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Patients' needs regarding chronic pain rehabilitation and management

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**Karolinska
Institutet**

Stockholm 2010

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ISBN 978-91-7457-147-9

Printed by



www.reproprint.se

Gårdsvägen 4, 169 70 Solna

To my mother

ABSTRACT

The overall aim of this thesis is to explore and describe patients' needs related to chronic pain rehabilitation and management from the perspectives of health care professionals and patients with chronic pain.

Study I explores indicators of need for referral to pain rehabilitation using a Delphi study with a multidisciplinary expert panel (n=23). The results show a multifaceted view of indicators, including aspects of physical and mental health, coping strategies, and work environment. Intuitive impressions of patients' overall clinical presentations and patients' ages are brought forward as indicators.

Study II explores specific needs for occupational therapy using focus group discussions (n=6) with occupational therapists (n=25). *Limitations of occupational performance* is the theme found. Explicitly, 13 indicators for occupational therapy are found; these include aspects of patients' behaviors, level of knowledge, level of occupational balance, mental health, and the physical or environmental strains that are present in the patients' living contexts.

In **Study III**, outcomes of an intervention, 'Balance in Everyday Life', are described and explored in terms of occupational performance and satisfaction using a single-case design (n=5). Results demonstrate that four out of five patients had improved their occupational performance (+0.1-2.3), two of which were of clinical significance. Also, five out of five patients had improved their occupational satisfaction (+0.1-5.3), and two were of clinical significance. Measures changed jointly and independently.

Study IV describes needs related to pain management of participants with chronic pain; they were portrayed in stories of daily life using individual interviews (n=10). Results describe how participants need to protect themselves from themselves and need to balance their eager mind and their painful body's need to rest. Participants also need to transform their self-image and to discover new behaviors, routines, and perspectives. The need for affirmation through communion and enjoyment of valued occupations is also highlighted as a prerequisite for successful pain management.

Indicators that either pain rehabilitation or occupational therapy is needed involved dysfunctional behaviors of the patient with chronic pain, demographics (e.g., age), as well as tacit knowledge of health care professionals. The occupational needs of participants living with chronic pain could to some extent be met by the intervention received. Engaging in valued occupations and adopting an altered perspective of one's priorities and occupational performance are highlighted as important for successful pain management.

Key words: activities of daily living, chronic pain, content analysis, Delphi, focus groups, needs, needs assessment, occupational therapy, pain management, pain rehabilitation, single-case design.

LIST OF PUBLICATIONS

This thesis is based on the following research papers, which are referred to in the text by their Roman numerals.

- I. **Skjutar, Å.**, Christensson, K. & Müllersdorf, M. (2009). Exploring indicators for pain rehabilitation: A Delphi study using a multidisciplinary expert panel. *Musculoskeletal Care*, 7(4), 227-242.
- II. **Skjutar, Å.**, Schult, M-L., Christensson, K. & Müllersdorf, M. (2010). Indicators of need for occupational therapy in patients with chronic pain: Occupational therapists' focus groups. *Occupational Therapy International*, 17(2), 93-103.
- III. **Skjutar, Å.**, Müllersdorf, M. & Schult, M-L. (2010). Improving occupational performance: A single case study of patients with chronic pain. *Submitted*.
- IV. **Skjutar, Å.** & Müllersdorf, M. (2010). Adapt, discover, and engage: A qualitative interview study with patients living with chronic pain. *Accepted for publication in Journal of Nursing and Healthcare of Chronic Illness*.

CONTENTS

1	INTRODUCTION.....	1
2	BACKGROUND.....	2
2.1	Disability leading to needs.....	2
2.2	Chronic pain.....	3
2.2.1	Definition and epidemiology.....	3
2.2.2	Consequences of chronic pain.....	4
2.3	Chronic pain rehabilitation.....	5
2.3.1	Chain of care.....	5
2.3.2	Chronic pain rehabilitation and effects thereof.....	6
2.3.3	Occupational therapy and pacing.....	7
2.4	Need.....	8
2.4.1	Need as a concept.....	8
2.4.2	Scientific theories and perspectives on need.....	9
2.5	Needs assessment.....	11
2.5.1	Definition and approaches of needs assessment.....	11
2.5.2	Assessment in chronic pain.....	12
2.5.3	Concerns of needs assessment.....	12
2.5.4	Specific research on needs assessment.....	13
3	RATIONALE.....	14
4	AIMS.....	15
5	METHODS.....	16
5.1	Study outlines and design.....	16
5.2	Participants.....	17
5.3	Data collection and procedures.....	20
5.4	Data analysis.....	24
5.5	Ethical considerations.....	26
6	RESULTS.....	29
6.1	Indicators for intervention (studies I and II).....	29
6.2	Latent interpretations (Study IV) related to manifest descriptions..... (studies I and II).....	32
6.3	Patterns of occupational performance (Study III).....	35
6.3.1	Individual versus group patterns.....	35
6.3.2	Participants' individual changes of occupational performance and satisfaction (Study III).....	38
7	DISCUSSION.....	39
7.1	Summary of main results.....	39
7.2	Need as reflection of values.....	39
7.3	Need as an additional perspective distinctive of risk.....	43
7.4	Need as opportunity.....	44
7.5	Methodological considerations.....	46
7.5.1	Validity and reliability (studies I and III).....	46
7.5.2	Trustworthiness (studies II and IV).....	49
7.6	Conclusions and implications for clinical practice.....	51
7.7	Future research.....	52
8	ACKNOWLEDGMENTS.....	53

9	REFERENCES	55
10	APPENDIX.....	64

ABBREVIATIONS AND DEFINITIONS

ABA	baseline-intervention-follow-up
BEL	Balance in Everyday Life
COPM	Canadian Occupational Performance Measure
FGD	Focus Group Discussions
ICF	International Classification of Functioning, Disability, and Health
n	quantity
PRP	Pain Rehabilitation Program
PRU	Pain Rehabilitation Unit

Chronic pain is pain that has persisted for more than six months (Merskey & Bogduk, 1994).

Indicator, when related to *needs* (e.g., in multidisciplinary rehabilitation) refers to a variable representing an important characteristic of a group or social situation (Witkin & Altschuld, 1995).

Multidisciplinary can refer to a rehabilitation team's constitution and way of working (King, Nelson, Blankenship, Turturro, & Beck, 2005; Loeser, 2001), and focus here is on the team constitution; different professions who work together (Loeser, 2001; Loeser & Turk, 2001; Norrefalk, 2003).

Need refers to a physiological or psychological necessity for the well-being of people and also to a condition (e.g., chronic pain) that, requires supply or relief (Need).

Pain is 'an unpleasant sensory and/or emotional experience associated with actual or potential tissue damage, or described in terms of such damage' (Merskey & Bogduk, 1994).

Pain management refers to procedures and behaviors that ease and provide long-term self-management of pain and its consequences (Main, Sullivan, & Watson, 2008). Accordingly, pain management will describe what patients do to deal with their chronic pain and its consequences.

Rehabilitation refers to 'interventions that should allow a person with an acquired disability, based on his/her needs and abilities, to regain or maintain the best possible ability to function and to create good conditions for an independent life and active participation in society' (Socialstyrelsen, 2007b). The goal of rehabilitation interventions is thus partly to improve remained function, and partly to reduce consequences of disability (Borg, Gerdle, & Stibrant Sunnerhagen, 2006).

1 INTRODUCTION

This thesis concerns patients living with chronic pain and their need for rehabilitation interventions, their outcome following intervention, and their experience of needs related to pain management. There are several incentives for conducting this research, which come from collective as well as individual standpoints.

Chronic pain is one of the most common reasons for sick leave in Sweden today, and the costs for chronic pain are estimated at 87.5 billion SEK per year (Statens beredning för medicinsk utvärdering [SBU], 2006). The negative consequences of living with chronic pain can be extensive and can include various forms of disability. Despite research in rehabilitation medicine and pain management, there is still room for developing an effective chain of care and rehabilitation interventions for patients who seek health care because of chronic pain. In the work of developing this chain of care, it has been suggested to take patients needs as a starting point (Frontera, 2009), and that is what this thesis seeks to do. Taken together, these studies can clarify health care needs in relation to interventions for patients with chronic pain. This is relevant to providing interventions that meet patients' needs, and it is also relevant to a sensible use of tax revenue.

The thesis has its foundation in rehabilitation medicine, specifically, interventions for patients with chronic pain. The thesis describes and explores needs by asking health care professionals as well as patients about chronic pain. From the perspective of health care professionals, what indicates that a patient living with chronic pain needs rehabilitation interventions? From the perspective of patients with chronic pain, what needs do they experience related to their pain management?

When I worked in chronic pain rehabilitation, the patients I met often complained that they had not been referred there soon enough. Sometimes, the different strands of the rehabilitation program were incompatible with what the patient expressed as a need. Using need as a core concept in formulating aims and questions related to these experiences proved complex but also enlightening. Because unidentified needs are hard to mend, needs must be sought after.

2 BACKGROUND

This section will introduce several areas on which the thesis is based. First, the concept of disability and how it leads to a set of needs is presented. Second, chronic pain and possible consequences are described. Third, needs as a concept related to theories is explained; fourth, aspects of needs assessment are portrayed.

2.1 DISABILITY LEADING TO NEEDS

People can be affected by health conditions, injuries, or illnesses that can render consequences in terms of dysfunction, disability, and decrements in health. One such health condition is chronic pain; once manifested, there might be numerous factors that have bearing on a patient's behavior and clinical presentation (Main et al., 2008).

The International Classification of Function, Disability, and Health (ICF) (World Health Organization [WHO], 2001) describes how a health condition can influence and be influenced by body functions and body structures as well as activity and participation. Furthermore, environmental factors as well as personal factors affect the person who has a specific health condition, such as chronic pain. Thus, built on the biopsychosocial model (Main et al., 2008), the ICF illustrates function and disability as a result of a complex interaction between the components: body functions, body structures, activities and participation, environmental factors, and personal factors. Patients can experience need in relation to one or several of these components.

Classification of function, disability, and health is often followed by health care interventions. An underlying assumption often made by health care professionals is that where a dysfunction or a disability can be observed, there is a need that has to be mended. In other words, the inability to perform activities of daily living calls for interventions to change this. The proposition is that the more negative consequences a health condition causes, the more interventions are needed. There is reasoning against this, however. The way a disability influences people is highly individual, and two people with the same disability might not have the same needs. According to Cooper (1975), 'Need, like beauty, is in the eye of the beholder' (p. 20). People prioritize differently; to create good health care, we must understand the health care needs of the patients (Stevens & Gillam, 1998; Stevens & Raftery, 1994). Something that is regarded as a need that must be mended can depend on how it is manifested. A disability or participation restriction per se might or might not be regarded as a problem to the individual and/or society.

Like disability in the ICF components, needs can occur in the body itself, in relation to doing something, with or without involvement of other people, or in relation to the surrounding context. While it is important to focus on needs as experienced by the individual it has also been suggested that it is imperative to do this in proportion to the demand from the surroundings and from society (Förbundet Sveriges Arbetsterapeuter

[FSA], 2005). Hence, studies of needs from the perspective of patients and health care professionals as an extension of society are apposite.

2.2 CHRONIC PAIN

Chronic pain and its consequences is the common denominator for the group of patients that this thesis concerns, and the following section gives a preamble to its complexity.

2.2.1 Definition and epidemiology

During the 1960s, researchers paved the way for the present definition of pain when they presented their gate control theory (Melzack & Casey, 1968; Melzack & Wall, 1965). They asserted pain is psychophysiological, based on findings of neuronal pathways between the sensory-discriminative, affective-motivational, and cognitive components in the brain. Based on this knowledge, pain has been defined as ‘an unpleasant sensory and/or emotional experience associated with actual or potential tissue damage, or described in terms of such damage’ (Merskey & Bogduk, 1994). Accordingly, experience of pain is subjective and may occur devoid of tissue damage.

At onset, pain is typically defined as acute. If lasting, acute pain can become chronic. In a clinical setting, pain that has not resolved within the expected time is defined as chronic. What this means in real time is dependent on the characterization of the pain; it can be anywhere from weeks to several months (Merskey & Bogduk, 1994). In research settings, chronic pain is often defined as pain that has lasted for more than three months (Bergman et al., 2001; Wolfe et al., 1990) or six months (Merskey & Bogduk, 1994; SBU, 2006). Apart from time, pain can be classified into types described by its origin: nociceptive pain, neuropathic pain, pain without obvious cause, and psychogenic pain (Norrbrink & Lundeberg, 2010). Chronic pain is mainly described in association with several diagnoses and health conditions, such as cancer, fibromyalgia, low back pain, neck pain, and whiplash-associated disorder etc. Because a lack of objective physiological findings is common (Jacobson & Mariano, 2001), some patients are left without a biomedical explanation for their chronic pain experience. This can leave patients with indistinct diagnoses, such as chronic intractable pain or other chronic pain. In this thesis, chronic pain will be used to describe nonmalignant pain that has persisted for more than three months. ‘Chronic pain’ and ‘pain’ will be used interchangeably.

A large (n=46394) European survey (Breivik, Collett, Ventafridda, Cohen, & Gallacher, 2006) showed a prevalence of chronic pain, ranging from 12% in Spain to 30% in Norway. For Sweden, prevalence rates of 4.2% (Lindell, Bergman, Petersson, Jacobsson, & Herrström, 2000), 7.4% (Gerdle et al., 2008), 11.4% (Bergman et al., 2001), and 18% (Breivik et al., 2006) have been reported. The prevalence variations can be explained by different definitions of pain, length of prevalence period (Gerdle et al., 2008), age stratification (Breivik et al., 2006), and use of different methodological techniques (Linton & Ryberg, 2000).

2.2.2 Consequences of chronic pain

Chronic pain can have negative effects on society at large, in terms of work loss (Breivik et al., 2006) as well as with increased costs for social insurance and health care utilization. For the individual, chronic pain can be associated with varying physical and psychological problems, disability, and a negative impact on quality of life (Bunketorp, Nordholm, & Carlsson, 2002; McWilliams, Cox, & Enns, 2003; Söderman, Lundman, & Norberg, 1999).

According to statistics from the Swedish Social Insurance Agency (Försäkringskassan, 2010), Sweden has the highest full-time work loss following illness or injury compared to Denmark, Finland, France, Germany, Great Britain, The Netherlands, and Norway. At the end of 2009 24.4% of the sick leave cases in Sweden were due to musculoskeletal problems (Försäkringskassan, 2009). The specific costs for chronic pain based on data from 2002-2003 have been calculated at approximately SEK 87.5 billion/year (SBU, 2006). This includes direct cost of health care as well as indirect costs of work loss. Chronic pain and its consequences are urgent issues to address.

In Europe, 60% of people with chronic pain visited their physician between two and nine times during a six-month period (Breivik et al., 2006). Additionally, a Swedish study showed that 30% of patients seeking primary care have pain related problems, of which 48% are chronic or intermittent (Hasselström, Liu-Palmgren, & Rasjö-Wrååk, 2002). Despite this, 40% of all Europeans (n=4627) and 45% of the Swedish participants (n=252) reported dissatisfaction with how their pain was controlled (Breivik et al., 2006). Together, this suggests a large expenditure of tax revenue but without the desired outcome of pain relief/management.

Among people with whiplash-associated disorders, remaining symptoms of headache and neck pain still exist many (17) years after the initial impact (Bunketorp et al., 2002). People living with fibromyalgia might experience symptoms such as constant muscle pain, fatigue, and sleep disruptions (Henriksson & Burckhardt, 1996; Henriksson, 1994). Experiences of pain and fatigue can make daily activities more demanding and can negatively affect an individual's performance of daily occupations (Henriksson, 1995a; Müllersdorf, 2000; Schult, 2002; Strong, Unruh, Wright, & Baxter, 2002), habits, routines, independence level (Henriksson, Gundmark, Bengtsson, & Ek, 1992; Söderback, 1999), and management of life roles (Harris, Morley, & Barton, 2003; Henriksson, 1995a). Sustaining a work role is described as a struggle by many people with fibromyalgia and their symptoms can hinder their ability to work (Henriksson & Liedberg, 2000; Löfgren, Ekholm, & Öhman, 2006).

Psychological comorbidity is common in relation to chronic pain (Linder, Schüldt Ekholm, Brodda Jansen, Lundh, & Ekholm, 2009; Tunks, Crook, & Weir, 2008). While depression at a specific point in time affects about 5.9% of the population without pain, it is as high as 19.8% (Currie & Wang, 2004) or 21% (Breivik et al., 2006) for people with chronic pain. Furthermore, generalized anxiety, panic disorders, and social phobia all increase with the presence of pain (Tunks et al., 2008). A

qualitative study (Thomas, 2000) that explored the meaning of living with pain reported that patients feel social isolation from others, hopelessness about pain relief, and lack of support and understanding from friends and family. Additionally, emotional pain and lack of control are experienced as a result of loneliness (Satink, Winding, & Jonsson, 2004). Similarly, women with fibromyalgia were found to suffer a loss of freedom due to changes in occupational performance; many felt that their integrity was challenged because their problem was invisible and therefore sometimes met with skepticism and mistrust (Söderman et al., 1999).

2.3 CHRONIC PAIN REHABILITATION

Many patients with chronic pain do not become significantly disabled by it. However, some do, and these patients might require rehabilitation interventions. The interventions offered can differ, depending on the health care setting, the complexity of the pain (Main et al., 2008), and available recourses (Ektor-Andersen, Ingvarsson, Kullendorff, & Ørbæk, 2008).

2.3.1 Chain of care

The overall aim of Swedish health care is good health and equal care for the population. Care should be of good quality, be easily accessible, and be planned in consultation with the patient if possible (SFS 1982:763). Parts of this thesis are concerned with health care provided to patients with chronic pain by county councils, and the chain of care provides an outline. *Primary care* provides basic treatment that does not require the medical or technical resources that hospitals have (SFS 1982:763). Specialized care is provided through *county care*, for example medical specialties such as a pain rehabilitation unit (PRU). *Regional care* and *national care* constitute highly specialized care (Ds 2003:56) characterized by state-of-the-art competence and nationally coordinated interventions (Socialstyrelsen, 2010). In addition to public health care, private practices and industrial health services are available to some patients. To sum up, several health care operators may be involved at the same time. The Swedish Social Insurance Agency [Försäkringskassan] is also often involved because it holds the right to make decisions regarding compensation (Ekholm & Vahlne Westerhäll, 2006).

In clinical practice, interventions for patients with chronic pain in Sweden commonly occur at two levels in the chain of care: primary care and county care (often referred to as specialist care). However, regional care might also be involved because some PRUs are located at the regional hospitals. In primary care, interventions can be separate (e.g., physiotherapy) or multidisciplinary (Borg et al., 2006); these are sometimes referred to as unimodal and multimodal interventions (SBU, 2006). Specialist care usually refers to a multidisciplinary rehabilitation unit or a pain clinic where more comprehensive interventions are provided than in primary care (Werner & Strang, 2003). Both in Sweden and abroad, interventions are provided through so-called pain rehabilitation and/or pain management programs (PRP) (Main et al., 2008). In clinical practice, each PRP can have a different focus such as education/information, behavioral interventions, cognitive-behavioral interventions, stress-pain management, or risk-factor targeting.

In describing interventions for chronic pain, the terms rehabilitation and management are frequently used (Main et al., 2008; Strong et al., 2002). Rehabilitation refers to restoration and treatment of disabling disorders and injuries (Borg et al., 2006; Socialstyrelsen, 2007b). Management can also refer to treatment, as a description of what is taught during pain rehabilitation. Furthermore, manage is a verb related to, for example handling an activity (Main et al., 2008; Manage). In this thesis, pain *rehabilitation* will be used to describe multidisciplinary interventions at rehabilitation units specializing in chronic pain. Pain *management* will be used to describe what patients with chronic pain actually do to deal with their pain and its consequences.

For the chain of care for patients with chronic pain to succeed, pathways into services and referral between different health care providers have to be developed and work efficiently (Main et al., 2008). Risk factors for chronic pain and predictive factors for long-term disability in chronic pain have been identified. These include age, catastrophizing, clinical history, comorbidity, depression, ethnicity, gender, duration of sick leave, job dissatisfaction, pain intensity, and psychological distress (Main et al., 2008). Despite this knowledge, the point of referral to the next level of care seems to be somewhat vague in Sweden. Patients with chronic pain describe a non-functioning chain of care that constantly passes them around (Ektor-Andersen et al., 2008), and they describe dissatisfaction with pain control (Breivik et al., 2006).

2.3.2 Chronic pain rehabilitation and effects thereof

The PRPs in some studies have been proven effective in terms of decreased disability (Krismer & van Tulder, 2007; Norrefalk, Linder, Ekholm, & Borg, 2007; Scascighini, Toma, Dober-Spielmann, & Sprott, 2008), and increased work participation (Jensen, Bergström, Ljungquist, & Bodin, 2005; Norlund, Ropponen, & Alexanderson, 2009; van Geen, Edelaar, Janssen, & van Eijk, 2007), but contradicting evidence is also found (Kääpä, Frantsi, Sarna, & Malmivaara, 2006; Ravenek et al., 2010). A recent review concludes that there is evidence that PRPs increase the chance for a return to work but that their effects on pain and function remain uncertain (SBU, 2010). It has not yet been fully established exactly which interventions within the PRPs cause positive outcomes. There might be several reasons that current rehabilitation interventions only work for some. First, there might be a difference in how health care providers and patients value needs (Kersten, George, McLellan, Smith, & Mullee, 2000a). The Swedish Social Insurance Agency coordinates rehabilitation interventions and defines rehabilitation as a process that primarily should lead to a return to work (Försäkringskassan, 2008). A patient's goals, on the other hand, might not be directed towards work but more towards general functional achievement (Hazard et al., 2009). Hence, there might be a discrepancy between the insurance agency's goals and the patient's goals. Second, the available intervention alternatives might not be beneficial, because few attempts have been made to customize treatments to meet individual needs (Turk, 2005). Instead, they might be based on a uniformity myth: patients who share a diagnosis have the same needs and can all benefit from the same type of intervention. Third, rehabilitation interventions might be delayed, causing patients' problems to become so manifest that they are less susceptible to change (Lydell, Grahm, Månsson, Baigi, & Marklund,

2009). This highlights the fact that further research of interventions is required to establish evidence-based medicine (Ravenek et al., 2010; Scascighini et al., 2008).

The multidisciplinary rehabilitation approach towards pain originates from after World War II. It was discovered that patients with complex pain problems were managed best by a multidisciplinary team of health care professionals who contributed from different areas of expertise (Loeser, 2001). This idea is still key in modern pain rehabilitation, whose objectives are to reactivate, to restore strength and fitness, to reduce the psychological impact of pain, to modify non-beneficial behavior and occupational orientation (Main et al., 2008). Interventions are often framed within a biopsychosocial model (Borg et al., 2006; Loeser & Turk, 2001; Main et al., 2008). A multidisciplinary rehabilitation team working with patients with chronic pain can have different compositions and might include an assisting nurse, nurse, occupational therapist, physician, physiotherapist, psychologist, and social worker (SBU, 2006).

2.3.3 Occupational therapy and pacing

As a strand within PRPs, occupational therapy is directed to prevent and curb further disability (American Occupational Therapy Association (AOTA), 2001). As a discipline, occupational therapy has been defined in several ways; one of the more recent is the following.

...the art and science of enabling engagement in everyday living, through occupation; of enabling people to perform the occupations that foster health and well-being; and of enabling a just and inclusive society so that all people may participate to their potential in the daily occupations of life. (Townsend & Polatajko, 2007, p. 27)

Enabling in this sense is to be understood as a process of facilitating people to choose, organize, and perform occupations they find useful and meaningful (Canadian Association of Occupational Therapists (CAOT), 2002). The aim of PRPs is often long-term self-management (Main et al., 2008); therefore, occupational therapists focus on the impact of pain in self-care, work, leisure, habits, roles, and social relationships, rather than the pain itself (Rochman & Kennedy-Spaen, 2007; Strong et al., 2002).

Interventions that are commonly used in PRPs by occupational therapists include occupational assessment and intervention (Strong et al., 2002), education on ergonomics (Main et al., 2008), adaptations of environment (Liedberg & Henriksson, 2006; Strong et al., 2002), coaching on pacing strategies (Birkholtz, Aylwin, & Harman, 2004b; Main et al., 2008), and work assessment with following interventions (Main et al., 2008). Pacing seems to be frequently used, because of its applicability to any occupational problem (Main et al., 2008; Strong et al., 2002). Pacing is the intervention under study in this thesis, and it will be further described in the following paragraphs.

Changes in activity pattern, both underactivity and overactivity are common when living with chronic pain (Birkholtz, Aylwin, & Harman, 2004a; Cunningham & Jillings, 2006; Main et al., 2008). To counteract this, pacing is an empowering

intervention that encourages patients to establish a level of activity that is predictable and avoids pain flare-ups while maximizing their abilities (Birkholtz et al., 2004a; Strong et al., 2002). By reducing the cognitive and affective component of pain through an understanding of their personal reaction to it, patients have the opportunity to master the pain (Liedberg & Henriksson, 2006; Strong et al., 2002). Increased self-confidence can then help patients realize their personal ability to live well despite pain. In practice, pacing has been suggested to include breaking down activities into smaller sets (Birkholtz et al., 2004b; Liedberg & Henriksson, 2006; Nicholas, Molloy, Tonkin, & Beeston, 2005; Rochman & Kennedy-Spaen, 2007), taking short breaks during occupational performance (Birkholtz et al., 2004b; Liedberg & Henriksson, 2006; Nicholas et al., 2005), and gradually increasing the amount done (graded exposure) (Butler & Moseley, 2003; Fordyce, 1976; Main et al., 2008; Nicholas et al., 2005).

Despite the fact that pacing is regularly described and suggested in chronic pain literature (Main et al., 2008; Strong et al., 2002) research on its effectiveness is scarce (Gill & Brown, 2009). A systematic review studying graded activity found it to be an effective treatment for persistent low back pain (Macedo, Smeets, Maher, Latimer, & McAuley, 2010). Yet, it was not found to be superior to traditional exercise programs. Moreover, pacing as an intervention by any means has been challenged, and it has been argued not to be associated with disability (Karsdorp & Vlaeyen, 2009a). The research by Karsdorp and Vlaeyen caused debate (Jensen, 2009; Karsdorp & Vlaeyen, 2009b; Murphy & Clauw, 2010) and Murphy et al. maintained pacing as a useful strategy that could also be related to lower objective physical activity. Further research is needed to examine clinical significance, experiences of, and cost-effectiveness of pacing.

2.4 NEED

As this thesis takes need as a stance while studying chronic pain rehabilitation and management, the complexity of need as a concept and how it is employed within health care is explicated.

2.4.1 Need as a concept

The definition of need is somewhat complex due to ambiguity in the language; need is both a noun and a verb, and they have different meanings (Finlayson, 2006; Need, ; Witkin & Altschuld, 1995). As a noun, need can mean the following.

- 1) necessary duty: obligation
- 2a) a lack of something requisite, desirable, or useful
- b: a physiological or psychological requirement for the well-being of an organism
- 3) a condition requiring supply or relief
- 4) lack of the means of subsistence; poverty. (Need)

As a verb, need points to what is required to fill the discrepancy between a present state and a desired state; a means to an end (Witkin & Altschuld, 1995), for example, 'I need to rest'. Need as a concept is heavily influenced by values, culture, politics, and beliefs; thus, it is important to recognize the context in which it is used (Finlayson, 2006; Wilcock, 1993).

In this thesis, need will be applied to health care and related to chronic pain rehabilitation and management. The center of attention will be on what aspects indicate need for chronic pain rehabilitation or occupational therapy, and which needs patients with chronic pain have in relation to pain management.

Needs can be normative, felt, expressed, and comparative, according to Bradshaw (1994). A normative need is identified by experts, professionals or policy makers; thus, it is highly subjected to cultural and value bias (Bradshaw, 1994; Finlayson, 2006). A felt need is always subjective but not always expressed. Expressed needs are needs that have been put into action by being articulated (Bradshaw, 1994). As an example, patients on a waiting list for health care intervention represent an expressed need (Finlayson, 2006). The comparative need refers to equity (Bradshaw, 1994); if one group of people has a certain need, an assumption is made that similar groups have this need too. This can contradict reality, however (Finlayson, 2006). This thesis explores normative, felt, and expressed needs.

2.4.2 Scientific theories and perspectives on need

In a scientific setting, the concept of need has been and is currently used in many different fields, including health care (Stevens & Gillam, 1998), nursing (Powers, 2006), occupational therapy (Wilcock, 2006), philosophy (Marx, 1959), and psychology (Maslow, 1934).

Several theories of need have been presented. The most widely known is probably Maslow's *hierarchy of human needs* (Maslow, 1934) which focuses on need as a desire that can explain the motives behind certain behaviors. Maslow argued that there are five basic needs: physiological, safety, love, esteem, and self-actualization. His point was that the human consciousness prioritizes these needs in a certain order; for example, physiological needs have to be met before safety needs will be dealt with.

Differing somewhat from Maslow, Doyal and Gough argue in their *theory of human need* that there are different types of needs (1991). Some needs are considered basic, and these make it possible to engage in social participation and to avoid serious harm. Other needs are believed to be the result of external sources or social construction, for example, drug abuse is a learned need. The first basic need is physical health, and it includes food, water, housing, a non-hazardous environment and appropriate health care. In several ways, this is similar to Maslow's physiological, and safety needs. The second basic need in Doyal and Gough's theory is autonomy. It describes the ability to formulate aims and strategies consistent with one's values, and it includes a secure childhood, significant relationships, physical security, economic security, safe birth control, safe child-bearing, and basic education.

The basic needs of physical health and autonomy are claimed to be the same for everyone and to be comparable both within and between cultures (Doyal & Gough, 1991). As an example, the extent to which the need of physical health is met can be studied through the prevalence of disabilities, the prevalence of people suffering from

pain, and morbidity rates. Implicit in this is the view that needs can exist at both an individual and a collective level. Doyal and Gough argue this point by advocating that human needs are best understood through the subjective individual and through society at large.

In an occupational perspective of population health, Wilcock (2006) draws upon and refers to Maslow as well as Doyal and Gough when explaining the third dimension of occupation: becoming through doing and being. Becoming points towards something that a person has in her future and what is needed for that something to come into being in the present. Becoming is further considered to be a biological universal need. When this need is met, it can provide the essence of well-being and personality, and it can lead to reaching one's fullest potential as a human. Maslow (1934) called this state self-actualization, and he felt that 'What a man *can* be, he *must* be' (p. 8) in order to be ultimately happy. Likewise, Doyal and Gough (1991) affirm this through their suggested basic need of autonomy. It is proposed that through self-understanding, one can reach the psychological capacity to formulate options for oneself and to create objective opportunities. As a result, it becomes possible to initiate actions in harmony with personal interests.

Focusing on health care needs, these have been described by Stevens and Gillam (1998) as 'the populations and patients who are recipients or potential beneficiaries of health care' (p. 1448). One does not have to seek out health care to have health care needs; additionally, a patient that receives health care can still have health care needs, because health care can be ineffective, inefficient, or inappropriate. It is to be noted that health care needs can be described in various ways, and in relation to several other concepts. Examples include community needs (Finlayson, 2007), health needs (Murray & Graham, 1995; Reid, 2004), health care needs (Müllersdorf & Söderback, 2000; Stevens & Gillam, 1998; Stevens & Raftery, 1994), psychosocial needs (Bunston & Mings, 1995), and rehabilitation needs (Kersten, George et al., 2000a).

The extent to which health care is provided depends on need, demand, and supply (Stevens & Raftery, 1994), and the need in this sense can be based on an individual or a population. The needs of a patient can be incompatible with the needs of a health care professional, a population, or a society (Reed & Sanderson, 1999; van den Bos & Triemstra, 1999). Prioritization of needs can be difficult, and ethical problems can arise (Stevens & Gillam, 1998). In circumstances like these, whose needs should be prioritized? And who is to decide that? Should priority go to the need that can most easily be met or should it go to the most severe need (Stevens & Gillam, 1998)? In response to these questions, which are part of an ongoing debate and increased demand for health care interventions, the National Board of Health and Welfare in Sweden (Socialstyrelsen, 2007a) has elaborated on this issue. In short, the board has decided that priorities should be set on usefulness for the individual patient and on cost-effectiveness rather than on a specific disease, because the consequences of the disease can vary in severity over time in the same patient.

In this thesis, the underlying idea about needs is that knowledge about patients health care needs are valuable in a society or an institution where the aim is to achieve good health. If the needs of patients are compatible with the values of society--and accordingly, are attempted to be met by health care professionals--personal satisfaction of patients' lives will increase along with their extended participation at different levels of society.

2.5 NEEDS ASSESSMENT

In health care, assessments are carried out as a base from which to set goals, plan interventions, and conduct evaluations. This section describes and analyzes needs assessment to highlight its position as a concept and as a clinical tool.

2.5.1 Definition and approaches of needs assessment

A general definition of needs assessment describes it as a set of procedures undertaken to set priorities, make decisions, and allocate resources (Witkin & Altschuld, 1995). In health care, needs assessment is the process of gathering information that is needed to determine what individuals or populations require to achieve health (Finlayson, 2006; Stevens & Gillam, 1998). Also, needs assessment is conducted to uncover unmet needs; these might be recognized by a patient, for example, or they might be dormant (Witkin & Altschuld, 1995). It is to be noted, however, that needs assessment carried out by health care professionals might or might not concern issues that the patient in question finds important. Though needs assessment can be part of a political process, this thesis will focus on the aspect of clinical investigation.

Needs assessment has been suggested to take place through the use of three different approaches (Stevens & Gillam, 1998). The first is the corporate approach. In this approach, a range of participants--including health care staff, patients, the general public, and organizations--can participate in the systematic collection of health care needs and services. The second is the comparative approach, which contrasts services for one population to another (e.g., in between countries). The third is the epidemiological/ cost-effectiveness approach, which is concerned with what is effective and for whom. In this thesis, the corporate and the epidemiological and cost-effectiveness approaches will be applied. These approaches were adopted because of their appreciation of participants with different perspectives. Each perspective is considered equally valuable to generate new knowledge. Also, if the development of needs assessment policies involve participants with 'local experience', local implementation might be better facilitated (Stevens & Gillam, 1998).

Knowing what type of need is of interest there is an array of data collection methods for needs assessment (Feher Waltz, Strickland, & Lenz, 2005; Witkin & Altschuld, 1995). Written questionnaires, are the most common way of gathering data in needs assessment (Witkin & Altschuld, 1995). Data can also be collected through individual interviews or observations as well as through group processes, such as focus groups and Delphi studies. In clinical practice, expert judgment as needs assessment is also used; this has not been proven reliable, however (Jensen, Bodin, Ljungqvist, Bergström, &

Nygren, 2000). All data collection methods have advantages and disadvantages and thus they are valuable in different situations. It has been recommended to use multiple and mixed methods to conduct a high-quality needs assessment (Finlayson, 2006; Müllersdorf & Söderback, 1998; Witkin & Altschuld, 1995).

In clinical practice needs assessment is conducted with the notion of change as its basis. It is essential to know what to change from, as well as what to change to (Stevens & Gillam, 1998). It is also important that the patient is involved in the process of needs assessment, because health care interventions should be planned together with patients (SFS, 1982:763). Needs assessment should not be an event 'done to' to patients by health care professionals as experts (Witkin & Altschuld, 1995). Rather, needs assessment should be a participatory process during which health care professionals and patients meet and make the most of their combined expertise and experience. Not only should the assessor know the purpose of the needs assessment, but so should the patient. It might be that neither the assessor nor the patient has reflected on what he or she needs and wants the outcome of intervention to be. Consequently, it might be critical to ask in plain language what the patient believes he or she needs or wants to gain from therapy (Laver Fawcett, 2007).

2.5.2 Assessment in chronic pain

In the chain of care for patients with chronic pain assessments are usually taking place on different levels in the health care system, by different health care professionals, in different ways, and with different purposes. The basic supposition is that if assessment identifies the inability to perform activities of daily living, then the patient has a need to improve the performance of these activities. Early on, risk factors and predictive factors for disability and chronic pain may be assessed (Hill et al., 2008; Linton & Halldén, 1998; Main et al., 2008; Waddell, Newton, Henderson, Somerville, & Main, 1993). Later on, a number of further assessments might be done (Main et al., 2008; Strong et al., 2002) with the aim of intervention planning and setting a baseline for evaluation (Main et al., 2008). Adopting the biopsychosocial model, the clinical expressions of pain are viewed in terms of behaviors (Waddell et al., 1993), coping strategies, culture, distress, pain (Huskisson, 1974), physiological dysfunction, social interaction, and the attached sick role. It is also common to make use of comprehensive disability measures during needs assessment (Kerns, Turk, & Rudy, 1985; Main et al., 2008). How well the assessment of symptoms or general disability corresponds to patients' needs, however, can be questioned (Feher Waltz et al., 2005).

2.5.3 Concerns of needs assessment

In one way, the assessment of a symptom or a function/disability as described above can be viewed as a potential needs assessment. For example, a rating of 75mm of pain on a horizontal visual analogue scale says something about the patient's state compared to a normative standard. Pain is then an indicator that represents a characteristic (Witkin & Altschuld, 1995), for example, being in need of pain relief. Yet, the written questionnaires often used in everyday practice are not necessarily the same as a needs assessment. Each assessment or measurement is originally developed for a specific

purpose, for example, to be used for a specific group of patients in a certain situation that must be taken into account before it is put into practice (Feher Waltz et al., 2005). Moreover, conceptual bias is common; the conceptual base on which an assessment was developed might not be congruent with how that concept is viewed in the context where the assessment is used. This might jeopardize assessments validity and thereby compromise how results can be interpreted. To overcome some of this problem, it has been recommended that questionnaires only compose one of several parts in needs assessment and that they should be supplemented with an interview, as one example (Witkin & Altschuld, 1995). To conclude, needs assessment can be done partly through the everyday questionnaires and measurements that exist if their conceptual bias is reduced to a minimum.

2.5.4 Specific research on needs assessment

Research on needs and needs assessment is somewhat limited in the fields of chronic pain, rehabilitation medicine, and occupational therapy. From a theoretical view, a study has been made of health care needs as a concept as well as a suggestion of how these needs could be assigned priority by ranking (Liss, 1990). Applying Liss's model of health care needs, Müllersdorf (2001) studied self-perceived activity limitations due to chronic pain and developed a measure of occupational therapy needs.

Health care needs related in relation to different populations have been studied: young people with stroke (Kersten, Low, Ashburn, George, & McLellan, 2002), people with rheumatoid arthritis (Brand, Claydon-Platt, McColl, & Bucknall, 2010), severely disabled people (Kersten, McLellan, George, Smith, & Mullee, 2000), and caregivers (Kersten, McLellan, George, Mullee, & Smith, 2001). Through these different perspectives, a study was performed on an evaluation of how well needs were met or not met (Kersten, George, McLellan, Smith, & Mullee, 2000b). Results showed that although people with disabilities might already be receiving health services, they still experience unmet needs.

There are specific measurements that include health care needs as a central construct (Müllersdorf & Söderback, 1998); some of the fields using theme include mental health, physical disabilities, and gerontology. For example, in the absence of a valid needs assessment research tool, the Southampton Needs Assessment Questionnaire (SNAQ) was developed and is designed to measure rehabilitation needs of disabled people (Kersten, McLellan, George, & Smith, 2000). Other examples include needs assessment of primary care (Dragone, 1990) and occupational therapy for patients with cancer (Söderback & Hammersly Paulsson, 1997) or chronic pain (Müllersdorf & Söderback, 2002).

3 RATIONALE

Although chronic pain has been researched extensively over the past decades, former studies in clinical sciences illuminate that the chain of care and interventions provided for patients with chronic pain is not necessarily effective. Patients describe being passed around in the chain of care, general dissatisfaction with their lack of pain relief/management, and a lack of responsiveness regarding their needs from health care professionals. Also, it remains largely unknown whether or not, and how, the interventions sometimes provided are effective. One reason for this might be that patients' needs, which play an important role in intervention outcome, are inadequately understood. Possibly, there is a discrepancy between how health care as a system and how its patients view needs, which contributes equally to ineffective interventions and disappointment. The experience of an indistinct chain of care and the uncertainty of intervention effects constitutes a problem for the patients who are encouraged to participate in this process. Given the currently restricted health care resources, it is possible to see a problem in spending tax revenue on health care that largely fails to meet the needs of the intended patients.

It is important to understand patients' individual health care needs in order to provide them with good health care. Finding a physical and/or psychological dysfunction is not necessarily the same as needs. Needs can be latent and unexpressed while being of utmost importance to the individual experiencing them. In clinical practice, needs assessment might involve a range of measurements. Nonetheless, mostly it is not needs that are assessed; rather, it is degrees of symptoms, disability, and beliefs. Not recognizing needs as a separate construct during needs assessment runs the risk that assumptions about patients needs will be based on undependable data and will leave the patient's own voice unheard regarding needs. Knowing this, need must be recognized on its own for its complexity, and to some extent it must be separated from the symptoms and risk factors known to be related to chronic pain.

Continuing to generate knowledge regarding the needs of patients with chronic pain is considered necessary in order to develop and organize a well-functioning chain of care that includes effective interventions. Studies that highlight how needs are indicated and how patients as receivers of health care view their needs could contribute to closing the gap of knowledge regarding needs as a concept in chronic pain rehabilitation and management. Recognizing indicators for pain rehabilitation or occupational therapy could provide an understanding of elements that are important to identify during the referral of a patient with chronic pain from primary care to a rehabilitation unit. Moreover, awareness of the needs that individuals living with chronic pain experience might encourage rehabilitation teams to consider interventions that fit patients' needs. Finally, a combined analysis of indicators of need to guide rehabilitation as well as individually experienced needs in patients living with chronic pain could provide a comprehensive perception of health care needs in the field of chronic pain.

4 AIMS

The overall aim of this thesis is to explore and describe patients' needs related to chronic pain rehabilitation and management from the perspectives of health care professionals and patients with chronic pain. The extended aim is to increase knowledge and understanding of rehabilitation of patients with chronic pain.

The specific aims of the four studies follow.

- Study I: Explore the indicators of need for pain rehabilitation among a multidisciplinary expert panel working with pain rehabilitation.
- Study II: Explore indicators of need for occupational therapy in patients with chronic pain from a professional perspective.
- Study III: Describe and explore occupational performance and satisfaction before, during, and after an occupational therapy intervention in a group of patients with chronic pain.
- Study IV: Describe needs related to chronic pain management as they are experienced by people living with chronic pain.

5 METHODS

The present thesis has various methodological approaches that were guided by the research aim. The corporate and the epidemiological/cost-effectiveness approaches of needs assessment were adopted to give voice to several groups of participants and to study outcome of intervention. Each study with its unique approach thus studied patients' needs regarding chronic pain rehabilitation and management from a different perspective. This combination of designs can describe and portray an area of research from different viewpoints, each being equally important and contributing to new knowledge.

5.1 STUDY OUTLINES AND DESIGN

Four studies were conducted, and the numbering of the study and the paper correspond. An overview of the study outlines is presented in Table 1.

Table 1. Overview of design, methods, and participants in studies I-IV

	Study I	Study II	Study III	Study IV
Design	Consensus study	Explorative	Single-case	Explorative
Data collection	Delphi study with three rounds	Focus group discussions (n=6)	Individualized outcome measure	Interviews
Number of participants	23	25	5	10
Time of data collection	Jan-Jun 2007	Jun-Dec 2007	Feb-May 2008	May-Aug 2008
Data analysis	Descriptive content analysis (Polit & Beck, 2004) Descriptive statistics Wilcoxon test	Content analysis (Graneheim & Lundman, 2004)	Visual inspection (Kazdin, 1982) Descriptive statistics	Thematic content analysis (Baxter, 1991)

The common thread through these four studies is studying health care needs from the perspective of health care professionals and then analyzing how these correspond with ratings and experiences of needs in those who receive health care, that is, patients with chronic pain.

Study I

In this consensus study, a multidisciplinary expert panel working with chronic pain rehabilitation at different PRUs took part in three rounds of Delphi. By collecting data through a Delphi study, it was possible to include participants from widespread parts of Sweden and to establish a written communication process aiming at consensus.

Study II

In this explorative study, six focus group discussions (FGD) were conducted with 25 occupational therapists. Facilitating an open discussion was believed to generate a range of ideas regarding indicators for occupational therapy. Also, the format of FGDs enabled participants to instantly confirm or refute what was being said and thereby validate results.

Study III

Study III was a single-case baseline-intervention follow-up (ABA) intervention study. Five patients were followed over a 12-week period: before (A1), during (B), and after (A2) a rehabilitation intervention. The particular design was based on an interest to study individual patterns of occupational performance and satisfaction. To explore and describe the variable condition that patients of chronic pain are believed to experience, weekly measures of occupational performance and satisfaction were seen as important.

Study IV

In this interpretative qualitative study ten participants were each interviewed once after participating in a PRP. By interpreting participants' experiences of daily life, the unexpressed needs related to pain management could be described. The attempt was to interpret needs in order to understand how they are represented in the participants' lives.

5.2 PARTICIPANTS

Four groups of participants participated in the studies. In Study I, participants were represented by a multidisciplinary expert panel. Participants in Study II were occupational therapists working in primary care or at a PRU. In studies III and IV, participants were groups of patients recruited from a PRP. Some patients participated in both in studies III and IV. Please see Table 2 and Table 3 for overviews of participants.

Table 2. Overview of participants in studies I and II

	Participants, n	
	Study I	Study II
Participants, n	23	25
Sex		
Female	21	25
Male	2	-
Profession		
Nurse	4	-
Occupational therapist in primary care	-	19
Occupational therapist at PRU	4	6
Physiotherapist	6	-
Physician	3	-
Psychologist	2	-
Social worker	4	-
Work experience		
Range years (mean)	10-35 (23)	1-32 (15)
Work experience with chronic pain,		
Range years (mean)	3-24 (10)	-

Table 3. Overview of participants in studies III and IV

	Participants, n	
	Study III	Study IV
Participants, n	5	10
Sex		
Female	4	7
Male	1	3
Age, years, range (mean)	39-50 (43)	23-50 (39)
Ethnicity		
Swedish	3	7
Nordic (non-Swedish)	1	1
European (non-Nordic)	-	1
Asian	1	1
Civic status		
Married/cohabiting	3	6
Not married/single	2	4
Educational level		
Nine-year compulsory- school	1	1
Upper secondary school	4	9
ICD-10 diagnosis represented among participants		
M522 Other chronic pain	4	8
M545 Low back pain	1	1
M549 Dorsalgia, unspecified	-	2
M750 Adhesive capsulitis of shoulder	1	1
M796 Pain in limb	1	1
S134 Sprain and strain of cervical spine	-	1
S320 Fracture of lumbar vertebra	-	1
F320 Mild depressive episode	1	1
F431 Post traumatic stress disorder	1	1
F438 Other reactions to severe stress	1	-
Years with pain,		
Range years (mean)	4-32 (14)	4-32 (9)
Professions represented among participants		
Administrator	1	1
Accounting economist	-	1
Assistant nurse	1	3
Carpenter	-	1
Cleaner	1	1
Construction worker	-	1
Mechanical worker	1	1
Salesman	1	1
Work status		
Employed	3	6
Unemployed	2	4
Source of income		
100% sick leave	4	8
50% sick leave + 50% compensation	1	1
100% unemployment benefit	-	1

Study I

Purposive sampling was used to form a multidisciplinary expert panel in Sweden. Health care professionals who worked in PRUs were identified, because the study's aim was to explore indicators of need for pain rehabilitation among such professionals. Through telephone mapping and internet searches of county websites, 32 PRUs were located; for the most part, they were found at county or regional hospitals. To participate in the Delphi study, one had to be a professional assistant nurse, nurse, occupational therapist, physiotherapist, physician, psychologist, or

social worker. Participants were also required to have at least three years of work experience related to patients with chronic pain. Twenty-three PRUs accepted participation, and each chose one health care professional to be its representative in the study. One participant did not fulfill the criteria of work experience. After the PRU chose a representative, permission to participate in the study was determined.

Study II

Participants were occupational therapists working in either primary care or at a PRU in central Sweden. To reach occupational therapists in rural and urban areas, four regions were mapped out. The criterion for inclusion was experience working with patients with chronic pain. Forty occupational therapists initially accepted participation, but 15 dropped out from the time of recruitment to the actual FGDs, leaving 25 participants. Reasons for dropping out included lack of time, sickness, and not working with patients with chronic pain. Figure 1 illustrates the recruitment of participants.

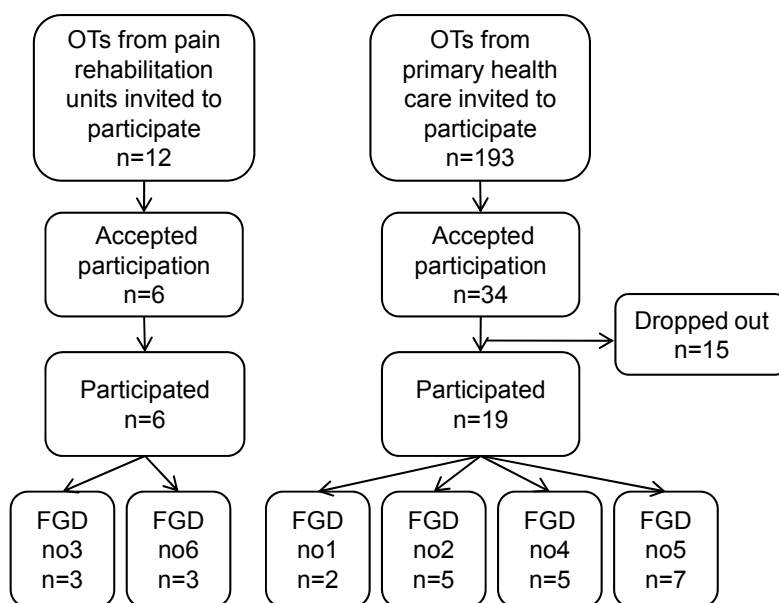


Figure 1. Flow chart of participation recruitment, OT= occupational therapist. Out of 205 participants invited, 25 took part in six FGDs.

Study III

Participants were recruited through a PRP at a hospital. A group of patients (n=10), scheduled to take part in the intervention ‘Balance in Everyday Life’ (BEL), was invited and accepted participation in this study. During the second week, one participant dropped out, leaving nine participants to be assessed through the A1 phase. Because participants serve as their own control in a single-case ABA design, several data points are desirable during the A1 phase. To secure baseline data that could be used as the patients’ own control data, it was decided that participants had to have data from all three data points during the A1 phase. This criterion led to the exclusion of two patients after the A1 phase. The remaining seven patients were assessed throughout the

B phase. In order to evaluate the outcome of the intervention, it was estimated that participants should have attended three out of five sessions to gain the benefits. This led to the exclusion of two more participants. The follow-up phase, A2, lasted four weeks; and it was decided that data from three out of four weeks were necessary to be able to contrast data from the baseline to the follow-up. The remaining five participants were assessed throughout the A2 phase. In the end, one out of the five participants had missing data for one week (week eight).

Study IV

Participants were recruited from the same PRP as participants in Study III. Convenience sampling was used, and eleven potential participants were invited (the same 10 who were available for Study III and one additional who was available only for Study IV). Ten of these accepted the invitation. Two participants were not native Swedish speakers and were offered a professional translator to be present during the interviews. However, both participants declined this offer and instead brought their daughters to assist them with communication during the interviews.

5.3 DATA COLLECTION AND PROCEDURES

For each of the four studies, separate data collections were conducted. Data were collected in the same order that the studies are numbered.

Study I

In Delphi studies, data collection occurs in rounds, which consists of sending out a questionnaire, receiving a participant's response, and finally analysis. In this study, three rounds were conducted, each lasting eight weeks. In the beginning of the first round, participants received questionnaire 1 (Appendix 1). This invited participants to provide indicators for referral to specialized pain rehabilitation in a written format. The qualitative data that was generated from questionnaire 1 was then analyzed using descriptive content analysis (Polit & Beck, 2004), and the results constituted the base for questionnaire 2. To create questionnaire 2 and to allow quantitative scoring of the qualitative results, results from the first round were reworded by adding, 'To what degree do you agree that...(insert of statement from first round) ...is an indicator for pain rehabilitation?' Beside each statement, response options formatted using a Likert scale were presented: totally agree (4), partly agree (3), partly disagree (2), and totally disagree (1). A response alternative of 'don't know' was also available.

In the beginning of the second round, participants received questionnaire 2 in which they scored their agreement with each statement. After the questionnaires were returned, ratings were tallied using descriptive statistics. To prepare for the third round, questionnaire 2 was used again. This time descriptive statistics that presented the level of agreement were added to each statement. Participants could see descriptive statistics for the group response as well as a reminder of how they had responded in round 2. See Appendix 2 for an example of the questionnaire design used in the third round. After scoring the third round, questionnaires were returned for analysis. See Figure 2 for the Delphi process.

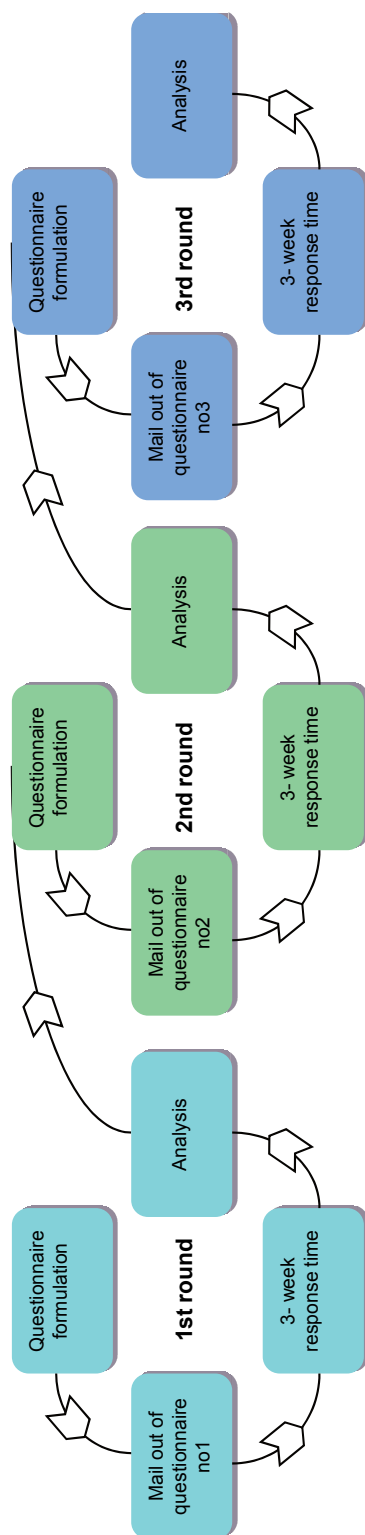


Figure 2. Illustration of Delphi process in study I

Study II

Prior to execution of the FGDs, reflexivity in the form of personal reflections on the upcoming topic was recorded; these were returned to during data analysis. Six FGDs were then conducted, which took place at a university (n=1), a conference center (n=1), and a hospital (n=4). The FGDs were planned with an intention to spark a discussion among participants. A research protocol with a structured discussion route was developed (Krueger & Casey, 2000); see Box 1. The purpose of the discussion route was to open the FGDs with a broad, general discussion and gradually lead it towards the key area of interest: indicators of need for occupational therapy.

Box 1 Discussion route for the FGDs.

We are interested in how needs in patients with chronic pain are assessed and this FGD will allow us to understand what you view as an indicator for occupational therapy for patients with chronic pain.

Opening

Tell us who you are and what made you want to participate in this study.

Introduction

What is your experience of working with patients with chronic pain?

Prompts

- Do you have experience working with patients with chronic pain in different settings? Please describe.
- What type/diagnosis of chronic pain have the patients that you have been in contact with had?

Transition into focused discussion

How have you worked as an occupational therapist with patients with chronic pain?

Key discussion

What do you consider to be an indicator that a patient with chronic pain needs occupational therapy?

Prompts

- How do you mean?
- Can you give an example?
- Do the others in the group agree with this?
- Is there any other way to look at this?
- Other suggestions of what an indicator for occupational therapy can be?

Ending after the assistant moderator's summary

Do you consider this oral summary to accurately represent your discussion here today?

Have we understood the essence of your discussion?

Have we missed anything you want to discuss?

In addition to the participants, the author (Å. S.) and the main supervisor (M.M.) were present during the FGDs and alternated being the moderator and assistant moderator. The moderator guided the FGDs, and the assistant moderator summarized the discussion. During the FGDs, both the moderator and the assistant moderator took field notes, which were about discussion content, questions raised, atmosphere, and conclusions made by the groups. All FGDs were digitally recorded and lasted 72-112 minutes. Directly after the FGDs, discussions between the moderator and assistant moderator took place to reflect on the sequence of events, the discussion that was held

and the experiences during the discussion. The participants' help in data collection were acknowledged. The moderator and assistant moderator expressed their appreciation by giving two lectures after the FGDs: one on occupational therapy interventions for patients with chronic pain and one on general needs assessment.

Study III

The BEL intervention

The BEL was eight hours long and was given by occupational therapists as one two-hour session per week. During the time of this study, however, the BEL course took place over a five-week period. This was to accommodate patients with children, because there is a week-long Easter break for schools in Sweden. Data collection continued during the Easter holiday (week five) and in the end; all five participants attended the PRP during the fifth week. Besides the BEL, which was one of the last group interventions of the PRP, participants took part in group and individual interventions according to their individual rehabilitation plans.

The BEL's principal intention was to present pacing as a self-management strategy (Gil, Ross, & Keefe, 1988) that could be used to level out the often irregular activity pattern that patients with chronic pain experience (Cunningham & Jillings, 2006; Henriksson, 1995b; Nicholas et al., 2005). Patients are encouraged to shift their thinking from 'I can't do this activity' to '**How** can I do this activity?' (Rochman & Kennedy-Spaen, 2007). The hypothesis is that by breaking down occupations or even activities into smaller elements, by taking short breaks during performance, and by gradually increasing the amount done (Kavanagh, 1995; Nicholas et al., 2005; Rochman & Kennedy-Spaen, 2007), occupational performance can be increased. In practice, pacing is doing something to avoid being laid up and also to avoid exceeding tolerance levels.

For participants to discern how the overactivity-underactivity cycle may be present in their own lives and to transfer theoretical and 'in-clinic' knowledge into their everyday lives (Gil et al., 1988) home assignments were given. These included use and analysis of an activity record (Kielhofner, 2002) as well as planning of lunch preparation which took place during the last BEL session. By planning and preparing lunch, participants practiced pacing components. During this session, participants were also encouraged to observe pacing and to give each other reminders as necessary. Throughout the lunch preparation, participants' behaviors were videotaped by an occupational therapist, and the video later provided a starting point for a group discussion (Pierce, 2005).

Measurement

The author conducted all data collection. Occupational performance and satisfaction with occupational performance was measured weekly, using the *Canadian Occupational Performance Measure* (COPM) (Law et al., 1998). The first assessment session was 60-90 minutes long, subsequent sessions were 5-20 minutes. Patients were regularly assessed on a seven-day interval, with a minimum of four days.

The COPM was used to identify, assess, and evaluate occupational problems that patients wanted to improve during the BEL. Through a semi-structured interview, patients' occupational problems were first identified. Up to five occupational problems to work on were then selected, prioritized, and rated in terms of importance, performance, and satisfaction. Ratings range from 1-10, where 1 represents low importance, inability to perform, and low satisfaction, and 10 represents high importance, high ability to perform, and high satisfaction. Mean values of occupational performance and satisfaction were then calculated by adding up the scores of the separate problems and dividing this number by the number of problems rated. A change score of >2.0 is to be considered clinically significant (Law et al., 1998; McColl et al., 2006).

A review of research (McColl et al., 2006) on the COPM evaluated its psychometric properties and demonstrated its validity (Carpenter, Baker, & Tyldesley, 2001), reliability (Cup, Scholte op Reimer, Thijssen, & van Kuyk-Minis, 2003; Pan, Chung, & Hsin-Hwei, 2003; Sewell & Singh, 2001), responsiveness to changes in client outcomes over time (Carpenter et al., 2001; Wressle, Samuelsson, & Henriksson, 1999), and clinical utility (Wressle, Eeg-Olofsson, Marcusson, & Henriksson, 2002; Wressle, Marcusson, & Henriksson, 2002). Moreover, the COPM has been used as an outcome measure in single-case design (Effing, van Meeteren, van Asbeck, & Prevo, 2006) and in repeated measure designs (Gentry, 2008), however, it had not been used concerning problems related to chronic pain.

Study IV

Ten individual interviews were conducted by the author. Nine interviews took place at the PRU where participants had been recruited, and one took place in a participant's home. An interview guide had been outlined to capture participants' everyday occupations and situations where need for pain management became evident. Before the actual data collection began, the interview guide was tested with a participant who had attended a PRU earlier. As a result of the test interview, the interview guide was revised in terms of clarity and follow-up questions. The interviews had one main question regarding how participants lived and experienced their daily life (see Appendix 3). Follow-up questions encouraged participants to give detailed descriptions of occupations and related experiences. Interviews lasted 30-60 minutes and were all digitally recorded. To establish trustworthiness, a reflexive journal and memos were used to record personal reflections before and throughout the data collection process.

5.4 DATA ANALYSIS

For each of the four studies, separate data analyses were conducted.

Study I

Data analysis in Study I was performed in several steps over the three rounds. Participants' writings from the first round were analyzed using descriptive content analysis (Polit & Beck, 2004). The analysis was used to organize the data and can be described as manifest: keeping analysis close to the original text and not making

attempts to be abstract. After the second round, scores from the four-point Likert scale were summarized using descriptive statistics of distribution and mean. A mean rating of 4.0 was regarded as complete consensus, 3.0-3.9 was regarded as consensus, and any mean rating <2.9 was regarded as no consensus. After the third round, descriptive statistics of distribution and mean were used along with Wilcoxon signed-ranks test.

Study II

Recordings from the FGDs were transcribed verbatim by the author. The texts were analyzed using content analysis (Graneheim & Lundman, 2004) to find descriptions of indicators for occupational therapy. First, meaning units about indicators for occupational therapy were highlighted. Meaning units were then condensed, coded, and organized into categories. The process of analysis, from meaning units to categories represents the manifest content of the data; 13 categories correspondent to different indicators for occupational therapy. After categorization, analysis proceeded, and sub-themes and a theme were found. The sub-themes and theme represent the latent meaning of the data. Analysis was done separately by the author and the main supervisor, and all parts of the results were discussed until agreement was found.

Study III

Data from the COPM over the 12-week data collection period were analyzed through visual inspection (Kazdin, 1982) and descriptive statistics. To make the visual inspection possible, data were plotted in separate graphs for each participant. While visual inspections of single-case data can include level, trend, slope, and variability, each of these analyses requires a set of criteria to be fulfilled for the analysis to be valid (Kazdin, 1982; Ottenbacher, 1986; Zhan & Ottenbacher, 2001). Based on this, the visual inspection in Study III examined variability across data points. Descriptive statistics were also used, through the calculation of mean scores for each phase (A1, B, and A2) (Kazdin, 2003). The mean scores for occupational performance and satisfaction scores were thus represented by several problems over three (A1), five (B), or four (A2) weeks. The intent with both visual inspection and descriptive statistics of mean values was to study possible weekly fluctuations while also evaluating mean occupational performance and satisfaction during each phase.

Study IV

Recordings from the interviews were transcribed verbatim by the author. To make data known and check accuracy of transcriptions, recordings of the interviews were then listened to repeatedly in parallel with repeated readings of the text. Thematic content analysis (Baxter, 1991) was used to interpret the underlying meaning of the texts, and manifest descriptions were abstracted into latent themes. To start out, meaning units, were highlighted; 'meaning units' were those parts of the text that described participants' experiences of needs related to pain management. Meaning units were then condensed, coded, and finally abstracted into three themes. Throughout the analysis process, each step was revisited to confirm and trail results. Also, analytical memos were kept to make it possible to go back and forth between the raw data and the final result. Rereading these analytical memos, it became evident that the level of

interpretation and abstraction was developed over an extensive period of time. See Table 4 for an example of the analytical process.

Table 4. Example of the analytical process from meaning units to theme.

Meaning unit	Condensed meaning unit	Code	Theme
Therefore it is not me, who is in charge –it is of course the [painful] body who says stop all the time	Not me who is in charge, it is the body	Body controls	Need to handle the painful body and the eager mind
I am a stubborn person, in a way. I don't want to stay at home, I don't want to be ill, I don't want to sit at home and think about the pain. I want to 'be' for a little bit.	I am stubborn, I don't want to just sit at home and think about the pain. I want to 'be'.	Want to 'be'	

Combination of studies I-IV

After all four studies were completed, a composite analyses of them were carried out in the following way. Studies I and II were analyzed together to gain an understanding of what might be included as indicators for pain rehabilitation and occupational therapy. This result was then related to the results of Study IV. Highlighted indicators were linked to the three themes and exemplified through data extractions.

5.5 ETHICAL CONSIDERATIONS

All studies in this thesis were approved by the Regional Ethics Committee, Uppsala, Sweden (Dnr 2005:248). On the basis of changed conditions for Study IV, an addendum of the ethics application was made on November 14, 2007. This application regarded permission to conduct individual interviews and was approved on November 20, 2007. The studies have also been guided by general ethical principles for research involving humans (Gustafsson, Hermerén, & Petersson, 2005; World Medical Association, 2008), for example beneficence, self-determination, full disclosure, and confidentiality.

The principle of beneficence serves to protect participants from harm and exploitation (Polit & Beck, 2004). Before any data collection began, a risk/ benefit analysis was conducted; benefits were considered to be in the majority and risk minimal. None of the participants in studies III and IV was deprived of any interventions nor were there any extra delays of intervention due to data collection. Participating in face-to-face discussions (Study II) or interviews (Study IV) and sharing personal experiences can be trying, can evoke uncomfortable memories, and can touch upon delicate subjects. This was observed closely during data collection, and participants were informed beforehand and reminded during the studies that their participation was completely voluntary and that they did not have to answer the questions asked. Several participants in Study IV did become emotional during the interviews; and when discussing this, they did not describe it as a negative experience. Instead, they expressed a sense of relief in talking about their everyday life and being listened to.

Self-determination concerns participants' rights to voluntarily decide whether or not to participate without risk of any negative consequences (Polit & Beck, 2004). In studies I and II, participants were invited to participate through a written letter. This was to allow time for the people invited to consider participation at a time that was convenient for them. In studies III and IV, participant recruitment took place in a clinical setting. Because a researcher is in a position of authority (Polit & Beck, 2004) and might influence potential participation, members of the rehabilitation team assisted during recruitment, asking patients if the author could approach them with further information about participation. Although this reduced the researcher's influence on participants during recruitment, it is of course still possible that participants felt obliged to participate when asked by a team member they knew.

Full disclosure was given to all participants. They were given full information on potential benefits and risks, data collection procedure, what would happen to data after collection, and how the results could be used. In studies III and IV, information was given both in a written and an oral format. Confidentiality (Feher Waltz et al., 2005) was sought through several steps. In Study I, no names of specific participants were shared. Names of participating rehabilitation units were shared to some extent, however, only after seeking permission to do so. The identities of participants in studies III and IV were only known to the author; data was coded before data analysis. Also, any information that could be linked to a specific participant was excluded.

All the studies used informed consent, which summarized issues related to the ethical principles being applied (Feher Waltz et al., 2005; Polit & Beck, 2004). In studies I and II, the informed consent was sent to participants. For studies III and IV, informed consent was given personally to participants. An offer was also made to read the informed consent out loud. Several participants accepted this offer.

During Study IV, two unexpected situations arose that call for additional ethical consideration. Two participants were not native Swedish speakers and were offered professional translators to support their communication during the interviews. Both participants determinedly rejected this proposition. Instead, they both suggested that their daughters could come to the interview and assist them. Being careful not to make any decisions on behalf of the participants, information about possible drawbacks to this idea were presented. Participants stood their ground, however, and insisted on having their daughters present during the interviews. The presence of a family member while on talks about daily life and how it is affected by living with chronic pain can be both supportive and hindering. Here, participants seemed to see it as a benefit; however, there is a question about how their choices affected their daughters. It might have been difficult or even impossible for the daughters to decline their parents' requests for communication support. Also, hearing detailed descriptions of a family member's daily life--of which one might not have been formerly aware--could cause distress.

In addition to the daughters' presence during the interviews, there was an unexpected situation during the interview that took place in the participant's home. While the interview was under way, a relative rang the doorbell and was welcomed in. To avoid putting the participant on the spot, the interviewer took a passive role to allow the participant to take the lead. The participant explained to the relative exactly what was happening, and the interviewer suggested that the interview be suspended and the recorder turned off. After the visiting relative left, the situation was discussed. From the interviewer's perspective, the problem was that the participant's integrity might have been compromised by putting her on the spot to explain why a stranger with a pocket recorder was in her home. The participant explained that she 'had nothing to hide' and that the relative came to visit almost every day. Yet, one reflection is that sometimes a situation can feel comfortable when it happens but unsatisfactory when contemplated later. Based on this, the participant was informed that if she wanted to talk about the situation later, she could contact the author/interviewer.

6 RESULTS

This section presents the main results from studies I-IV, first through an overview (Table 5) and then through a description of how they relate to each other. For detailed information, see each separate paper.

Table 5. Overview of main results from studies I-IV.

	Study I	Study II	Study III	Study IV
Aim	Explore the indicators of need for pain rehabilitation among a multidisciplinary expert panel working with pain rehabilitation.	Explore indicators of need for occupational therapy in patients with chronic pain from a professional perspective.	Describe and explore occupational performance and satisfaction before, during, and after an occupational therapy intervention in a group of patients with chronic pain.	Describe needs related to chronic pain management as they are experienced by people living with chronic pain.
Main results	Consensus was reached on 19/20 suggested indicators. The indicators spanned physical and mental health, activities of daily living and aspects of work. Personal feelings based on tacit knowledge of a patient's complete situation were also highlighted as important.	Initially, 13 categories were found, and each of them was viewed as a separate indicator. Also, five sub-themes were identified; pain behavior, lack of knowledge, occupational imbalance, emotional stress and physical strain. Finally, one theme was found: <i>limitations of occupational performance</i> .	Five patients identified occupational problems that they worked on towards the end of a PRP. Individual changes of -0.3-+5.3 in occupational performance and satisfaction were found.	Three themes were found: <i>Need to handle the painful body and the eager mind, need for transformation of self-image, and need for affirmation through communion and enjoyment</i> . The interpreted needs could be met through internal changes and in relation to the environment.
Aspect of need	Normative indicators of need		Expressed needs	Latent needs

6.1 INDICATORS FOR INTERVENTION (STUDIES I AND II)

In studies I and II, the needs being studied were stated beforehand: pain rehabilitation and occupational therapy. Combined analysis of the two studies form an understanding of what health care professionals in primary care and county/regional care view as indicators for pain rehabilitation or occupational therapy.

In Study I the multidisciplinary expert panel ranked the suggested indicators, and 19 out of 20 of these reached a level of consensus. In Study II, analysis generated 13 indicators although these were not ranked in any way. While representing two diverse research methods, when combined, studies I and II produce an overview of what is regarded as the most important indicators of intervention in a multidisciplinary expert panel (Study I) and in a group of occupational therapists (Study II). See Table 6.

Table 6. Results from studies I and II are shown together to illustrate overlap and differences. Indicators from Study I are presented in the same order as they were ranked in the third round.

No	Indicators that a patient needs pain rehabilitation, as found in Study I.	Indicators that patients need occupational therapy, as found in Study II.
1	Chronic pain in combination with deficient coping strategies, such as passive measures and short-term solutions.	Passive behavior waiting for pain relief (also fits no. 16) Lack of coping strategies
2	The health care professional gets the feeling that the chronic pain is complex, and available interventions will not change the progress within two months.	
3	Chronic pain in combination with some kind of avoidance behavior, such as fear of movement.	Fear-avoidance behavior Disturbed body image
4	Chronic pain in combination with catastrophizing, such as exaggerated anxiety about the patient's problems.	Pain obsession
5	Chronic pain in combination with lack of recovery, such as clear sleep problems or clearly deficient balance between activity and rest.	Disproportionate activity pattern (also links to no. 10)
6	Chronic pain spreading to new areas of the body or intensifying.	
7	Personnel in primary care cannot move the pain management process forward, expressed as "gotten stuck."	
8	Chronic pain in a patient under the age of 30.	
9	Chronic pain combined with both psychosocial difficulties and negative influence on function and activity level.	
10	Chronic pain and change in activity level--either too high or too low.	Disproportionate activity pattern (also links to no. 5)
11	Chronic pain in combination with sick leave.	
12	Chronic pain and psychological problems caused by, for example depression, trauma, or anxiety	Depressed feelings
13	Patient estimates a high level of pain.	
14	Chronic pain difficult to relieve.	
15	Chronic pain in combination with impaired physical function, which in turn causes at least 50% sick leave.	Physical injury
16	Chronic pain in combination with lack of motivation to be active in the pain management process, for example, participation in physical activity changes or routines change in order to deal with pain.	Passive behavior waiting for pain relief (also fits no 1)
17	Chronic pain in combination with problems related to pharmaceutical treatment/ adjustment, for example, increased need of medicine or need to evaluate medicine intake.	
18	Chronic pain in combination with psychosocial problems, such as lack of social support, family-related problems, or financial problems.	
19	Chronic pain in combination with existential problems.	
20	Chronic pain in combination with work-related problems, such as high workload, low work comfort, or lack of support in the workplace.	Unfit physical environment Heavy workload

Three indicators from Study II could not be linked to results from Study I. These were:

- Body language signaling pain
- Ignorance concerning pain and patient entitlements
- Lack of enjoyable activities

Similarities and differences found in studies I and II

Lack of coping strategies and lack of handling the stress involved in managing chronic pain was found to be an indicator both for pain rehabilitation and for occupational therapy. It was also found that poor coping skills--such as application of passive approaches, waiting for pain relief, and short-lived treatments--were an indicator of need for pain rehabilitation and occupational therapy. In addition, fear-avoidance behavior (as a general thought and as a specific fear of movement) ranked third in Study I. This was also something that drew the attention of the occupational therapists when they compared patient's daily routines before and after the development of chronic pain.

One participant (Study I) expressed herself like this in the first round:

The patient shows fear of movement, which comes out during assessment of how daily activities look now compared to before the pain developed. If this [fear of movement] is confirmed by a physiotherapist's assessment, it is a strong indicator.

Work-related problems were another indicator found in studies I and II. The indicator 'chronic pain in combination with work-related problems, such as high workload, low work comfort, and lack of support in the workplace' reached consensus in round two but not in round three (Study I). Furthermore, environmental factors were found to be an indicator for occupational therapy, both in terms of products and technology that can be used to facilitate work and in terms of adequate support from colleagues and peers (Study II). A disproportionate balance among work, leisure, and rest was found as an indicator to pay attention to. This point was brought out as a patient's overactivity, underactivity or experience of an imbalance between activity and rest in general (Study I). Study II found the same, while the occupational therapists put an emphasis on how well the patients carried out daily routines in light of the patients' energy levels.

When perspective was altered and the dissimilarities of suggested indicators were studied, several aspects were found. The multidisciplinary expert panel (Study I) gave four indicators that were explicitly related to the pain: pain spreading, high level of pain, pain difficult to relieve, and insufficient pharmacological treatment. The occupational therapists did not mention pain in itself to be an indicator for intervention. Yet, Study II found one indicator that was not mentioned in Study I: lack of enjoyable activities. In their line of reasoning during the FGD, it was emphasized that energy or stamina to deal with chronic pain was not something that could be acquired solely through rest but also through engagement in activities that can recharge a person.

Besides personal characteristics in the patient, Study I found that events taking place in a health care professional's sphere can be important and can indicate a need for pain rehabilitation. With the second highest ranking, the indicator 'The health care professional "gets the feeling" that the chronic pain is complex, and available interventions will not change the progress within two months' shows that tacit knowledge and experience are important during the assessment of patients' needs. Another indicator in line with this reasoning is when staff in primary care feel stuck,

that is, when they experience that the patient is not making progress in the pain management process.

6.2 LATENT INTERPRETATIONS (STUDY IV) RELATED TO MANIFEST DESCRIPTIONS (STUDIES I AND II)

The latent described interpretations (Study IV) below relate to the manifest results above (studies I and II).

Initially, the everyday lives of the participants with chronic pain had been a struggle most often won by their chronic pain (Study IV). Studies I and II found that patients who adopt passive behavior or lack adequate coping skills to handle the pain were eligible for rehabilitation and occupational therapy. Confirming this, participants in Study IV had previously mostly focused on short-term solutions to find pain relief. They believed that they simply needed to know what was hurting and then get that ‘problem solved’.

Participant: *You have to be gentle to yourself to realize, you know it, but you don't really realize.*

Interviewer: *You don't realize.*

Participant: *You don't really want to realize. You think it [pain] will pass, it will be good. If I take a couple of pills tonight, I will be fine tomorrow.... Today I listen to my body, I didn't do that before.* (Study IV)

Eventually, sometimes after many years, participants (Study IV) realized that a quick-fix for pain relief was never going to come. They had to tackle the pain themselves, find lasting coping strategies, and change the content of their thoughts. If not, the mind would go downhill into a black hole. This description matches results from studies I and II; when pain management strategies do not work long term, a change (possibly through intervention) is necessary. In the present, participants had adopted new ways of carrying out daily routines. It was not the case that the pain won and the mind, which was eager to do or engage, surrendered. As a replacement for living a life led by pain, participants were now conscious mediators between their experienced pain and their willingness to engage fully in everyday life.

Participants in Study IV carried out a risk benefit analysis on whether or not they find it worthwhile to engage in activities. In this study, potential pain following an activity is weighed against the joy of being with family.

I have managed to come here without any severe neck pain, and that feels like a lottery prize to me.... I've put myself out there, took a chance, you know I could have gotten a major back pain flare-up, but I've made it It strengthens me, it does, and my self-esteem is raised. (Study IV)

In the theme of *need to handle the painful body and the eager mind*, the participants' coping skills, ways of handling stress, and content of thought is present. Carrying out

daily routines is based on careful consideration. Participants described (Study IV) a quite different life in the present compared to the past. Before the chronic pain developed, participants commonly gained self-esteem through performance of daily occupations and hobbies. As the chronic pain became part of everyday life, they regularly cut short their occupations of work and leisure.

I would like to read more, because I used to be a real bookworm before the accident. Before you go to sleep and have a moment to yourself, that's when I used to read a lot. But now it has become so difficult to hold the book that I have to put it away on the shelf. (Study IV)

Some participants became depressed, some experienced anxiety, and others surrendered to the complex situation and became passive observers of their lives. All these experiences were also reflected by the views of participants who were health care professionals (studies I and II), regarding indicators for pain rehabilitation or occupational therapy. When negative thoughts and emotional problems arise, intervention might be necessary.

It was through a journey of discovery that everyday pain management could be improved, and in Study IV this was illustrated through the theme *need to transform self-image*. How participants viewed themselves--both in relation to who they once were and in relation to who they were now--was challenged. Participants described occurrences of sudden revelation and enlightening. Through changes in everyday priorities and through altered conceptions of how self-worth is measured, a new view on the current situation arose.

I have come to realize that I have a disability that cannot be seen. And I have come to accept that. I have come to accept that today I am who I am. I can say that I don't have the energy. (Study IV)

Another example of a transformation was the acceptance of the need to ask for help to avoid major pain flare-ups. The following data extraction refers to a problem with lifting a rug.

A man walked by, and I said, "Excuse me, would you help me with this rug and just put it under my arm?" And he just said, "Ok." I would never have asked for something like that before.... It felt soooo good, and it wasn't even strange [to ask for help]. (Study IV)

Participants further expressed that well-adjusted work places could be of help in accepting a new self. If they only encounter environments that are not adapted to their experienced limitations, acceptance of disability is difficult. In contrast, well-adapted environments and knowledge about entitlements can facilitate pain management in everyday life. An echo of this is found in studies I and II, where an unfit physical

environment and lack of support in the workplace were suggested as indicators for intervention.

The need for affirmation through communion and enjoyment was illustrated through daily occupations in different contexts. Experiencing joy helped create positive thoughts and an affirmative outlook on the future. Support from family, friends, peers, and colleagues was found to play an important role in the management of chronic pain. Participants described that when they were alone, emotions easily became negative and thoughts circled around the chronic pain and the problems it had brought on. Having someone to turn to and also being that someone for a friend could make all the difference.

Every day isn't unpleasant, there are also days that are nice. It's always nicer when I spend time with my partner, those are much better days. Sure it is, oh yes, and then you can take the moment when you don't have the energy to do something physically active, to play some Yahtzee or yes, just be. Sit outside and have a cup of coffee. (Study IV)

I call my mum.... 'I didn't mop my floors today.'

Mum: *"That's good Karen, let it be! It will still be there; the floors aren't going anywhere."*

She boosts me quite a lot. That feels good, it does. (Study IV)

Having ceased several occupations due to chronic pain, participants experienced that the occupations that they could still perform meant even more to them. This was particularly true for occupations related to leisure. What leisure and enjoyment meant to the participants had also taken on a new meaning. They described that occupations that formerly seemed ordinary had now taken on a deeper meaning and played an essential role in well-being.

We often drive to a garden center and just look at the flowers.... To drive around and look at flowers, that, I really like. (Study IV)

The idea that occupations can serve as a recharging source was further found in Study II. Lack of enjoyable activities was suggested in Study II as an indicator for need of occupational therapy. The same was recognized by participants in Study IV, and an episode of doing woodwork during rehabilitation illustrates this.

You get to do a lot, you sandpaper, you drill, you know, saw, grind, there is a mixture of elements, it doesn't get monotonous. Plus, you can stand there, and sometimes I just daydream in some way, and I become one with the sound from the sandpaper going back and forth which is relaxing in itself even though you're working. (Study IV)

Through occupation it becomes possible to explore emotions and new behaviors. The participants discover that being engaged in occupation is not only about performance but also about reflecting and being in the present.

6.3 PATTERNS OF OCCUPATIONAL PERFORMANCE (STUDY III)

Results from Study III will be presented on both an individual and a group basis to highlight the individual patterns of change in occupational performance and satisfaction seen over the 12-week period.

6.3.1 Individual versus group patterns

The individual patterns were not apparent when all the patients' ratings were combined, but they became apparent when each individual was analyzed separately. See figures 3-6 for a graphic illustration of results; note that the patterns are to be highlighted, not the change scores on a group level. Two participants had clinical significant increases (>2.0) of occupational performance for two problems each, and their mean change score was also clinical significant. Of the remaining three participants, one had a mean change of +1.4 and the other two +0.1 and -0.3. For occupational satisfaction, one patient had clinical significant increases for all three problems; one person had clinical significant increases for two problems, and another for one problem. Clinical significant mean change scores were found in two of these patients. Other mean changes scores for occupational satisfaction were +1.9, +1.6, and +0.1.

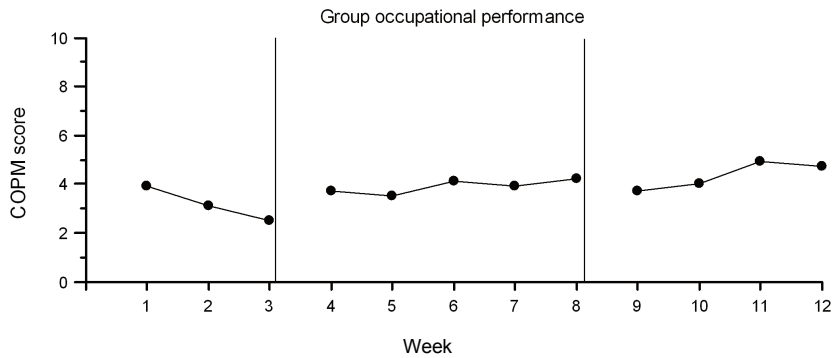


Figure 3. Scores from the participants; 15 occupational problems combined to produce a graph of group occupational performance to illustrate a change pattern, change A1-A2= 1.1. A higher score indicates greater performance.

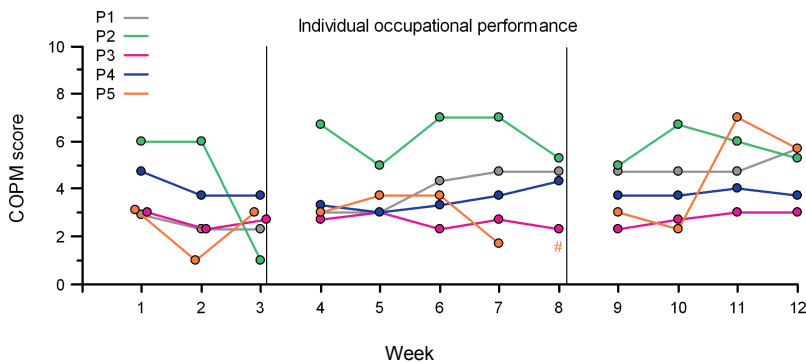


Figure 4. Scores from each individual participant's occupational problems combined to produce five individual graphs of occupational performance to illustrate individual change patterns, change A1-A2= -0.3-+2.3. # represents missing data. A higher score indicates greater performance.



Figure 5. Scores from the participants; 15 occupational problems combined to produce a graph of group occupational satisfaction to illustrate a change pattern, change A1-A2= 2.4. A higher score indicates greater satisfaction.

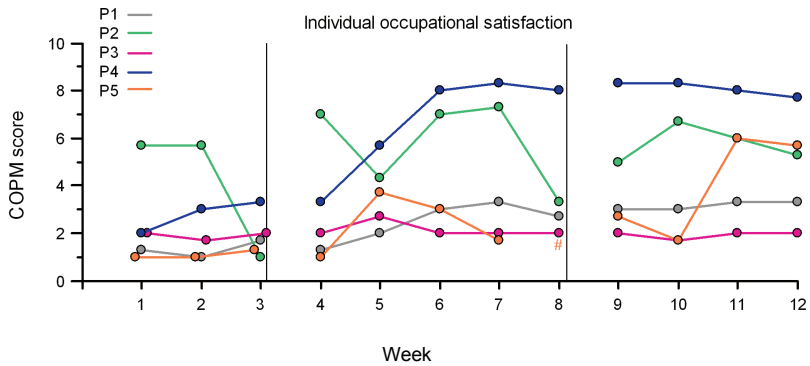


Figure 6. Scores from each individual participant's occupational problems combined to produce five individual graphs of occupational satisfaction to illustrate individual change patterns, change A1-A2= +0.1-+5.3. # represents missing data. A higher score indicates greater satisfaction.

6.3.2 Participants' individual changes of occupational performance and satisfaction (Study III)

A slow but steady increase in occupational performance and satisfaction was seen during the study for Participant 1. She had chosen folding sheets, walking 5 km outdoors, and cleaning the house as her occupational problems to work on. Comparing mean values at baseline (A1) with the follow-up period (A2), an increase of +2.3* (+1.8-3.0 for separate problems) for occupational performance and +1.9 (+0.5-3.2 for separate problems) for occupational satisfaction were found.

The change pattern for occupational performance and satisfaction in Participant 2 showed clear variations from week to week. Ratings ranged from 1-7 for both occupational performance and satisfaction. Her chosen problems were taking a walk, riding a bike, and socializing with friends. During the follow-up period there was a change of +1.4 (+0.8-1.8 for separate problems) for occupational performance and +1.6 (+1.5-1.6 for separate problems) for occupational satisfaction.

Participant 3's ratings of occupational performance and satisfaction during the 12-week period showed minimal changes, either positive or negative. He had chosen to lie down comfortably, cook at the stove and stand in line as his problems to work on. During follow-up, results showed changes of +0.1 (-0.5-+0.8 for separate problems) for occupational performance and +0.1 (-0.2-+0.5 for separate problems) for occupational satisfaction.

Participant 4 had a pattern showing minimal changes for occupational performance but a clear improvement for occupational satisfaction. At follow-up, occupational performance for cooking, setting the table, and folding laundry had all decreased -0.3, while occupational satisfaction had increased +5.3* (+5.1-5.5 for separate problems).

For Participant 5, a pattern with variability was found for occupational performance in all three phases and for occupational satisfaction during the B and A2 phases. For the chosen problem--socializing with friends, hanging laundry and carrying the laundry basket--occupational performance had increased +2.2* (+1.6-2.8 for separate problems) and occupational satisfaction increased +2.8* (+1.8-3.5 for separate problems) at follow-up.

7 DISCUSSION

This section will discuss the results and the methodology used. Conclusions will be presented along with implications for clinical practice and possible future research.

7.1 SUMMARY OF MAIN RESULTS

The overall aim of this thesis was to explore and describe patients' needs related to chronic pain rehabilitation and management from the perspectives of health care professionals and patients with chronic pain. A prominent result is that the need for intervention--either pain rehabilitation or occupational therapy--can be identified through a biopsychosocial lens that takes into account not only the presence of chronic pain but also physical, mental, and environmental aspects. Assessments of need were conducted that balanced societal, professional, and personal values of patients with chronic pain. In addition to characteristics that are susceptible to change in the patient with chronic pain, other indicators for pain rehabilitation were brought forward. These included personal factors such as the patient's age and the assessor's intuitive impressions of the complexity or a lack of progression in the rehabilitation process. Patients living with chronic pain had several needs related to their pain management, of which only some could be met by the BEL intervention they received. Patients did, however, agree with health care professionals that passive or short-term pain management, depressive thoughts, and environmental obstacles all had to be worked on and replaced with recognition of a new self and a changed life in order for pain management to be successful. The expressed needs of patients with chronic pain were related to occupations that were part of daily routines, such as domestic life. Present but unexpressed needs, on the other hand, were related to sweeping changes in behavior, thought patterns, and prioritization of time.

7.2 NEED AS REFLECTION OF VALUES

Values are unique to each individual (Pentland & McColl, 2009); and they are the standards for attitudes and decision making (Rohan, 2000), for what is worth doing (Witkin & Altschuld, 1995), and for what behavior is adopted in any circumstance. This notion can imply that the indicators found for pain rehabilitation (Study I) and occupational therapy (Study II) are reflections of how health care and specifically health care needs were viewed and valued by the participants. Their expressions can be understood to be imprints of personal and professional values that can shape and contribute to a specific type of practice (Reed & Sanderson, 1999). In studies III and IV the values of the participants are articulated through their descriptions of what is worth doing and what should be done. Problem prioritization (Study III), time use (Study IV), and occupational desires (Study IV) are all thereby viewed as manifestations of occupational integrity (Pentland & McColl, 2009).

Values of society, professionals, and individuals

Ideas and expressions of needs within a society are subject to many influences, for example politics (Finlayson, 2006); they are also strongly related to principal beliefs

and values of whoever is expressing the need (Witkin & Altschuld, 1995). Based on this, it could be argued that the results (studies I and II) that relate to a number of areas in fact reflect values of society, professionals, and individuals. Values of Sweden as a society might be present because the politics of practicing rehabilitation has an effect on participants. Professional values might also be represented, because participants responded to questions through their occupational lenses. Also, the participants' personal values may well be present, because they were free to suggest and discuss indicators 'outside the box' and according to their own beliefs. Following this line of reasoning, indicators related to work (studies I and II) and sick leave (Study I) reflect a moral belief within society that economical independence is good and that long-term sick leave is not. From the perspective of a health care professional, working life might be acknowledged as an important aspect of a balanced life because it involves participation in and contribution to society (Matuska & Christiansen, 2009; Townsend & Polatajko, 2007). In this matter, however, it is to be noted that PRUs are reimbursed for certain types of interventions. Thus, the indicators brought forward by the health care professionals (studies I and II) might be based on political rather than professional values.

It was suggested that chronic pain in a patient under the age of 30 was an indicator for pain rehabilitation (Study I). Although being older could be related to poor recovery (Cobo et al., 2010), or could be associated with comorbidity (Main et al., 2008) (both of which can complicate rehabilitation), it can be questioned as an indicator for pain rehabilitation. Also, the values behind an age-related indicator might be interesting to examine. Applying legal equality as an argument, health care should be provided with no regard to age and giving priority to those who need health care the most (SFS 1982:763). Hence, prioritization of patients under the age of 30 cannot be appropriate. Shifting perspective, budget-constrained health care seeks to optimize the fit between the available treatment options and the patients receiving it (Stevens & Raftery, 1994). If a specific treatment directed towards patients under the age of 30 has been proven effective, then it might be acceptable for chronic pain in patients under the age of 30 to be an indicator for pain rehabilitation. Finally, recalling that values are reflected in individual attitudes (Rohan, 2000) and culture (Finlayson, 2006), it could also be argued that prioritizing patients under the age of 30 is a suggestion based on personal interest. To summarize, there could be several values underlying the suggestion that patients under the age of 30 should be prioritized, which reinforces the importance of interpreting results with caution and with relation to the context in which data were collected.

Because values might differ among professional cultures (Finlayson, 2006), the differences in the rankings of indicators for pain rehabilitation (Study I) and all indicators found (studies I and II) can be understood as manifestations of two somewhat different professional cultures and their attached values. Subjective assessments of worth and value are attached to health care professionals' expressions of what is desirable and appropriate (Banja, 1998). If a PRP has the aim of increasing return to work, then issues related to that are probably highlighted. On the other hand, if

the aim is to help patients live their best lives according to their personal values, then indicators of need congruent with this aim might be suggested. The various working contexts of the participants could have played an important role in the results, which should be acknowledged when interpreting results.

The way that participants view central concepts might explain the different results in studies I and II. An exclusive result in Study II, whose participants were occupational therapists, was 'lack of enjoyable activities'. A core value of occupational therapy is that occupation is a human need (Townsend & Polatajko, 2007). Occupational therapists also believe that occupational balance and well-being involves living according to values (Pentland & McColl, 2009) and enjoyment (Csíkszentmihályi, 1990). Occupational therapists are trained within a culture that has occupation as a core concept, and therefore they might highlight enjoyable activities as an indicator of need for occupational therapy. Indeed, it could also be argued that the differences found in studies I and II simply reflects differences in the focus of health care professionals in pain rehabilitation and occupational therapy. These differences lead to a suggestion that multidisciplinary team members have to be familiar with the core concepts of each profession represented in the team in order to understand the needs assessment process fully. Although this might seem obvious in team work, it is not; as proposed, a shared understanding of patients' needs requires time, ongoing discussions, and recognition that this understanding is not obvious (Main et al., 2008).

Recognizing a 'lack of enjoyable activities' is important when assessing needs for occupational therapy as well as for pain rehabilitation. Evidence of need for enjoyable activities is found. Westman and colleagues (2006) conducted a longitudinal study and found that performance of leisure activities was associated with being at work five years post rehabilitation in patients with chronic pain.

The results not only reflected community values but also values that were shared by health care professionals and patients living with chronic pain. 'Enjoyable activities' was seen as an indicator of need (Study II), and results from studies III and IV also found that participants need affirmation through enjoyment of valued occupations. Health care professional and patient values are thus identified as overlapping somewhat.

Enjoyable activities and pleasure as an integral human need has been recognized when studying how people stay healthy (Csíkszentmihályi, 1990). In Study III, participants wanted to improve socializing with friends, walking, and riding a bike. The chosen problems can be appreciated as valued occupations meeting their needs, because values are reflected through behavior (Pentland & McColl, 2009). In Study IV, the participants' descriptions of what they believe to be good and beneficial for their pain management can be indicators of their values although they are not expressed as straightforward needs. Engagement in valued occupations then reflect certain attitudes and symbolize who we are and what we stand for (Pentland & McColl, 2009; Persson & Jonsson, 2009).

Values related to individual needs of those living with chronic pain were not just found in studies III and IV, whose participants experienced chronic pain, but also in Study I. ‘Patients having chronic pain in combination with existential problems’ (Study I) was brought forward as an indicator of need for pain rehabilitation. Recognizing a patient’s doubtfulness about existential meaning might not be a PRP’s primary objective. However, problems with understanding who one is and the place one has in the world can lead to difficulties in finding meaning in life (Pentland & McColl, 2009; Townsend & Polatajko, 2007). Also, not living congruently with one’s values could lead to occupational imbalance (Pentland & McColl, 2009). Together, it is important for health care professionals to attempt to take the patient’s perspective when assessing needs. Professional conduct should be guided both by the values of society and the values of the person receiving the health care services (FSA, 2005).

Value of professional experience and tacit knowledge

The second highest ranked indicator in the third round of Study I was ‘the health care professional gets the feeling that the chronic pain is complex, and available interventions will not change the progress within two months’. This result can be understood as participants who rely on their tacit knowledge that might be a result of professional experience (Mattingly & Fleming, 1994). Through experience, practitioners have direct access to a type of knowledge that might not be possible to learn through professional education (Main et al., 2008; Mattingly & Fleming, 1994). Time on the job and learning by doing can help clinical reasoning and decision making, such as referring of patients from one level to the next in the health care system. Conversely, it can be argued that this is not necessarily for the good of the patient. If a health care professional has experience but loses critical thinking and reasoning, the patient might not be seen as an individual but rather as stereotype, which might not correspond to his or her needs.

Given that the indicator *getting a feeling* as described above got the second highest ranking (Study I), it is possible to reflect on the possibility that this indicator is not an independent indicator in itself; instead, perhaps it is a combination of all of the other indicators in Study I. When a plethora of problems related to activity level, behavior, coping, increased pain, mental health, and sick leave are seen, participants might make an unconscious clinical reasoning and conclude something like, ‘As I see this clinical presentation of this patient, I think referral to pain rehabilitation is in order’. By this line of reasoning, no single indicator in the multifaceted chronic pain syndrome is singled out or prioritized. All the complex indicators are weighed together, participants trust their judgment that comes from their experience. The tripod of evidence-based medicine has been described as the combination of clinical experience of the health care professional responsible for giving interventions, the best available scientific evidence, and the patient’s goals/wishes (Taylor, 2000).

Another indicator of need for pain rehabilitation (Study I) that might reflect professional experience and tacit knowledge is ‘Personnel in primary care cannot move the pain management process forward, expressed as “gotten stuck”’. Preventing further

manifestations of chronic pain consequences is important (Main et al., 2008), and the patient should not simply wait out the pain. Rather, the process of referring a patient with a complex clinical presentation to a level of health care that includes specialist knowledge should speed up. Although not confirmed by clinical research, a recent systematic review (SBU, 2010) is in line with this result from Study I. This review recommends interventions for patients with chronic pain at specialized pain clinics when their pain management process has not proceeded as hoped. On the continuum of referral decision rules that range from standardized questionnaires to instinct, perhaps empirical know-how is as reliable as any other method (Linton et al., 2005).

7.3 NEED AS AN ADDITIONAL PERSPECTIVE DISTINCTIVE OF RISK

From the perspective of former reports and research regarding guidelines for management of pain (Airaksinen et al., 2006; Kendall, Linton, & Main, 1997; Kendall, 1999; Koes, van Tulder, Ostelo, Burton, & Waddell, 2001; SBU, 2006, 2010), results from studies I-IV raise the issue of how need as a concept can be contrasted to risk.

A particular difference between the results of this thesis and the existing guidelines is that the guidelines tend to recommend assessment of risk factors for disability and work loss (Airaksinen et al., 2006), rather than indicators of need for rehabilitation. A common approach used in assessing patients with chronic pain is the 'flag' system (McCarthy, Gittins, Roberts, & Oldham, 2007; Shaw, van der Windt, Main, Loisel, & Linton, 2009; Shipton & Tait, 2005), which describes obstacles to recovery (Linton et al., 2005; Main et al., 2008). Though obstacles and needs are not the same, results shows that there is some overlap between risk factors for disability and indicators of need for pain rehabilitation or occupational therapy. Several of the so-called yellow flags involving psychosocial factors--catastrophizing, coping, distress, and fear avoidance--were identified as indicators of need in studies I and/or II. This research embraced need as an additional concept besides risk, which in turn added the following indicators: pain spreading, high level of pain, pain difficult to relieve, insufficient pharmacological treatment, and lack of enjoyable activities. This indicates that current assessment of patients with chronic pain could be expanded by recognizing the fact that risk and need indeed overlap; it also emphasizes different aspects of disability. A suggestion is made that during initial assessment the concepts of risk and need be clearly separated. If using assessment as a base from which to plan interventions, it would be extremely important to discuss with patients how they themselves interpret assessment findings and what they perceive as their needs. If there is a discrepancy between what the assessment questionnaires find and what the patient expresses, then this must be further elucidated with the intent of involve the patient in the planning process.

Continuing, although it is recommended to screen for red flags associated with possible pathology and yellow flags representing psychosocial factors known to predict disability (Airaksinen et al., 2006), at no point in the guidelines are the patient's needs in focus. Instead, it is described that the health care professional should assess the degree of pain and disability, and this assessment becomes the basis for pain

rehabilitation. The research community has brought forward some self-critique, declaring that guidelines or flag identification is not enough for assessment and screening accuracy (Linton et al., 2005; Shaw et al., 2009). Guidelines ought to have qualitative research incorporated into them to understand how they might be implemented (Rossignol, 2001). The results from studies III and IV, where patients' priorities and experiences come out could thus be used to provide important knowledge about what the recipients of health care expect interventions to focus on.

7.4 NEED AS OPPORTUNITY

Participants' occupational problems, rated in terms of occupational performance and satisfaction (Study III), were seen as expressions of needs. It is through these explicit expressions of needs that the opportunity to meet them arises (Witkin & Altschuld, 1995). In the course of expressing one's needs, the overall awareness of needs is also raised. Participants initially rated their current occupational performance and satisfaction, and it was then and there that their thoughts and hopes were put into action and their problem was made known. How the articulation of individual needs is experienced is not known, but it provided the opportunity to take the present as a starting point (Law, Baum, & Dunn, 2005; Lawton, 1999), from which to change and create an altered future.

On deliberation of expressed needs as opportunity, it is important to be aware that the opportunity presenting itself is related both to the underlying issue of the expressed need and to its solution (Bradshaw, 1994). As an example, one participant found it problematic to cook by the stove (Study III) and wanted to improve skills related to this activity. For the health care professional, this information can provide ideas about the underlying issue of finding it problematic to cook by the stove. Needs assessment can be a guide for planning the future (Witkin & Altschuld, 1995) and planning how the problem can be fixed through intervention. The health care professional and the patient become involved in a mutual learning process (Guba & Lincoln, 1989). Based on this, a suggestion is made that needs assessment can be explained to patients as a mutual opportunity to explore underlying grounds for experience of occupational performance problems and ideas about how a positive change can come about.

When asked to identify problems that they needed to work on to improve occupational performance and satisfaction, participants chose activities related to practicalities of everyday life, such as household chores and some activities related to social engagement and enjoyment (Study III). Similarly, results from Study IV found that participants needed to get practicalities of everyday life worked out while also setting aside time for enjoyment and relaxation. The differences in the results mostly lie in the level of abstraction. When asked directly (Study III), participants highlight concrete activities; and when given the opportunity to reflect on daily life in general (Study IV) and on what they do to manage pain, other more general and nonfigurative needs become visible.

The needs seen in the results of Study IV offer a solution to the problems identified in Study III. Though the needs of Study IV are unexpressed, they hold the key to successful pain management. To pace, avoid stress, learn new daily routines, and take a new perspective on occupational performance (Study IV) can all be applied as strategies to improve occupational performance and satisfaction in the stated problems of Study III. Perhaps it is the case that participants manage their pain successfully in some areas but have difficulty transferring their pain management skills from one activity to others. Thus, it would be interesting to present this association of results and discuss them with the participants. Possibly, the focus should be on helping patients with chronic pain realize that they already have the means for successful pain management and helping them transfer their skills from one situation to another that they still find problematic. Needs assessment and intervention planning should not just center on expressed problems but should look for solutions to presented problems in areas that the patient is already managing well.

Former research investigating the role of the performance of valued activities in relation to the progression of depressive symptoms have found that a decline in leisure activities and social engagements is linked to the onset of new depressive symptoms in patients with rheumatoid arthritis (Katz & Yelin, 2001). Because depression appears to be more prevalent among patients with chronic pain as well as patients with rheumatoid arthritis, this result might also be true for patients with chronic pain. If so, patients' expressed needs related to leisure and social engagement should not be neglected but should be paid attention to and acknowledged as important for the patients' overall well-being. Among the problems reported in the COPM (Study III), productivity (clean the house, cook, and do laundry), leisure activities (socialize and walk), and self-care (lie down, ride a bike, and stand) were represented. In Study IV, participants also described a need to recharge themselves through valued occupations. The specific valued occupations highlighted by each patient can thus provide an opportunity. If performance and satisfaction with the valued occupations is increased, there might be an overall positive effect. Although this is an interesting hypothesis, it requires further investigation to have bearing on clinical interventions.

Results (Study III) revealed deteriorations--not of clinical significance, however--in occupational performance for four separate problems in two participants (P3, P4) and in occupational satisfaction in one separate problem (P3). Because recordings of scores were kept covert to reduce testing, no action was taken in this matter during the data collection. It was not possible to determine if the deteriorations were caused by the intervention itself or if they were a result of external factors. One explanation can be that 12 weeks is a short period of time to change performance or satisfaction with an occupational problem that might have been present for years. Another possible explanation for the results is patients are involved in a pending disability decision or pending litigation (Carpenter et al., 2001; Gil et al., 1988). Likewise, patients with an overly solicitous spouse/family might not be motivated by the BEL intervention, which emphasizes self-management strategies (Gil et al., 1988). These same explanations might apply to the participants with no change as well, although it cannot be definitely

known. The scores for mean occupational performance and satisfaction were entirely or partially unchanged in two participants (P3, P4).

7.5 METHODOLOGICAL CONSIDERATIONS

Originating from different research traditions, quantitative and qualitative research use different expressions and have separate criteria for determining good research and extracting valid conclusions (Creswell, 1998). Quantitative approaches use validity and reliability, while qualitative approaches use trustworthiness. These will be discussed separately here.

7.5.1 Validity and reliability (studies I and III)

Design

The present thesis included two studies with quantitative measures: Study I $n=23$ and Study III $n=5$. An advantage of the Delphi study proved to be the possibility of bringing a geographically widespread group of experts together over several months. Also, it was possible to collect a large number of ideas while giving and receiving continuous feedback. Still, one critique of Delphi studies is that the results might not be consistent with reality (Feher Waltz et al., 2005). Study III used a single-case ABA design to study five participants, with the intention of retrieving detailed information through the different phases (Kazdin, 2003). Although this single-case design might not provide a basis for causal relations, it does provide continuous assessment, which then leads to an appreciation of different routes of change during intervention. A problem that arose with this single-case design was that the A1 phase could only be three weeks, which can be considered a weakness. If the A1 phase had been longer with more data points, further analysis (such as a split middle trend line) could have been conducted. Another predicament with the single-case design that became apparent was the risk of testing, that is, the risk that a participant's behavior is altered simply by the process of measuring the behavior over a period of time (Ottenbacher, 1986). The frequent contact that the author had with participants might have affected results. Therefore, it is important to be aware that testing can interact with the introduction of the treatment phase and that effects can then appear greater than they are.

Participants

In Study I, the strength lay in the fact that the participating PRUs represented rural and urban geographically dispersed areas in Sweden. Selection bias might have occurred during sampling and participant recruitment. Of the 32 PRUs invited, 23 accepted participation. There is a risk that health care professionals in the non-participating units would have had other ideas and opinions regarding indicators of need, which could cause the results to be biased. Potentially, those accepting participation might have been favorably disposed towards research and interested in contributing their opinions. In contrast, those declining participation might not have been interested in needs or might have made a decision that this type of research (stretching over several rounds) would claim too much time from other clinical duties.

Eligible participants in Study III came from an already existing group of patients: those attending a PRP and on a waiting list to participate in the BEL. Although all the participants in the PRP are on the same premises, the particular patients under study here may well have had certain characteristics that make them unique compared to others attending the same PRP at other times. This would mean that the results are exposed to selection bias and that external validity could be compromised, which is why it is suggested that results are interpreted with caution. All potential participants (n=10) were invited to participate, and no inclusion or exclusion criteria were set at this time. This led to a diverse group of participants with regard to years of living with pain, age, and work status. However, this is a just reflection of how the PRP from which participants were recruited is operated. At this specific rehabilitation unit, there are no specific PRPs for certain characteristics, such as diagnosis, years with pain, age, sex or if the goal is return to work. Instead, all patients with chronic pain attend the same PRP, based on the belief that they experience similar consequences of their pain.

On one hand, the fact that some participants participated in both studies III and IV can be viewed as an asset. Participants and the author/interviewer had the opportunity to build rapport before the individual interviews. Knowing the author/interviewer might have made it easy for the participants to describe their daily lives and experiences related to pain management. On the other hand, this familiarity might have led to a lack of sufficiently in-depth probing. The author/interviewer might have taken for granted certain knowledge rather than asking the participants thorough questions.

Data collection

The questionnaire used in the second and third rounds of Study I was based on participants' responses from the first round. Although this is according to Delphi methodology (Linstone & Turoff, 1975), it created problems of validity. The questionnaire used for the second and third rounds had not been subjected to psychometric testing, which could result in weak content and construct validity (Feher Waltz et al., 2005; Kazdin, 2003). Another issue of concern is that even though the first round called for indicators of need, it is possible that participants gave responses for other constructs; for example, predictive factors of positive intervention outcome or risk factors for long-term sick leave.

It was a challenge to select appropriate measures for Study III. The aims were to select measures designed to identify participants' problems and needs, to allow the possibility to use it at weekly intervals, and to make it easy for all participants to score. An attempt was also made to avoid too many measures and to only measure those dependent variables hypothesized to change as a result of the BEL. The aim of the BEL was to increase occupational performance, and therefore one or several outcome measures had to be constructed with this intention in order to avoid conceptual bias (Feher Waltz et al., 2005). At length, the COPM (Law et al., 1998) was selected to measure occupational performance, and satisfaction. The COPM is not commonly used with intervals of one week as in Study III. However, it has been used in repeated measure designs (Gentry, 2008); and because the day-to-day conditions of patients with chronic

pain varies (Cunningham & Jillings, 2006; Nicholas et al., 2005), it was considered suitable for the study's purpose.

The COPM has been proven effective to measure occupational performance and satisfaction in patients with chronic pain (Carpenter et al., 2001). Also, the COPM proved applicable to participants' occupational problems in Study III. Nonetheless, there are some problems with the COPM, one of them being the level of measurement. The scale has the characteristics of an ordinal scale with ten points, and it measures a qualitative concept without exact intervals or an absolute zero. Even so, scores are summed and averaged to produce a summary score (McColl et al., 2006); this is something to recognize while interpreting results. Also, the mean COPM scores are more accurate, because they include a decimal, while the original scores are ordinal. The results in this study were, however, presented according to the instruments manual.

Data analysis

There are few guidelines for data analysis of Delphi studies, and this might cause problems with both reliability and validity (Feher Waltz et al., 2005; Hicks, 2005). After the first round, data was to be summarized into categories, and the strategy for this was to adopt descriptive content analysis to form the first questionnaire. There is, however, uncertainty if the questionnaire would have been the same (reliability) if the analysis were done again by another team of researchers, because interpretation is involved. A further challenge proved to be the actual content analysis. Data were analyzed manually, which means experimenter bias cannot be ruled out. Responses from the first round could have been misunderstood and/or randomly categorized under broad headings that represent the author's own agenda (Hicks, 2005). Being aware of this and trying to reduce bias, first round responses were coded separately by the author and the main supervisor, and the results from that showed concordant coding.

Single-case data are usually analyzed without relying on statistics, which is something that has raised concerns (Kazdin, 2003). In Study III, however, the visual analysis was somewhat facilitated by the suggestion that a change score of >2.0 for either occupational performance or satisfaction in the COPM is to be considered clinically significant (Law et al., 1998). Accordingly, this was also the main concern during analysis. Whether or not to draw any other conclusions from the visual inspection is for each person to judge individually (Kazdin, 2003). On the positive side, the strength of visual inspection is to let each data point speak for itself; the patterns of data are just as valuable as the change scores. On the negative side, it became apparent that trend and slope as part of visual inspection could not be calculated because the baseline phase had fewer than eight data points (Ottenbacher, 1986). Moreover, level was not analyzed. This is because changes in level refer to the shift or discontinuity of performance from the end of one phase to the beginning of the next (Kazdin, 1982), and the intervention was not expected to have an immediate effect at the beginning of the B phase.

7.5.2 Trustworthiness (studies II and IV)

Quality and verification of studies where a human is the research instrument and qualitative data are analyzed to produce results reflecting true human experience can be considered through different perspectives (Creswell, 1998). The one used here is Lincoln and Guba's model of trustworthiness (Lincoln & Guba, 1985), with the main constructs of *credibility* (truth value), *transferability* (applicability), *dependability* (consistency), and *confirmability* (neutrality).

Design

Study II had an explorative design with FGDs for data collection. The explorative design made it possible to study how 'need for occupational therapy' was manifested in everyday practice of occupational therapists (Polit & Beck, 2004). In Study IV, an interpretive design was developed to portray needs related to pain management as experienced by people living with chronic pain. Results aspired to describe different dimensions of the phenomena and the meaning they had in people's lives. Though both of these designs do not lead to neutral observations, they do explore phenomena and realities in detail as they are experienced by individuals or groups (Creswell, 1998).

Participants

The purposive sampling of participants in Study II generated a diverse group of occupational therapists. Participants worked in different communities, at different levels in the chain of care, and with a variety of backgrounds and experiences of working with patients who had chronic pain. This mix proved to be valuable during the FGDs. Sharing the same profession seemed positive, because there were times that the FGDs had a sense of community while discussing the importance of occupation. Also, it was believed that rich data were generated as participants sometimes disagreed and were eager to discuss the different opinions that came up.

Participants in Study IV were selected based on convenience sampling: they were part of the same PRP at the time of data collection. It was believed that this group of participants all contributed with their own unique experience (Dahlgren, Emmelin, & Winkvist, 2007) of living with chronic pain. One challenge was the fact that two participants were not native Swedish speakers. Irrespective of the language barrier during the interviews, participants with different cultural backgrounds are common in Sweden, and their experiences add valuable data.

Data collection

One of the advantages of the FGDs was that indicators for occupational therapy could be explored in an efficient way while suggestions could be discussed, validated, or refuted all at once (Kitzinger, 1995; Polit & Beck, 2004). An unexpected problem, however, was the amount of time it took to prepare for the FGD. Reaching a total of 205 occupational therapists, forming the groups, and preparing the days of data collection proved time-consuming and required minute organization. A challenge of the lively FGDs was the large amount of data they produced. It proved difficult and slow to transcribe the recordings and to capture what was actually said in the midst of

sometimes very fast conversations. An effort to increase credibility of data was made through the use of triangulation of investigators. The author and the main supervisor both participated during the FGDs, and a great gain from this was mutual assistance in logging observations, probing, and recapping what had been discussed.

Before the individual interviews, an effort was made to gain an understanding of the participants' language and culture through prolonged engagement (Lincoln & Guba, 1985). During the 12-week period before the interviews took place, the author was present at the PRU conducting data collection for Study III. This time was also used to build rapport and trust for Study IV. By demonstrating to participants that their confidences were valued and not misused in any way, it is believed that there was an increase in the likelihood of obtaining accurate data during the interviews. Yet, participants were in a state of dependence, and the possibility of feeling compelled to participate and talk about certain issues cannot be eliminated.

Data analysis

Data analysis of Study II used triangulation of investigators to establish credibility (Lincoln & Guba, 1985). After transcribing the FGDs the author and the main supervisor each analyzed them separately. After this, meetings were arranged to go through the separate results and discuss similarities and differences. The idea is that if two people are analyzing, they will keep each other honest, thus increasing the probability of credible results. The discussions of data analysis continued until all issues of disparity were resolved. During these meetings, notes taken at the FGDs were also reviewed to assure that those parts of the text that represented the categories had been analyzed in their proper contexts. To assure dependability and confirmability, an audit trail was kept to make it easy to retrace each step of analysis. After analysis ended, the two other supervisors (M-L.S. and K.C.) critically checked the concordance of codes, themes, and data extractions as an additional step to increase credibility. Despite the measures taken, a possible threat to the credibility of results is the fact that the author, the main supervisor, and one assistant supervisor (M-L.S.) all share the professional background of being occupational therapists. This could constitute a problem, in that as it is possible that they view results from the same perspective and fail to see other perspectives.

The thematic content analysis (Baxter, 1991) employed in Study IV proved to be a drawn-out process with several challenges. Keeping an audit trail was of utmost importance because of the large amount of data to be organized and coded. Also, several of the participants had what could be described as an inner dialogue with themselves, which led to long meaning units in which the core of what was expressed sometimes lay between the lines. Once again, triangulation of investigators was used to ensure credibility; in other words, results were derived from data and not from preconceptions. To increase credibility, each step of analysis was gone over by the author, the main supervisor and one researcher from another university who was familiar with content analysis.

While writing up the method used and the results, one aspiration was to provide such thick descriptions that the reader could regard results as transferable to other settings. In this work, peer debriefing at research seminars was used to verify the written text as clearly describing how the research had been conducted and to delve into credibility. Comments from research participants led to linguistic revisions in order to clarify and avoid misinterpretations of the results.

7.6 CONCLUSIONS AND IMPLICATIONS FOR CLINICAL PRACTICE

The need for intervention in terms of pain rehabilitation or occupational therapy in a patient living with chronic pain should be assessed by health care professional as well as by the patient. Apart from characteristics within the patient, tacit knowledge of the health care professional might be worth considering as an indicator of need. Patients who undergo group interventions, such as the BEL, should have interventions individually tailored to their needs because variations in occupational performance and satisfaction can be found before, during, and after intervention. Health care needs in patients with chronic pain involve not only extinguishing symptoms but also adding occupations that can function as sources of energy.

The results found in this thesis offer knowledge about how needs as a separate concept plays an exclusive role in rehabilitation and management of chronic pain. Results can be implemented into the process of referring patients from primary care to specialized pain clinics or rehabilitation units involved in county care. Furthermore, results can be put into practice when planning PRPs that include an occupational therapy strand.

The results demonstrate that a number of aspects are involved in clinical needs assessment and decision making regarding when a patient with chronic pain should be considered for pain rehabilitation and/or occupational therapy. When the results of the thesis are weighed against former research and needs assessment basis, it becomes evident that health care professionals involved in needs assessment should choose their tools for needs assessment carefully and consider their relevance to needs as a concept. Also, the needs assessment process should be permeated with a close awareness of how one's values might or might not correspond with the values of the patient being assessed. Needs assessment can also be supported by specific knowledge and experience of working with patients with chronic pain. As a whole, the needs assessment process offers a mutual opportunity for the health care professional and the patient in terms of understanding underlying causes of experienced disability or clinical presentation together with an exploration of what and how forthcoming interventions should be carried out.

Results show that occupational performance and satisfaction can change according to highly individual patterns before, during, and after participating in an occupational therapy intervention. This stresses that occupational therapists must pay close attention to each patient's progress or regression and adjusts interventions accordingly. Also, in order to foster realistic expectations before the interventions, it is very important to discuss with patients the knowledge that different patterns of change can be found.

Another important task for occupational therapists is to ask patients about their needs and then use this as a starting point to discuss the possible interventions to meet these needs. Occupational problems might both improve and deteriorate, and patients need to be informed of this and supported to watch this process themselves. If patients are aware of how needs might change over time they can develop skills to meet their needs.

When patients express their needs and problems in everyday life, this must be viewed as an opportunity to discover the areas in which the patients find motivation, energy, and creativity. The importance of performing enjoyable activities and being satisfied with how they are carried out is vital for well-being and overall pain management. Through valued occupations, patients have the opportunity to both rest and develop. Health care professionals should emphasize that patients need to continue their valued occupations and that finding enjoyment in everyday life is an important part of successful pain management.

7.7 FUTURE RESEARCH

To gain a more comprehensive view of the process of referring patients with chronic pain between different levels in the chain of care, further research is needed. For example, it would be valuable to study how health care professionals in primary care or specific professional groups other than occupational therapy view indicators for intervention in relation to chronic pain. It could also be important to study more specifically how needs assessment is carried out, both in terms of using measures/questionnaires and clinical reasoning. Studies on if, and how, ICF can be used as a starting point for needs assessment could add valuable knowledge about the reliability of needs assessment.

The patterns of improvement, deterioration, and no change that were seen in the participants undergoing the BEL convey a demand for further studies wherein measures are repeated with short intervals. This could provide a better understanding of everyday life with chronic pain. Further, if qualitative data were collected throughout the entire rehabilitation process, insight into the experience of undergoing rehabilitation might be gained while it happens.

The importance of enjoyable and valued occupations to manage chronic pain indicates that future research could investigate the ways in which enjoyable and valued occupations can be incorporated into PRPs. Also, the results that participants need to handle both their eager mind and painful body suggests that it might be important to study how the Shifting Perspectives Model of Chronic Illness (Paterson, 2001) fits with and can be included into contemporary PRP development.

8 ACKNOWLEDGMENTS

I would like to thank all of you who have supported me during the research and writing of this thesis. In particular I would like to thank the following.

I am truly grateful to all the **participants** for sharing their views and for so generously offering their time to fill out forms and to take part in focus groups or interviews.

I have had the privilege of having three supervisors, and I owe many thanks for the inspiration and support you have given me. Without your determination and tireless encouragement, this thesis would not have been possible. Associate Professor **Maria Müllersdorf**, my main supervisor, who has provided continuity and direction from the start; Ph.D **Marie-Louise Schult**, for initial inspiration and minute attention to detail; Professor **Kyllike Christensson** whose experience strengthened me and provided a comprehensive view of this thesis.

My mentor, Associate Professor **Carl Molander**, who guided me in the process of being a PhD student and on questions regarding pain and the Swedish health care system.

Professor **Kristian Borg** and **Karin Rudling**, Head of the Department of Rehabilitation Medicine, for providing me the conditions necessary for these post-graduate studies.

Nina Ringart and **Håkan Wallén** at the Department of Clinical Science, Danderyd Hospital, for your administrative support.

Jan Ekstrand, **Ingeborg van der Ploeg**, **Lena von Koch**, **Birte Bergling**, and **Åsa Trulsson** for organization at the Health Care Sciences Postgraduate School.

Staff at Mälardalen University Library for being service minded regarding information retrieval and use of EndNote.

Lisbet Broman, medical laboratory technologist and genius when it comes to figures, graphs, and tables who helped me make my results clear.

Faith Short for excellent revision of my English.

Colleagues at the Department of Rehabilitation Medicine, Danderyd Hospital AB and at School of health, care and welfare at Mälardalen University. A special thanks to the **administrators**.

My fellow doctoral colleagues from The Health Care Sciences Postgraduate School and School of health, care and welfare at Mälardalen University for interesting and stimulating discussions, scientific support, and friendship. **Eva Flygare Wallén, Maria Harder, Åsa Audulv, and Henrietta Forsman**, you are a source of inspiration, and I am very thankful for our meetings. **Christine Gustafsson, Cia Rydlo, and Catharina Frank**, you welcomed me to Mdh and have offered me your friendship and knowledge.

All the colleagues who have helped me with participant recruitment along with tremendous support and reminders of what clinical work is about, **Karin, Anna, Carmen, Caroline, Åsa A, Lena, Sara, Per-Olof, Linnéa, Lotta, Heidi, Diana and Åsa S**. Extra thanks to **Carmen and Åsa A** for help with testing some questionnaires.

To **Annika, Linda, Anders, and Janne**, who have helped me take photos of various occupations for me to use in presentations.

My dear colleagues and friends in ‘Basgrupp 5’, **Annica, Mari and Matilda**; together we learned occupational therapy, and our regular meetings have kept me grounded and up-to-date on clinical work.

The group of friends I call the 38’s, **Silje, Silje, Elin, and Pernilla**, who have encouraged me and kept me updated on the broad field of occupational therapy.

My dear friend, walking buddy, and sounding board, **Linda** who listened tirelessly and helped me keep my focus on the right stuff.

To the Woo-Woo club, **Kristina, Åsa, Annika and Karin**; you girls re-charge me and with you I can be myself whether it is laughing out loud, reflecting on life, or crying. Let’s celebrate in our own special way!

My parents-in-law, **Amie and Perran**, for editing of layout and language.

To my private career counselor, my mother **Ingegerd**, who would have loved to see this thesis being defended but who unfortunately is no longer with us. I am immensely thankful for your everyday support, love, and Spanish phrases right to the end.

To my father, **Erik** who over our coffee and cookies offered me a break and perspective, and to my brother **Magnus** for being a rock to lean on.

Super cute Kooiker dog, **Tassman**. Many ideas have come from our walks together.

Last but not least, I would like to thank the love of my life and my partner in the dream team that we have together: **Janne**. Your support and patience is priceless. Thank you for your humor and positive outlook on life.

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10 APPENDIX

APPENDIX 1

Questionnaire, first round

Instructions

The wording of the questions assumes that the specialized multidisciplinary teams are the ones that you as a participant are working in at the county level of health care. You do not need to describe how you work today or how you comply with any guidelines or provide references. What is important is what you believe based on your experience. If you wish, you can give examples of a patient or patients. Write your answers on a separate sheet.

Indicators

On what basis, or based on what indicators, do you think that primary care health care professionals should refer a patient with chronic pain to a specialized multidisciplinary unit for further pain rehabilitation? Please write all the indicators you can think of, and also write why you think these are indicators. Examples of indicators might be difficulty performing daily activities, previous sickness, symptoms, medication use, coping strategies, functional and activity level, psychosocial factors, or a combination of several factors. Again, you do not need to specify credentials or follow certain guidelines; what is important is what you think.

Example of questionnaire used in the third round

Statements on indicators	Totally agree	Partly agree	Partly disagree	Totally disagree	Don't know	No answer
Chronic pain and change in activity level: either too high or too low.	<input type="checkbox"/> 60,9%(14)	<input type="checkbox"/> 26,1% (6)	<input type="checkbox"/> 0%(0)	<input checked="" type="checkbox"/> * 4,3%(1)	<input type="checkbox"/> 4,3%(1)	<input type="checkbox"/> 4,3%(1)

This percent of those who responded gave this answer.

This number of those who responded gave this answer.

Your response in the second round.

Interview guide, Study IV

The principal question and supplementary questions

Can you describe what a typical day looks like for you? Please tell me about your daily life, what you do, and how you experience it.

- How might another day look? What else do you do?
- Think back to how it was before you took part in rehabilitation. What was a typical day like then?
- Is there any difference, and if so, how is it different now?
- Can you give an example of an activity that has changed?
- How has it changed?