) and it has been shown that both over and under-stimulation is detrimental to people's well-being (Eklund, Leufstadius & Bejerholm, 2009; Wästberg, Eklund & Erlandsson, 2013). Such findings indicate an urgent need to match intervention methods with patients' needs. It seems likely that some patients need to slow down and some need to be activated. Which need is most frequent for the individual patients can, however, be difficult to know and a comprehensive occupation-based assessment before rehabilitation is needed in order to establish this.

Occupational therapy interventions are designed to be set in at an early stage in the rehabilitation process. Long-term sick leave infers altered roles and negative changes in daily habits, routines and participation, which in turn have a negative influence on social relationships (Johansson & Isaksson, 2011) and occupational performance. Early interventions may break an undesired development in those respects. Moreover, van Huet et al. (2009) found that patients who had the ability to adopt positive meaning attributes and who used a variety of strategies were those patients who were most successful in their ongoing pain management. Very little is known about the most effective elements in pain management programmes. Further evaluation of the effectiveness of occupational therapy and other interventions for patients with persistent pain is a research domain that needs to be further investigated (SBU, 2006; Müllersdorf & Söderback, 2002). The kind of occupational performance problems that different groups of patients with persistent pain have is also unknown. Nor is it known which benefits may follow an intervention that uses occupation-based theories and praxis models and occupation-based methods for patients with persistent pain.

Occupation as means and ends for occupational therapy

The concepts of activity and occupation are defined both as separate variables and are closely linked. Activity represents the individual perspective of functioning, bringing in the aspect of a person's involvement in life situations. Occupational performance is defined as a person's subjective experience of activity and participation and denotes what an individual situated in her or his current environment does. In the Canadian Model of Occupational Performance and Engagement (CMOP-E) (Townsend & Polatajko, 2007) occupational performance is defined as the ability to choose, organize, and satisfactorily perform meaningful occupations (Townsend, 1997). Occupation is further specified as all types of everyday activities perceived as meaningful and important for the individual. It has been said to be important to emphasize the whole occupational repertoire in rehabilitation in order to facilitate engagement in valued activities and create a sound base for the process of returning to work (Eriksson et al., 2012) and entering former life roles in general. Occupational therapists' strategies involve assessing and intervening regarding performance capacity, the client's occupational roles and habits and her or his perception of their own abilities, values and interests (Kielhofner, 2008b). Occupational therapists use activity-based treatments with occupations as the main therapeutic tools and enhanced occupational performance as the main goal. To promote behaviours directed toward achievement of meaningful and successful daily occupational lives, rather than giving up activities and focusing on pain, is the main strategy in occupational therapy for patients with pain. By receiving guidance in a positive direction, they may also become aware of previous or new occupations they want and need to perform in their everyday lives. By recognizing the individual's needs, the occupational therapist can assist her or him in adjusting to the new circumstances. Together they can solve how each relevant occupation can then be trained, evaluated and adjusted to suit the person, while acknowledging the interplay between the person, the occupation and the environment in which the occupation should be performed.

Hammel (2004) maintained that everyday occupations contribute and create meaning in people's lives, while also furthering the suggestion that the term occupation can comprise several dimensions of meaning: doing, being, belonging and becoming. Implications for occupational therapists can be that patients may either view treatment as irrelevant for their future selves or see the self-images reflected in treatment activities as being at odds with their habitualized self-concepts (Charmaz, 2002). The more persons who are committed to various life domains the more they are engaged in the performance of daily occupations (Schult et al., 2000).

Person-occupation-environment around pain rehabilitation

The CMOP-E model states that the fit, or lack of fit, between a person's cognitive, affective and physical abilities, the occupation and the environment is essential to understand why people with pain may have problems in performing everyday occupations. How well a person can perform and actively engage in an occupation is also determined by the occupation that is to be performed. The person's environment impacts on how well the performance can be done. The assessment of the fit between person, occupation and environment can, however, be very complex (Polatajko, Davis, Cantin, Dubouloz-Wilner & Trentam, 2007b). The circumstances during which people experience their occupational engagement and in what way their belief about their own capacities affects the occupational behaviour must be addressed. This can be accomplished by a combination of occupational, behavioural-psychological, physical functioning or social assessments. Those assessments must include the person's capacity and the mediating variables that affect occupations. The person's functions (physical, cognitive and affective), and performance (motor, process and communications skills) are central and must be considered against the specific occupation (activity analysis) and the specific environment in which the occupation is being performed. The person's motivation, interests, perceived meaning and self-efficacy mediate the fit between the person, the occupation and the environment. The relations between these variables are described in Figure 2.

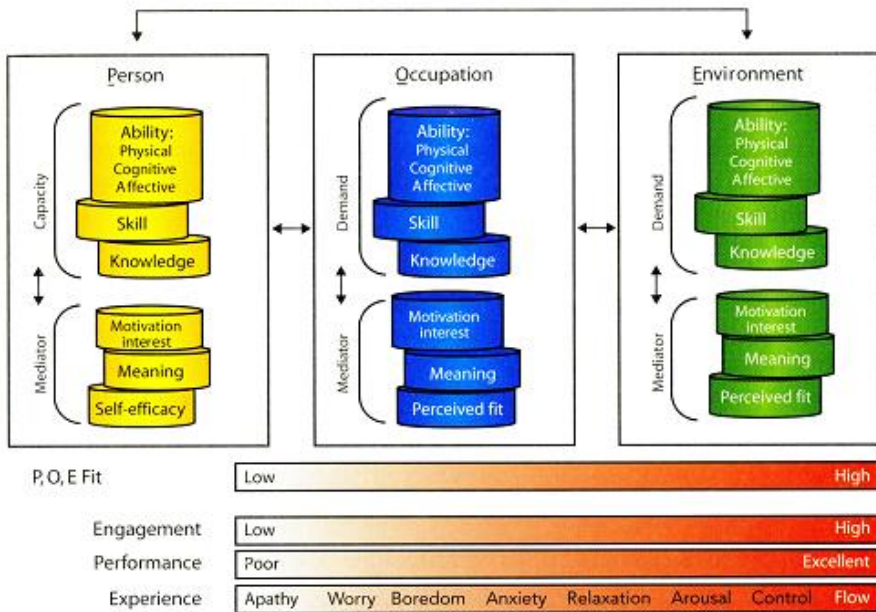


Figure 2.

Polatajko et al. (2007b). Figure 8.2 Fit chart. In E.A. Townsend, & H.J. Polatajko, *Enabling occupation II: Advancing an occupational therapy vision for health, well-being, & justice through occupation*. P. 213, Fig Ottawa, ON: CAOT Publication ACE. Reproduced with permission from CAOT Publications. ACE.

Other important parameters are the levels and qualities of the person's engagement, performance and experiences of the occupations. The latter may be operationalized as a continuum from apathy to flow.

Finally, when the focus is on occupational performance the broad spectrum of interwoven relationships between persons, the environment and the meaning or purposes of the occupations are emphasized. Often the person's experiences of engagement and of their own performance are barriers and these may be as important as physical or psychological dysfunctioning. Then rehabilitation may enable change, but to accomplish improved occupational performance appropriate knowledge and methods need to be used by the therapists. The occupational therapist is specialized to focus on the patient's occupational and time-use strategies, and whether the patient's environment and occupational patterns are beneficial or not. Occupational analyses and activity training are useful occupational therapy methods in these respects and favouring experience-based learning. In an interdisciplinary team the psychologist focuses on how thoughts

and emotions affect the patients and the social worker addresses social or economic factors that may be of importance. The physiotherapist teaches patients to improve body functioning and the physician has the overall medical responsibilities for diagnoses, medication and information on pain physiology and inform clients why no treatment can cure the symptoms but that self-management strategies may be beneficial. There are, however, knowledge gaps in what makes the most important elements in fostering patients' improvements in everyday occupational performance and satisfaction with the performance during interdisciplinary pain rehabilitation.

What is known and not known about pain rehabilitation?

During the last decades the amount of research on pain has increased enormously. The decade 2001 to 2010 was declared “the Decade of Pain Control and Research”. The main focus in pain research is on neurobiology and neurochemistry of pain to behavioural sciences and pain psychology (Castro-Lopes, 2009). In spite of a large amount of research in the field of pain, many questions still remain unanswered. Several systematic reviews have reported that multidisciplinary pain rehabilitation programmes (MdPR) are more effective as compared to single treatments (SBU, 2006; SBU, 2010; Scascighini, Toma, Dober-Speilmann & Sprott, 2008). No other pain treatment approach has a stronger evidence basis for efficacy, cost-effectiveness, and lack of iatrogenic complications than multidisciplinary pain programmes (Schatman, 2012). Although, many domains still are little or not at all evaluated. Some of what is known and not known is described below.

Measuring outcomes

The measurement of pain is important for the study of pain mechanisms and for the evaluation of methods or treatments (Turk & Melzak, 2001a). Self-report measures are part of comprehensive assessments (Turk & Melzak, 2001b). These are subjective and influenced by patients' motivation, effort, and psychological state (Turk & Melzak, 2001b). Objective measurements, based on performance, using apparatuses, are unlikely as they are too costly. Even these are in some sense also subjective. Self-reports that are psychometrically tested are found to be practical to administer and these can capture outcomes from all participants.

Core outcome measures for chronic pain have been recommended by the IMMPACT group. The authors stated that it is important to remember that these measures are just for recommendation and should not to be seen as a requirement either for journal publication or for regular agencies (Dworkin et al., 2005). The authors established that clinical conditions or treatments must be considered

relevant for the outcomes to be used. The measures that are used should be determined by which domains of improvements that seem important for the clients, reflecting the treatment methods and the aims of the interventions. Different measures are needed, for example, for evaluating client's occupational goal fulfillments, physical functioning or pain-related behaviours. Assessments in pain rehabilitation are recommended to focus on variables of psychological functioning, workability, physical functioning and pain (Dworkin et al., 2005). In addition assessments that address patients' self-defined goals, occupational problems and activity limitations have also been asked for (Turk et al., 2008) as persistent pain affect occupational performance (Fisher et al., 2007). There has been some criticism of self-reporting methods focusing on physical disability, where some measurements are found not to mirror the problem that the patients report as important (Hush, Refshauge, Sullivan, De Souza & McAuley, 2010; Walsh et al., 2004).

Effects of pain rehabilitation programmes

Pain rehabilitation has been investigated extensively during the past 35 years in order to determine its benefit for people having persistent pain. In Table 1 results from differently designed original studies, from several countries, focusing pain and rehabilitation outcomes are presented to get an overview. Results indicating pain reduction, improved quality of life, and psychosocial functioning are common outcomes and additionally, increased return-to-work rates and vocational outcomes are commonly used. Flor, Fydrich and Turk (1992) wrote that multidisciplinary patients were functioning better than 75% of those in a control group (unimodal care) regarding function, pain intensity, pain behaviours, and medical use. Cutler et al. in 1994 concluded that multidisciplinary treatment was effective at returning patients to work.

Table 1 . Studies focusing pain rehabilitation.

Authors, country	Methods; (participants). Outcomes/measurements. Setting/treatment	Results	Discussions and conclusions
Bergström, C. <i>et al.</i> , 2012. <i>Disabil Rehabil</i> , 34 , 110-118. Sweden.	RCT 10 y f-up. (N=214, spinal pain). Sickness absence and MPLS ⁵ (Profiles; AC ⁶ , DYS ⁷ , ID ⁸). (PT) CBT ² , (MdPR) ³ , (CG) ⁴ .	MdPR ³ best for AC compared with CG on long-term sickness absence. PT, CBT, MdPR ³ , CG similar on sickness absence for ID and DYS.	MdPR ³ most beneficial regarding long-term sickness absence for AC and DYS. CBT and PT failed to benefit any patient group.
de Rooij <i>et al.</i> , 2013. <i>BMC Muscul Dis</i> , 14 , 133. Netherlands.	Prospective cohort study (N=120 CWP ⁹). Pain, MPI (LI) ¹⁰ , depression, perceived effect (GPE). Predictor: psychological, disability, socio- demographic factors. MdPR ³	Improvements predicted by: pain-more BL ¹¹ pain, male; LI ¹⁰ -more BL LI, low anxiety, control, less belief in consequences, male, higher education; depression-higher BL depression, control, higher education; better GPE-less pain, less fatigue and higher education.	Tailoring treatment or selecting patients to these specific patient characteristics (anxiety, control, belief in consequences, pain, fatigue, level of education and gender) may further improve treatment outcomes.
Ehrenborg <i>et al.</i> , 2013. <i>Disabil Rehabil</i> , Early on line , 1-8. Sweden.	Mixed-method, explanatory design, 1 y f- up ² . (N=53, Whiplash). ADL ¹³ , MPI, RTW ¹⁴ , interviews. MdPR ³ with p ¹⁵ (rehab spec.), PT ¹⁶ , OT ¹⁷ , PS ¹⁸ , SW ¹⁹ , N ²⁰ , ass N.	Improved ADL ¹³ , LI ¹⁰ , control and more RTW ¹⁴ at 1 y f-up. Increased RTW ¹⁴ . Key success factors clients treated with respect are part of a social context, obtained new knowledge.	MdPR ³ initiated a process to more active life, new ways of managing lives despite of pain and better ADL ¹³ and RTW ¹⁴ .
Fedoroff <i>et al.</i> , 2013. <i>Clin J Pain</i> , July 24. Canada.	Group-based and individual responsiveness of change out and f-up ¹² (N=263 outpatients). 3 criteria for assessing (MIC). MdPR ³ .	Improvement all measures post-treatment, largely maintained at f-up ¹² . Variability in improvement and individual differences predict responsiveness. No differences between responders and non-responders.	Highlights MdPR ³ to improve well- being for chronic pain patients. MIC important and variability analyses allows evaluation of individual responsiveness.
Gagnon <i>et al.</i> , 2012 <i>Pain Practice</i> , 13 , 282-288. U.S.A.	Pre-post test, retrospective (N=101 chronic low-back pain). Program completion (PC), Release to Work Status (RW), RTW ¹⁴ , depression, catastrophizing, anxiety, sensory/affective/evaluative factor, ability for work tasks (FCE), MdPR with SW, PS, OT, PT, P, N.	65% patients graduated MdPR ³ (=PC). PC-91% released to RTW ¹⁴ and 80% full-time work, 11% RW, but 49% RTW. Improved on depression, pain catastrophizing, and pain intensity, not anxiety. For non PC last pain rating higher than baseline.	4-week MdPR ³ decrease emotional distress, reduce pain intensity and improve RTW. Patients reporting increased pain or non-completers may have been to operant factors.
Gatchel <i>et al.</i> , 2002. <i>Clin J Pain</i> , 18 , 139-143. U.S.A.	Prospective pre-post (N=65, persistent pain). Standard evaluation battery: pain, disability, psychosocial functioning, helpfulness of programme, medication. MPI ¹⁰ (profiles). MdPR ³ with OT, P, PS; PT.	Improvements: less narcotic medicine (40% to 20%), improvement on most evaluations. More AC, less DYS, better f-up for AC, followed by ID and DYS. Overall AC best and DYS worst scores, MdPR ³ effective across pain/disability, regardless of initial MPI profile.	The MPI (profiles) predicted not response to MdPR ³ that may achieve full effectiveness across a wide array of outcome variables, regardless of baseline MPI profiles.

<p>Haldorsen <i>et al.</i>, 2002. <i>Pain</i>, 95,49-63. Norway.</p>	<p>RCT design (N=654 musculoskeletal pain). RTW. Ordinary treatment (OrT), light MdPR³ (LT), extensive MdPR. Patients randomized due to prognoses 1-3.</p>	<p>Prognoses level 2 benefit equally from LT and MdPR. Prognoses level 3 (worst) higher rate of RTW at MdPR than those OrT (55 vs. 37%). MdPR effective on RTW.</p>	<p>Cost-benefit of the LT and MdPR³ a positive net social value of the treatment. Simple, standardized, screening instrument and observations beneficial.</p>
<p>Keponen <i>et al.</i>, 2006. <i>Scan J Occup Ther</i>, 13, 211-220. Finland.</p>	<p>Qualitative, narratives to identify experiences of doing occupations in everyday life. (N=17 women with chronic pain).</p>	<p>Solution for problems and occupational performance was: "moving forward", "slowing down", "fighting" and "standing still". Tone vary from hopeful to hopeless, fearful to frustrated. Narratives differed tones, meanings of occupation, how others related to doing, how future is envisioned.</p>	<p>Experience of occupation in the lives with chronic pain is heterogeneous and depends on the underlying meaning of the narrative used to experience and interpret occupational life.</p>
<p>Luk, <i>et al.</i>, 2010. <i>J Orthop Sur</i>, 18,131-138. Hong Kong.</p>	<p>Assessment at baseline, week 7, week14, 6 months (N=65 low-back pain). Pain, disability, physical tests and depression. Demographical variable as predictors. Comparison of patients RTW vs. not RTW. MdPR³ with P, PT, OT.</p>	<p>52% RTW and 48% did not RTW. Older age, longer work absence associated with not RTW. MdPR helped regain of physical function and ability to work. Those RTW greater improvements on disability and physical function.</p>	<p>MdPR facilitated regain of physical function and RTW. Pre-programme employment status, duration of work absence, age was most predicting work resumption.</p>
<p>Löfgren <i>et al.</i>, 2006. <i>Disabil Rehabil</i>, 28,447-455. Sweden.</p>	<p>Qualitative methods. Diaries, focus groups and interviews, 6-8 years after rehabilitation aimed at exploring strategies used (women with FM who worked). MdPR with OT, P, PT, PS.</p>	<p>Categories: 1/'constant struggle' =enjoying life, taking care of oneself, positive thinking, setting limits, using pain as a guide, creative solutions, learning/being knowledgeable and 'walking a tightrope'; 2/'grieving process' prerequisite for managing the struggle 3/'social support' facilitated the struggle</p>	<p>Informants had a constant struggle against the symptoms and consequences. Strategies used were action-oriented and a positive spirit, to have grieved and accepted their situation was a prerequisite for managing, support from the family was a help.</p>
<p>Nordström <i>et al.</i>, 1998. <i>Scan J Rehab Med</i>, 30, 31-37 Sweden.</p>	<p>Follow-up 2-4 y after rehab (N=34 musculoskeletal pain <2 month sick-listed from hospital work, N=72 reference group). Health-related QoL (HQoL), pain drawing, VAS, physical disability, RTW. MdPR with OT, P, PT, SW.</p>	<p>Improved energy, HQoL, at discharge. Difference between participants and references group regarding RTW after 2-4 y. 77% and 58% RTW at 2-4 y f-up, respectively.</p>	<p>MdPR³ offered for hospital employees beneficial at early state of sick-list, including work-place visits by OT and PT from occupational health units, structured f-up at clinic resulted in 75% RTW after 1 y maintained after 2-4 y.</p>
<p>Norrefalk, <i>et al.</i>, 2008. <i>J Rehabil Med</i>, 40, 15-22. Sweden.</p>	<p>3 diff methods: matched sample, regression analysis, propensity score match (N=67 persistent pain, n=322for comparison). Estimated by sick-leave compared with actual cost of rehab. MdPR with 1 P, 3 PT, 3OT, 1 PS, 1SW, 1nurse, 1secretary.</p>	<p>Benefit of MdPR³ was €3,799-7,515 per patient and year. Total cost of MdPR €5,406/patient. Total cost recovered when successfully rehabilitated patients worked for 9-17 months. Any additional work after that yielded net economic benefits.</p>	<p>A large proportion of patients working after one year if also working after 3 and 6 years, concluded this MdPR³ for patients with persistent pain most likely generates substantial net economic gains.</p>

<p>Rydstad <i>et al</i> 2010. <i>Disabil Rehabil</i>, 32, 1810-1818. Sweden.</p>	<p>Qualitative design to analyze 1 y f-up experience on gainings of rehab for handling daily occupations. (N=9, with WAD).MdPR³ with P (rehab specialist), N, OT, PT, SW, PS.</p>	<p>1 core category 'learning to manage and 3 associated categories: 'chaos in life', 'a light in the tunnel' and 'managing long-term pain', describing process from experienced life at baseline to one year after IRP.</p>	<p>Living with long-term WAD = 'chaos' at baseline and MdPR³ helped realizing a way to control pain, regain in daily occupation and return to work. One year after MdPR acceptance of situation stratred and regained occupations and life roles.</p>
<p>Scascighini <i>et al.</i>, 2011. <i>Pain Medicine</i>, 12, 706-716. Zwitzerland.</p>	<p>Prospective, clinical study, baseline, post, at 3, 6, 12 months f-up (N=175, chronic pain). 1st outcomes: Pain rating (NRS), disability, ADL rating, pain experiences (FESV),VEV ≈pain management. 2nd.outcome: physical test. MdPR³, CBT approach, with P, PT, OT, SW, PS</p>	<p>Improvement after on all but pain intensity. At 1y f-up only psychological strain remained better. Migration background predicted pain, well-being, and FESV outcomes. After 12 months 40% improved VEV, 23% no changes, 28% deteriorated. Gender and age did not influence 12 months results.</p>	<p>Evidence for short-time effect of the MdPR and long-term effect on pain-related psychological strain.</p>
<p>Soares <i>et al.</i>, 2002. <i>Scan J Occup Ther</i>, 9, 35-45. Sweden.</p>	<p>Randomized control comparison (N=53 women, fibromyalgia). Coping strategies, pain questionnaire, symptoms, sleep, social support, self-efficacy, before, after and 6 m f-up. Education (EI), behavioural interventions (BI), waiting-list control (CG).</p>	<p>EI no changes, BI improved coping, disability, pain and sleep after but only sleep remained improved at f-up. CG deteriorated in coping and pain</p>	<p>More research is needed as there were few improvements. Only one remained at f-up. Essentially no differences between EI, BI, CG in terms of effectiveness.</p>
<p>Van Huet <i>et al.</i> 2009. <i>Disabil Rehabil</i>,31, 2031-2040. Australia.</p>	<p>Qualitative (N= 15, 2 narratives in-depth interviews) aim to explore factors that predicted successful pain management after MdPR³.</p>	<p>The meanings and beliefs attributed to pain at time of program and after. Completion (being ready to program, acceptance or not of long term pain). Strategies continued to apply pacing and reengaging valued routines and tasks.</p>	<p>Ability to adopt positive meaning attributes and use a variety of strategies was related to successful in ongoing pain management. Importance of these factors should be considered for those attending chronic pain programs.</p>
<p>¹PT=Physical therapy, ²CBT=Cognitive Behavioural Therapy, ³MdPR=Multidisciplinary Pain Rehabilitation, ⁴CG=Control Group, ⁵MPI-S=Multidimensional Pain Inventory-Swedish, ⁶AC=Adaptive Copers, ⁷DYS=Dysfunctional, ⁸D=Interpersonal Distressed, ⁹CWP=Chronic Widespread Pain, ¹⁰MPI=Multidimensional Pain Inventory, LI=Life Interference, ¹¹BL=Baseline, ¹²f-up=follow-up, ¹³ADL=Activities in Daily Life, ¹⁴RTW=return To Work, ¹⁵P=Physician, ¹⁶PT=Physical therapist, ¹⁷OT=Occupational therapist, ¹⁸PS=Psychologist, ¹⁹SW=Social worker, ²⁰N=Nurse.</p>			

These studies (Table 1) describe different outcomes and also variability and subgroup dependent outcomes as treatment dependent outcomes. In some of the studies socio-demographic variables had relevance for outcomes and also patients' baseline status.

In a large survey of chronic pain in Europe, one third of those reporting chronic pain were not treated for their pain-related problems and less than 2% reported that they had been managed by pain specialists. About 50% of those with moderate to severe pain reported experiences of inadequate pain management (Breivik et al., 2006). Increased number of interdisciplinary treatment programmes is asked for (Schatman, 2012). Multidisciplinary pain rehabilitation programmes are found to improve personal, societal and economic situation for persons enrolled in such programmes (SBU, 2006; Momsen, Rasmussen, Vinther Nielsen, Iversen & Lund, 2012; Norrefalk, Ekholm, Linder, Borg & Ekholm, 2008; Scascighini, Litschi, Walti & Sprott, 2011). Multidisciplinary pain programmes have mostly been shown to be effective in terms of reducing pain, medical care or back-to-work rates (Flor et al., 1992; Scascighini et al., 2008; Airiksen et al., 2006, Norrefalk et al., 2008). Treatment-as-usual was in 2001 found to be the most common in visits to physicians (59%) or to physiotherapists (53%), fewer had visited an occupational therapist (3%) (Marhold et al., 2001). The broad and coordinated interdisciplinary pain programmes have been found to improve disability, pain severity, and psychosocial functioning among the participants (SBU, 2006; Norrefalk et al., 2008; Skouen, Grasdal & Haldorsen, 2006; Patrick, Altmaier & Found, 2004). Multidisciplinary rehabilitation has also been found helpful for heterogeneous patient groups, including those with chronic pain, low back pain and fibromyalgia (Momsen et al., 2012). A key component to program success is, however, collaborative ongoing communication among team members, the patient, and the case manager Stanos & Houle, 2006).

Increased back to work rates are an important outcome investigated in several studies (SBU, 2010; Norrefalk et al., 2008; Skouen et al., 2006; Norlund, Ropponen & Alexanderson, 2009; Oslund et al., 2009; Cutler et al., 1994; Bergström, Jensen, Hagberg, Busch & Bergström, 2012). Norrefalk et al. (2008) described the economic benefit for the society by such a pain programme. Integrated multidisciplinary pain rehabilitation has been confirmed as more successful than no or less intensive treatments (Flor et al., 1992; SBU, 2006; SBU, 2010). Significant reduction in pain intensity, improvement of health related quality of life and a decreased use of short acting opioids after a multidisciplinary pain programme, as compared to a waiting list group and treatment at general practice, have been found. A pain specialized assessment only even if including a plan for further treatment at general health care were found not to be sufficient enough to help chronic pain patients (Becker, Sjøgren, Bech, Kornelius Olsen. & Eriksen, 2000). Eljersen Wæhrens, Amris & Fisher (2010) showed that performance-based assessment of motor ability in activities of daily life (ADL)

was only weak correlated with self-reported ADL ability and for evaluate outcomes. This indicates that both performance-based and self-reported assessments are needed to establish improved abilities. Patients with long-term whiplash-associated pain describe their lives as 'chaos' before pain rehabilitation programme and reported the pain program being helpful to control pain, regain daily occupations and return to work. One year after rehabilitation they had started to accept their situation and regained occupations and life roles (Rydstad et al., 2010). These findings indicate that a long-term process can be started during pain rehabilitation but also that time is needed for pain strategies to become a part of participants' everyday life. Limitations in activity performance and reappraising daily doing is found to be a core concept for people with persistent pain in order to cope with it and maintain well-being (Müllersdorf, 2001; Skjutar & Müllersdorf 2010; Satink, Winding & Jonson, 2004; Persson et al., 2011).

In spite of all this evidence, there are still several questions that need to be better understood and the knowledge is still inconsistent or lacking in several domains related to pain rehabilitation. Some of these questions concern finding predictors for outcomes and a fit between patients' needs and the rehabilitation provided. A careful assessment at baseline has been found to be important in order to know which patients may be in greatest need for MdPR (Stanos, 2012; Skjutar, Schult, Christensson & Müllersdorf, 2010; Norrefalk et al., 2008; Haldorsen et al., 2002).

Black box – what is still unknown?

Pain rehabilitation appears in some ways to be a neglected area in health care, as several patients have not been helped, and several report that they do not get treatment for their pain (Breivik et al., 2006; Schatman, 2012). Henriksson (1995) wrote more than 20 years ago that a prolonged period of time for the process of assessing and diagnosing pain provoked anxiety and increased stress reactions among people with persistent pain. Lynch et al. (2008) found, more than ten years later, an escalating public health care problem with significant human and economic costs as patients with chronic pain still had to wait long periods of time before treatments and during this time they deteriorated in health-related quality of life and psychological well-being. This indicates that it is important to find those patients most in need for treatment, and to find how to best design treatment to meet different needs among subgroups of patients with persistent pain.

Cognitive behavioural interventions have been subject to significant amount of research and mostly found to have a positive impact on depression alleviation, pain coping and reduced pain behaviours. The effectiveness of cognitive behavioural approaches has, however, also been questioned, as found non-effective on follow-up (Soares & Grossi, 2002) and weak methodological designs in studies were found and they were “muddied” with varying types of outcomes and methods (CAOT, 2007). It could be debated which types of functionings that

can be improved over time after cognitive-behavioral treatments. Many psychological states can only be measured through self reports and the development of robust measures of direct observation or independent blind assessors have been called for (Morley, Eccleston & Williams, 1999; Straube & Derry, 2011). Vowles and McCracken (2010) maintain that influencing clients' psychological flexibility may promote behaviours that can positively influence clients' achievements of successful daily activities. That appears to be a reasonable conclusion, but on the other hand whether a client's daily activities are limited by deficient flexibility or by other causes should be evaluated firstly. Limited occupational performance may be impacted by psychological factors, although affective and cognitive functioning, physical functioning, occupational patterns and environmental factors may be equally important. Improvements on the patients' own prioritized problems are found to be associated with change scores on psychosocial and behavioural functioning, variables of psychosocial well-being at discharge from pain rehabilitation (Persson et al., 2004). However, whether such associations are relevant after a longer time follow-up is unknown. It may be practical to start with ascertain the client's goals, then finding out what may influencing their goal achievements and thereafter focusing interventions on those factors that may influence goal achievements.

In order to be better able to understand which patients have the greatest benefit from a particular programme and how to best individualize group-based programmes, knowledge of associations between pain diagnoses, patients' characteristics and effectiveness of treatments is needed (Henschke, Maher, Refshauge, Das & McAuley, 2007). Matching treatment with patient characteristics needs to be further focused in pain research (McCracken & Turk, 2002) and studies focusing on treatment outcomes are needed (Scascighini et al., 2008). The evidence for multidisciplinary pain rehabilitation needs to be further analyzed (SBU, 2010; Ravenek et al., 2010; CAOT, 2007). In a study Ravenek et al. (2010) aimed at updating the evidence for multidisciplinary treatment of chronic low back pain, inconsistencies with respect to intensity of treatments and of evaluated outcome variables were found. These results are partly confirmed by other authors (Turk et al., 2008). In that review by Ravenek et al. (2010) occupational therapists were found to be underutilized. It was thus maintained that future MdPR should take advantage of the skills that occupational therapists contribute with in this practical field. Such domains are: enabling occupational performance in those occupations that are difficult for patients, whether subgroups of pain patients differ regarding which everyday occupations they find difficult and which important needs to be further focused.

In a review examining prognostic factors of musculoskeletal pain a number of adjustment processes such as disability management with work participation, coping and duration of episode were found to strongly predict pain outcomes (Laisné, Lecomte & Corbière., 2012). There is a need to be better able to

understand those factors that are most prominent for outcomes and those factors that are improved after pain rehabilitation. Pain coping strategies constitutes such a factor. A good coping, termed adaptive copers AC, is found to increase and a less good coping profile, dysfunctional DYS profile, to decrease immediately after an interdisciplinary pain programme (Gatchel et al., 2002). Whether pain coping profiles change or remain changed after a longer follow-up after discharge is still mostly unknown. Furthermore whether a good coping at follow-up is associated with improvements of occupational performances is unknown. Morley (2011) described the time line in CBT strategized over 50 years. He established further needs for i) developing measures with robust criteria to index meaningful clinical change in addition to statistical estimations of significance, and ii) methods for assuring the integrity and quality of treatment implementation. Soares & Grossi (2002) found only one remaining improvement for women with fibromyalgia, sleep, at a 6 month follow-up after comparing two interventions focusing behavioural intervention (BI) (psychologist or cognitive behavioural therapist) and educational interventions (physiotherapist and occupational therapist). More research to clarify interventions for fibromyalgia patients was called for.

It thus seems important to match the interventions used to the outcomes that adequately measure patients' most important needs. Interventions focusing physical functioning such as increased motor skills, movement patterns and motor behaviour are seen not to automatically be transformed into increased performance of daily activities by patients with persistent musculoskeletal pain (Linton, Melin & Gotestam, 1984). Thus knowledge of factors related to improved occupational performance is an important issue to focus on as well as, knowledge of which types of occupational problems that are most relevant for patients with pain entering pain rehabilitation programmes. According to Wade (2005) the underlying theory of principles guiding actions should be described. Therefore actions aimed at increased physical functioning and those aimed at increased occupational performance should be described and differently evaluated. Furthermore knowledge about long-term improvements after pain rehabilitation and stability of discharge outcomes appears to be important as a longer period of time may be needed for pain strategies to become an integral part of participants' everyday life.

Rationale

As demonstrated in the introduction knowledge about various aspects of pain rehabilitation is lacking. Outcomes in terms of occupational performance, psychosocial functioning, physical disability, and improved coping behaviour need to be further addressed. These outcomes concern overall goals of interdisciplinary pain rehabilitation and should be considered as core outcome domains. Research also needs to explore whether some subgroups benefit more than others from pain rehabilitation. Furthermore, which patient characteristics predict worse or better pain-related health has not been consistently described in the literature. Moreover it is not known which types of occupational problems patients regard as most important when entering a pain rehabilitation programme, and if this differs between subgroups. No study has, to our knowledge, focused on associations between occupational performance and psychosocial coping profiles at follow-up. Such knowledge would increase our understanding of relationships between “doing” and “thinking”, both key aspects in pain rehabilitation. The gaps mentioned here should be further addressed in research in order to improve the knowledge base regarding pain rehabilitation, which can in turn be important for improving the rehabilitation for pain patients and for tailoring pain rehabilitation programmes to match individual patient’s needs.

Aims

General aim

The overall aim of this thesis was to study outcomes in terms of occupational performance, satisfaction with performance, psychosocial functioning, disability, and coping profiles at a one-year follow-up after a musculoskeletal pain rehabilitation programme. A part of the aim was to evaluate differences among subgroups of participants based on baseline characteristics and pain-related severities, regarding outcomes described above.

Specific aims

The specific aims of this thesis were:

- to investigate how socio-demographic factors, pain duration and pain diagnostic groups were associated with psychosocial functioning and physical disability at admission to a musculoskeletal pain rehabilitation program and at one-year follow-up.
- to describe everyday occupational problems among patients with musculoskeletal pain enrolled in a pain rehabilitation programme, and to compare subgroups based on socio-demographical characteristics, pain duration and pain diagnostic subgroups.
- to assess outcomes after pain rehabilitation in terms of occupational performance and satisfaction with occupational performance, and to investigate if socio-demographic factors and pain-related factors were associated with outcomes at follow-up.
- to assess changes in MPI profiles from baseline to a one-year follow-up, whether AC profiles at follow-up were associated with improvements in occupational performance, and whether socio-demographic characteristics, pain duration, pain diagnostic groups and occupational performance and satisfaction with performance at baseline predicted having an AC profile at follow-up.

Methods

Design and study context

This thesis is based on observational pre-post data collected in a clinical setting and stored in a database. In Papers I-IV data were collected prior to a first team-based assessment, at discharge from the pain rehabilitation programme (Papers III and IV only) and at a follow-up one-year after discharge from the programme (Papers I, III and IV). The participants in all four papers were recruited from the same population (Figure 3).

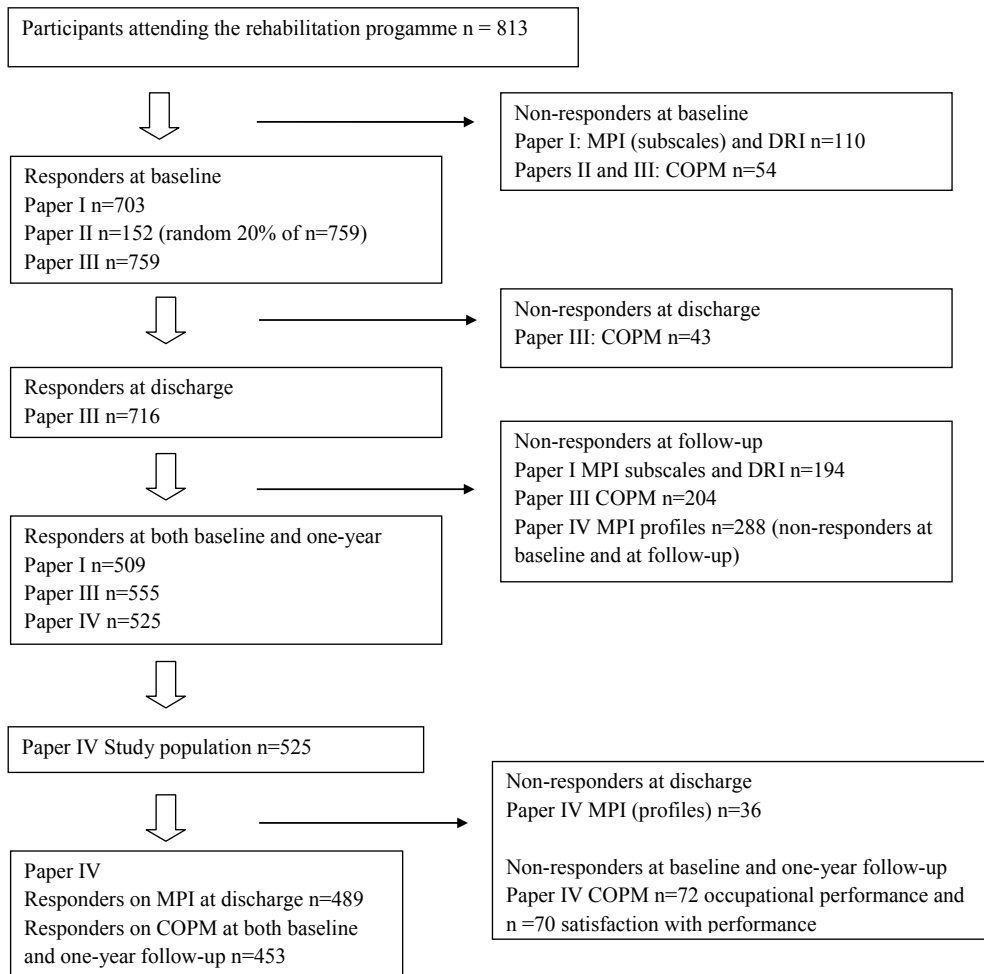


Figure 3.
Flow chart describing the inclusion of participants in this thesis.

Participants and inclusion criteria

All participants took part in a five-week pain rehabilitation programme at a university hospital. Inclusion criteria for entering the rehabilitation programme were: i) a completed one day team-based assessment, ii) an additional occupational therapy assessment before the start of the programme, iii) the presence of persistent pain with a significant impact on everyday life, iv) no further medical investigations needed, v) an age of 18 to 65 years, vi) fluency in Swedish, and vii) the ability to participate in a group. Exclusion criteria were: i)

ongoing substance abuse, and ii) acute psychological or mental disorders. The most frequent pain diagnostic groups were neck disorders, fibromyalgia and low back pain. Patients enrolled in the pain rehabilitation programme were recruited from 2003 to 2008. The characteristics of the participants at baseline in each of the four papers are described in Table 2. Because of the use of different measures in the four papers, the samples were not identical in the papers. Papers I, III and IV included participants responding to the outcome measure at admission, discharge (not Paper I), and the one-year follow-up. In Paper II a randomized selection (20%) was made and only measures before inclusion in the programme were used.

Table 2.
Description of participant characteristics in Papers I – IV.

Paper	Female	Age	Nordic Born	Marital status (Married/cohabiting)	Educa-tion ^a	Vocational situation, (Not working) ^b	Pain duration (Years)	Pain diagnoses ^c
Number participants	%	Mean (SD)			%		Median/IQR	%
I 509	79	40 (9.6)	86	74	A:19 B:62, C:19	64	4.1/ (2.3-8.4)	Neck Dis 29 Fibrom. 24 LBP 14 Myalgia 14 Other ^d 8
II 152	79	42 (8.6)	85	79	A:22 B:57 C:21	62	6.7/ 2.5-8.8)	Fibrom 25 Spine ^e 51 Other II ^f 24
III 555	79	40 (9.5)	86	73	A:20 B:60 C:20	64	4.2/ (2.3-6.6)	Neck Dis 28 Fibrom. 24 LBP 23 Myalgia 15 Other ^d 9
IV 525	79	40 (9.5)	85	77	A:19 B:62 C:19	64	4.1/ (2.3-8.3)	Neck Dis 29 Fibrom. 24 LBP 15 Myalgia 15 Other ^d 8

^a Education: A= Secondary school, B=Upper secondary school, C=University, ^b out of those not working/studying most patients were on fulltime sick-leave or had full-time disability pension, ^cPain diagnoses; Neck Dis=neck disorders, Fibrom=fibromyalgia, LBP=low back pain, Myalgia=myalgia or unspecified pain, ^dOther=diagnoses less common (per diagnosis <10 participants), ^eSpine=pain related to the spine, ^fOther II=diagnoses less common (per diagnosis <10 participants), myalgia and unspecified pain.

The most common pain diagnoses (ICD-10) were: M 79.0 Rheumatism unspecified (fibromyalgia), M 53.1 Cervicobrachial syndrome (neck-disorder), S13.4 Luxation and distortion of joints and ligaments in the neck and cervical spine (neck disorder), M54.4 Lumbago with sciatica (low back pain), M53.0 Cervicocranial syndrome (neck disorders), M54.5 Lumbago (low back pain). In Paper II the pain diagnoses were categorized in three pain diagnostic groups as the sample was smaller (n=152).

The rehabilitation programme

An overview of the main actions before, during and after the pain rehabilitation programme is presented in Figure 4.

Pain rehabilitation			
Before rehabilitation		The five-week rehabilitation programme	After the programme
1/ Referrals (mostly from primary health care)		Week 1 Individual assessment (P, PT, OT, SW) ¹ and goal-setting. Team-based individual rehab-plan. Group-based interventions starts	Team-based records sent to client, the physician/therapist who sent the referral and social insurance office when required.
2/ Initial questionnaire and referral group (P, SW, N) ¹ for decision about further actions needed		Week 2-4: Group-based interventions OT-, PS- and PT-groups ¹ and education/discussion-groups (1P, 3OT, 1PT, 1SW) ¹ . Schedules daily 9.00-15.00 total 21 days during 5 weeks.	Eventual further needs, mostly contacts with other therapists or workplace visits were organized and planned for..
3/ Team based assessment (P, PT, PS, SW) ¹ If programme, waiting list (N) ¹	→	Weekly formal team-meetings, daily informative team meetings.	8 week follow-up for 2 days
4/ OT ¹ assessment before inclusion in programme (2-6 weeks before programme start)		Week 5 individual assessments (with P, PT, OT, SW) ¹ goal and treatment followed up, further needs decided.	Each client Individual follow-up of rehab-plan with (P, PT, PS; OT and PS when needed) ¹ PT ¹ - tests Two groups sessions led by PS ¹
5/ 2 day information before programme (N and assistant N) ¹		Individual discharge meetings with whole team, client and guests. Final questionnaires after all meetings ended	One-year follow-up A questionnaire was sent by mail, a reminder when needed after 1 month.

¹ P=Physician, OT=Occupational Therapist, PT=Physiotherapist, PS=Psychologist, SW=Social worker, N=Nurse.

Figure 4.

Overview of the main actions before, during and after the five-week rehabilitation programme.

Procedures before the programme

The participants proposed by the referral group to be in need of pain rehabilitation underwent a team-based assessment during one day. The assessment teams included a physician (P), a physiotherapist (PT), a social worker (SW) and a psychologist (PS). Each profession interviewed the patients individually for one hour. The PT and the P also examined the patients. The P confirmed or set the pain diagnosis, made an assessment of the patients' medical situation, assessed whether adjustment of medications was needed and established if further medical

diagnostic procedures were relevant. The PT assessment focused on the patients' body and movement patterns, physical fitness, muscle and bone assessments, fitness-training routines and included a physical examination to ensure that correct physical treatment was given and that no further individual PT-specific treatments were needed. The SW interviewed patients to assess their social network, family life, vocational situation and further needs for economic or social assistance. The PS assessed problems related to psychological functioning with a focus on each patient's current life situation. The team discussed their findings and thereafter provided a recommendation that was discussed with the patients at a final team meeting during this first day. If the patient fulfilled the inclusion and exclusion criteria and the pain rehabilitation programme was recommended, the patients were put on a waiting list. Approximately 40% of the patients referred to the clinic were included in the pain programme. When eight to nine patients were placed on the waiting list they constituted a group. These patients, and two to three reserve patients, were then referred to an occupational therapist (OT) at the clinic for an assessment of occupational performance. The OT interviewed the patients for one hour, focusing on their current occupational performance, balance between daily occupations and rest, time-use strategies and resources and barriers for everyday occupational functioning. The assessment concentrated on the main reasons for occupational performance problems and it was established whether the patient was in need of the group-based activity training and OT interventions that were available during the programme.

The patients then had opportunities to ask questions about the programme, prior to receiving their individual schedule for the five weeks programme. The patients also met a SW once more in order to assess any practical obstacles for participation during the five week programme, such as unsolved needs for organized childcare, economical arrangements, contact with social insurance office, discussion with employers and possibility to travel to the clinic each day or whether overnight accommodation was needed. If the OT or SW saw potential obstacles for the patient to participate, this was then discussed with the initial assessment team to decide if further arrangements were needed. The patients were then called to two days of pre-treatment preparation on two separate occasions, led by a nurse and an assistant physiotherapist. These group-meetings focused on presenting the content of the programme, goal formulation and information about health prevention activities, such as physical training and nutrition advices.

The five-week programme

The musculoskeletal pain rehabilitation programme lasted for five consecutive weeks based on the praxis models and interventions of the included professions and on cognitive behavioural principles. Two months after discharge a two-day follow-up was conducted to evaluate strategies recommended in the discharge plan. The programme was staffed by two teams. Each profession's focus, methods,

and time spent in the programme are shown in Table 3. Each team consisted of 75% physician, 75% occupational therapist, 100% physiotherapist, 50% psychologist and 75% social worker. A further 25% physiotherapist, 75% assistant physiotherapist and 50% occupational therapist assisted the teams and the patients.

Table 3.

Each profession's main focus, methods and available time for each patient during the five week programme.

Profession	Focus	Methods	Individual time ¹	Group sessions (Wgr/Hgr) ²
Physician	Diagnosis Medication Information on pain physiology, medicines and stress Medical records and sick leave documents	Interview/examination Lectures Collect all team- members records	2x45 minutes W ¹ and 5	3x1 hour lectures in W ³ 2-4, Wgr
Occupational therapist	Occupational goals Ergonomics/ occupational performance habits Experience-based learning Pacing with focus on doing Balance rest and activities Relaxation during occupation	Interview Video-recording and feedback Activity-training Education: ergonomic, life balances and PEO ⁴ model, practice occupational strategies, Occupational diary, EMG- Biofeedback, Timer Written feedbacks	2x45minutes W ³ 1 and 5 15 minutes W ³ 1 (video)	8x1½ h (4-5 patients) activity group, Hgr 3x1-1½ h (8-9 patients) lectures/discussion groups, Wgr 4x1-1½hour assistant in PS- CBT group
Physiotherapist	Body functions Physical fitness Body awareness Relaxation	Interview Group-training Body awareness Relaxation training Admodum Schult Education	2x30 minutes W ³ 1 and 5 interviews 2x30 minutes W ³ 1 and 5 tests	8x1½ hour (4-5 patients) physical training, Hgr 1x 1½ hour (8-9 patients) Wgr 7x1 hour body awareness, Wgr Lectures/discussion groups, Wgr 8x30 minutes relation training, Wgr 3x1-1½hour assistant in PS- CBT group
Assistant nurse (assistant physiotherapist)	Physical fitness training Information on food	Warm-water pool-training Walking or bicycle Interview	Only for patients wanting to Reducee weight	3x2 hour pool training, Hgr 7x30 minutes physical fitness, Wgr
Psychologist	CBT skills Behavioral adjustments Stress-management techniques Relaxation	Education /discussion group		14x1-1½ hour lectures/discussion groups, Wgr
Social Worker	Advices on social matters Contact with authorities		2x45 minutes W ³ 1 and 5 interview	1x2 hour education, Wgr 7x1-1½hour assistant in PS- CBT group
All team members	Rehabilitation plan Goal evaluation Information on programmes' focuses Information significant other Write professional-based records	Team discussions with patients - individual rehab-plan Daily information Team-based information on self-management strategies used in all programme	2x45 minutes W ³ 1 and 5 rehab. plan	1½ hour W ³ 1 information, Wgr 12x15 minutes daily information, Wgr 3x1 hour W ² 2 Significant others and participants, Wgr
Secretary	Telephone service, Medical record writing, database registration, mail to patients			
Psychotherapist	Individual therapies before or after programme when needed			
Nurse	Waitinglist, medical tests			

¹Individual time = minutes or hour the profession has for each patient, ²Wgr= Whole groups (8-9 patients); Hgr= Half groups (4-5 patients), ³W= week, ⁴PEO=Person, Environment, Occupation.

Most team members had extensive experiences from teamwork, pain rehabilitation and knowledge of cognitive behavioural techniques. Other health-care professionals (e.g. assistant nurses, a psychotherapist, a manager, nurses and

secretaries) assisted the teams and the participants. The programme emphasized education about pain and pain-related consequences, with a focus on self-management strategies and practical training sessions. In the programme each profession used their specific professional knowledge and methods (Table 3). Theories from Cognitive Behavioural Therapy (CBT) were used by the whole team as guidelines in communication, questioning, work tasks to complete at home and goal settings. The practical training sessions led by the PT or OT amounted to about 55% of the time for each patient during the five weeks, 10% was lectures (by P; PT, OT and SW), 20% were group discussions led by the PS and 15% involved time when the entire team and the participants were involved in individual team meetings and team-based lectures or information for all participants. Each patient had an individual meeting for an initial assessment of goals and needs at week one, and another at week five for following up of goals, interventions and further needs. An individual video recording was offered during the first and last week by the OT, who together with each patient assessed body awareness during the performance of activities. This was to enhance the patients' awareness of their motor and process skills and habits, and to assess that they performed the activities in the most ergonomically possible way. The prioritized occupational problems were focused during activity training and the strategies used were evaluated in writing protocols by the participant after each OT group. In the second week all participants and their significant other were invited to a half-day information about pain, pain-related consequences, programme content, strategies and pain communication skills. Work place visits were done if needed. At discharge the patients could evaluate their performances by viewing videos from week one and five and observe any progress. At discharge, the whole team and the patient reviewed the rehabilitation plan focusing on goal attainment in an individual meeting. This was followed by a meeting where the whole team, together with an official from the social insurance office, a representative of the employer and the patient's significant others met with the participant. A revised rehabilitation plan was written, including further goals and self-management strategies that the patients would carry on with during the coming eight weeks before a follow-up.

The clinic is accredited by the Commission on Accreditation of Rehabilitation Facilities (CARF). Data is continuously collected from baseline to follow-up as part of the CARF accreditation follow-up standards. Data were thus systematically collected and entered in a clinical database. The clinic takes part in a national quality registry, the Swedish Quality Registry for Pain Rehabilitation (SQRP) (Nyberg, Sanne & Sjölund, 2011a), and send data annually to the SQRP for national comparisons of patient characteristics and outcomes from pain clinics.

Procedures after the programme and the one-year follow-up

Eight weeks after discharge, all patients in the same group came back to the clinic for two days of follow-up (Figure 4). Each patient had an individual meeting with the whole team and any invited guests. The rehabilitation plan was evaluated and a new plan with further recommendations was written. There were two group meetings lead by the PS and the team during the first day and with the PS and the OT the second day. The pain rehabilitation programme was then completed and further needs were referred to the primary health care. One year after discharge, a follow-up questionnaire was sent by mail (see below).

Assessments in this thesis

The various outcome measures used in the thesis are presented in Table 4. Occupational performance and satisfaction with performance were assessed by the Canadian Occupational Performance Measure (COPM) (Law, Baptiste, McColl, Polatajko & Pollock, 1998). Psychosocial functioning was assessed by subscales of the Multidimensional Pain Inventory (MPI) (Kerns et al., 1985), pain coping by the MPI, and physical disability by the Disability Rating Index (DRI) (Salen et al., 1994). Socio-demographic factors, pain duration and pain diagnoses were collected from background questionnaires.

Canadian Occupational Performance Measure (COPM)

The Canadian Occupational Performance Measure (COPM) is a client-centered measure (Law et al., 1998), found to be useful for evaluation of everyday occupational problems. It is also used for the following-up of team-based interventions and is widely used in research (McColl et al., 2006). The COPM is administered according to a stepwise procedure, starting with an interview identifying the patient's problems with everyday occupations, then followed by ratings of the importance of being able to perform each of the targeted occupations on a scale from 1-10, where 1=not important at all and 10=most important. The participants are then asked to prioritise a maximum of five important problems of relevance during the programme. Each of the occupational problems is rated on a performance scale (1=not able to perform, 10=able to perform extremely well) and a satisfaction with performance scale (1=not satisfied at all, 10=extremely satisfied).

The COPM has shown high/adequate discriminant validity, test-retest reliability and responsiveness to change as an aspect of validity (Wressle, Samuelsson & Henriksson, 1999; Dedding, Cardol, Eyssen, Dekker & Beelen. 2004; Cup,

Scholte op Reimer, Thijssen & Kuyk-Minis, 2003). Adequate concurrent validity has been tested among patients with psychological distress (Harper, Stalker & Templeton., 2006). Validity and sensitivity to change among patients with low back pain and general persistent pain are also good (Walsh et al., 2004; Carpenter, Baker & Tyldesley, 2001). The COPM is considered to improve the process of goal-setting and to be a responsive outcome measure for pain programmes (Carswell, McColl, Baptiste, Law, Polatajko & Pollock, 2004; McColl et al., 2006; Samuelsson et al., 2011; Van Huet et al., 2009; Wressle, Lindstrand, Neher, Marcusson & Henriksson, 2003). The Swedish version, also shown to be responsive to change over time (Wressle et al., 1999), was used (FSA, 2006).

Multidimensional Pain Inventory (MPI)

The MPI is a self-rating questionnaire used to assess psychosocial and behavioural functioning (Kerns et al., 1985). It focuses on multiple dimensions of adaptation to chronic pain without placing an excessive response burden on patients and is regarded as a valuable assessment tool (Bradley & McKendree-Smith, 2001). The MPI consists of aspects related to the perception of pain and pain-related consequences and is divided in three sections consisting of 61 items. Section one focuses on psychosocial functioning and section two and three on behavioural functioning. There are five subscales in section one: pain severity, life interference, life control, affective distress and social support. The questions in sections two cover patients' assessments of behavioural responses from significant others to their displays of pain, conceptualized as punishing, solicitous, and distracting responses. Section three includes four subscales describing frequency of participation in several daily occupations: household chores, outdoor work, activities away from home, and social activities. These four subscales are mostly combined to an index of general activity (Kerns et al., 1985). The internal consistency of the MPI has been found to range from 0.70 to 0.90 and the test-retest reliability over a 2-week interval ranged from 0.62-0.91 (Kerns et al., 1985). A Swedish translation, further described by Nyberg, Novo & Sjölund, (2011b), was used.

By using a cluster analysis and a computer scoring system, Multiaxial Assessment of Pain software, three pain coping profiles can be generated from the MPI (Rudy, 1989). The three profiles are labelled: Adaptive Copers (AC), Dysfunctional (DYS) and Interpersonally Distressed (ID). The AC profile is characterized by a low score on pain severity, interference, and affective distress and high scores on life control and general activity. The DYS profile is characterized by high scores on pain severity, interference, and affective distress and low scores on life control and general activity. The ID profile is characterized by high scores on punishing responses from significant others and low on social support, solicitous and distracting responses (Rudy, 1989; Turk & Rudy, 1990). Those who share features with more than one profile are labelled hybrids. Those with significantly different

scores from the three profiles of AC, DYS or ID are labelled anomalous. The anomalous and the hybrid group were in this thesis further referred to as “non-classified” (NC). Those with missing data on more than two of the subscales were labelled unanalysable.

Disability Rating Index (DRI)

The Disability Rating Index (DRI) was used to measure physical disability. It has been constructed as a self-administered questionnaire in which patients indicate their perceived ability to perform 12 daily physical activities according to visual analogue scales (Salen et al., 1994). The items are arranged in increasing order of physical demand with reference to low back pain. The anchor points are 0=“without difficulty” and 100=“not able to perform at all”. The DRI is a robust and useful clinical and research instrument to assess physical disability caused by impairments of common motor functions, and to measure changes in functional status (Grotle et al., 2004; Salen et al., 1994). It has shown high reliability with test-retest correlations of 0.83 to 0.95 and internal consistency of 0.84. Construct validity has also been found to be good (Salen et al., 1994).

Background questionnaire

A back-ground questionnaire including information about socio-demographic and clinical factors, designed for the SQRP registry, was used in all four papers in this thesis. The socio-demographic factors were: gender, age, country of birth, marital status, educational level and vocational situation. Vocational situation was based on whether the patients worked/studied or not prior baseline. This information was categorized so that those who worked/studied less than 25% were classified as not working/studying and the remainder as working/studying. The clinical factors retrieved from the background questionnaire and used here were pain duration and pain diagnoses. The socio-demographic factors and pain duration were self-reported. Pain duration was based on the date the patient had felt the pain the first time. The attending physicians set the pain diagnoses according to the International Classification of Diseases (ICD), 10th revision, and with use of the diagnostic manual of the Swedish Quality Registry for Pain Registry (Nyberg et al., 2011a)

Table 4.
Outcome measures used in Papers I-IV.

Outcome Measure	Subscales	Paper I	Paper II	Paper III	Paper IV
MPI ¹	Pain severity (PS)	x		x	
	Life Interference (LI)	x		x	
	Life Control (LC)	x		x	
	Affective distress (AD)	x		x	
	General activity level (GA)	x			
	Pain coping profiles (AC ² , DYS ³ , ID ⁴)				x
DRI ⁵	Sum score	x		x	
COPM ⁶	Performance		x	x	x
	Satisfaction		x	x	x
SQRP ⁷	Background questionnaire	x	x	x	x

¹MPI=Multidimensional Pain Inventory, ²AC=Adaptive Copers, ³DYS=Dysfunctional, ⁴ID= Interpersonally Distressed, ⁵DRI=Disability Rating Index, ⁶COPM=Canadian Occupational Performance Measure, ⁷Swedish Quality Registry for Pain Rehabilitation.

Data collection and procedure

The background questionnaire and the MPI and the DRI were sent home to the patients by mail before the first team-based assessment (Table 4). The COPM was administrated during the first OT assessment. At discharge the MPI and the DRI were administered by the PS and the COPM was again administered by the OT. On this occasion the participants were asked to reassess their initially prioritised most important occupational problems, without seeing their previous scores. At the one-year follow-up all questionnaires were sent home to the patients, with one reminder for those who did not answer within a month. The mailed one-year follow-up COPM questionnaire again contained the initially prioritised occupational problems. A mailed follow-up procedure has been described as reliable (Harper et al., 2006). To further strengthen this follow-up procedure, a pilot study was performed in order to ensure that a mailed questionnaire was reliable in the present rehabilitation context (personal correspondence).

Data analyses and statistics

Several statistical methods were used in the papers (Table 5). Non-parametric statistics were mostly used, as all data, except for age, were ordinal or categorical. In Papers I-IV quantitative analyses were used and in Paper II a qualitative analysis was used.

The Mann-Whitney U-test was used to analyse differences on ordinal scales between two independent groups and the Kruskal-Wallis test was used with more than two groups. The independent-sample t-test was used to analyse differences between two groups on continuous variables. The Wilcoxon signed-rank test was used to analyse changes in ordinal data between two occasions. McNemar's test was used to analyse changes between two time points (Paper IV). The Chi² test of independence was used to analyse differences between subgroups of participants on categorical data. To identify predictor variables, univariate and multivariate logistic regression analyses (enter method) were performed. A p-value smaller than 0.3 for the association between a predictor variable and the criterion variable was set as a limit for including variables in the multivariate analyses. In Paper II, data were first categorized according to the COPM manual which discerns three categories, self-care, productivity and leisure, and nine sub-categories with reference to the reported problematic everyday occupations. The categories refer to the main purposes with performing an everyday occupation. Twenty per cent of the occupations were categorized by two persons independently and then compared.

Minimal important change (MIC), the cut-off for change presumed to be clinically relevant, was regarded to be 0.6 for the MPI (Dworkin et al., 2008). The level of change needed on the DRI to describe a MIC was not found in the literature. Ratios for cut-off points of 10%, 13%, and 15% were tested. No differences were found between analyses based on these percentages and 10% was used as MIC level for the DRI. The levels for deteriorations were set as the negative opposite of the MIC, consequently a change of -0.6 for the MPI and -10% for the DRI (Paper I). A MIC on the COPM was a change of at least 2.0 points (Law et al., 2005) and the MIC cut off was thus used when dichotomizing change scores for further analyses. Distribution-based effect size (ES) (Cohen's effect size) was calculated, and a small ES is 0.2, a medium is 0.5 and a large ES is 0.8 (Cohen, 1988; Streiner & Norman, 2008).

The reliability of the scale within the studied sample was analysed with the Cronbach's alpha test and 0.7-0.9 was regarded as satisfactory (Streiner & Norman, 2008). The Nagelkerke test was used as an indication of the amount of variation in the dependent variable explained by the model in the logistic

regression. The Hosmer-Lemeshow test was used to estimate the model; a poor fit is indicated by a p-value less than 0.05. The Omnibus test of the model was also employed. The predictor variables used in the logistic regression analyses were tested for multicollinearity, by use of Spearman's correlation test. Inter-rater reliability was calculated as $\alpha = 1 - (\text{observed disagreement}/\text{expected disagreement})$. An alpha value of 0.9 was obtained, which is considered satisfying (Krippendorff, 2004). Descriptive statistics were used to present occupational problematic occupations, as perceived by the participants.

The SPSS for Windows versions 17.0 to 20.0 were used for all statistical analyses and a p-value smaller than 0.05 was considered statistically significant.

Table 5.

A summary of data analyses used in the present thesis.

Data analysis	Paper I	Paper II	Paper III	Paper IV
Wilcoxon signed rank test	x		x	
Spearman correlation	x		x	x
Chi ² test/Pearson's chi ²		x	x	x
Mann -Whitney U-test	x		x	x
Kruskal Wallis test	x			x
Independent sample t-test	x		x	x
Chronbach alpha	x			
McNemars test				x
Univariate logistic regression	x		x	x
Multivariate logistic regression	x		x	x
Effect size	x		x	
Content analyses		x		
Krippendorff inter-rater test		x		

Ethics

All patients who participated had received written and verbal information regarding data being registered in the clinical database and in the Swedish Quality Registry for Pain Rehabilitation (SQRP) registry. The patients were informed that group-based data are used for annual national comparisons, occasionally (about each fourth years) for social insurance data comparisons (data not available for this thesis) and for research. Before the registration took place of data the participants had the option to decline being registered in the database. They had the right to, at any time thereafter, decline further participation and demand personal information to be deleted from the registry. All data extracted from the registry database and used in the analyses were coded and no individual patient could be identified. The principles of the Declaration of Helsinki were followed for all data handling. The study (Papers I-IV) was approved by the Regional Ethical Review Board in Lund, Sweden (No H4 269/2006).

Results

Situation at baseline

The median score on occupational performance was 3.4 (IQR 2.6-4.2) and the median score on satisfaction with performance was 2.4 (IQR 1.6-3.4) at baseline (Paper III). It was not analysed whether baseline scores on occupational performance and satisfaction with performance differed among subgroups of participants. Further supplementary analyses are described in the last part of the results section of this thesis.

Positive baseline scores on psychosocial functioning (above the median score) were found to be associated with being older than 40 years, being at work, being Nordic born, attainment of a higher educational level, and a diagnosis of fibromyalgia (compared with a neck disorder) (Paper I). Worst situation, higher level of pain severity, was found among non-Nordic born participants and those with fewer years of education. More negative life interference was found among non-Nordic born participants and those not working. Lower levels of perceived life control were found among non-Nordic born, those with shorter education and those not working. Those participants being younger than 40 years, non-Nordic born, having shorter education and not working reported worst affective distress. Non-Nordic born and those with a neck disorder, as compared with fibromyalgia, had lower activity levels. Being at work and having a diagnosis of fibromyalgia (compared with low back pain) was associated with more positive scores on the DRI (a sum score below the median).

The proportions of pain coping profiles at baseline were found to be 46% having a dysfunctional (DYS) profile, 21% with an interpersonally distressed (ID) profile, 17% with an adaptive copers (AC) profile and 17% with a non-classified (NC) profile (Paper IV). Having an AC profile or not at baseline was significantly associated with country of birth ($p=0.003$) and with being at work ($p=0.004$). Ninety-five per cent of those with an AC profile were Nordic born and 50% were working. Having a DYS profile or not was also significantly different for subgroups based on country of birth and being at work. Among those with a DYS profile only 77% were Nordic born ($p>0.001$) and 30% were at work ($p=0.006$).

Specific everyday occupational problems

The 152 participants in the subgroup studied in Paper II reported 706 prioritized everyday occupational problems, categorized as self-care (37%), productivity (32%), and leisure (31%), based on the occupational performance interview. The subcategories with most problematic occupations were found to be household management, personal care, quiet recreation, functional mobility and social recreation (Figure 5). The most common specific occupational problems were working, sitting, cleaning the house, cooking and sleeping. Women reported significantly more occupations related to productivity and men reported more self-care occupations.

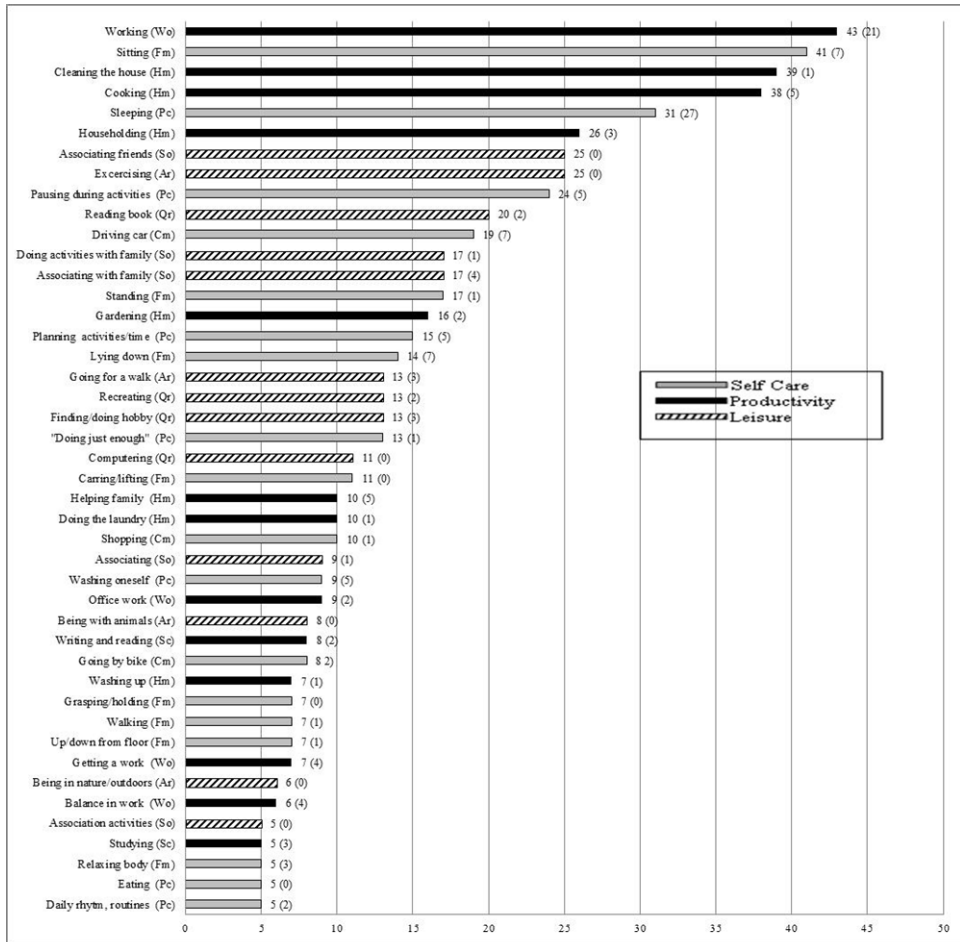


Figure 5.

Specific everyday occupational problems occurring five times or more. The abbreviation for each sub-category is given in parentheses: Pc=personal care, Fm=functional mobility, Cm=community management, Wo=working, Hm=household management, Sc=studying, Qr=quiet recreation, Ar=active recreation, and So=socialization. The Figures in parenthesis represent the total number of times that the specific occupation was first prioritized.

The significant gender differences found in prioritized occupational problems in the main categories were not possible to perform per subcategory as there was too few men in each group. A supplementary frequency analysis is reported in the last part of the result section.

Outcomes at discharge and one-year follow-up

Statistically significant improvements were seen on occupational performance and satisfaction with occupational performance at discharge and at the one-year follow-up. Between discharge and the one-year follow-up there were statistically significant differences only for change scores on the occupational performance subscale. At the one-year follow-up a total of 39% improved on occupational performance according to a MIC, thus a change score of 2.0 or more as compared with baseline, and 47% improved (change score ≥ 2.0) on satisfaction with performance at the follow-up. Effect sizes of the changes were large (≥ 0.8) on both occupational performance and satisfaction with performance (Paper III).

On the basis of cut points for MIC on psychosocial functioning, participants rated themselves as most improved on the Affective Distress (52%), Life Control (49%) and Pain Severity (43%) subscales at follow-up (Paper I). On the DRI index, the improvement rate was only 22%. The effect sizes for change on pain severity (0.5), affective distress (0.5) and life control were of medium size, whereas those on life interference (0.3), general activity level (0.2) and DRI index (0.1) corresponded to a small effect size. Data at discharge were not analysed in Paper I.

Figure 6 presents the proportions of pain profiles and the p-values for changes between all three occasions. There were statistically significant increased proportions of participants with an AC profile and with an NC profile at discharge and at the one-year follow-up, and a decreased proportion of DYS profiles at both discharge and the one-year follow-up. There were no changes between discharge and follow-up on any of the four profiles. The Interpersonally Distressed (ID) profile did not change significantly on any occasion. Sixty-four per cent of those with an AC profile at baseline remained as AC at the one-year follow-up, while 48% of those being DYS at baseline remained DYS at follow-up. Forty-nine per cent remained as ID and 34% remained as NC. Of those 105 becoming AC at one-year follow-up, 50% were DYS at baseline, 23% were ID and 32% ID (Paper IV).

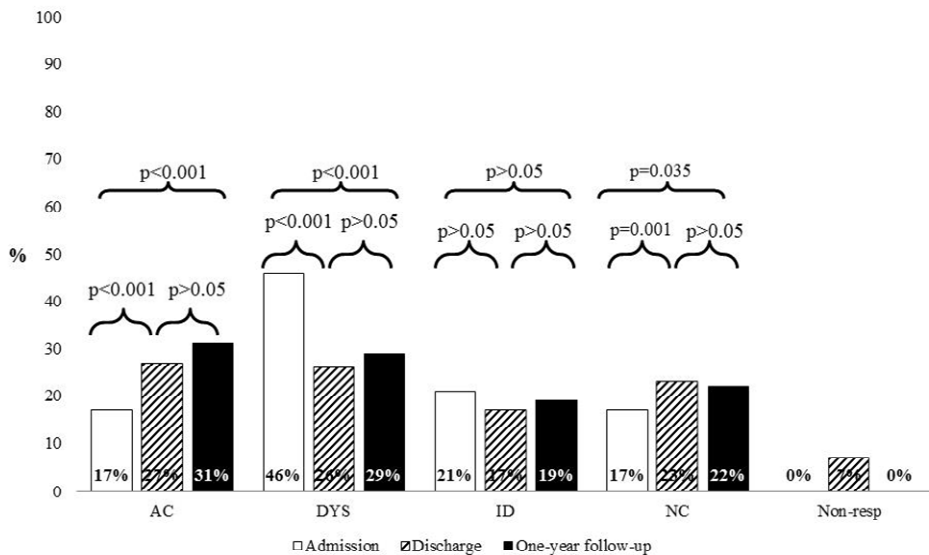


Figure 6.

Proportion of participants in each of the four MPI profiles at baseline, at discharge and at the one-year follow-up.

The changing patterns on the MPI profiles were used to analyse associations with change scores on the COPM from baseline to follow-up. Four changing categories were identified on the MPI profiles: “never AC” (including participants not classified as AC profiles at baseline or at follow-up); “losing AC” (including participants classified as AC profiles at baseline but not at follow-up); “gaining AC” (including participants classified as AC profiles at follow-up but not at baseline); and “stable AC” (including participants classified as AC profiles both at baseline and at follow-up). The “gaining” AC group included 105 participants, the “stable AC” included 56, the “losing AC” group included 32 and the “never AC” group included 332 participants. Having an AC profile at follow-up was associated with clinically relevant improvements on the occupational performance and satisfaction with performance. The AC profiles at the one year follow-up typically had a change score on occupational performance and satisfaction with performance above 2.0 and those not being AC at follow-up were more likely than the AC profiles to have minor changes, below 2.0, on occupational performance and satisfaction with performance. Both being in the “gaining AC” group and in the “stable AC” group were significantly associated with improvements on occupational performance and satisfaction with performance.

At the one-year follow-up 39% (n=177) were improved on occupational performance and 49% (n=214) on satisfaction with performance. Out of those “never AC” 30% improved on occupational performance and 41% of the “losing

AC”, 57% of the “gaining AC” and 59% of the “stable AC” improved on occupational performance. Out of those “never AC”, 38% improved on satisfaction with performance and 47% of the “losing AC”, 63% of the “gaining AC” and 73% of the “stable AC” improved on satisfaction with performance.

Variables associated with outcomes

In multivariate logistic regression analyses that included socio-demographic factors as predictors for improved occupational performance and satisfaction with performance female gender, lower age, Nordic born, and being at work prior to the programme were associated with improvements. Less severity on baseline physical disability and a better situation with regard to life interference and life control were factors pertaining to physical and psychosocial functioning of importance to improvements on occupational performance and satisfaction with performance. In a final step of the analyses, which included both socio-demographic and physical and psychosocial functioning, the baseline scores of less severe physical disability ($p=0.001$), more life control ($p<0.001$) and more severity, and a higher score on occupational performance ($p<0.001$) were associated with a clinically relevant improvement regarding occupational performance at the one-year follow-up. Female gender ($p=0.014$), less severe physical disability ($p=0.021$), less life interference ($p=0.003$), more life control ($p=0.039$) and higher score on baseline satisfaction with performance ($p<0.001$) were associated with improvements on satisfaction with performance at one year after the programme (Paper III).

Variables associated with improvements and deteriorations above or below a MIC on psychosocial functioning or physical disability at the one-year follow-up were assessed in Paper I. Improvements are reported as $>MIC$ and deteriorations as $<-MIC$. Age-group was the only variable in the univariate analysis being significantly associated with $<-MIC$ on pain severity ($p=0.038$). Among the participants deteriorated on pain severity, 56% were younger than 40 years and 43% were older. Neither socio-demographic nor pain duration or pain diagnoses were significantly ($p<0.05$) associated with clinically important improvements on the MPI and the DRI (Paper I).

Nordic born participants, those having longer education, those with an AC profile at baseline and participants with higher admission scores on satisfaction with performance were more likely to have an AC profile at the follow-up (Paper IV).

Supplementary analyses

Supplementary analyses regarding subgroup differences at baseline on occupational performance and satisfaction with performance between socio-demographic subgroups, pain duration and pain diagnostic subgroups were made. Participants not at work had a significantly lower ($p=0.003$) median score on occupational performance, 3.4 (IQR 5.80) compared to those at work (median 3.2, IQR 6.50). No other subgroup difference was found for baseline occupational performance or satisfaction with performance.

The frequencies of the first prioritised occupational problems in each COPM subcategory are presented in Figure 7 together with a description of the most common specific first prioritized occupations in each subcategory. The most common specific occupation in each subcategory were: social recreation – associating with friends, active recreation – exercising, quiet recreation – reading books, household management – cleaning the house, work – working, community management – driving car, functional mobility – sitting and personal care – sleeping. In the subcategory play/school there were too few activities to specify any most common.

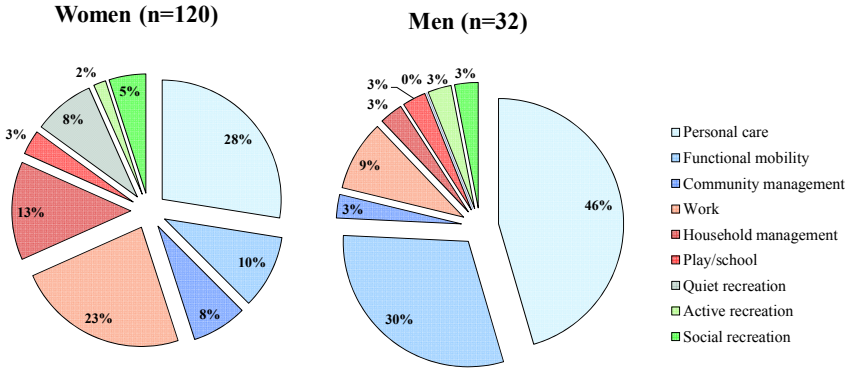


Figure 7. Description of per cent of everyday occupational problems reported in each of the nine subcategories on the Canadian Occupational Performance Measure, described for the women and men.

Discussion

The findings in the four papers in the thesis will be discussed in relation to the aims and the results. The main intentions were to evaluate occupational performance, psychosocial functioning, physical disability and pain-coping at a one-year follow-up after a musculoskeletal pain rehabilitation programme. Three of the four papers concerned data on occupational performance (Papers II, III and IV) and the discussion will expand on these. It will also be discussed whether clients' base-line characteristics have relevance for base-line variables or outcomes. In the discussion the term 'participants' is used when referring to clients involved in the four studies and the term 'clients' is used when referring to patients or clients in other studies or in a general discussion of patients or clients. Client is the general term used in the literature focusing occupational praxis and theories and in client-centred healthcare services (Townsend & Polatajko, 2007; Kielhofner, 2008).

Occupational performance

The occupations that the participants prioritized (Papers II) were focused during occupational therapy sessions, and progresses and actions needed were discussed on team conferences. Mapping and communication focusing specifically on activity and participation goals have recently been found to facilitate a more integrated and effective care and such activity goal concepts have been found to be linked to the ICF model (Bagraith, Hayes & Strong, 2013). However, evaluations of procedures on reliable ratings for clients and clinicians are called for. A profile of a modified brief ICF Core Set has been found useful in interdisciplinary team assessments (Löfgren et al., 2013). The COPM measure, used in the present thesis, has by Wressle et al. (2003) been considered to improve the process of goal-setting in pain rehabilitation teams.

Performance and satisfaction with performance

Outcomes in terms of occupational performance and satisfaction with performance in the present thesis were assessed at discharge and at a one-year follow-up (Papers III and IV). Significant improvements, both at discharge and at follow-up,

were found (Paper III). At baseline the reported scores on satisfaction with occupational performance were reported as being lower than the scores on occupational performance. Participants improved, however, more on satisfaction with performance than on occupational performance at follow-up (Paper III). Improvements on daily activities have been found to be associated with treatments satisfaction among pain clients (McCracken et al., 2002). Whether improved occupational performance was equivalent to treatment satisfaction was not evaluated in this thesis. Such associations need to be investigated.

Several other studies have revealed improvements on occupational performance and satisfaction with performance following pain rehabilitation programmes as has been found in the present thesis (Carpenter et al., 2001; Walsh et al., 2004; Mead, Theadom, Byron & Dupont, 2007; Samuelsson et al., 2011; Ehrenborg et al., 2013). No randomized controlled study has, however, to the best of my knowledge, yet been performed on the use of interventions and methods with occupation-based theoretical ground for pain rehabilitation. Occupational performances are known to be important outcomes for people with persistent pain, there thus appears to be a need for confirming the benefit of occupation-based methods, by using controlled studies and comparative interventions. Occupation-based methods have, however, been used in interdisciplinary cognitive behavioural pain programmes for a long time (Fordyce, 1968; Unruh & Harman, 2002; Scascighini et al., 2008). Several studies have evaluated interdisciplinary pain programmes using such occupation-based methods, however, these methods are not explicitly evaluated (Flor et al, 1992; Soares & Grossi, 2002; Nordström et al, 1998; Norrefalk et al, 2008; Hamer, Gandhi, Wong & Mahomed, 2013). In a randomized controlled comparison of an educational (OT and PT) and a behavioural (PS/cognitive behavioural therapist) intervention for women with fibromyalgia the outcomes at a six months follow-up were found to be mainly the same for both interventions (Soares & Grossi, 2002) This result may indicate that there should be both educational/behavioural and practical training situations for reaching beneficial outcomes at follow-up. Strategies aimed at maintaining clients' valued roles, good social support, use of pacing activities and relaxation have been found beneficial for goal fulfilment from a doing or occupational therapeutic perspective. (van Huet, Innes & Stancliffe, 2013). Engagement in meaningful occupations are by clients reported beneficial because they focused on something else than pain (Fisher et al., 2007). Recommendations from the IASP association is that occupational therapy interventions should be used to focus on assessing pain in relation to activity patterns, time use, goal-fulfilment, changes in routines, habits and roles and clients' skills related to goal fulfilment (IASP, 2014). Clients' abilities in setting realistic goals have been found important and those unable to set goals, or who did not use strategies, were afraid, looked for cures or did not know what to expect had worse outcomes in comparison with those who accepted pain as long-term, or were prepared to change their thinking about pain and develop

new habits (van Huet et al., 2013). The results in the study by van Huet et al. (2013) are in line with other findings, showing that factors that enhance clients' satisfaction with treatments include: assessments perceived as being completed and clients perceiving they have received explanations for clinical procedures (Mc Cracken et al., 2002).

Specifik everyday occupations

In order to help clients improve occupational performance it is necessary to evaluate their abilities in relation to the demand of the occupation and to the environments in which the occupation is to be performed (see, fit-chart Figure 2, Introduction). Occupations create different demands during performance. It is thus important to find out which occupations most often being difficult for clients to do, in order to have the ability to offer the opportunity for clients to practice and explore strategies that can be the most beneficial and for therapist to have the ability to assess client skills during their occupational performances. The participants in the present thesis reported all kinds of occupational problems such as looking after themselves (self-care), contributing to the society (productivity) and considering enjoying life and recreation (leisure) (Paper II). In terms of self-care sleep was of the greatest importance and in terms of productivity work-related occupations and household management were important occupation areas. Most of the participants (68%) reported problems concerning household management. Almost half of the participants, 46%, reported quiet recreations as difficult, whereas only 36% and 39% reported active recreation and socialization as being difficult respectively. All occupational goals were reported through a client-centred approach and the participants defined which occupations being most important for them to focus on to find more beneficial occupation-based strategies during the rehabilitation. Client-centred occupational goals have been discussed as not being appropriate, as such goals eventually should not be "behavioural" and may not agree with prioritized goals and outcome expectations among professionals (Åsenlöf, Denison & Lindberg, 2004). However, if a client sets goals that are not appropriate for the treatment or culturally unacceptable these should be discussed. If an agreement cannot be reached about an occupational goal then the treatment should be terminated. Such procedures are included through discussing occupational needs, and by prioritizing the most valued needs related to the clients' everyday lives through client-centred interventions (Wressle et al., 2002).

Household management has been described as a difficult domain for clients with persistent pain (Samuelsson et al., 2011; Eriksson et al., 2012, Amris, Eljsersen Wæhrens, Jespersen, Bliddal & Danneskiold-Samsøe, 2011). The women in this thesis had significantly more problems related to productivity, including household management, than the men did (Paper II). This result is also in line with

other findings of women reporting more problems with household management than men do (Merritt & Fisher, 2003; Boonstra et al., 2011).

Work-related occupations were reported as being important for 38% of the participants, which implies that work did not constitute a major problematical occupational domain (Paper II) and 62% of the participants were not working prior to rehabilitation. It was, however, not evaluated whether work was prioritized by those working or by those not working. Being on long-term sick leave has previously been found to be associated with changed roles, daily habits and routines (Johansson & Isaksson, 2011), which could indicate that non work-related occupations may be more relevant during sick-leave. Participants who had work as a prioritized occupation were offered workplace visits when needed. Pain rehabilitation teams who collaborate with employers have been found to be of greatest importance in helping clients back to work (Williams, Wetsmorland, Lin, Schmuck & Green, 2007; Carroll, Rick, Pilgrim, Cameron & Hillage, 2010; Nordström-Björverud & Moritz, 1998) and may therefore be important.

Persistent pain causes high societal costs, mostly in terms of indirect costs due to the loss of work productivity and high levels of people sick-listed due to persistent pain (Ekman et al., 2005; van Tulder et al., 1995; Dagenais, Caro & Haldeman, 2008). One common outcome domain of pain rehabilitation is thus the return to work rate. Having an ability and capacity to work are important factors for most people. There may, however, be a risk that economic incentives force health-care services to mainly focus on participants' work-related occupations. Costs for sick leave raised in Sweden during the 2000s and work-related rehabilitation decreased during the same time. The focus on people being sick listed increased and a debate whether they needed to be sick-listed or not was reported (Johnson, 2010). The Swedish government focused increased back-to-work-rates as important outcomes of rehabilitation (SOU, 2011). It might thus be a risk that other, non-work-related everyday occupation or life problems can be neglected, even though these might indirectly be most relevant for work capacity, people's overall health and also be prioritized as important by clients (Paper II).

Several participants (78%) found leisure occupations problematical (Paper II). Quiet recreation was the subcategory, within leisure that most participants reported problems on. Examples of such occupations were painting, ceramics, handicraft, reading, watching TV and photography (Paper II). The use of "creative activity groups" has throughout history been common in occupational therapy (Bathje, 2012), explicit use of painting as a therapy are described to reduce stress and anxieties by helping people express thoughts and emotions (Rubin, 2010; Slayton, D'Archer & Kaplan, 2012; Sandmire, Roberts Gorham, Rankin & Grimm, 2012). Leisure occupations have been found to be negatively affected among people on sick leave (Floderus, Göransson, Alexanderson & Aronsson, 2005). An explorative study designed to further understand a creative activity group in a "Play and Flow" perspective corroborated that such an activity group promoted

play and experiences of flow among clients with persistent pain (Persson, 1996). Clients with stress-related disorders, many of whom often have persistent pain experienced occupational performance as promoting relaxation and enjoyment. Gaining the ability to perform new occupations or performing those that clients had not been able to do for a long time contributed to changes in the clients' self-image and in the values attached to everyday occupations towards more beneficial occupational repertoires (Eriksson, Karlström, Jonsson & Tham, 2010).

There was a tendency for the importance of problems to decrease in order of self-care > productivity > leisure when each participant's first prioritized occupation only were ranked (Paper II). Sleep was then the most frequently first prioritized specific occupation (20% of participants reported sleep as being prioritized). It is well known that people with persistent pain often have sleep problems (SBU, 2006; Dworkin, et al., 2005; Green, 2008; Walsh et al, 2004), and sleep function is described as an ICF pain core set (Schwartzkopf, Ewert, Dreunhöfer, Cieza & Stucki, 2008; Löfgren et al., 2013). Core set being an item retrieved from the ICF model and having specific relevance for a disease group. Reading, listening to music and relaxation are described as useful strategies for achieving better sleep by individuals having sleep problems (Morin, LeBlanc, Daley, Gregoire & Mérette, 2006). Aspects of daily occupations and total time devoted to activities have been shown to influence sleep (Leufstadius & Eklund, 2008) and clients with persistent pain who work have been found to have better sleep than those who do not worked (Liedberg, Hesselstrand & Henriksson, 2004). There is, however, a discussion among occupational therapists whether sleep should be seen as an occupation or not and in ICF it is described as a function (ICF, 2003). Sleep, however, may be clinically important to acknowledge for occupational therapists working with clients with persistent pain, as occupational therapy interventions should focus on clients' occupational patterns, time use and changes in routines (IASP, 2014) and as occupational patterns and sleep have been found to be related. It is also reasonable to discuss that performing those everyday occupations that bring meaning to one's life may result in better sleep. Enhanced occupational patterns and more beneficial everyday occupational repertoires may thus have relevance for better sleep in turn. Occupational therapists can use time-geographical diaries to describe client's rhythmic patterns and daily projects (Liedberg et al., 2004; Orban, Edberg. & Erlandsson, 2012).

Psychosocial functioning, physical disability and coping

Psychosocial functioning

In this thesis each participant's psychosocial functioning at baseline was associated with a number of socio-demographic characteristics (Paper I), further described below. The aspects of psychosocial functioning that were most improved at follow-up were affective distress, life control and pain severities, less improvements were found on life interference and general activity levels. Such findings may implicate the necessity for assessing client's psychosocial functioning to find out which domains that may be improved the greatest. There were, however, some participants who had deteriorated at follow-up (Paper I). Further investigation into of the reasons for some participants deteriorating needs to be carried out and some participants may need other more beneficial interventions not currently in place.

Physical disability

Not surprisingly, the result focusing physical disability indicated that not being at work prior to baseline was associated with more baseline physical disability (Paper I). Fewer good results were, however, attained on physical disability at follow-up, and similar results have been found elsewhere (Merrick & Sjölund, 2009). This indicates that either interdisciplinary programmes are not sufficiently beneficial for improving physical disability or the measure used, the DRI, does not focus on variables relevant for outcomes of interdisciplinary pain rehabilitation. A measure focusing on physical disability may be correct for physical therapy interventions as these are mainly aimed at increasing fitness or physical functioning. The programme under investigation in this thesis was not specifically aimed at decreasing physical disability, even if such outcomes may have been beneficial. Another explanation for less good results on the DRI may be that this measure is better suited for assessments while not being appropriate for measuring outcomes of interdisciplinary interventions, as in this thesis project. Further investigations need to be performed to ascertain whether those participants who had increased on physical disability deteriorated also in respect of other outcomes.

Pain coping

The pain coping profiles used in the present thesis were derived from the MPI subscales and described how participants managed pain-related consequences. At baseline most participants belonged to the Dysfunctional, DYS, profile (46%), whereas fewer belonged to the Adaptive Copier, AC, profile (17%), the

Interpersonally Distressed, ID, profile (21%), and a profile displaying Non-Classified, NC, profile (17%) (Paper IV). The distribution among the pain coping profiles varies between studies and pain populations, which may indicate that there are different selection criteria for including clients in rehabilitation. Among clients with Whiplash associated disorder 42% had an AC profile, 34% an DYS profile and 24% an ID profile (Söderlund & Denison, 2006), and in clients with chronic disabling occupational musculoskeletal disorder 33% had an AC profile, 44% a DYS profile, and 23% an ID profile (Choi, Mayer, Williams & Gatchel, 2013). These comparisons indicate that different sample of clients with persistent pain can differ in terms of pain coping. The participants in this thesis seemed to less good coping strategies, 17% AC, in comparison with 42%, and 33% in these other samples. During such circumstance it is obvious how difficult it may be to use evidence from different pain research samples, even if the research designs used are best possible.

The analyses of changing patterns on coping profiles from base-line to one-year follow-up in this thesis indicated several interesting results (Paper IV). A statistically significant increase in the number in the AC profile and a corresponding decrease in the number in the DYS profile at follow-up were found. On the other hand the ID profiles did not significantly change. It thus appears to be important to further assess the needs of those the ID profile. Silvemmark, Källmén, Portala and Molander (2008b) described that clients reporting an AC profile in general perceived a higher level of life satisfaction than those with a DYS or an ID profile, indicating that an emphasis on increasing the number of clients in AC profiles at follow-up should generate an overall improved life satisfaction among clients.

The ID profiles report more punishing responses from significant others, implying a lack of social support, which is a risk factor among pain populations (Linton, 2001; Ariens et al., 2001). In order to bring about a change into more beneficial coping profiles a person from the ID profile may need additional support during rehabilitation. Particularly since, behaviours of significant others may reversal impact on clients' choices of coping strategies. It has been found that clients with spouses who are critical may be more likely to employ maladaptive coping strategies, while those with more supportive spouses tend to employ more adaptive and problem-focused coping strategies (Manne and Zautra, 1989; 1990). When a person does not receive social support he/she may have difficulties in coping with a new situation, such as constant pain. The result in this study described no changes among ID profiles that suggest a need for a continuous assessment of possible family or social problems among them. Such assessments may identify the possible social problems that need to be focused on in order to better help such subgroups. Those clients with an ID profile at baseline, however, have been found to improve their occupational performance at discharge (Persson et al., 2004), which may indicate that this subgroup even if not changing into another coping

profile, may still benefit from pain rehabilitation in other ways. A client's social situation is important as it may fulfil needs for receiving support and having positive feedback from significant others. In turn, when a client begins to adapt to their illness this may relieve the spouses' feelings of needing to monitor them or even to control their activities. Chronically ill people may feel that they have lost control over their bodies and lives and by regaining control and coping with bodily changes they may learn to live with their illness and emotions of anger, self-pity, guilt, and blame are more likely to be relieved (Chamaz, 1995).

An interesting association between beneficial pain coping strategies at follow-up and improvements on occupational performance and satisfaction with performance was found in this thesis (Paper IV). No study has, to our knowledge, focused on such associations with long follow-up times previously. There is, however, a need for further studies to evaluate which pathways during a rehabilitation process facilitates or hinder outcomes in terms of coping and of occupational performances. Among a sample of people with knee osteoarthritis it has been found that increased activity performance and ignoring pain (described as "good" pain behaviours) as coping strategies at one-year follow-up showed no improvements or even worse reports on pain levels and functioning (Alschuler et al., 2013). That result might implicate the urgent need of assessing which specific clients may benefit from particular pain-coping strategies. It seems as those with decreased knee functioning are not helped by increased physical activities, as such a coping style may even worsen their situation. This discussion could be applied to the findings of few improvements on physical disability in the present thesis (Paper I). Alschuler et al., (2013) argued that there may be a need to evaluate which types of activities that the clients improves on as one activity may be pleasant for one client but not for another.

Participant characteristics' relevance for pain-related health and outcomes

It is known that relatively stable demographic characteristics such as age, gender, race and social class contribute to how people perceive and interprets having a chronic illness (Maes et al., 1996). Not surprisingly socio-demographic subgroups containing ethnicity, educational levels and being at work were associated with psychosocial functioning in this thesis (Paper I). Social determinants as well as social status have great impact on health factors. Accessibility to health care has in fact been found to be less important than social determinants are for survival (Marmot & Wilkinson, 2006). Such evidence shows the importance for health researchers of estimating outcomes and health severity in relation to a complex environment that impacts people's health. Health is not solely dependent on the

treatments given but a client's social environment might also have significant overall influence. The results in the present thesis shows that socio-demographic variables such as gender, ethnicity, educational level, being at work together with the participant's pain diagnoses were associated with variables at baseline health or one-year outcomes.

Marital status, pain duration and age were variables of minor relevance for baseline health and for outcomes in the present thesis (Papers I, III and IV) as they mainly did not influence base-line health or improvements. Furthermore, socio-demographic characteristics, pain duration and pain diagnoses were found not to be associated with improvements on psychosocial functioning and physical disability at the follow-up. A review concluded that socio-demographic factors mostly did not predict change after completion of pain rehabilitation (van der Hulst, Vollenbroek-Hutten & Jzerman, 2005). However, the results are far from conclusive and other reports have pointed in the opposite direction (SBU, 2006).

Improvements should perhaps be measured on an individual basis as the rehabilitation mostly focuses on each participant's individual rehabilitation plan, and her or his needs and resources. Furthermore, a group-based programme may not suit all clients' individual needs; some subgroups may have external life circumstances that may be difficult to cope with. Moreover some individuals may improve in respect to one variable but not in respect to another. Other relevant questions that need to be answered are whether interdisciplinary pain rehabilitation programmes should focus on those having most needs, being most disabled, or on those known to have the best outcomes. This is an ethical question that cannot be answered from the results in this thesis, but is still important. Furthermore, it should be established which outcomes are "good enough". If the focus is to be on those clients known to benefit the most, how should those with most needs then be met?

Gender

Women are found to have a greater risk for developing persistent pain than men do (SBU, 2006; Unruh, Ritchie & Merskey, 1999). The participants in the present thesis had a wide range of occupational problems that needed to be solved. Gender differences were found in terms of occupational problems (Paper II) and on opportunity for improved satisfaction with performance (Paper III). Women had more problems related to productivity including household management, than the men had. It is important to stress that men may choose to perform, and are familiar with, many tasks that are considered by some to be traditional female tasks (e.g. ironing, cooking, vacuuming) (Merrit & Fischer, 2003). It is reported that women takes more responsibility for household chores and child care than men (Pickering 1997). Unruh et al., (1999) have also found that interference of pain has a greater impact on threat appraisal of pain for women. Threat appraisal, in turn, is

associated with more frequent health care utilization for women, especially those women with less well functioning coping strategies. This gender difference may have relevance for findings in the present thesis where the majority of clients were women. Fillingim et al. (2009), reported, in a critical review, substantial sex differences for pain responses and demonstrated some evidence indicating different responses to pain treatment between women and men, which are partly in line with results in this thesis.

In a supplementary description in the present thesis (Results section) the number of occupations being reported by men and women in the occupational subcategories in the COPM also indicated that there were gender differences, however a small number of cases did not allow statistical analyses. Women reported more problems with leisure occupations than men did and the latter reported more problems related to functional mobility and self-care than women did. Valuable occupations occur in a context that is unique for each client and as well as gender differences, there may also be age differences, even if this was not found in the present thesis.

The different needs reported by men and women imply that therapists need to be observant about men and women's potentially differing needs for occupational strategies. Women were more likely to improve satisfaction with occupational performance (Paper III) and the therapist should therefore be specifically observant on how to help men. It maybe that the rehabilitation under investigation was in some means designed to meet women's occupational needs to a greater extent than that of the men. An overrepresentation of female clients and therapists (acknowledged by personal communication) may be relevant here.

Ethnicity and educational level

It was found that subgroups of participants with shorter educational level and being non-Nordic born had more problems at baseline and fewer opportunities for improvements (Papers I, III and IV). Non-Nordic born and participants with lower educational level had a worse baseline situation regarding psychosocial functioning (Paper I) and these subgroups had fewer chances for belonging to the AC profile at one-year follow-up (Paper IV), however, ethnicity and educational level did not determine improvements in psychosocial functioning (Paper I). Higher educational levels have been found to be associated with more positive outcomes in another study (Tan, Jensen, Thorny & Anderson, 2006). During a specialized pain programme, it is important to focus on how to best help those who are the most severely disabled, and to support all clients who are likely to benefit from the treatment. The pain programme under investigation was solely group-based and additional individual interventions or adjusting interventions to better suit all clients may be needed. It should be beneficial to identify any specific therapeutic factor of more relevance for the improvements and to set a goal for the

level of improvements that could be defined as a “golden standard” for rehabilitation programmes like this one. If clients do not improve it may not be ethical to suggest rehabilitation efforts that not are beneficial.

Pain diagnoses

A diagnosis of widespread pain in this thesis, such as fibromyalgia, was associated with higher levels of general activity, as compared with neck disorders, and with less physical disabilities as compared to low back pain. Improvements at follow-up were however, not related to any specific pain diagnostic subgroup (Papers I, III and IV). This result is in line with preliminary results from a study aimed at evaluating differences between clients with a neck disorder and those with fibromyalgia (Persson & Rivano-Fischer, 2011). Less physical functioning among clients with low back pain as compared with other pain diagnoses has been found elsewhere (Rogers, Wittink, Wagner, Cynn & Carr, 2000). These results indicate a specific need to more carefully assess physical and occupational functioning among clients with neck disorders or with low back pain.

Work

Being at work was interestingly not significantly associated with pain severity or activity levels at baseline (Paper I). Those not working reported, however, worse life interference, less life control, more affective distress and more physical disabilities at baseline (Paper I). Being at work at baseline significantly increased the chance of improving on occupational performance (Paper III). Those working also had an indicated greater chance for reporting an AC profile at follow-up ($p=0.054$) (Paper IV). Among all participants 36% were working at baseline and among those with AC at the one-year follow-up 47% worked at baseline. Clients enrolled in interdisciplinary pain rehabilitation reporting an AC or a DYS profile at baseline have been reported with better long-term outcomes of sickness absence, AC having best outcomes with least sickness absence (Bergström et al, 2012). The result in this thesis appear to concur with that result in terms of efforts needed to determine if any specific intervention would be beneficial for those with an ID profile into better long-term outcomes.

Enabling occupational performance in a “doing-thinking” perspective

Associations between a beneficial coping profile, AC, and improved occupational performances and satisfaction with performance were evaluated in the present thesis (Paper IV). The ability to cope with a situation and improved ability to

perform everyday occupations are prioritized concerns among clients, and important for a successful pain rehabilitation. Occupational performance could be termed as a “doing” aspect and pain coping a “thinking” aspect.

An AC profile, “thinking”, at follow-up was associated with clinically relevant improvements on “doing” in the present thesis and those not having an AC profile had significantly less improved “doing” (Paper IV). Even if the “thinking” aspects were improved, most participants (69%) did not attain an AC profile at follow-up. Why such a substantial proportion of participants did not reach a more beneficial “thinking” is unknown. It could be that some of the participants have several complex personal or environmental barriers that hinder change. Another explanation could be that the programme was not focused on interventions that could contribute to more beneficial “thinking” at one-year follow-up. However, several participants improved “doing” without reporting an improved “thinking” (n=98). Most of these (88%) belonged to the subgroup that never reported an AC profile and a minor proportion (12%) were those being AC at baseline but not at follow-up (Paper IV). The processes or circumstances that facilitated or hindered these changes are important. It is not known which factors that are most beneficial for improving “doing” or “thinking” aspects. This “doing” and “thinking” association needs to be further evaluated, in order to ascertain which pathway during rehabilitation would be relevant for a beneficial change of both these aspects. Moreover it is not known whether some participants were improved at discharge, but deteriorated between discharge and follow-up. Maybe participants improving on one of the aspects “doing” or “thinking” should be considered “good enough” for a successful treatment.

The meaning of losing the abilities needed for performing everyday occupations, which are aimed at fulfilling life roles and goals, is a negative process that may have impact on a person’s self-identity. The way to take back control over the illness is also a process that may take time (Charmaz, 1995). One important core issue in enabling occupational performance is thus the role of a client’s self-identity. Some issues may be psychological and physical functioning, but also other factors such as occupational patterns, habits, routines, time-use and environmental demands may be equal important.

During an interdisciplinary rehabilitation focusing on self-management strategies the efforts, skills and capacities of both the client and the therapist are of importance. Mattingly (1994) stated that occupational therapists are “transporters”; they help the client’s transition from a sick role to one being an active social member in the society. The results in this thesis are from an interdisciplinary team rehabilitation context, all team-members should thus be termed as “transporters”. Another issue of importance is thus the therapist’s emphasis on facilitating occupational performance. The therapist’s abilities in creating the best possible therapeutic alliance with the clients are important (Ferreira et al., 2013) maybe even more important than which professions or which methods are used. Other

factors that may be important are a client's overall pain-related consequences and that the treatments given match the client's needs. The result in Paper IV highlighted that higher levels of satisfaction with occupational performance at baseline, an AC profile at baseline, being Nordic born and having longer education increased the probability for an AC profile at follow-up (Paper IV). That result indicates that several environmental factors as well as internal personal factors may have relevance for belongings to an AC profile.

The fit chart described by Polatajko et al. (2007b) may be useful for understanding how to facilitate a person's "doing" (see Figure 2 Introduction). Complex associations of capacities, demands and mediators are involved in these processes. Some of the construct used are closely related to "thinking" constructs, such as motivation, meaning and self-efficacy. Basic occupational therapy assumptions are that humans need occupations, and occupation influences health, organizes time and brings structure and meaning to life. Occupation per se has therapeutic potential (Townsend et al, 2007d) and perhaps an expertise on "doing" and "thinking" should be used in combination in order to create useful models, as both "doing" and "thinking" aspects appear to be needed. The need for transformation of self-image and the need for performing valued occupations indicate that clients may have internal needs, but they also have needs that can only be met through interaction with the surrounding context (Skjutar & Müllersdorf, 2010) and by performing their everyday occupations. Performing occupations may generate energy and satisfaction and may be helpful strategies. Through occupational performance people use the potentials that are generated from experience-based learning and such strategies may lead to the use of beneficial management strategies in the "doing" and "thinking" perspective.

Methodological considerations

One major limitation of the present studies (Papers I, III and IV) was that no control group and comparative treatment group was available. We can thus not conclude that the observed outcomes were a result of the intervention. The use of waiting list control subjects, which would have been an alternative, was not feasible. All clients must according to Swedish legislations be offered adequate medical interventions within 2 months. Using waiting list controls, however, is not without problems because clients waiting for treatments can seek health care elsewhere during the waiting-time. The difficulty in obtaining the conditions needed for controlled studies have been demonstrated (Perski & Grossi, 2004).

The participants in the present thesis constituted a heterogenic group and were unselected clients, which means that generalization of the results is limited to interdisciplinary pain rehabilitation programmes with heterogenic groups of clients

like those in the present thesis. However, unselected status may also be a strength because the participants in the present thesis are most likely to be representative of those generally being treated at tertiary pain rehabilitation clinics.

Since we have mostly used data from an already existing clinical data base, run for a number of years, and as data from three different occasions were used, there were drop-outs, which can be a source of uncertainty. However, differences on sociodemographic variables were in general not found between the dropouts and the participants and nor were any differences found between the participants and the nonparticipants with regard to scores on measures (Papers I, III, and IV).

Non-parametric statistics were mostly used, as all data, except for age, were ordinal or categorical. Such recommendations are also suggested for ordinal measures as those used here (Pallant, 2007). Logistic regression analyses were used for assessing continuous or discrete predictors on a dichotomous criterion variable which also is recommended analyse method for predicting discrete outcomes such as a group membership from a set of variables that may be continuous, discrete, or a mix (Tabachnick & Fidell, 2014).

A major problem when using rating scales is to define the change needed for determining levels for clinically meaningful changes. It may have been important to identify what symptom reduction being clinically important from the participants' view, however, such data were not retrieved. The percentage of reduction was described in addition to the absolute decrease. The use of cut-off points for minimal (clinically) important change (MIC) are important as it may guarantee for more relevant changes than when change scores solely above a zero limit are used. However, whether the cut-off points used in the present papers (Papers I, III, IV) are relevant can be discussed. The MIC points used for the COPM and the MPI were those established in the literature (Law et al., 2005; Dworkin et al., 2008). The MIC for the DRI was, however, not found in literature and the ratios for cut-off points of 10%, 13%, and 15% were tested, and no differences were found and thus a cut-off score of 10% was used. Dworkin et al. (2008) indicated the need for investigating the most relevant cut-off points for different populations. There does not, however, seem to be any "best method" to determine the minimal important change (MIC) and large variations have been found among studies in how to deal with the MIC. Improvements on methodology and standards for methods have been proposed (Terwee et al., 2010). Articles should specify the rationale for expected clinically meaningful change (Sprangers et al., 2002), however, such information seems to absent in several studies.

In the present thesis, responsiveness was tested by effect sizes (Pallant, 2007). The set of predictors in the multivariate logistic regression models were tested by the Omnibus Test of Model coefficient. Information about the usefulness of the model, by providing an indication of the amount of variance in the criterion variable explained by the model, was tested in Model summary, the Nagelkerke-

test and the Hosmer and Lemeshows tests (Pallant, 2007) (Papers I, III and IV). These calculations supported the strengths of changes and of the multivariate models that were used.

Study II, qualitative content (manifest) analysis was applied to categorize the occupations into main and sub categories according to the COPM manual (FSA, 2006). A procedure to calculate inter-rater reliability proposed by Krippendorff (2004) was employed for 20% of the occupations. This procedure corrected for chance agreements and the results was considered satisfying. Such analysis was seen as a strength of the study, but it would have been preferable to report the categorizing as performed in the context of the interviews by using the participant's descriptions. This information was, however, no longer available since it was not entered in the database.

Measures used

Because of the multidimensionality of pain several measures should be used for assessing outcomes, as no single measure can adequately assess the totality of the pain construct (Jensen & Karoly, 2001). This thesis focused on outcomes of occupational performance and satisfaction with performance, psychosocial functioning, physical disability and pain coping, and measures focusing these areas were therefore used.

Differences have been found in the literature concerning what were the most common occupations retrieved from the COPM. Differences depended on several circumstances one being the population used, such as clients with specific diseases having certain problems. However, the routine when to use the COPM seems to be important. In one study on low back pain clients, walking was found to be the most reported problem (Walsh et al., 2004), however, the interviews were employed in close connection to a walking test. Such situations must be discussed among therapists in order not to generate result biases. Another important issue when using the COPM is to calibrate the therapist's interview styles. There are recommendations that before performing COPM interviews a one-two day education focusing on occupational enablement strategies and the CMOP-E model is required. In one study it was found that therapists had difficulties in performing the interview and retrieving problematic occupations on clients having pain (Enemark Larsen & Carlsson, 2012), which implies that it is essential to have knowledge of pain-related consequences when using the COPM among clients with persistent pain.

The (WHY) MPI is a measure that is theoretically linked to cognitive-behavioural perspectives on pain and it is recommended for use of pain rehabilitation outcomes (Jacob & Kerns, 2001). In the present study the original English version of the MPI was used, described by Nyberg et al. (2011b). This version is used in the SQRP from which data were retrieved. Bergström et al. (1998) and Bergström,

Jensen, Linton & Nygren (1999) have psychometrically tested this measure, although mostly among clients with neck- or low back pain. They recommended the use of a Swedish MPI-S version where the factor structure for section three, measuring daily occupations, could not be confirmed and section three did not display a satisfactory sensitivity either for females or males. Sections one and two, however, described acceptable factor structure, reliability and generalizability, with some few adjustments. The fifth subscale was by Harlacher, Persson, Rivano-Fischer & Sjölund (2011) found to be difficult to interpret, and this subscale was generally not used in the present thesis (Paper I and III).

According to the DRI (Paper I), no cut-off point for MIC was found in literature. This measure of physical disabilities includes items such as dressing, sitting, lifting, carrying and running and these items are not specified in terms of their relevance for the participant. Activity or occupational limitations, also termed occupational performance in this thesis, however, was assessed on items that were prioritized by the participants themselves and occupational performance was improved more than physical disability. The reasons for such inconsistencies between results delivered on, in some cases, closely related issues, such as items describing activities and occupations, are interesting but as far as we know not explained in the literature.

An implication of this result may be that caution on outcomes termed as “activities or physical disabilities” should be observed. These constructs are obviously not comparable and comparisons between studies cannot be carried out. There appears to be a need for verifying which domains of concepts that are most beneficial to assess in order to get results from the domains that are most important. Turk (2002) stated that chronic pain interferes with daily activities, and many studies have demonstrated that pain intensity and physical functioning are only modestly associated which supports the importance of including measures of functioning in chronic pain clinical trials. This seems reasonable, but more dubious conclusions are found in the literature as well. Dworkin et al. (2005) stated that measures of physical functioning typically assesses multiple aspects of functioning, including activities of daily living and SBU (2006) stated that physical functioning may be exemplified by ability to do household chores, work, or traveling (“Activities of Daily Living”). According to the findings of this thesis, however, conclusions like these are not valid. Physical functioning, physical disability, behaviours and activities of everyday life need to be treated as separate phenomena, each in its own right.

Conclusions

Based on the four papers included in this thesis the following conclusions can be made:

- A substantial proportion of participants with musculoskeletal persistent pain improved after a comprehensive, goal-oriented, interdisciplinary pain rehabilitation programme. However, the results also indicate that the benefits can vary among different subgroups
- The participants reported a wide range of gender specific everyday occupational problems, from basic ADL to leisure activities that need to be addressed in pain rehabilitation programmes.
- A pain programme appears to be beneficial for reaching client-centred occupational goals, when interventions based on occupational theories and praxis is used along with other interdisciplinary methods.
- A pain rehabilitation programme also appears to be relevant for improving psychosocial functioning regardless of participants' initial characteristics, but is less effective in improving physical disability. Pain duration, pain diagnoses or socio-demographic belongings were not determinants of improvements on psychosocial functioning or physical disability one year after completed rehabilitation.
- Occupational performance may be termed “doing” aspects and pain coping strategies “thinking” aspects. Improved “thinking” was found to be related to improved “doing” and improved satisfaction with one’s “doing”. However, improved “doing” was found among several participants who did not improve their “thinking”. Such associations between “doing” and “thinking” aspects need to further studied.
- Participants with worse pain-related consequences at baseline may need additional or modified interventions focusing on improvements of occupational performance (occupational goals) and of more beneficial pain coping. Lower educational level and

being non-Nordic born were related to worse outcomes regarding “doing” and “thinking” about pain. These findings further indicate that participants with such socio-demographic circumstances may need pain rehabilitation that is not currently in place.

- Improvements should be evaluated at long-term follow-up times, as some changes at discharge were further improved at the one-year follow-up
- In summary several improvements were found one year after an interdisciplinary pain rehabilitation programme. The results of this thesis imply that physical disability had little relevance for improvements, whereas constructs addressing “doing”, in terms of occupational goals, and “thinking”, in terms of pain coping strategies, are of vital importance.

Clinical implications

Based on the conclusions made, there are several clinical implications:

- The findings indicate that occupational performances and satisfaction with performances are essential for the improvements. The programmes should thus have expertise familiar with occupation-based praxis models, occupational science and theories that focus on human occupational life, including its association to health. Clients should have access to such expertise to improve their occupational performance. This may help them to get appropriate advices for how to enhance everyday occupational life in a balance between their capacities, needs and demands.
- It appears to be important to communicate and discuss the findings of this investigation, that occupational performance and satisfaction should be viewed as separate constructs from physical functioning and behaviours, not necessarily related to each other.
- The findings indicate that occupation-oriented goals should be integrated in team-based rehabilitation plans and the interdisciplinary team needs to discuss how to facilitate strategies for reaching these goals.
- Before treatment planning client should be assessed with reliable and valid measures specifically for their occupational performance problems, in order to get suitable treatments for such problems.
- Some subgroups appear to have specific needs that should be met regarding improvements on occupational performance and belongings to more beneficial pain coping strategies. Baseline assessments should pay particular attention to subgroups with worse pain-related consequences, in order to evaluate their needs for additional interventions during or before a pain rehabilitation programme for reaching their occupational goals and for improving to more beneficial coping profiles.
- Clients with a neck-disorder and low back pain may have specific needs for occupation-based assessments, as these groups were found to have more problems concerning general activity and

physical disability. Clients with lower education levels and non-Nordic born may also need to be especially assessed and focused on with respect to capacities, occupational demands and coping strategies.

Implications for future research

- It seems important to further evaluate the associations between “doing” (occupational performance) and “thinking” (pain coping strategies) aspects and how these constructs are interactively involved during a rehabilitation process for clients with persistent musculoskeletal pain.
- There is also a need for randomized and controlled studies designed to specifically evaluate the benefits of occupation-based methods and interventions. Research designed to evaluate whether any specific occupation-based strategies may be more beneficial than other for improving occupational performance and satisfaction with performance among clients with musculoskeletal persistent pain seems urgent.
- Further research should be focus on how interdisciplinary teams define client-centred goals in team-based rehabilitation plans and how these teams assess actions for reaching the goals aimed at improving outcomes for clients regarding their everyday occupational life.
- Another important research area is to establish which factors are most likely to determine occupational performance and satisfaction with performance among clients with musculoskeletal persistent pain. Variables in focus should be personal functioning (physical, cognitive or affective functions), occupational performance habits, occupational demands, and environmental demands. Such knowledge may provide insights into which interventions that may be most relevant for each client.
- The phenomena of occupational performance, behavioural functioning and physical disability need to be further investigated and conceptualized among pain researchers. The concepts should also be evaluated against their relevance for clients. Concepts should be properly addressed and evaluated in a client-centred context before they are used to describe and guide health care and rehabilitation.

- The benefits for use of detailed and reliable observation-based investigations, into functional abilities of clients have recently been highlighted, whether such investigations supply better knowledge of client's needs and which treatments that are needed should be evaluated. This as, self-reports have shown low associations with observation-based assessments of activities of daily life.
- The COPM is shown to be a catalyst for moving to a more occupation-based practice. However, the therapist's process during data retrieving of clients' needed, wanted and expected occupational goals, should be evaluated.
- Finally, variables reflecting the concepts just mentioned need to be assessed properly. Research is warranted on how to best establish and use proper and thorough team-based assessments focusing on clients' needs, capacities and barriers and how such assessments best should be carried out.

Summary in Swedish - svensk sammanfattning

Interdisciplinära smärtrehabiliteringsprogram har visat bättre resultat än mindre intensiva åtgärder. Det saknas dock kunskap inom flera olika områden. Denna avhandling har bland annat fokuserat vilka aktivitetsproblem som personer som genomgått ett sådant program upplever viktigast att förbättra. Alla deltagarna i programmet hade långvarig muskuloskeletal smärta med komplexa negativa konsekvenser för deras vardagsliv. Vi har undersökt hur personer som genomgått ett smärtrehabiliteringsprogram skattar sin hälsa före rehabiliteringen, vid avslut och ett år efter deltagandet i programmet. Aktivitetsförmåga och tillfredsställelse med denna har skattats i de aktiviteter som deltagarna själva har rapporterat som mest betydelsefulla. Vi undersökte vilka de viktigaste aktivitetsproblemen var och om dessa aktivitetproblem var olika för olika grupper av deltagare. Psykosociala faktorer, rapporterad förmåga i förutbestämda fysiska aktiviteter, fysisk funktionsnedsättning, och rapporterad förmåga att hantera smärtan, sk copingförmåga har också fokuserats. Vi har också undersökt om det finns grupper av deltagare som mår sämre vid rehabiliterings start eller som uppvisar sämre resultat efter ett år. De sociodemografiska grupperingar som användes var: kön, ålder, födelseland Norden eller utanför Norden, utbildningsgrad, om man var i arbete före rehabiliteringen eller inte samt civilstånd. Vi grupperade deltagarna efter olika diagnosgrupper och undersökte om smärtdurationen hade betydelse för måendet eller för förändringarna vid ett års uppföljning.

Deltagarna hade ett brett utbud av aktivitetsproblem som de ville ha hjälp att hitta strategier för att klara av. Dessa aktivitetsproblem visade sig vara olika för männen och kvinnorna. Kvinnorna hade huvudsakligen problem att utföra sysslor relaterade till hushållet eller arbetet, medan männen rapporterade mer problem relaterade till personlig vård och förflyttning. Deltagarna hade problem inom alla olika aktivitetsområden, personlig vård, arbete och hushållsarbete och fritidsaktiviteter. Att arbeta, att sitta och att städa var de enskilda problem som rapporterades mest, medan flest problem fanns inom gruppen hushållsgöromål.

Deltagarna beskriver en förbättrad förmåga att utföra de aktiviteter i sin vardag som är mest meningsfulla för dem och ännu fler var mera nöjda med hur de klarade av att utföra dessa deras viktigaste vardagsgöromål. Vi hittade också signifikant förbättrade värden på gruppnivå såväl vid avslut som efter ett år,

förbättringarna i utförandet fortsatte att öka efter programmets avslut. Deltagarna beskrev positiva förändringar avseende smärtans intensitet, känslomässigt mående och upplevd kontroll ett år efter programmet. Smärtdurationen, diagnosgrupp eller sociodemografiska faktorer påverkade inte resultaten avseende psykosocial funktion eller fysisk funktionsnedsättning. Civilstånd, ålder, diagnos eller smärtduration hade ingen betydelse för resultaten vid ett års uppföljningen.

Männens tillfredsställelse med sin aktivitetsförmåga förbättrades dock i mindre grad än kvinnornas. Självrapporterat fysiskt funktionshinder, relaterat till fysiska aktiviteter som deltagarna inte hade prioriterat själva, förbättrades i mycket liten omfattning. Deltagare som rapporterade större fysiskt funktionshinder och sämre psykosocial funktion initialt hade dock mindre chans att förbättra sin aktivitetsförmåga. Medan personer med mer problem i de egenprioriterade aktiviteterna förbättrades mer än de som hade mindre problem i dessa. Personer som inte var födda i Norden, hade lägre utbildning och som inte var i arbete hade sämst psykosocial funktion före rehabiliteringen. Dessa resultat tyder på att grupper av personer kan behöva en mera anpassad rehabilitering eller rehabilitering med delvis annat innehåll än den som idag finns.

Copingförmågan förbättrades signifikant efter ett år och en bra copingförmåga vid uppföljningen var associerat med förbättrad aktivitetsförmåga i egenprioriterade aktiviteter. Däremot var det en stor grupp deltagare som ett år efter programmet fortfarande inte tillhörde gruppen ”adaptiv copier”, dvs den grupp som beskrivs ha bäst copingförmåga. Flera av deltagarna som inte tillhörde denna coping-grupp efter ett år hade ändå förbättrat sin aktivitetsförmåga. Personer med lägst utbildning och som inte var födda i Norden hade minst chans att förbättra sin coping förmåga. Personer som beskrev sämst socialt stöd förändrade sin copingförmåga minst. Sambandet mellan förbättrad coping, ”tänkande” och förbättrad aktivitetsförmåga, ”görande”, är intressant. Detta samband behöver undersökas vidare för att vi bättre ska förstå vilka processer under en rehabilitering, ”görande” respektive ”tänkande”, som hjälper olika grupper av personer och hur dessa processer är relaterade till varandra. ”Görandet” verkar förbättras för fler deltagare än ”tänkandet”.

Vissa deltagare verkar vara i behov av mera individualiserade eller anpassade åtgärder för att förbättras. Personer med ländryggsmärta och nackrelaterad smärta verkar också ha mer problem relaterat till aktivitetsförmåga eller fysisk funktionshinder än vad deltagare med fibromylagi har. Sammanfattningsvis visar resultaten på förbättringar som också bibehålls ett år efter rehabiliteringen, ibland fortsätter förbättringen till och med att öka efter avslut. Det finns grupper av deltagare som verkar behöva mera anpassade åtgärder än vad programmet har erbjudit. Det verkar också finnas behov av att undersöka samband mellan förbättringar i olika utfallsmått mera ingående.

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